Wiley Blackwell Handbooks of Behavioral Neuroscience

The Handbook of Behavioral Medicine

Edited by David I. Mostofsky

Volume 1

WILEY Blackwell

Wiley Blackwell Handbooks of Behavioral Neuroscience

The Handbook of Behavioral Medicine

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Volume 2

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Handbooks of Behavioral Neuroscience

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Foreword

Handbook of Behavioral Medicine

Anne Harrington

Historically, behavioral medicine has aimed to be a big tent of people who care about behavioral science and care about human health, and want to apply the former to improve the latter. It has been dominated by people who understand that study of the course of disease in isolation from any attention to the behaviors and lifestyle choices of real people will always fall short. And it has been dominated by people for whom the bottom line has always been very practical: What helps? What works? Where and how do we intervene?

Where did it all come from? A changing postwar medical landscape increasingly dominated by a concern for chronic health conditions rather than acute infectious disorders helped set the stage. A robust and often applied tradition of behaviorist laboratory research in university psychology departments in the 1950s and 1970s helped provide methods and techniques. And a rising new trend toward health consumerism in the 1970s increasingly opened up opportunities for a wider range of health professionals with practical interventions to offer. The social, the academic, and the economic all came together to make behavioral medicine possible.

Initially, the term "behavioral medicine" was associated with a rather narrow range of concerns that hardly captured all that the field would become. The first time the term seems to have been used was in the subtitle of a 1973 textbook devoted to a new behavioral health intervention: biofeedback (Birk, 1973). Several years later, in 1977, a conference at Yale University established a broader definition for the field that would guide it for some years: it would be "concerned with the development of behavioral science knowledge and techniques relevant to the understanding of physical health and illness and the application of this knowledge and techniques to prevention, diagnosis, treatment, and rehabilitation" (Schwartz & Weiss 1978). The emphasis here on physical illness is significant. The participants in the Yale conference were concerned about differentiating their work from that of the older field of psychosomatic medicine, with its tendency to focus on the neurotic or characterological origins of physical symptoms and assume that the best intervention for all of them would be insight-oriented psychotherapy – Freudian or otherwise. Behavioral medicine aimed to be different from psychosomatic medicine. It would not worry about unseen entities such as the unconscious or try to discover the alleged deep roots of maladaptive behaviors in its patients' childhoods or personalities. Taking its cue from the laboratory, it would instead emphasize techniques that had a proven capacity to change discrete behaviors. The techniques, moreover, would be wide ranging and eclectic, with something for everyone: not just biofeedback, but EMG feedback, autogenic training, skin temperature feedback, self-monitoring, operant conditioning, cognitive therapy, hypnotherapy, and relaxation training.

By the 1980s, the field had built productive relations with a range of medical and paramedical health disciplines (Agras, 1982). It had also developed particular strength and expertise in chronic health conditions for which mainstream medicine often had few tools, or had a record of poor results: hypertension, smoking, pain, obesity, diabetes, eating disorders, and sleep disorders. While it continued to refine its knowledge-base in these areas, the rise of psychoneuroimmunology at the end of the 1980s began to give new ambition to its therapeutic remit: by the 1990s, increasingly, heart disease, cancer, and AIDS all seemed potential targets of behavioral intervention in ways that had felt less obvious before (Blanchard, 1992).

By the 1990s, the field also began to rethink its original categorical resistance to dealing with mental health issues, conventionally understood. The reason is not hard to see: psychiatry itself had changed since the 1970s. Psychoanalytic approaches were in decline, classical psychosomatic medicine had lost credibility, and there was a general turn within the field toward conventional medical, evidence-based approaches. Perhaps this meant, some felt, that a recalibration was in order. Signaling that new thinking, a 2002 special issue of the *Journal of Consulting and Clinical Psychology* decided for the first time to extend the title of its special issue on "behavioral medicine" (the third such special issue in three decades) to include the phrase "clinical health psychology" (Smith, Kendall, & Keefe, 2002).

Surveying the scene in 2002, the contributors to the special issue found much to like about what they saw. However, they also saw unrealized goals. For too long, they said, the field had focused on intervention at the individual level. Work in the social sciences, however, made clear how much individual behavior is conditioned by context and social conditions. To truly impact health, there was a need for the field to begin to move in a more systems-oriented, public health, and preventative direction. It needed to start asking questions about the behaviors of spouses and caregivers and not just of patients. It needed to ask how far work conditions, school conditions, and neighborhood conditions all affect health and illness, and what intervention looks like when the focus is on the behavior of a community rather than an individual (Keefe, Buffington, Studts, & Rumble, 2002).

Where are we now, some 30 years down the road? The evidence from this handbook is encouraging. Behavioral medicine has remained true to its twin commitments – translational research and evidence-based interventions. It has continued to focus on chronic health conditions amenable to behavioral interventions – from obesity to diabetes to arthritis – and that is only right. The numbers of people suffering from such conditions have grown exponentially since the founding of the field. More than ever, we need behavioral methods that work, and experts who can explain to us how and why they work. The clinically oriented chapters in this handbook are marked by a reassuring granularity that perhaps only comes with maturity: they tell us what happens using *this* kind of technique, for *this* kind of syndrome, and for *that* kind of population.

At the same time, the contributions in this handbook show that the field has also taken to heart the more recent call for directing research to broader collective and contextual factors that lead to poor health choices. Chapters discussing the most intimate dyad in healthcare – the doctor–patient relationship – sit alongside chapters concerned with institutions such as schools and the workplace. Other chapters reflect a sensitivity to the special needs of young children, of women, and of people with life-threatening illnesses. Put another way, if this handbook is any indicator of the health of behavioral medicine – and I think it is – then it seems safe to conclude that, in 30 years, behavioral medicine has managed something quite remarkable. It has matured into a no-nonsense, evidence-based field of research and practice – one that also clearly has grown a social conscience and cultivated a big heart.

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Preface

"Behavioral medicine" is a shining example of a popular buzzword: translational research – the transfer of laboratory science to the patient's bedside. The behavioral emphasis in behavioral medicine continues to enjoy considerable activity in research, publications, and, most importantly, in clinical applications. For years, if not centuries, there has been a continuing interest in the phenomena associated with the variables responsible for the maintenance and change of human and animal behaviors, and the field is currently witnessing more sophisticated conceptualizations and interactions involving biochemistry, genetics, and immunology along with refined technologies with which to study traditional nervous system and physiological functions (Mandell, 1985). Rigor in the conduct of clinical trials has become an expected standard, and efficacy criteria for accepting alternatives to exclusive reliance on drug and surgical solutions increasingly have been met with acceptance from the medical community – criteria such as statistical significance compared to control groups, similar efficacious results reported from replications, confirmation of efficacy following long-term follow up, and the absence of contraindications (Shellenberger, Amar, Schneider, & Turner, 1994). As the separate specialties of enquiry and experimentation went their own ways, the professions of psychology, nursing, social work, sociology, public health, physical and occupational health, rehabilitation, and others became identified with their own disciplinary flavors of clinical health activities. Each, in its own way, contributed significantly to nurture behavioral medicine as an *inter*disciplinary field, by integrating theory and practice from the social and behavioral sciences. Although still a relatively young area of specialization, behavioral medicine has been cited as "the third therapeutic revolution in the history of medicine," following the surgical and chemical revolutions (Basmajian, 1999), and the pages of this volume try to capture selected highlights of this revolutionary adventure – revolutionary for both traditional medicine and for the social sciences. This handbook is organized to provide a survey of representative areas of research and application in behavioral medicine that are relevant for the practicing clinician, and that can enhance the performance of the health professional. It is hoped that the handbook will inspire sharing of ideas, developing research and clinical collaborations, undertaking coordinated training, and the management of clinics across the separate disciplines in medicine and the social sciences. It is not, however, the final word or definitive comprehensive description of the field. It is not an encyclopedia.

The ultimate goal for the practice of medicine is to improve the health and quality of life for the patient, along with enhancing the theoretical and methodological bases for the techniques that are employed. Many sciences contribute to this effort, and the challenge to the physician is to provide relief from health complaints that are not considered to be primarily in the class of "mental health" problems, as generally understood. However, quite often, health specialists who are not physicians may be asked to design a course of treatment from their respective area of expertise such as nutrition, physical therapy, or psychotherapy. The solution to many health problems may also require attending to psychosocial variables dealing with family and social support systems, public education, as well as altering legislative and corporate policies that govern employment and insurance coverage. To be sure, diagnostics (medical, physical, and psychological) comprise a critical element to understanding and addressing the target goal, but medicine itself, as a profession, is not solely defined by its diagnostic prowess and is perhaps better known by its achievements in the realm of treatment. Too often, the "allied health professions" have been viewed as providing only secondary support and facilitative services on behalf of medicine. The perception of their role as actively providing *treatment* is a relatively recent and landmark development. This new characterization, which embraces treatment and intervention services for health by non-physicians, is part of the revolution associated with "behavioral medicine." It will not suffice to recognize such efforts as a specialty within some parent profession, such as health psychology, medical psychology, medical sociology, or medical anthropology, etc. Neither is behavioral medicine a sub-specialty of clinical psychology, and indeed the range of its targeted applications often extends beyond psychology itself. It is the emphasis on *treatment* that gives behavioral medicine a unique meaning. It has probably been best summarized by the following (unpublished) statement: "Behavioral medicine as used herein is a non-specific term used to characterize a range of interventions by behaviorists with medical patients. The interventions always are designed to be therapeutic, although they may be implemented within a research context as well as within a fee-for-service context. The designation, behaviorist, is usually self-styled; however, most behaviorists are psychologists. A medical patient is anyone who is being treated in a medical or surgical service, and who does not regard his or her clinical problem as a mental health problem requiring conventional psychological or psychiatric treatment. Such patients are seen by health professionals from disciplines that include medicine, nursing, dentistry, PT/OT, rehabilitation, social work, psychology, sport psychology, and nutrition. Patient problems that have benefitted from behavioral medicine protocols generally fall in any of these four categories: (1) the patient is behaving in a way that increases the probability of either jeopardizing his or her health (e.g., smoking cigarettes), or aggravating a pre-existent medical problem (e.g., not complying with medical advice); (2) there is a putative relationship between the patient's behavior and his or her symptoms (e.g., "stress-disorders"); (3) there is a scientifically established, neural-mediated control mechanism that can be implemented to modify a pathognomonic sign (e.g., biofeedback of external sphincter response in patients with fecal incontinence who have established organic pathology that has affected their external anal sphincters); (4) there is a putative relationship between the chronic disorder and the presence of functional, emotional, and socially damaging behavior in the patient, caregiver, or health professional" (anonymous mimeo).

Many reports are scattered in the scientific and health-related literature that have previously addressed such problems, together with reliable technologies that have proven useful in providing relief. The focus on "intervention" and treatment represents one element of a larger enterprise that is identified as "behavioral medicine" and which serves as a rallying theme for comprehensive health management. The popularity of behavioral medicine is largely due to the interdisciplinary message that it espouses, the range of non-mental-health medical disorders and problems that it serves, and the integration or potential application of many areas in behavior science to issues of medicine. It is such qualities that seem to differentiate behavioral medicine from allied disciplinary interests such as health psychology, neuropsychology, and psychiatric medicine (to name a select few).

In addition to flagship journals for behavioral, health, or medical societies, a host of monographs, handbooks, edited volumes, and invited chapters are available in the public domain that deal with aspects of behavioral medicine. In addition, special issues of many journals are dedicated to critical reviews and assessments of the behavioral medicine enterprise. Striking confirmation that the area of behavioral medicine has come of age, and has earned the serious attention of scientists and clinicians, is evident from some periodicals that have almost institutionalized periodic updates of the topic (e.g., *Journal of Consulting and Clinical Psychology*, Vol. 50, #6, 1982; Vol. 60, #4, 1992; Vol. 70, #3, 2002). Attempts to succinctly yet faithfully define the field continue, although, at the end of the day, a field becomes defined by the scholarly and scientific activities of its practitioners and advocates. Similarly, historical reviews of behavioral medicine are commonly found in a number of collected works and health psychology texts. Several valuable and articulate presentations deserve particular mention, such as Miller (1983) and Kennerly (2002), as well as the seminal analysis by Taylor (1982), differentiating the components of sickness, diseases, illnesses, and predicaments.

It may be easier and more informative at this point to outline what should *not* be expected from this handbook. There will be no subtle assumption that every aspect of behavioral medicine will be discussed. Neither will there be a presumption that only those with advanced competence in medicine or psychology will benefit from this handbook. In the main, the volume will attempt to present a point of view that differs markedly from most works of this kind. In doing so, it will attempt to allow the reader to develop a sensitivity to the multifaceted considerations facing a clinician, and present representative examples of successful applications of familiar behavioral protocols, including (but not limited to) conditioning, biofeedback, relaxation, behavior modification, hypnosis, and stress management. Such discussions will be integrated with an appreciation of the relevant biological systems, and referenced to data-driven analyses. Not every chronic medical condition will be represented, and not every behavior-based strategy will be examined.

This handbook has been fortunate to attract authors whose expertise has earned them international recognition. In addition, the editorial support from Wiley-Blackwell is most appreciatively acknowledged. Above all, all who have been party to bringing this project to fruition hope that it will serve as a meaningful contribution to the literature, and that the reader will be able to derive substantial utility from its inclusion among other publications of which they are fond.

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Part I

Domains of Concepts, Theories, and Treatments

1

Depression in Chronic Physical Illness

A Behavioral Medicine Approach

Golan Shahar, Dana Lassri, and Patrick Luyten

In this chapter, we address the prevalence, consequences, and presumed causes of unipolar depression in chronic, non-lethal, physical illness. We begin by outlining the central role of chronic physical illness (CPI) in medicine. Next, we consider the various manifestations of depression in CPI, focusing on the distinction between categorical approaches to depression (i.e., a diagnosable condition such as major depressive episode) and dimensional approaches (i.e., elevated levels of depressive symptoms in the absence of a diagnosable episode) to depression. From a behavioral medicine point of view, we argue, it makes more sense to address depression as a continuous dimension rather than to distinguish between diagnosable and "subsyndromal" depression. Next, we present a tentative model accounting for depression in CPI, which focuses on *person–context exchanges.* We conclude by discussing the implications of this view for assessment/screening, treatment, and prevention.

Chronic Physical Illness: Definition, Prevalence, Costs

The World Health Organization (WHO) defines chronic diseases as diseases of long duration and generally slow progression. According to the US National Center for Health Statistics, a disease lasting 3 months or more is considered chronic (http://www.who.int/topics/chronic_diseases/en). Chronic diseases refer to a variety of medical and functional somatic conditions (i.e., cancer, chronic kidney disease, chronic obstructive pulmonary disease, chronic pelvic pain, chronic pain, chronic

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respiratory diseases, diabetes, epilepsy, fibromyalgia, headache, heart disease, rheumatoid arthritis, systemic lupus erythematosus, etc.) characterized by different levels of life-threatening conditions (terminal vs. non-terminal conditions), symptom severity and duration (constant, episodic flare-ups or exacerbations, or remission with an absence of symptoms for long periods of time), illness appearance (suddenly or through an insidious process), etc. As opposed to an acute disease, which is typically characterized by an abrupt onset of symptoms that terminates in a relatively short period, either with recovery or with death, chronic illness might continue endlessly, and often becomes a defining part of the individual's life experience.

Chronic illnesses constitute a growing proportion of the total global disease burden (Katon & Ciechanowski, 2002; Lopez, Mathers, Ezzati, Jamison, & Murray, 2006; Welch, Czerwinski, Ghimire, &Bertsimas, 2009). Over the last 50 years, chronic illnesses have steadily overtaken acute medical conditions as the primary cause of disability and use of health services in the United States. Studies show that 45% of the US population is afflicted with CPI, which accounts for 78% of health expenditure (Anderson & Horvath, 2004; Holman, 2004). Chronic illness is predicted to become ever more prevalent as populations age across developed countries and effective treatment is found for acute conditions. In fact, it is predicted that, by the year 2020, CPI will account for 60% of the global disease burden (Murray & Lopez, 1997; Welch et al., 2009).

A distinction between "disease" and "illness" is made in (behavioral) medicine in general, and particularly with respect to CPI. While the term *disease* pertains to the pathophysiology underlying the syndrome/symptoms, (e.g., an alteration in structure and function), the term *illness* pertains, more broadly, to the *human experience* of symptoms and suffering, and pertains to how a disease is perceived, lived with, and responded to by an individual and his family (Larsen & Lubkin, 2009, p. 4). Related to this distinction, Curtin and Lubkin (1995, pp. 6–7), define chronic illness as the irreversible presence, accumulation, or latency of disease states or impairments that involve *the total human environment* for supportive care and self-care, maintenance of function, and prevention of further disability.

In accord with the aforementioned definition, *chronic illness* may be considered a *chronic stressor*. As explained in more detail in the following text, stress may be defined as a threat (or perceived threat) to the organisms' allostasis or dynamic equilibrium (McEwen, 2007), caused by a physical and/or psychosocial burden (Van Houdenhove, Egle, & Luyten, 2005). Stress is thought to influence health both indirectly by promoting behavioral coping responses detrimental to health and by activating physiological systems (i.e., the sympathetic nervous system and directly by its effects on the hypothalamic–pituitary–adrenal (HPA) axis; Cohen, 2004; Lupien, McEwen, Gunnar, & Heim, 2009). Prolonged or repeated activation of these systems is thought to place persons at risk for the development of a range of physical and psychiatric disorders (Anda et al., 2006; Luyten, Van Houdenhove, Lemma, Target, & Fonagy, in press), and depression in particular (Monroe & Reid, 2009; Pae et al., 2008).

Prevalence of Depression in Chronic Physical Illness

It is therefore of no surprise that unipolar depression is highly prevalent in CPI. Depression ranks fourth for disability-adjusted life-years worldwide (Insel & Charney, 2003), and is estimated to rise to second by 2020 (Murray & Lopez, 1997). Every year, 6% of adults will suffer from depression, and more than 15% of the population will experience a depressive episode during their lifetime (Pilling, Anderson, Goldberg, Meader, & Taylor, 2009). Recently, the 1-year prevalence of a depressive episode among the chronically physically ill, based on ICD-10 criteria, has been shown to range between 9.3% and 23% and to be significantly higher than the likelihood of having depression in the absence of a CPI (Moussavi et al., 2007).

Extensive research has demonstrated the association between depression and high utilization of medical services, indicating significantly higher medical costs among patients with either depressive symptoms or major depression in comparison to non-depressed patients (Katon & Ciechanowski, 2002; Welch et al., 2009). This increase in costs is seen in a variety of categories, including primary care visits, medical specialty visits, lab tests, pharmacy costs, inpatient medical costs, and mental health visits. This was also found after adjusting for chronic medical illness. Additionally, depressed patients were found to have higher costs than non-depressed elderly (Katon & Ciechanowski, 2002).

Welch et al. (2009) have shown that depressed patients had higher non-mental-health costs than non-depressed patients in 11 comorbid illnesses studied, while the per-patient difference in non-mental-health cost between depressed and non-depressed patients ranged from US$1,570 in obesity to US$15,240 in congestive heart failure. The ratio of cost between non-depressed and depressed patients ranged from 1.5 in obesity to 2.9 in epilepsy. Depression was associated with significantly higher cost of non-mental healthcare in 10 of 11 chronic comorbid diseases studied. Even while controlling for number of chronic comorbid diseases, depressed patients had significantly higher costs than non-depressed patients. Though the magnitude of the cost difference was similar to that reported in previous studies, the consistency of the magnitude across 11 chronic comorbid diseases has not been previously reported. Also, the largest components of higher cost in depression were higher pharmaceutical and outpatient costs. Further research is necessary to determine the underlying reasons for these variations. However, these differences in utilization do indicate that depressed patients not only saw doctors more often, but also were prescribed non-mental-health drugs at higher cost or in greater quantity than non-depressed patients.

Though the increased cost of general medical services associated with depression has been established in several different medical settings, using cost of services as a measure of utilization of care, the cause of higher cost in depressed patients remains unclear. Thus, it is unclear whether these individuals suffer chronic comorbid illnesses of greater severity, or if they are seeking more medical care than non-depressed individuals, independently of illnesses severity, or whether they have poor compliance with medical care or even alterations in pathophysiology triggered by depression.

Depression: Categorical and Dimensional Approaches

However, what exactly *is* depression? For the last two and a half decades, depression researchers have been discussing whether depression is a binary, all-or-none, clinical entity such as the ones described in leading psychiatric diagnostic manuals such as the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR, published by the American Psychiatric Association, 2000) or the *International Statistical Classification of Diseases and Related Health Problems–10* (ICD-10; World Health Organization, 2008), as opposed to a continuous variable denoting various levels of severity that might be ordered along a known and measurable continuum, such as scores on the Center for Epidemiological Studies Depression Scale (CESD; Radloff, 1977). Two scientific approaches were taken in order to resolve the debate: employment of new taxometric procedures to examine the extent to which depression is a continuum or a taxon on the one hand and the systematic examination of impairment associated with "subsyndromal depression" on the other, namely, whether elevated levels of depressive symptoms, in the absence of a formal DSM/ICD diagnosis, are associated with impairment. Evidence pertaining to both approaches is briefly reviewed.

Developed by Waller and Meehl (1998), taxometics is a statistical procedure aimed at identifying categories from dimensions, so as to establish the optimal indicators and base rates of the putative category (taxon). Simply put, taxometrics purports to provide an answer to the question "is a certain variable (e.g., depression) binary or continuous?" The idea behind taxometrics is that valid indicators of a potential taxon intercorrelate in which taxon members and non-members are mixed, but do not correlate in "pure" samples. Thus, the size of the correlation between key indicators of depression (e.g., self-report measures such as the CESD or the Beck depression inventory–II [BDI-II]; Beck, Steer, & Brown, 1996), computed for samples comprised of either depressed, non-depressed, and mixed individuals, should indicate the existence – or not – of a depression taxon. The problem, however, is that there are few studies that rely on this sophisticated procedure in depression research, and, thus far, results have been mixed, some consistent with the presence of a depressive taxon while some are not (e.g., Beach & Amir, 2003, Franklin, Strong, & Greene, 2002; Grove et al., 1987; Hankin, Fraley, Lahey, & Waldman, 2005; Ruscio & Ruscio, 2000; Whisman & Pinto, 1997; for a review, see Pettit & Joiner, 2006, p. 15).

Another approach is to examine whether elevated levels of depressive symptoms, assessed as a continuous variable, are associated with psychosocial and medical impairment, regardless of the presence or absence of a depressive taxon. This approach might be extended by comparing individuals with a formal diagnosis of major depressive disorder (MDD), with those who do not meet criteria for such a diagnosis, but who have elevated scores on a depression measure. Here, the pattern is clear: elevated scores of depressive symptoms on the CESD, BDI-II, or other measures are associated with substantial psychosocial impairment, which is sometimes equivalent to the impairment experienced by people with MDD (e.g., Judd, Akiskal, & Paulus, 1997).

Taking into consideration the two lines of evidence, we conclude that, for practical purposes, unipolar depression in chronic illness should be considered as serious even when it is subsyndromal, namely, when patients reported elevated levels of depression on a self-report measure, but do not meet criteria for an MDD diagnosis. Accordingly, henceforth, we use the term "depression" in its wider use, denoting elevated levels of depressive symptoms.

Role of Depression in CPI

Various models of the relationship between depression and CPI have been proposed, and evidence seems to support in part each of these approaches.

First, CPI might *lead to* depression. For instance, in a prospective study of nondepressed elderly living in the community, the most common stressful life event that was associated with the onset of major depression was the development of a life-threatening medical illness in the respondent or his/her spouse (Wells, Golding, & Burnham, 1988). Studies addressing the onset of depression as a secondary consequence of the existence of a chronic illness were conducted in the context of a variety of chronic medical conditions, consistently pointing to higher levels of depression associated with chronic illnesses (Harpole et al., 2005; Katon & Schulberg, 1992; Moussavi et al., 2007). For example, while controlling for sociodemographic differences between groups, depression was found to be more common among patients with rheumatoid arthritis than in healthy individuals (Dickens, McGowan, Clark-Carter, & Creed, 2002). In a large, nationally representative sample, very high 12-month prevalence and age/sex-adjusted odds of major depression were found in individuals with common chronic medical conditions (i.e., hypertension, diabetes mellitus, coronary artery disease, congestive heart failure, stroke or cerebrovascular accident, chronic obstructive pulmonary disease, and end-stage renal disease). Specifically, the 12-month prevalence estimates of major depression ranged from 7.9% to 17%, and the age/sex-adjusted odds of major depression ranged from 1.96 to 3.56 (Egede, 2007).

Second, depression might be *a causal factor* in CPI, such as ischemic heart disease (IHD), stroke, cancer, and epilepsy (e.g., Evans et al., 2005; Frasure-Smith, Lespérance, & Talajic, 1993). In a large, population-based sample, based on the US Health and Retirement Survey (HRS), depression was significantly associated with the onset of diabetes, heart problems, and arthritis, but not cancer, as examined during a 12-year follow-up study among older working-age adults (ages 50–62), even while controlling for demographics, health risk indicators (body mass index [BMI] and smoking), income, and other relevant variables. Hence, working-age older people with depression at baseline were at significantly higher risk of developing chronic illnesses (Karakus & Patton, 2011).

Another very large population-based worldwide study demonstrated that comorbid state of depression incrementally worsens health as compared with depression alone, with any of the chronic illnesses alone, and with any combination of chronic illnesses without depression. Depression comorbid with other chronic illnesses produced significantly greater decrements in health than from one or more chronic illnesses, even after adjustment for socio-demographic, country of origin, and economic factors (Moussavi et al., 2007).

Studies have also associated depression with increased morbidity and mortality (Bair, Robinson, Katon, & Kroenke, 2003; Katon, 2003; Moussavi et al., 2007). Moreover, another review showed that the impact of depression on chronic diseases (i.e., asthma, arthritis, cardiovascular disease, cancer, diabetes, and obesity), as well as the tendency of chronic disease to worsen symptoms of depression, both accounted for the significant associations found between depression and chronic diseases (Chapman, Perry, & Strine, 2005).

Third, there is evidence for *reciprocal relationships* between chronic illness and depression. For instance, reciprocal relationships have been found between chronic pain and depression (for a review, see Bair, Robinson, Katon, & Kroenke, 2003), and between depression and neurological diseases such as Parkinson's disease, epilepsy, and Alzheimer's disease (Evans et al., 2005). Evidence suggests that depression might develop either as a consequence of the psychological stress associated with neurological diseases, or as a result of underlying neurodegenerative process (Zubenko et al., 2003). Yet, a history of depression has also been depicted as a risk factor for the development of Alzheimer's disease (Green et al., 2003) and epilepsy (Forsgren & Nystrom, 1990; Hesdorffer, Hauser, Annegers, & Cascino, 2000), suggesting common pathogenic mechanisms. Additionally, Evans et al. (2005) suggested that biological mechanisms (i.e., increased serum glucocorticoids, catecholamines, and growth hormone which counter the effects of insulin, insulin resistance, secretion of inflammatory cytokines, HPA axis hyperactivity, and increases in plasma cortisol) might link depression with chronic illnesses such as diabetes and congestive heart failure. Similarly, pain and depression might occur simultaneously because of their respective neurochemical associations with serotonin and norepinephrine, and altered levels of these neurotransmitters might affect changes that precipitate the occurrence of pain and depression (Evans et al., 2005). Congruent with this assumption, there is increasing evidence that depression and several chronic pain disorders are part of a spectrum of disorders with high familial aggregation (Hudson et al., 2003).

Diverse behavioral factors might account for the effect of depression on chronic illness and its adverse course. These are listed in the following text:

1. *Poor self-care and non-adherence* (i.e., non-compliance with treatment recommendations). Self-management of chronic illness includes working effectively with healthcare providers, self-monitoring (i.e., checking blood glucose), implementing medication regimens, following prescribed diet and exercise

regimens, quitting smoking, and minimizing drinking as well as minimizing the impact of medical illness on social role functioning. A concerning large percentage of medical patients do not consistently adhere to the recommendations of their physicians for prevention or treatment of acute or chronic conditions (i.e., by not taking their medication correctly, persist in lifestyles that endanger their health, etc.). Non-adherence can result in exacerbation of illness, incorrect diagnoses, as well as patient and physician frustration, and generally has a consistently negative effect on treatment outcomes. Medical patients may be non-compliant for many reasons, including their disbelief in the efficacy of treatment, barriers such as adverse effects and financial constraints, and lack of help and support from family members (Katon & Ciechanowski, 2002). Based on a large meta-analysis, DiMatteo, Lepper, and Croghan (2000) found that depression, but not anxiety, was strongly associated with the risk of being non-compliant with medical treatment recommendations.

There might be a variety of reasons as to why depression is significantly associated with non-adherence. Depression may hamper self-management of chronic illnesses, including impairments in cognitive functioning, cognitive focus, energy, and motivation caused by depression that in turn might have an effect on the ability and willingness of patients to follow through with treatment. Also, depression involves a sense of hopelessness and even lack of self-efficacy and optimism that any action will be worthwhile that might also hamper the ability and motivation to adhere to treatment. Finally, social support, which is eroded by depression, might complicate the self-management of chronic physical illness (Gallant, 2003), and lead to poor adherence (DiMatteo, 2004).

2. *Amplification of symptoms and illness intrusiveness.* Substantial evidence demonstrates that patients with both mental disorders and subsyndromal psychological distress report significantly more physical symptoms than non-distressed populations, even while controlling for the severity of medical illness (Katon & Ciechanowski, 2002). One of the challenges patients with chronic medical illness are dealing with is managing to live and adapt to the chronic medical symptoms caused by their medical illness, and most patients habituate to these chronic aversive symptoms quite well (at least until they reach severe levels that might markedly affect functioning). However, an extensive data suggest that having comorbid depressive illnesses in patients with chronic medical illness interferes with this adaptation process and is associated with amplification of both symptoms from the CPI as well as physical symptoms associated with other body organ systems. Several studies have shown that, when major depression was effectively treated among chronically ill patients, they reported being able to cope more effectively with their illness, and that their symptoms of medical illness were less distressing despite little change in objective measures of their medical disorder (Borson et al., 1992; Sullivan, Katon, Russo, Dobie, & Sakai, 1993).

Related to the issue of symptom amplification is *illness intrusiveness*. Illness intrusiveness pertains to encompassing illness- and treatment-induced disruptions to the individual's lifestyles, valued activities, and interests. Conceptualized as a facet of the chronic illness experience that is common across conditions, illness intrusiveness is a fundamental determinant of subjective well-being (Devins, Edworthy, & ARAMIS Lupus State Models Research Group, 2000; Devins et al., 2001). The concept's central assumption is that chronic illness and its treatment affect subjective experience through illness intrusiveness, an intervening variable, which is also affected by moderating psychological and social factors (Devins et al., 2000, 2001). The applicability of the illness intrusiveness concept to CPI has been demonstrated in various illnesses (bone marrow transplants, irritable bowel syndrome, rheumatic diseases, SLE), cardiac events, and others (Devins et al., 2000, 2001). Evidence for a negative reciprocal longitudinal relationship between chronic illness and depression was also found in systemic lupus erythematosus (SLE) patients (Schattner, Shahar, Lerman, & Abu Shakra, 2010). While increased levels of depression were predicted by illness intrusiveness and symptom concealment, initial (baseline) levels of depression were associated with an increase in illness intrusiveness over time, thus suggesting a reciprocal relationship between depression and illness intrusiveness in SLE.

3. *Effect on the social context.* As noted, depression is known for having a deleterious effect on the social context (Pettit & Joiner, 2006), which, in turn, is likely to exacerbate the course of chronic illness (Ranjan, 2001). According to Wells et al. (1989), patients with major depression perceive their social and occupational functioning, as well as their general health, as more impaired than patients with several other medical disorders. Also, when major depression was comorbid with a medical disorder, there was an additive functional impairment. Subsyndromal depressive symptoms were also correlated with additive disability among patients with chronic medical illness (Wells et al., 1989).

A Heuristic, Behavioral-Medicine Perspective on Depression in Chronic Illness: Depressive Vulnerability and Person–Context Exchanges

Based on the literature reviewed, we propose a heuristic perspective on depression in CPI. Faithful to the mission of this book, this perspective is behavioral, namely, it is based on psychosocial research identifying key variables and processes in depression, and – more recently – in depression in CPI. Central to this perspective are two constructs: depressive vulnerability and person–context exchanges.

Depressive vulnerability pertains to individuals' *proclivity* to develop depressive (and related, anxious, and other) symptoms, particularly in the face of life stress (Shahar, 2001). Individuals' cognitive–affective (i.e., the ways in which they think about the world) or personality (Blatt, 2004, 2008) style plays a key role in explaining depressive vulnerability. There are numerous dimensions of psychological vulnerability "out there." These include, but are not limited to, personality features such as dependency, sociotropy, autonomy, perfectionism, rejection sensitivity, dysfunctional attitudes, harm avoidance, neuroticism, anxiety sensitivity, looming maladaptive style, and self-criticism). The last four decades, however, have brought about an appreciable amount of research, implicating two dimensions as "arch-villains" in explaining vulnerability to depression: neuroticism and self-criticism (Kotov, Gamez, Schmidt, & Watson, 2010; Steel, Schmidt, & Shultz, 2008; Blatt, 2004, 2008; Shahar, 2001, respectively).

Neuroticism pertains to a broad, higher-order personality factor referring to an enduring proclivity for experiencing negative affect. Neuroticism is generally considered to be a major risk factor for psychopathology, and depression in particular (Costa & McCrae, 1992; Goldberg, 1993; Lahey, 2009). However, important criticism has been leveled against this construct (e.g., Spitzer, First, Shedler, Westen, & Skodol, 2008). For instance, it has been suggested that, because this dimension is defined from the outset as the proclivity to experience negative affect, the use of this construct to predict emotional disorder is circular (Farmer et al., 2002). On the other hand, the predictive power of neuroticism vis-à-vis various forms of psychopathology, not just emotional disorders, is so impressive that it should not be dismissed out of hand. Neuroticism appears to tap into the temperamental underpinning of psychophysiological vulnerability to depression, challenging other putative vulnerability dimensions to demonstrate their predictive power over and above neuroticism. Of all the present dimensions, self-criticism is perhaps the only personality–cognitive one meeting this challenge (Bareket-Bojmel & Shahar, 2011; Clara, Cox, & Enns, 2003; Dunkley, Sanislow, Grilo, & McGlashan, 2006; Johnson, 2003).

Self-criticism is a more specific personality dimension and pertains to individuals' tendency to adopt a punitive stance toward the self once self-standards are not met (Shahar, 2001). Studies suggest that self-criticism, like neuroticism, is a transdiagnostic vulnerability factor, which has been implicated in the onset and course of depression, anxiety, eating, and personality disorders (for a review, see Blatt, 1995, 2004; Luyten & Blatt, 2011), as well as suicide. It has also been shown to negatively affect the course of chronic illness (Luyten et al., 2011)

For instance, recent research attests to the role of self-criticism in CPI, such as in chronic fatigue (Kempke et al., 2011 ; Luyten et al., 2011) and pain-related disorders (Rudich, Lerman, Weksler, Gurevitch, & Shahar, 2008; Rudich, Lerman, Gurevitch, & Shahar, 2010; Lerman, Shahar, & Rudich, 2012). Studies suggest that self-criticism is associated with increased vulnerability for these disorders and also negatively influences their course (Kempke, Van Den Eede, et al., in press; Luyten et al., 2011). Congruent with the active person–context exchange model proposed in this chapter, Luyten and colleagues found that self-criticism and related traits (e.g., persistence and "action-proneness") were not only associated with increased stress sensitivity in patients with chronic fatigue syndrome (CFS), but also with the generation of daily stress, leading to increased levels of depression in the daily course of life (Luyten et al., 2011). In a subsequent study, these authors demonstrated a prospective relationship between self-criticism and daily fatigue and pain symptoms in CFS patients (Kempke, Luyten, et al., 2013). Moreover, they also demonstrated that self-criticism was clearly distinct from adaptive strivings and adaptive perfectionism (Kempke, Van Houdenhove, et al., 2011) and was related to low self-esteem, leading to a downward spiral of increased levels of depression, fatigue, and pain over time (Kempke, Luyten, Van Houdenhove, et al., 2011). Studies in this context suggest that self-criticism may be a coping style to compensate feelings of low self-esteem related to a history of intrusive parenting and/or trauma (Luyten et al., in press; Soenens, Vansteenkiste, & Luyten, 2010). The clinical importance of these findings cannot be underestimated, particularly since self-criticism, as in other conditions (Blatt, Zuroff, Hawley, & Auerbach, 2010), has been negatively related to treatment outcome in both CFS and chronic pain conditions over and above cognitive factors and severity of depression (Kempke et al., 2010; Kempke, Luyten, Van Wambeke, Coppens, & Morlion, 2011).

Studies in this area are also beginning to shed more light on the mechanisms involved in the relationship between self-criticism, depression, and chronic illness. Some evidence suggests, congruent with studies outlined previously, that self-criticism is associated with a dysregulation of the main human stress system, the HPA axis, leading to a cascade of psychological (e.g., depression) and somatic consequences (e.g., dysregulation of immune and pain processing systems), resulting in increased levels of depression, fatigue, and pain.

In Israel, a similar line of inquiry has focused on chronic pain. Patients with chronic pain conditions (e.g., fibromyalgia, chronic low back and neck pain, CRPS, neuropathic pain, headache) were assessed prior to a first visit to a pain clinic as to their pain level, depression, and self-criticism. Subsequent to the visit, physicians were assessed as to their pessimism/optimism regarding patients' prognosis. Self-criticism was the sole predictor of physicians' pessimism regarding prognosis (Rudich et al., 2008). A follow-up on a subset of these patients revealed that physicians' pessimism predicted an increase in the affective component of pain, as well as in depression (Rudich et al., 2010). Moreover, in two separate studies, self-criticism was shown to interact with the affective, but not sensory, component of pain to prospectively predict an increase in depression (Lerman, Shahar, & Rudich, 2011), anxiety, and pain-related disability (Lerman, Shahar, Brill, & Rudich, in preparation). In the latter study, self-criticism also predicted an increase in both affective and sensory pain.

According to the *congruency hypothesis* (Hammen, Marks, Mayol, & DeMayo, 1985; Zuroff & Mongrain, 1987), depression and related psychopathology are expected to ensue from interactions between specific psychological vulnerability and vulnerability-congruent life events. Accordingly, self-criticism is expected to interact with failure-related stress, but not with other types of life stress (e.g., interpersonal strife), in predicting depression's onset and/or maintenance. Nevertheless, self-criticism has been found to interact *with all types of life stressors in predicting* psychopathology (Lassri, Soffer-Dudek, Lerman, Rudich, & Shahar, 2012; Lerman et al., 2011; Shahar, Joiner, Zuroff, & Blatt, 2004), attesting to its broad and general vulnerability status. More importantly, various investigators, primarily in Canada and Israel (e.g., Dunkley, Zuroff, & Blankstein, 2003; Mongrain, 1998; Mongrain, Vettese, Shuster, & Kendal, 1998; Shahar & Priel, 2003; Zuroff, 1992), have demonstrated that self-criticism confers *an active vulnerability* (Shahar & Priel, 2003): it is associated with stress generation, particularly in close relationships, and also "degenerates" (fails to generate) protective interpersonal factors such as positive events and social support (Mongrain, 1998; Priel & Shahar, 2000). As noted in the preceding text, it derails interpersonal relationships both within and outside treatment, thereby impeding therapeutic response (Shahar, Blatt, Zuroff, Krupnick, & Sotsky, 2004; Shahar, Blatt, Zuroff, & Pilkonis, 2003; see Shahar, 2006, see Blatt et al., 2004, for a review). The aforementioned studies attesting to the demoralizing effect of patients' self-criticism on their physician's evaluation of their prognosis exemplify this active nature of self-critical vulnerability.

In fact, we deem active person–context exchanges to be central to the understanding of the role of depression in chronic illness. In Figure 1.1, we present a tentative model describing such exchanges. As shown in the figure, CPI patients' depressive vulnerability (e.g., self-criticism, but also other vulnerabilities such as dependency, pessimism) interferes with relationships in patients' social environment (SE, namely, relationships with family members and friends), as well as with patient–provider relationships (PP), in turn leading to depression. Such an active, albeit pernicious, interpersonal cycle might be activated, or exacerbated, by the onset and fluctuations of chronic illness, and is likely to lead to depression. In turn, depression might complicate the course of chronic illness via the earlier-mentioned mechanisms including non-adherence; symptom amplification and illness intrusiveness; adverse effect on the social context; and the effect on stress, immunity, and pain processing mechanisms, leading to a vicious cycle. Indeed, extant research suggests that dysregulation of the HPA axis typical of depression (Heim, Newport, Mletzko, Miller, & Nemeroff, 2008) is associated with suppression of natural killer cell function and cell-mediated immunity, abnormal activation of innate immunity, the release of proinflammatory cytokines, often giving rise to a so-called "sickness response," a combination of feelings of lethargy, general malaise, sleepiness, concentration difficulties, headache, mild fever, and widespread musculoskeletal pain (Dantzer, O'Connor, Freund, Johnson, & Kelley, 2008).

Finally, the stress associated with CPI as well as depression also may lead to impairments in (embodied) mentalizing, i.e., the capacity to understand the (bodily) self in terms of intentional mental states. As a result, patients revert to the so-called "physical stance," being only able to see the body as a dysfunctional organism or machine, instead of the embodied seat of emotions and feelings (Luyten, Fonagy, et al., 2012; Luyten, Van Houdenhove, et al., 2012). In this mode, patients often cling desperately on to some hoped-for biological "miracle" cure, often leading to desperation in professionals and those close to the patient. Others are often seen as unsupportive, uncaring, or indifferent. Although understandable, the dramatic effects that CPI may have on patients' reflective capacities, both with regard to the

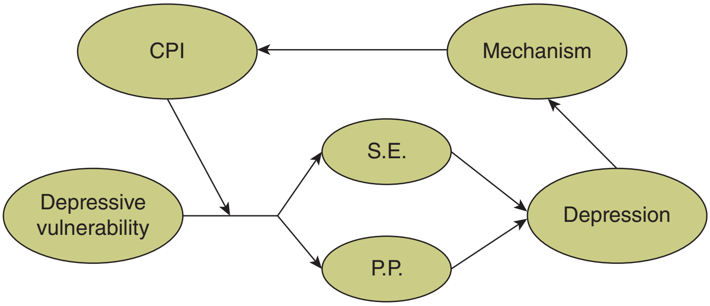

Figure 1.1 A theoretical model describing the role of depressive vulnerability and depression in Chronic Physical Illness (CPI).
Notes: CPI = chronic physical illness, S.E. = social environment, P.P. = patient–provider relationships

embodied self and others, often further puts patient–provider relationships under pressure, is associated with behaviors that perpetuate and exacerbate symptoms (e.g., catastrophizing, unhelpful illness beliefs and behaviors, increased feelings of helplessness and depression), and hinder acceptance and/or attempts to find a new balance in life.

Practice Implications and Recommendations

The implications of the active person–context exchange view on CPI and depression proposed in this chapter is that one has to adopt a person-centered and not purely disorder-centered approach to patients with CPI, attending to the complexity of interactions among psychosocial and biological factors, and between the person and his or her context (family, professionals). This necessarily requires narrative competence of the clinician (Charon, 2001): the ability to appreciate and understand the complex interactions between the patient's disease, his or her life history, and past and current (interpersonal) context.

A good screening for depression (including depression history to assess potential vulnerability for depression) is crucial in this regard, and appropriate treatment should be considered when feelings of depression exceed "normal" feelings of dejection and despondence that are associated with CPI. In addition, the focus should not only be on vulnerabilities of the individual, but also on his or her strengths and resilience. Reinforcing areas of strength and resilience in the person and/or his context may often be more important than focusing on vulnerabilities.

This is particularly true for those with high levels of self-criticism. For these individuals, normalizing possible feelings of depression and despair when confronted with CPI may already bring considerable relief, as these individuals often struggle to admit that they feel despondent. Similarly, pointing out the high emotional and interpersonal costs of attitudes and coping strategies that are associated with self-criticism (e.g., the belief that one should be able to cope with problems without the help of others) is often extremely helpful to these patients. Yet, when self-critical depressive tendencies are more persistent, patients may benefit from a range of more specialized interventions, ranging from interventions that specifically address self-criticism and related features (Arpin-Cribbie, Irvine, & Ritvo, in press; Brooks, Rimes, & Chalder, 2011; Gilbert, 2009; Mongrain & Trambakoulos, 2007; B. Shahar et al., 2012) to specialized treatments that target vulnerability for depression, such as cognitive-behavioral therapy (Beck, Rush, Shaw, & Emery, 1979) or brief dynamic therapy (Lemma, Target, & Fonagy, 2011; Luyten, Van Houdenhove, et al., 2012).

Conclusions

This chapter clearly attests to the importance of considerations concerning the role of depression in CPI. Depression can be a pernicious consequence of CPI. Also, depression can have a massive impact on the course and prognosis of CPI, both directly and indirectly thought its effect on adherence and relationships with professionals, and the patients' support system.

In addition, we have emphasized the importance of attending to possible depressive vulnerability. CPI seriously threatens the person's resources, and, particularly in those with low levels of resilience and high levels of self-criticism, this can lead to a depressive response. Psychoeducation about the impact of CPI, the effect of self-criticism on coping, and the social environment promises to lead to a more positive course. However, in severely depressed patients, appropriate treatment is indicated.

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2

Non-adherence to Medical Treatment

Christian P. Selinger and Andrew Robinson

Introduction

Advances in medical sciences have made many previously untreatable conditions controllable, if not curable. Physicians and patients alike need to engage with each other and contribute to the treatment to achieve cure or disease control. The nature of the doctor–patient relationship has, however, changed from a rather one-sided interaction to a more cooperative partnership (Akerkar & Bichile, 2004). In the past, both patients and doctors often expected a doctor to issue advice without too much time spent on taking the patients' view into consideration (Akerkar & Bichile, 2004). This advice may then have been followed (patient accepting the doctor's authority) or ignored (silent protest, but patient keen not to openly question the doctor). A more modern doctor–patient relationship is based on cooperation aiming to include the patient's perspective into the management plan, but whether this management plan is followed more often is unclear.

While highly efficacious treatments are available for many medical conditions, their real-life effectiveness is often impaired by patients not following the treatment plan (Haynes et al., 2002a). This phenomenon occurs across many medical fields and may affect drug treatments, lifestyle advice, smoking cessation, attendance for diagnostic tests, surgical interventions, and psychological treatments. For the purpose of this chapter, the authors will restrict the review on deviations from medical treatments, often using treatment for inflammatory bowel disease (IBD) as an example. IBD is a group of lifelong inflammatory disorders of the intestinal tract, requiring maintenance medication for the vast majority of patients. Due to the relapsing–remitting nature of IBD, deviations from treatment plans are very common (Selinger et al., 2011, Jackson et al., 2010). Long-term medications for

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chronic conditions require patients to stick with a treatment plan often without seeing immediate benefit. As such, deviation from treatment plans is particularly common in chronic conditions.

Definitions

Deviation from a treatment plan can be described as non-compliance, non-adherence, or non-concordance. These terms are often used interchangeably, but their detailed definitions reflect the changing nature of the doctor–patient relationship. *Compliance* is generally defined as "the extent to which the patient's behaviour matches the prescriber's recommendations," while *adherence* is defined as "the extent to which the patient's behaviour matches agreed recommendations from the prescriber." *Concordance*, in contrast, is "the extent to which the patient's behaviour matches a mutually agreed plan" (Horne et al., 2006). In clinical practice, the term "adherence" is most commonly used. Non-adherence is arbitrarily defined by a cut-off of 80%, which has been accepted internationally and is widely used in many studies (Shale & Riley, 2003, Kane & Robinson, 2010).

Compliance, adherence, and concordance are usually measured for an individual patient or a group of patients at a specific point in time, while in contrast persistence is measured as the percentage of patients remaining on therapy over time. Persistence studies usually stem from large healthcare provider databases, which hold limited data on demographics and disease specifics. Therefore, persistence studies rarely account for the reason for non-persistence. Deceased patients, patients intolerant to a drug, or those no longer in need of a drug are all counted as non-persistent, while adherence studies largely aim to only include patients with an ongoing indication. However, as persistence is usually measured across a large prescription database, it offers examination of larger patient cohorts.

How to Detect Non-adherence?

Non-adherence is rarely detected during routine clinical encounters. Doctors struggle to identify patients non-adherent to treatment (Trindade et al., 2011), as there is a general tendency to overestimate adherence. Simply asking "Do you take all of your medication?" is at best a blunt method and may, at worst, offend the patient. More detailed and personalized questioning may detect non-adherence, but is generally time intensive and not validated. Visual analog scales and validated assessment tools such as the medicine adherence report scales (MARS) are simple tools that can be used in routine clinical setting or research. They offer a scale of possible answers and therefore can produce reliable results in contrast to Yes/No answers. Such self-report tools can miss non-adherence if patients report incorrectly, but this is not a frequent problem (Moshkovska et al., 2009). The main advantage of these

Table 2.1 Tools available for measuring adherence in research and routine clinical practice.

Method	*Validated*	*Objective*	*Time intensive*	*Price*	*Practical in routine practice*
Metabolite level from urine or blood sample	Yes	Yes, but: not for partial adherence false positive if meds only taken around visits	Yes	High	In specialist setting
Tablet counts	Yes	Yes, but no guarantee meds have been taken	Yes	Low	No
Pharmacy refills	Yes	Yes, but no guarantee meds have been taken	Yes	Low	No
Unstructured interview	No	No: recall bias patient may not want to "disappoint"	Yes	Medium	Yes
Questionnaires / visual analog scales	Yes	Yes, but: recall bias patients may report incorrectly	No	Low	Yes
Electronic pill bottle sensors	Yes	Yes, but no guarantee meds have been taken	No	High	No

tools lies in their speed and ease of use, thereby allowing for use in routine clinical encounters. Drug and metabolite levels offer objective assessments, but are expensive, and not universally available. While total non-adherence is easily detectable, intermediate levels may relate to differences in metabolism between patients rather than adherence. Pharmacy refills and electronic bottle opening recorders are methods restricted for use in research.

Extent across Medical Fields

Non-adherence occurs in many medical fields, but is most prominent in chronic conditions requiring maintenance therapy. Often, no immediate short-term benefit is derived from maintenance therapy, and, as many patients feel well, non-adherence may occur. Depending on the condition, consequences of non-adherence – for example, a stroke from hypertension or a flare from IBD – may only occur after some time, thereby providing no feedback on the negative effects of non-adherence to the patient.

Patients with chronic respiratory disorders are also often non-adherent to medication (40–80% for chronic obstructive pulmonary disease (COPD) and up to 78% for asthma (Axelsson & Lötvall, 2012). Diabetic patients fail to adhere to anti-hyperglycemic agents in over a third of cases and to preventative statin therapy aimed at reducing cardiovascular risk in nearly 50% (Yang et al., 2009). Non-adherence to maintenance medication for IBD occurs in a third of patients (Selinger et al., 2011).

Non-adherence to antiviral medication is of great importance as even adherence rates of 80%, which are considered good for most other conditions, may lead to the emergence of resistant viruses. Hence, most researchers define good adherence for antiviral medications as adherence in excess of 90%, or even 95%. Patients with hepatitis B are non-adherent in at least 33% of cases (Giang et al., 2012). Non-adherence to antiviral medication for HIV/AIDS occurs in at least 15% of patients (Kastrissios et al., 1998).

Non-adherence is also common among psychiatric patients requiring maintenance medication, and 20–60% of patients suffering from bipolar disorders fail to adhere (Pompili et al., 2009).

Consequences of Non-adherence

Patients non-adherent to a medication can obviously not derive any benefit from it. Not every patient with, for example, hypertension will however develop a complication directly associated with it – for example, a stroke. The negative effects of non-adherence can therefore not be automatically assumed. In the field of IBD, it has been shown that patients non-adherent to medication are significantly more likely to experience a flare than adherent patients (Kane et al., 2003). The risk of IBD associated colorectal cancer is also much lower in adherent patients (Moody et al., 1996). Finally, despite higher costs for medication, overall healthcare costs are much lower for adherent patients as they require less emergency hospital care (Kane & Shaya, 2008). Patients suffering from COPD have worse functional outcomes, increased mortality, and higher healthcare costs if they are non-adherent (Agh et al., 2011).

Non-adherent patients suffering from bipolar disorders have worse clinical outcomes than adherent patients with higher rates of relapse, hospital admission, and suicide attempts (Colom et al., 2005, Hong et al., 2011). This in turn leads to significantly higher overall healthcare costs (Colom et al., 2005).

The real-life effectiveness of medication is often lower than as could be expected from clinical trial data, which is at least partly attributable to poor adherence. It has been suggested that addressing non-adherence may improve population-based outcomes to a greater extent than a newly developed drug (Haynes et al., 2002b). More effective use of existing medication should therefore be a priority in routine clinical management.

Intentional versus Non-intentional Non-adherence

It is important to differentiate between intentional and non-intentional non-adherence. The latter may be related to external circumstances beyond the influence of the patient, which may include availability of medication (in some countries) or the patient's inability to pay for medication (in non-universal healthcare systems). Most non-intentional, non-adherent patients, however, simply forget to take the medication. This might affect elderly patients and those with memory problems, but could also be common in busy patients with a hectic life style. Memory aids and pill dispensing boxes can help forgetful patients, but will make little difference to patients who actively choose not to adhere to medication. Differentiation between intentional and non-intentional non-adherence can be difficult, as some patients will state forgetfulness as their reason for non-adherence, in the belief that this is more acceptable than intentional non-adherence (Giang et al., 2012). Forgetfulness is a mix of a cognitive and a motivational process, thereby representing a more complex challenge than the simple lack of a reminder (Giang et al., 2012). Furthermore, a recent study revealed that "unintentional" non-adherence is associated with beliefs about medicine and predicts future intentional non-adherence (Gadkari & McHorney, 2012). It is therefore doubtful that strict differentiation between intentional and unintentional non-adherence is of clinical value.

Risk Factors for Non-adherence

Many studies have previously examined non-modifiable risk factors for non-adherence, thus, for example, suggesting that being single, being male, in full-time employment, and in clinical remission increase the risk for non-adherence in patients with IBD (Jackson et al., 2010). Some studies shave reported that patients from ethnic minorities and those with multiple comorbidities are at greater risk of non-adherence (Giang et al., 2012; Yang et al., 2009). These are, however, often contradictory and offer little for the practicing clinician. At best, non-modifiable risk factors allow for the better identification of non-adherent patients (Figure 2.1).

Access to medication may be difficult for patients who have to shoulder the majority of medication costs themselves. In countries with universal cover for medication costs, small gap fees do not seem to influence adherence, however (Agh et al., 2011). Financial pressures are an important risk factor for non-adherence in countries with self-funded healthcare systems, and patients with low incomes are more often non-adherent (Piette et al., 2011). However, poorer patients persist

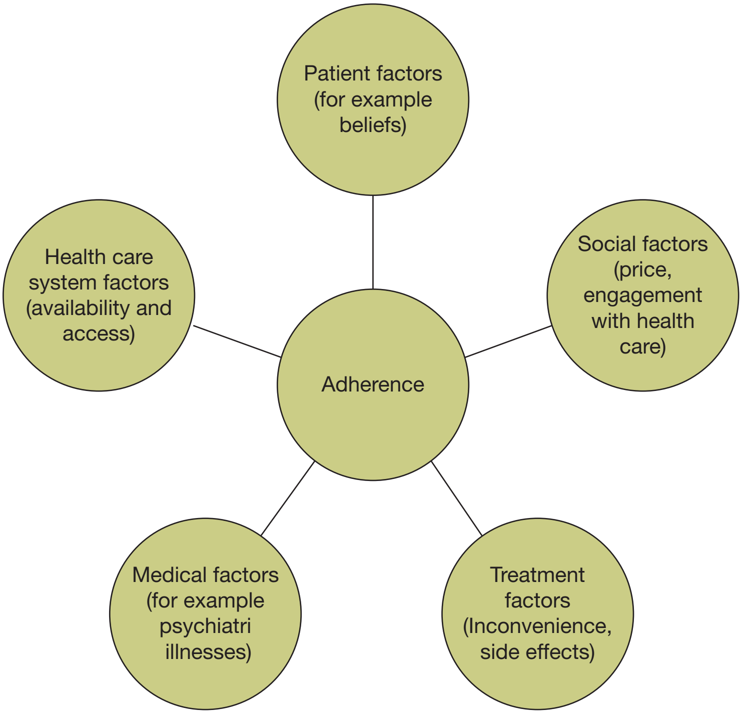

Figure 2.1 Multi-factorial model of adherence.

despite financial difficulties, and richer patients may become non-adherent for financial reasons (Piette et al., 2011). This highlights the complexity of non-adherence, which needs to be taken into account by physicians.

Modifiable risk factors, in contrast, may not only increase our understanding of non-adherence, but also offer potential targets for interventions. Disease-related patient knowledge, anxiety and depression, belief toward medication, administration of drugs (hospital infusion versus community injection), frequency of administration (once daily versus multiple daily doses), and membership in a patient support organization are all potential modifiable risk factors.

Disease-related patient knowledge

While an older study found that education improved adherence in schizophrenic patients, two studies have found no association between disease-related patient knowledge and non-adherence in patients with IBD. Furthermore, an interventional study improved knowledge but not adherence (Waters et al., 2005). General disease education may, therefore, not have a great influence on adherence.

Anxiety and depression

Some studies have found that a formal diagnosis of a psychiatric illness is associated with non-adherence, but in more recent studies greater anxiety or depression levels are often not associated with non-adherence.

Belief toward medication

Patients' beliefs toward their medication can be easily assessed using the necessity–concerns framework, by determining the patients' belief of need for the medication and concerns over possible rather than actually experienced side effects. The beliefs toward medication have been shown to significantly influence adherence across a range of diseases including asthma, IBD, etc. Non-adherent patients have both a lower belief of necessity and a greater concern over possible side effects. Patients can be categorized according to their beliefs into "accepting," "ambivalent," "indifferent," and "skeptical" attitude groups (see Table 2.2). Adherence falls significantly in this order (Horne et al., 2009). The importance of the belief of necessity and concerns about side effects have been using different assessment tools replicated by large-scale studies among a variety of chronic illnesses (Piette et al., 2011). An intervention changing the beliefs toward medication may therefore also improve adherence.

Mode and frequency of administration

For some drug classes, a choice of different administration or daily dosing regimens exists. Less frequent daily dosing and hospital-administered drugs have been associated with better adherence in some, but not all studies. While less frequent daily dosing in COPD patients is associated with better adherence (Agh et al., 2011), this was not the case in IBD patients (Selinger et al., 2013). A simplification of the treatment regimen (where feasible) may help adherence, but rarely in itself will improve adherence significantly.

Table 2.2 Attitudes and beliefs toward medication.

Group	*Adherence*	*Belief of necessity*	*Concerns about potential side effects*
Accepting	Highest	High	Low
Ambivalent	High	High	High
Skeptical	Low	Low	High
Indifferent	Low	Low	Low

Patient support organizations

Members of patient organizations experience peer support, have access to a professional support network, and receive regular educational and motivational material. Such support may explain why members have better adherence levels than non-members, but it is also conceivable that patients who join these organizations take greater responsibility for their disease management in the first instance. As membership is inexpensive, all patients with chronic illnesses should be advised to join relevant disease-specific patient support groups.

Physician-related factors

The nature of the doctor–patient relationship may significantly influence adherence. Patients having more trust in their doctor and reporting to have a better relationship also have better adherence rates (Jackson et al., 2010). A doctor's communication skills, empathy, interaction may influence patient adherence, demonstrated by a large study reporting significant differences in adherence rates between the patients of different physicians (Sherman et al., 2011).

Should Physicians Address Non-adherence?

As demonstrated, non-adherence, which is widely prevalent across all medical fields, is associated with adverse medical outcomes and overall increased healthcare costs. Better adherence should therefore lead to better health outcomes and better use of restricted funds available for healthcare. This undoubtedly makes a strong argument for trying to improve adherence overall.

On the other hand, the patient's right of self-determination is one of the highest goods in modern society. Informed consent is required for all medical investigations and treatments, and practitioners have to respect a patient's decision (Selinger, 2009). Irrational decisions about treatments are in themselves not indicative of a lack of mental capacity and can be perfectly legally valid (Selinger, 2009). It could therefore be argued that physicians should accept non-adherence as a valid although non-rational patient decision and not aim to improve adherence.

To examine the validity of this argument, focus needs to be placed on informed consent, which requires the patient to understand and weigh up the information necessary to make a decision (Selinger, 2009). Non-adherence can be associated with poor patient knowledge of the underlying health issues and lack of belief for the necessity of treatment as well as increased concerns about side effects. These views are often contrary to medical facts, and patients may therefore not be fully informed when they become non-adherent. The authors argue that it is therefore morally and ethically important to aim to improve non-adherence rather than to accept it as a given fact.

Interventions to Improve Adherence

Despite the near-universal occurrence of non-adherence, relatively little emphasis has been placed on improving adherence. Guidance and review articles often rely on expert opinion and extrapolation of data rather than solid evidence. Furthermore, the few existing studies are often of poor quality and rarely report on intervention easily implementable in routine clinical care. Indeed, a Cochrane review concluded in 2002 that most interventions are either ineffective or too complicated (Haynes et al., 2002a).

It is important to differentiate between interventions aimed at preventing non-adherence in the first instance (i.e., programs for all patients) and interventions aimed at improving adherence in patients who have already become non-adherent. Programs trying to prevent non-adherence need to address many patients, and therefore need to be simple and reasonably cheap to implement. Examples may include web-based support programs or reminder services using text messaging.

Simple interventions such as weekly reminders by an automated text messaging service have been shown to improve adherence in two randomized controlled trials from Kenya with patients suffering from HIV (Horvath et al., 2012).

A trial of a "multifaceted" intervention in IBD patients was successful, but the intervention itself was rather ill-defined and all patients only received parts of the offered package (Moshkovska et al., 2011). Hence, it remained unclear what part of the intervention worked and how to implement the study findings.

Education may play a role in improving adherence in some diseases (schizophrenia), but is unlikely to succeed in other areas such as IBD. General disease-related education can play an important role for self-management (Robinson et al., 2001), but has in all likelihood not a great effect on adherence. Several educational strategies to improve adherence to asthma medication have shown initial promise, but the studies' designs were not robust enough to fully assess the effects (Axelsson & Lötvall, 2012).

A close support system using nurse-led or Internet-based support may improve adherence in some patients, but the evidence is currently too weak to suggest general implementation. Furthermore, the practicality of a time-intensive person-led support program is doubtful. Internet-based approaches to improve medication use and adherence have been tested for diabetic patients and for those with asthma. Such programs offer assessment of patients' situations and beliefs, which is then followed by targeted information based on the patient's personal situation. As such, relevant content can be delivered in a fast and cost-effective manner. These approaches have been able to reduce non-adherence in a number of studies (Linn et al., 2011). With the increasing use of the Internet in all aspects of life, such programs may come to play an important role in future healthcare.

Once non-adherence has occurred, a different and more targeted approach may be required. Personal face-to-face drug counseling by professionals, based on addressing the individual beliefs toward medication, may alter the underlying issues for adherence and, thereby, later, adherence itself. It can be tailored much better to the individual patient than computer-based approaches, and may therefore offer better counseling. Furthermore, the collaboration with the counselor is more interactive and may be better suited to help anxious patients. Trials are currently underway to test the feasibility and efficacy of such an approach.

While Internet-based approaches can be applied to large numbers of patients and therefore maybe be best placed to prevent non-adherence, personal counseling may be best placed to treat already non-adherent patients.

Advice for Clinicians

Awareness of non-adherence is of critical importance. Many clinicians will find the thought that many of their patients choose not to follow their advice uncomfortable. It is all too natural a response to not believe that one's own patients may be non-adherent. Only once non-adherence has been accepted as a normal phenomenon by clinicians will it be possible to address the problem. Adherence should be part of the routine assessment for patients experiencing treatment failures such as flares; there may even be ground for routine adherence testing of all patients. A non-judgmental attitude toward non-adherent patients can help avoid disturbances of the doctor–patient relationship and should build the basis for future care. Visual analog scales or MARS are easy to use and allow for widespread screening for non-adherence.

Unfortunately, there is currently little evidence to guide clinicians aiming to improve adherence. The authors suggest an assessment of the patient's understanding of the concept of long-term medication; in other words, whether the patient understands that medication may aim to keep him or her well rather than to treat active symptoms. Assessing the beliefs toward medication can unravel the reason for non-adherence and guide the consultation. Addressing specific concerns may improve adherence and beliefs alike.

Medical research has yet to answer many questions regarding the understanding and treatment of almost all long-term conditions. Great hope has been placed on the potential discovery of more effective and less harmful medications. It is important to remind clinicians that, often, very effective treatment plans may not bring the intended results due to non-adherence. Non-adherence remains one of the biggest challenges of modern medicines. There is a need for recognition of this problem, so that appropriate attempts to improve adherence can be made.

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3

Placebo and Nocebo Effects

Elisa Carlino and Fabrizio Benedetti

Defining Placebo and Nocebo Effects

Two terms are commonly encountered in the placebo literature: *placebo effect* and *placebo response*. Although they are often used interchangeably, they refer to different concepts. The placebo effect is that observed in the placebo arm of a clinical trial, and is produced by the real placebo psychobiological phenomenon in addition to other potential factors contributing to symptom amelioration, such as spontaneous remission, regression to the mean (a statistical phenomenon whereby the second measurement of a symptom is likely to yield a value nearer to the average, i.e., an improvement), biases, and judgment errors. The placebo response, on the other hand, designates the real psychobiological phenomenon in isolation, as can best be studied in specifically designed experimental protocols (Benedetti, 2008a). Despite these differences in definition, many authors use the words "placebo effect" and "placebo response" as synonymous.

The definition of *nocebo effect*, or *nocebo response*, also needs to be stated precisely. The term "nocebo" was originally introduced to designate noxious effects produced by a placebo, for example, side effects of the drug that the placebo is substituting for (Pogge, 1963). In this instance, however, the negative outcome is produced despite an expectation of benefit. True nocebo effects, on the other hand, are always the result of negative expectations – specific (e.g., increase in pain perception after treatment interruption) or generic (e.g., a pessimistic attitude).

Therefore, placebos are not inert substances, as thus far believed. They are made of words and rituals, symbols and meanings, and all these elements are active in shaping the patient's brain. Inert substances, such as saline solutions, and inert treatments, such as sham surgery, have long been used in clinical trials and

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double-blind randomized protocols in order to assess the efficacy of new therapies. Although inert substances are of great validity in the clinical trial setting, the clinical trialist has always drawn his or her attention on the inert substance itself, thus diverting it from the real meaning of placebo (Moerman, 2002). The placebo is not the inert substance alone, but rather its administration within a set of sensory and social stimuli that tell the patient that a beneficial treatment is being given. Drawing attention to the inert substance is correct in pragmatic clinical trials, in which the only purpose is to see whether drugs are better than placebos, but this approach does not help understand what a placebo is (Benedetti, 2008b).

A real placebo effect, or response (we will use these two words as synonymous throughout this chapter), is a psychobiological phenomenon occurring in the patient's brain following the administration of an inert substance, or of a sham physical treatment such as sham surgery, along with verbal suggestions (or any other cue) of clinical benefit (Price, Finniss, & Benedetti, 2008). Therefore, the effect that follows the administration of a placebo cannot be attributable to the inert substance alone, for saline solutions or sugar pills will never acquire therapeutic properties. Instead, the effect is due to the psychosocial context that surrounds the inert substance and the patient. In this sense, the term "placebo effect/response" has different meanings for the clinical trialist and the neuroscientist. Whereas the former is interested in any improvement that may occur in the group of patients who take the inert substance, regardless of its origin, the latter is only interested in the improvement that derives from active processes occurring in the patient's brain. In fact, as already mentioned in the preceding text, the improvement in patients who are given a placebo can be ascribed to a vast array of factors, such as spontaneous remission of the disease, patients' and doctors' biases, and unidentified effects of co-interventions. In pragmatic clinical trials, the trialist is interested in the improvement irrespective of its cause, because he or she only needs to establish whether the patients who take the true treatment, be it pharmacological or not, are better off than those who take the placebo. Conversely, if we are interested in understanding what a real placebo effect is and how it works, we need to separate it from other factors such as spontaneous remissions and biases (Figure 3.1) (Benedetti, 2008b).

Taking all these considerations into account, this review deals only with a portion of the improvement that may take place in the placebo group of a clinical trial, that is, the improvement due to active processes in the patient's brain (the real psychobiological placebo response). It is possible to rule out other phenomena by using the appropriate methodological approach. For example, in order to rule out spontaneous remission, the placebo group must be compared with a no-treatment group, which gives us information on the natural history of the disease. Likewise, in order to rule out biases, such as those that may occur in subjective symptoms such as pain, objective outcome measures must be assessed. From this methodological perspective, placebo research is not easy to perform, for it requires rigorous experimental protocols and plenty of control groups.

Within the context of behavioral medicine, it is surely more interesting to approach the placebo effect from a psychological and biological perspective, rather

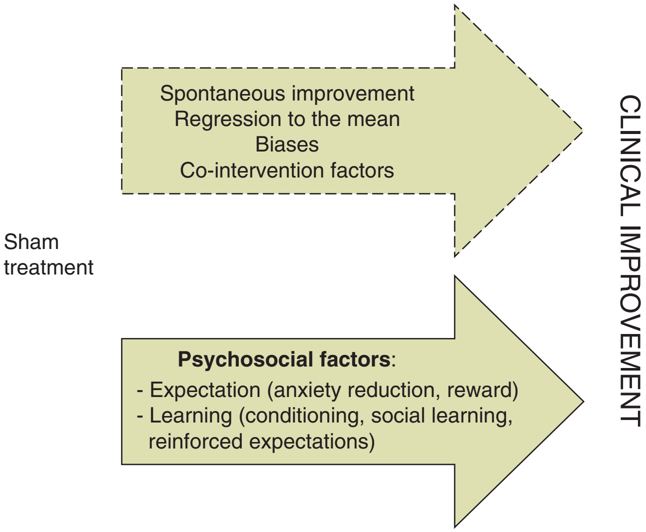

Figure 3.1 The clinical improvement that takes place after the administration of a sham (or placebo) treatment is due to many factors. However, the real placebo effect or placebo response is only the improvement due to psychosocial factors.

than from a methodological point of view in the clinical trials setting. In fact, as complex cognitive factors such as expectations are involved in this phenomenon, the psychological and neuroscientific study of the placebo response represents an excellent model to understand different higher brain functions; the intricate links between mind, brain, and body; as well as the factors that affect the doctor–patient relationship and the therapeutic outcome.

The Psychological Approach

Different explanatory mechanisms have been proposed for both placebo and nocebo effects, each supported by experimental evidence. They need not be mutually exclusive, and can actually be at work simultaneously (Figure 3.2).

The first theory considers the placebo effect as an example of classical conditioning. The repeated co-occurrence of an unconditioned response to an unconditioned stimulus (e.g., salivation after the sight of food) with a conditioned stimulus (e.g., a bell ringing) induces a conditioned response (i.e., salivation that is induced by bell ringing alone). Likewise, aspects of the clinical setting (e.g., color, taste, shape of a pill, as well as concurrent aspects of the therapeutic environment, such as white coats) can also act as conditioned stimuli, eliciting a therapeutic response in the absence of an active principle, just because they have been paired with it in the past (Wickramasekera, 1985; Siegel, 2002; Ader, 1997). Similarly, a conditioned response can also occur for a nocebo effect. For example, nausea can be elicited by the sight

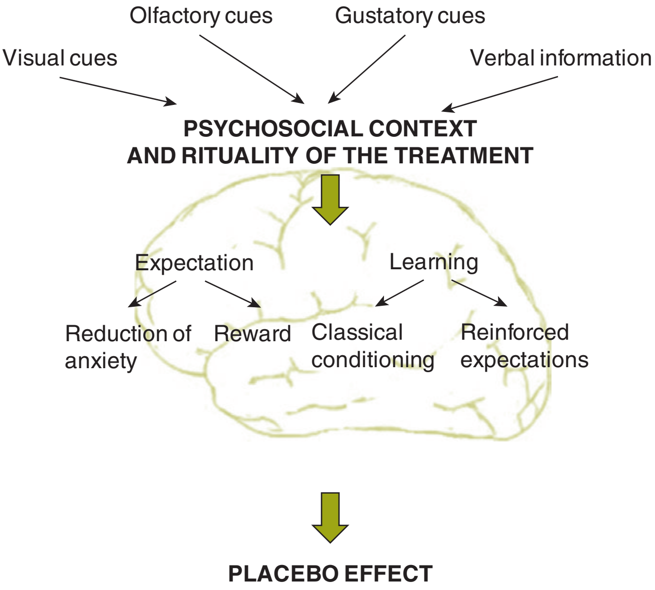

Figure 3.2 Different mechanisms and factors are at play in generating the placebo effect. Expectation and learning are the most studied and understood.

of an environment where chemotherapy has been administered in the past. According to the cognitive theory of conditioning, conscious expectations are also involved: indeed, the pairing between conditioned and unconditioned stimuli can lead to the expectation that a given event will follow another event, and this occurs on the basis of the information that the conditioned stimulus provides about the unconditioned one (Reiss, 1980; Rescorla, 1988).

Conditioning has been used in many placebo studies. For example, Voudouris and colleagues paired a placebo analgesic cream with a painful stimulation, which was surreptitiously reduced with respect to a baseline condition to make the subject believe that the cream was really effective. Direct comparison between a conditioned and an unconditioned group showed that pain reduction following conditioning was invariably larger, indicating the effectiveness of conditioning in mediating a placebo response (Voudouris, Peck, & Coleman, 1990).

Conditioning seems to be the sole mechanism involved in the generation of the placebo response in the case of those physiological functions that are only unconsciously controlled, like those involving the immune or the endocrine systems. Thus, placebo modulation of growth hormone (GH) and cortisol secretion could be obtained after conditioning with sumatriptan (a selective 5-HT$_{1B/1D}$ receptor agonist stimulating GH and inhibiting cortisol secretion). However, it was impossible to induce the same modulation by suggestion alone, in the absence of conditioning. It was also not possible to reverse the modulation achieved by conditioning by inducing in the subjects the opposite expectation by verbal instruction. Notably, it was indeed possible to exert this counteracting effect with the induction of opposite expectations in the case of placebo analgesia/hyperalgesia, where cognitive conscious processes play an important role (Benedetti et al., 2003).

Immune functions have also been repeatedly conditioned, both in animals and in humans. For instance, in multiple sclerosis patients, decrements in peripheral leukocyte counts induced by cyclophosphamide could be conditioned by pairing the drug with a strongly flavored beverage (Giang et al., 1996), and more recently, in healthy subjects, a similar conditioning with cyclosporine A produced immunosuppression after placebo, as assessed by depressed mRNA expression of IL-2 and interferon-gamma, and lymphocyte proliferation (Goebel et al., 2002), mediated (at least in rodents) by calcineurin inhibition (Pacheco-López et al., 2008). Recently, much work has been devoted to the identification of the neural structures involved centrally (amygdala, insular cortex, hypothalamus) and peripherally (cholinergic and catecholaminergic output in the autonomic nervous system) in conditioned immunosuppression (Pacheco-López et al., 2005).

The second explanation centers on expectations, generated as the product of cognitive engagement, when the patient consciously foresees a positive/negative outcome, based on factors such as verbal instructions, environmental clues, emotional arousal, previous experience, and the interaction with care providers. This anticipation of the future outcome in turn triggers internal changes resulting in specific experiences (e.g., analgesia/hyperalgesia). By grading the degree of expectation, graded responses can be obtained: the same placebo cream applied onto three contiguous skin areas induces a progressively stronger analgesia, according to the strength of the accompanying words (Price et al., 1999). This is true also in the clinical setting, where changing the symbolic meaning of a basal physiological infusion in postoperative patients resulted in different additional painkiller requests. In spite of all patients receiving a physiological solution, those who believed that they would receive an analgesic drug demanded significantly less pain reliever than those who believed that they would receive no analgesic at all. An intermediate level of certainty in those believing to have a 50% chance to receive the drug resulted in an intermediate request (Pollo et al., 2001).

The expectation of forthcoming pain can further be modulated by a number of emotional and cognitive factors, such as desire, self-efficacy, and self-reinforcing feedback. Desire is the experiential dimension of wanting something to happen or wanting to avoid something happening (Price, Finniss, & Benedetti, 2008), while self-efficacy is the belief to be able to manage the disease, performing the right actions to induce positive changes, for example, to withstand and lessen pain. Self-reinforcing feedback is a positive loop whereby the subject selectively attends to signs of improvement, taking them as evidence that the placebo treatment has been successful. This has sometimes been termed the "somatic focus." It is the degree to which individuals focus on their symptoms (Price, Finniss, & Benedetti, 2008).

A related proposed mechanism posits that anxiety reduction also plays a role in placebo responses, because the subject interpretation of ambiguous sensations is turned from harmful and threatening to benign and unworthy of attention.

Accordingly, Vase and coworkers showed decreased anxiety levels in patients with irritable bowel syndrome who received a placebo treatment (Vase, Robinson, Verne, & Price, 2005).

A particular type of expectation that contributes to the genesis of placebo effects is the expectation of reward. Our brain is endowed with a so-called reward system, which, through the activation of the mesolimbic and mesocortical pathways and the release of dopamine, fulfills its natural task of providing pleasurable feelings in response to life-sustaining functions, such as eating, drinking, or having sex, in order to encourage the repetition of those functions. Placebos have reward properties as well, and these are associated with the beneficial outcomes they provide. In other words, the expected clinical benefit is a form of reward that triggers the placebo response (Lidstone, & Stoessl, 2007).

Recently, medical anthropologists have proposed a constructionist view of the placebo experience, which has at its core the concept of embodiment. According to this idea, the human mind is strongly influenced and shaped by aspects of the body, such as the sensory systems and interactions between the environment and the society. Thus, our experiences can not only be consciously stored as memories, but also imprinted straight onto our body, without involvement of any cognitive process. According to this theory, the placebo effect is a positive effect of embodiment, and the nocebo effect is a negative one. Lived positive experiences can be channeled into objects or places, which then acquire the potential to trigger healing responses. Importantly, this process need not involve conscious expectation or conscious attribution of symbolic meaning to the object or place (Thompson, Ritenbaugh, & Nichter, 2009).

All the mechanisms described in the preceding text may contribute to a given placebo or nocebo effect, with varying weight and reciprocal influence in different contexts. For example, both conditioning and expectation can be triggered independently in the same experimental protocol, and their effects are additive (Amanzio, & Benedetti, 1999).

The Biological Approach

The discovery that endogenous opioids are released following a sham treatment in the nervous system can be regarded as a landmark achievement in understanding the biology of the placebo response. Until the late 1970s, when Levine and colleagues first showed that the opiate antagonist naloxone was able to reduce the placebo response in dental postoperative pain (Levine, Gordon, & Fields, 1978), the placebo effect was only considered as a nuisance that had to be taken into account in order to properly assess the effects of medicaments in clinical trials. However, Levine's and subsequent work in the 1980s and 1990s left little doubt that specific biochemical events were taking place after placebo administration. Among the relevant findings, placebo responders were found to have levels of β-endorphin in the cerebrospinal fluid that were more than double those of non-responders (Lipman et al., 1990); opioids released by a placebo procedure displayed the same side effects as exogenous opiates (Benedetti, Amanzio, Baldi, Casadio, & Maggi, 1999); naloxone-sensitive cardiac effects could be observed during placebo-induced expectation of analgesia (Pollo, Vighetti, Rainero, & Benedetti, 2003). Indirect support also came from the placebo-potentiating role of the colecystokinin (CCK) antagonist proglumide. In fact, the CCK system effects counteract those of opioids, delineating a picture where the placebo effect seems to be under the opposing influence of facilitating opioids and inhibiting CCK (Benedetti, Amanzio, & Maggi, 1995; Benedetti, Amanzio, & Thoen, 2010).

The opioid antinociceptive system is certainly the best documented in different placebo studies, but not the only one implicated. Knowledge of other systems is scarce, but their existence emerges from the fact that, in some situations, a placebo effect can still occur after blockade of opioid mechanisms by naloxone (Gracely, Dubner, Wolskee, & Deeter, 1983; Grevert, Albert, & Goldstein, 1983; Vase, Robinson, Verne, & Price, 2005). It seems that different agents can bring about different placebo effects. For example, with a morphine conditioning and/or expectation-inducing protocol, Amanzio and Benedetti could, with naloxone, completely reverse placebo analgesia induced in experimental ischemic arm pain. With the use of ketorolac, a non-opioid analgesic, in the same protocol, however, only a partial blockade was observed (Amanzio & Benedetti, 1999). Recently, an important non-opioid component of placebo analgesia has been identified, and this is represented by the endocannabinoid system (Benedetti, Amanzio, Rosato, & Blanchard, 2011).

Along a different line of research, dopamine has also been suggested as a putative substance involved in placebo analgesia. The placebo response was first linked to this neurotransmitter after observations in Parkinson's disease, where it usually takes the form of motor improvement following the administration of an inert substance that the patient "believes" to be an effective anti-Parkinsonian drug. Here, it is mediated by dopamine release in the *dorsal* striatum, a key structure in the motor circuit affected by the disease (de la Fuente-Fernández et al., 2001). However, it must be noted that dopamine is also released in the *ventral* striatum, notably in the nucleus accumbens, involved in the reward circuit. Contrary to the dorsal striatum, release in ventral striatum was not correlated with the experienced clinical benefit, leading the authors to suggest that this release might be related to the expectation of reward, rather than to reward itself (de la Fuente-Fernández et al., 2002, de la Fuente-Fernández & Stoessl, 2002). As such, this dopamine mechanism might not be limited to effects in Parkinson's disease, but could be a generalized process underlying all placebo responses. For example, in a study combining placebo analgesia and a monetary reward task, it was demonstrated that the subjects with stronger nucleus accumbens synaptic activation (as measured by functional magnetic resonance imaging, fMRI) during the monetary reward anticipation also showed more robust placebo responses and greater dopamine activity in the same nucleus (as measured with dopamine-agonist [11C]raclopride positron emission tomography, PET) (Scott et al., 2007). Moreover, in a subsequent PET study using the μ-opioid receptor-selective radiotracer [^{11}C] carfentanil and [11C]raclopride, both opioid and dopamine neurotransmission were assessed with a pain placebo procedure. It was found that they were both coupled with the placebo response, with changes of activity induced in several brain regions associated with the opioid and dopamine networks (Scott et al., 2008).

Besides all this pharmacological approach, positron emission tomography (PET), functional magnetic resonance imaging (fMRI), magneto-electroencephalography (MEG), and electroencephalography (EEG) have all been usefully employed to characterize the spatial and temporal domains of placebo analgesia (Rainville, & Duncan, 2006; Kong, Kaptchuk, Polich, Kirsch, & Gollub, 2007; Colloca et al., 2008).

Reduced pain-related brain activation during placebo analgesia has been repeatedly and independently reported in many studies, often with strict correlation with psychophysical pain measures, supporting the view that, during placebo analgesia, what is altered is not the evaluation of an unchanged incoming pain information, but rather a direct modulation of nociceptive afferent signals (Wager et al., 2004; Lieberman et al., 2004; Koyama, McHaffie, Laurienti, & Coghill, 2005; Bingel, Lorenz, Schowll, Weiller, & Buchel, 2006; Kong et al., 2006; Watson et al., 2009). Areas of the pain matrix showing decreased activation include thalamus, insula, rACC, primary somatosensory cortex, supramarginal gyrus, and left inferior parietal lobule. For example, in irritable bowel syndrome patients, by long-duration rectal distension with a balloon barostat, Price and colleagues showed that placebo analgesia was accompanied by reductions in brain activity similar to those resulting from lowering the strength of stimulation (in the thalamus, somatosensory cortex, insula, and ACC) (Price, Craggs, Verne, Perlstein, & Robinson, 2007). Notably, this study was conducted on a clinically relevant model of placebo analgesia and showed large placebo effects. Scalp laser-evoked potentials' (LEPs) amplitude was also found to be reduced during the placebo analgesic response, namely in the N2-P2 components, thought to be originated in the bilateral insula and in the cingulate gyrus (Wager, Matre, & Casey, 2006; Watson, El-Dereby, Vogt, & Jones, 2007; Colloca et al., 2008).

Modulation of pain-related neural activity by placebo has been shown to extend down to the spinal cord level. Recently, an elegant study demonstrated the direct involvement of the spinal cord in placebo analgesia, by showing with fMRI that the responses to painful heat stimulation are reduced under placebo analgesia in the ipsilateral dorsal horn (Eippert, Finsterbusch, Bingel, & Büchel, 2009).

Data from imaging studies neatly converge with the neuropharmacological evidence described earlier to support the model of the recruitment of the descending pain inhibitory system to negatively modulate pain processing during the placebo response. The first indication came from a PET study measuring regional cerebral blood flow (rCBF) in healthy volunteers, which showed overlapping of opioid-induced (by the μ-agonist remifentanil) and placebo-induced analgesia, with similar activation of the rostral anterior cingulate cortex (rACC) and the orbital cortex by pharmacological or psychological means (Petrovic, Kalso, Petersson, & Ingvar, 2002). Direct demonstration of endogenous opioid release was obtained 3 years later in another PET study, in which the radiotracer [^{11}C] carfentanil was displaced by the activation of opioid neurotransmission, showing significant binding decrease after placebo in pregenual rACC, insula, nucleus accumbens, and dorsolateral prefrontal cortex (DLPFC). In all areas except DLPFC, this decrease was correlated with placebo reduction of pain intensity reports (Zubieta et al., 2005). Observations along the same line were also made by Wager and colleagues in a PET study with in vivo receptor binding, where they reported potentiation of endogenous opioid responses during placebo analgesia (Wager, Scott, & Zubieta, 2007).

Focusing strictly on the pain anticipatory phase, i.e. on the time lag between the display of a cue signaling the impending pain stimulus and the delivery of the stimulus, Wager and coworkers observed an increase in DLPFC activity, negatively correlated with the signal reduction in thalamus, ACC, and insula and with reported pain intensity, but positively correlated with increase in a midbrain region containing the PAG (Wager et al., 2004). Further support for a link between limbic areas and the PAG came from a connectivity analysis showing correlation between the activation of rACC and that of PAG and bilateral amygdala (Bingel et al., 2006). In a recent paper, the same authors also showed strict opioid-specificity of this coupling, which was abolished by naloxone administration (Eippert et al., 2009).

By piecing together all these data, a central role for cognitive and evaluative processes seems to emerge, whereby the prefrontal cortex (namely, the DLPFC) could drive the activation of the descending antinociceptive system just before the onset of placebo analgesia. Watson et al. (2009) and Lui et al. (2010) further elaborated on the specific role of the prefrontal cortex in the anticipation phase. By fMRI, they specifically analyzed anticipatory brain activity before a painful stimulus, during placebo conditioning (with stimulus intensity surreptitiously reduced) and during placebo analgesia (with stimulus intensity restored to the initial level). They found that the same areas were modulated during placebo conditioning and placebo analgesia – DLPFC, medial frontal cortex, and the anterior mid-cingulate cortex (aMCC), with the addition of the orbitofrontal cortex (OFC) in placebo analgesia.

Therefore, the prefrontal regions seem to play a key role in placebo analgesia. This notion is supported by additional studies. For example, in Alzheimer's disease patients, loss of placebo responses on one hand and reduction of connectivity between the prefrontal lobes and the rest of the brain on the other progressed in parallel (Benedetti et al., 2006). In addition, transitory inhibition of excitability in the prefrontal cortex, as can be obtained by repetitive transcranial magnetic stimulation (rTMS), has also been shown to be equally effective in producing abolition of placebo analgesia (Krummenacher, Candia, Folkers, Schedlowski, & Schönbächler, 2010) (Figure 3.3).

The Mechanisms of Nocebo Effects

As for the placebo counterpart, most of our knowledge about nocebo effects comes from the field of pain and analgesia. However, to design experiments aimed at gathering information on the negative outcome of sham treatments is not an easy task, all the more so when pain is involved. Ethical limitations forbid inflicting deliberate harm, and many studies are carried out on healthy volunteers (rather than

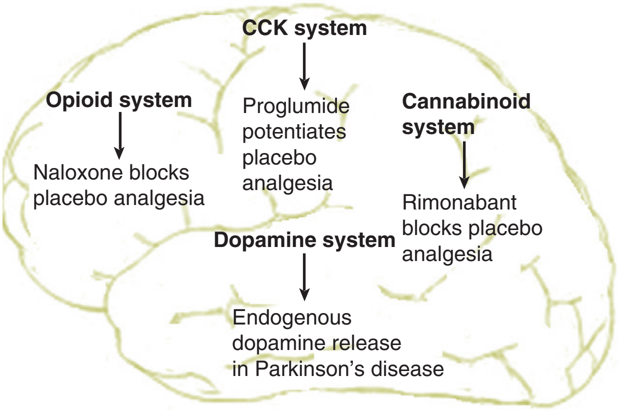

Figure 3.3 Different neuronal networks are involved in placebo responsiveness. Opioid, cholecystokinin, and cannabinoid systems have been documented in different studies on pain, whereas the dopaminergic activation in the striatum has been described in Parkinson's disease.

patients), in whom only expectations about incoming pain are negatively modulated, without actual administration of any drug. In this context, it is not surprising that our knowledge on nocebo hyperalgesia still lags behind the more detailed understanding of placebo analgesia (Benedetti, Lanotte, Lopiano, & Colloca, 2007; Colloca, & Benedetti, 2007).

In an early study, the authors showed that nocebo pain responses induced in postoperative patients by negative expectation regarding a saline infusion could be prevented by the CCK antagonist proglumide, a non-specific CCK-1 and CCK-2 antagonist, in a dose-dependent manner. This blockade was not mediated by endogenous opioids, as it was unaffected by naloxone (Benedetti, Amanzio, Casadio, Oliaro, & Maggi, 1997). As the expectation of pain increase is a highly anxiogenic process, and both anxiety and anxiety-induced hyperalgesia have been shown to be enhanced by CCK and attenuated by CCK antagonists in animal models (Lydiard, 1994; Hebb, Poulin, Roach, Zacharko, & Drolet, 2005; Andre et al., 2005), it is also rational to assume that anxiolytic drugs can interfere with nocebo hyperalgesia. In a study on healthy volunteers employing a protocol of experimental ischemic arm pain, it has been shown that nocebo hyperalgesia can indeed be regarded as a stress response as it is accompanied by increased levels of adrenocorticotropic hormone (ACTH) and cortisol, which indicates hyperactivity of the hypothalamic–pituitary–adrenal (HPA) axis. After administration of a benzodiazepine anxiolytic drug (diazepam), both HPA hyperactivity and nocebo hyperalgesia were blocked. When proglumide was given together with nocebo suggestion, only hyperalgesia was completely prevented. There was no effect on the HPA axis (Benedetti, Amanzio, Vighetti, & Asteggiano, 2006). This suggests that CCK does not act on the general process of nocebo-induced anxiety, but rather specifically on nocebo/

anxiety-induced hyperalgesia. Put differently, nocebo suggestions induce anxiety, which in turn separately induces both HPA and pain enhancement. While diazepam acts on anxiety, thus blocking both effects, proglumide acts only on the pain pathway, downstream of the nocebo-induced anxiety. Neither diazepam nor proglumide showed analgesic properties on baseline pain, since they act only on the increase in anxiety-induced pain.

As for placebo analgesia, neuroimaging techniques have also highlighted important contributions to our knowledge of nocebo hyperalgesia. Inducing negative expectations results in both amplified unpleasantness of innocuous thermal stimuli as assessed by psychophysical pain measures (verbal subject report) and increased fMRI responses in the ACC and in a region including parietal operculum and posterior insula (Sawamoto et al., 2000). Together with the hippocampus and the prefrontal cortex, these are regions also involved in pain anticipation (Koyama, Tanaka, & Mikami, 1998; Chua, Krams, Toni, Passingham, & Dolan, 1999; Hsieh, Stone-Elander, & Ingvar, 1999; Ploghaus et al., 1999; 2001; Porro et al., 2002; Porro, Cettolo, Francescato, & Baraldi, 2003; Koyama et al., 2005; Lorenz et al., 2005; Keltner et al., 2006). In some cases, the same study has addressed both positive (placebo) and negative (nocebo) expectations, with opposite modulation of pain-related brain areas (Koyama et al., 2005; Lorenz et al., 2005, Keltner et al., 2006).

Recently, Kong et al. (2008) emphasized the effect of negative expectations about pain perception following sham acupuncture, and compared fMRI responses following thermal stimuli of equal intensity delivered at control sites, or at sites along the suggested course of an acupuncture meridian (nocebo). Increased pain reports for the nocebo sites paralleled increased activity in several areas of the medial pain matrix (including bilateral dorsal ACC, insula, left frontal and parietal operculum, OFC, and hippocampus). Of particular interest is the involvement of the hippocampus (never shown so far to be involved in placebo analgesia), as its activity is also anxiety-driven (Ploghaus et al., 2001).

Negative expectations can impact clinically relevant pain. Irritable bowel syndrome, a gastrointestinal disorder often accompanied by hyperalgesia, and visceral and somatic hypersensitivity, is highly modifiable by placebo and nocebo factors with synergistic interaction. This suggests that negative emotional regulation can enhance hyperalgesia, likely through the facilitation of nociceptive input (Price et al., 2009).

From all these studies, it appears that the circuitry underlying nocebo hyperalgesia largely involves, with opposite modulation, the same areas engaged by placebo analgesia. The current model suggests that the DLPFC here too might exert active control on pain perception, by modulating corticosubcortical and corticocortical pathways.

Two Phenomena along a Continuum

Placebo and nocebo effects are not two “all-or-none” or opposite phenomena; rather, they can be represented along a straight line going from bad to good, from worsening to improving. All experimental evidence supports this finding. Behaviorally, it is possible to turn an analgesic placebo response into a hyperalgesic nocebo one. An example is shown in the study by Benedetti et al. (2003), where pain lessening induced by pharmacological pre-conditioning with ketorolac together with placebo suggests that it could be turned into pain exacerbation just by reversing the verbal instructions. From neurochemical studies, we have also shown how the opioid and CCK-ergic systems, respectively, induce or prevent placebo effects, and how, on the contrary, nocebo effects can be mediated by the CCK system (Benedetti et al., 2007, 2010). Although evidence for a role of opioids in nocebo effects is still missing, animal studies indicate that an anatomical substrate could underlie interaction between the two systems. In rats, rostroventromedial medulla neurons have been found, expressing both μ-opioid receptors and CCK-2 receptors. Selective lesions of these cells do not alter the basal sensory thresholds but abolish the hyperalgesia induced by microinjection of CCK into the rostroventromedial medulla, suggesting that these CCK-2/μ-opioid co-expressing rostroventromedial neurons facilitate pain (Zhang et al., 2009). Finally, we know from imaging studies that often the same pain-related brain areas are modulated bidirectionally by positive or negative pain expectations. Thus, it can be speculated that the placebo–nocebo phenomenon exists on a continuum, representing a sensitive target that can be influenced and shaped in the experimental and clinical setting.

How to Use Placebo Mechanisms in Clinical Practice

It appears clear from the previous sections that the placebo effect is an excellent model for the neuroscientist to understand how our brain works. Since many mechanisms are involved, ranging from expectation to anxiety modulation and from classical conditioning to reward mechanisms, the placebo response is actually a melting pot of concepts, ideas, and models for neuroscience (Carlino, Pollo, & Benedetti, 2011). However, some practical implications that have emerged in the course of the past years have the potential to positively affect the practice of all health professionals who have to use the appropriate words, and who have to adopt the adequate attitudes and behaviors in their everyday medical practice (Carlino, Pollo, & Benedetti, 2012). We will try to summarize these implications and applications in the following text (Figure 3.4).

Consider patient's previous experience

Different studies support the idea that the placebo effect is, at least in part, a learning phenomenon that takes place after the repeated pairing between a conditioned stimulus and an unconditioned one. Several studies have been designed to explore the factors that can influence learning, in order to use this knowledge to enhance the efficacy of a treatment in clinical practice. Indeed, the higher the number of

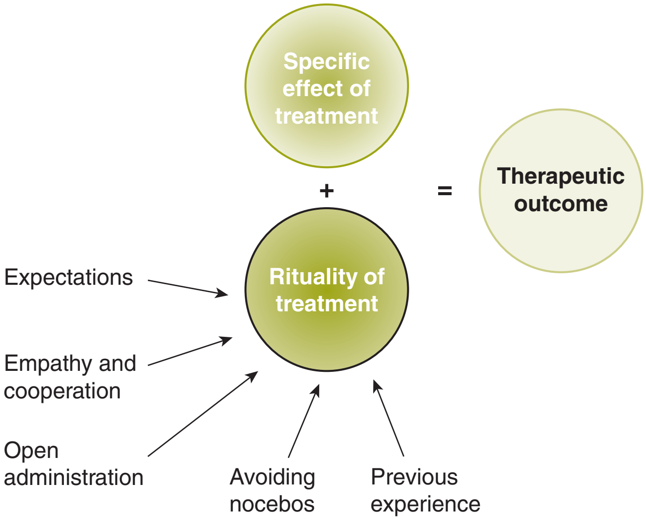

Figure 3.4 The recent insight into the mechanisms of the placebo effect lead to a sort of "vade mecum" for better clinical practice. In order to enhance the effectiveness of a treatment, health professionals have to consider different factors such as the patient's expectations, previous experience, empathy, and cooperation.

pairings is, the stronger the placebo response will be. In a recent study, Colloca and coworkers delivered tactile and painful stimuli on the dorsum of the foot, and exposed volunteers to one or four conditioning sessions in which decreased (placebo) or increased (nocebo) perceived intensities (unconditioned stimulus) were induced and paired with green or red lights (conditioned stimulus), respectively (Colloca, Petrovic, Wager, Ingvar, & Benedetti, 2010). After four conditioning trials, subjects experienced more robust placebo and nocebo responses that also lasted for the entire experiment. This study suggests that the administration of placebo is more effective after many exposures to effective treatments.

In another study on patients with chronic neuropathic pain, the authors compared the placebo effect induced by sham repetitive transcranial magnetic stimulation (rTMS) that either preceded or followed a successful or unsuccessful active rTMS (Andrè-Obadia, Magnin, & Garcia-Larrea, 2011). Patients were divided into three groups: the first received the sham rTMS before the active rTMS; the second and third groups received, respectively, ineffective or effective active rTMS before the sham session. Thus, only this latter group experienced a positive treatment before the placebo session. The results showed that the sham rTMS induced a pain relief of 11% when applied after a successful active rTMS, whereas the same procedure increased the pain scores by 6% when preceded by inefficacious active rTMS. Hence, the patient's past experience is an important factor that strongly affects the efficacy of future treatments.

Use verbal suggestions to increase treatment effectiveness

When a treatment is delivered, different conscious processes are at play in the patient's brain, such as expectancy about the outcome, motivation, desire and anticipation of relief, trust in the doctor, beliefs, and optimism (Geers, Helfer, Kosbab, Weiland, & Landry, 2005). These processes are conscious and activated by different factors, such as verbal instructions provided to the patient, patient–doctor interaction, and emotional state of the patient. All these factors are important determinants in the healing process of every medical practice.

The power of expectation through verbal suggestions has been documented in several clinical conditions. In a clinical study, patients with asthma were randomly assigned to receive four different treatments: an active treatment with an albuterol inhaler (drug group), a placebo inhaler (placebo inhaler group), sham acupuncture (placebo acupuncture group) or no intervention (control) (Wechsler et al., 2011). Even if albuterol administration resulted in a 20% increase in the forced expiratory volume (FEV_1), the patients in the drug and placebo groups reported no subjective differences between the treatments. Thus, the study suggests that, in terms of subjective outcome, the placebo efficacy proved equivalent to the drug efficacy, confirming the importance of the patient's expectation about therapy effectiveness. In a different study with Parkinson's disease patients, the authors investigated how the strength of expectancy influences the clinical benefit and the degree of striatal dopamine release after a placebo administration (Lidstone et al., 2010). Patients were informed that they had a specific probability (25%, 50%, 75%, or 100%) of receiving active drug when they in fact received a placebo. Clinical improvement and significant dopamine release in the nigrostriatal and mesoaccumbens pathways occurred when the declared probability of receiving active medication was 75%, suggesting a close relationship between the expectation of therapeutic benefit and the resultant clinical benefit.

Moreover, it was demonstrated that even the open-label administration of a placebo can produce a clinical improvement (Kaptchuk et al., 2010). Patients with irritable bowel syndrome received a placebo along with the information that "the placebo, at least in some circumstances, works as a real drug through the release of endogenous opioids." In this study, patients were aware that the treatment was a placebo, but they were also informed about the positive effect of placebo administration. In other words, they expected a symptom relief. Open-label placebo produced a significant reduction of symptom severity and an improvement in quality of life. Therefore, the knowledge and the understanding of a treatment boost positive expectations that, in turn, lead to symptom amelioration. However, adverse reactions can also be produced in clinical practice by informed consent, in which the possible occurrence of side effects is usually described to the patient in some detail (Amanzio, Corazzini, Vase, & Benedetti, 2009). It is therefore necessary to find a compromise between the opposing needs of information disclosure and nocebo effects minimization.

Increase treatment efficacy using an empathic and cooperative approach

Patient's needs are key factors in every medical treatment. Beside the cognitive need of receiving a proper therapy with clear information, the affective need for an empathic doctor–patient relationship is crucial. Kelley and colleagues (2009) investigated the role of empathic communication in an experimental design with placebo acupuncture. Irritable bowel syndrome patients were assigned to three different groups: two groups were treated with placebo acupuncture with either a warm and empathic interaction (empathic group) or a minimal and neutral one (neutral group). A third group (waiting list group) was periodically monitored, but no treatment was delivered. The empathic group showed a symptoms improvement compared with the neutral or waiting list groups, suggesting the importance of clinical interaction during the healing process. A second study also differentiated between cognitive and emotional needs (Verheul, Sanders, & Bensing, 2010). Either empathic or cold communication (emotional needs) was combined with positive or uncertain expectations (cognitive needs) about the effect of an analgesic drug on menstrual pain, in a 2 x 2 randomized trial. Only warm and empathic communication combined with positive expectations led to a relevant decrease in anxiety state, suggesting the importance of communication style.

Beside the communication differences, a recent study investigated cooperative or directive doctor–patient relationship (Rose, Geers, Rasinski, & Fowler, 2011). The authors studied the effect of this cooperative relationship by testing the effect of the treatment choice. Participants underwent the cold pressor test for pain tolerance following the application of a novel analgesic drug, which actually was a placebo. They were split in three groups: a "choice" group was permitted to choose the analgesic treatment to be used during the cold pressor task, a "no-choice" group received a random treatment, and a control group was administered a treatment without eliciting expectations or giving a choice. Pain ratings were obtained during the test at different times, and after the test by means of a questionnaire. The choice group experienced less pain during and after the test compared with the no-choice and control groups, suggesting that the involvement of the patient in a therapy enhances the placebo component of the therapy and, accordingly, its overall effectiveness.

Deliver treatment overtly and interrupt treatment covertly

In current medical practice, the doctor usually delivers a treatment using an "open" or "expected" approach, overtly informing the patient about the timing of a treatment and its effects. Using this approach, he produces expectations about the therapeutic outcome. Conversely, when the patient covertly receives the treatment, without receiving information about its administration (e.g., when the therapy is delivered by an automatic infusion machine), the condition can be defined as "hidden" or "unexpected," because no expectations about the therapeutic outcome are elicited. It is important to point out that, in both the open and hidden conditions, the same painkiller is administered, so that the only difference is represented by the psychological component of the treatment, for example, by the patient's expectations of clinical improvement (Benedetti, Carlino, & Pollo, 2011). An analysis of the differences between open and hidden injections of analgesics was carried out comparing four different analgesic drugs (buprenorphine, tramadol, ketorolac, and metamizol) in postoperative patients (Amanzio, Pollo, Maggi, & Benedetti, 2001). The authors found that hidden injections were significantly less effective compared with open injections. Indeed, the analgesic dose needed to reduce the pain by 50% was higher after hidden infusions than after the open ones for all four painkillers. Moreover, the time course of pain during the first hour was significantly different, with an increase in rating with a hidden injection than with an open one. Similar results have been documented in Parkinsonian patients after the implantation of electrodes for deep brain stimulation, using a hand-movement analyzer to assess movement velocity (Benedetti et al., 2003). Hidden deep brain stimulation was less effective than open stimulation. Similarly, the open interruption of the stimulation resulted in a larger reduction of movement velocity compared with a hidden one.

The effects of open treatment administration and interruption have been reported in a recent fMRI study (Bingel et al., 2011) in which subjects received the same analgesic drug with three different instructions: the hidden group received no information about the treatment, the open administration group received positive expectations about the treatment, and the open interruption group was told that the analgesic treatment would be interrupted. The hidden administration of an analgesic drug induced pain decrease, associated with decreased activity in several pain matrix regions, such as the primary somatosensory cortex, the insula, the anterior cingulate cortex (ACC), and the thalamus. However, the effect doubled after an open administration, with increased activity in the pregenual ACC and the dorsolateral prefrontal cortex (DLPFC). Therefore, an individual's expectation of the drug's effect enhanced the pharmacological effect of the treatment. Furthermore, the authors found an attenuated analgesic effect in the open interruption group, also reflected by an increase in brain activity in the hippocampus.

Therefore, the patient's knowledge about the treatment makes a big difference. The open administration of a treatment boosts the pharmacological effect of the drug, whereas the open interruption leads to reduced effects of the therapy that is being administered.

Conclusions

The placebo effect is an interesting topic for neuroscience because it represents a good example of the top-down influence of cognitive/affective factors on the whole body and behavior. Health professionals have long known that emphatic communication and cooperation, attention to the context, and patients' expectation and previous experience are important factors to be considered for a positive outcome. This common knowledge is now given scientifically compelling evidence by the findings of placebo research, which can be incorporated into a sort of "vade mecum" for better clinical practice.

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4

A Stage Approach to Enhancing Adherence to Treatment

Janice M. Prochaska and James O. Prochaska

To date, existing interventions designed to improve adherence have had limited success. According to a recent review of randomized clinical trials of adherence interventions (McDonald, Garg, & Haynes, 2002; Van Dulmen et al., 2007), theoretical, multifaceted interventions in clinic settings are common. The most effective interventions were multifaceted, combining several of the following common strategies: increased patient education and counseling, convenience of care, and patient involvement in care; use of reminders; and rewards or reinforcements for adherence (McDonald et al., 2002). Although these complex interventions may produce greater success in many cases, there are several limitations. Such interventions are not typically based on an empirically supported theoretical model, and thus combine various strategies in a "hit or miss" fashion. This makes it difficult to determine which strategies were most effective with which patients. Moreover, interventions that adopt a one-size-fits-all approach are not tailored to an individual's unique needs (Miller, 1997) and assume readiness to be adherent. Finally, using a wide variety of strategies with all patients is expensive and impractical to deliver.

The transtheoretical model of behavior change (TTM) has been suggested as an approach to overcome these limitations by delivering individualized, theoretically delivered interventions for entire populations of individuals (Willey, 1999; Willey et al., 2000), including those individuals who may not be ready to be adherent. The TTM systematically integrates four theoretical constructs central to change:

1. *Stage of change:* Readiness for treatment adherence
2. *Decisional balance:* Pros and cons associated with treatment adherence

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3. *Self-efficacy:* Confidence to practice and sustain treatment adherence, especially when tempted to relapse
4. *Processes of change:* Ten cognitive, affective, and behavioral activities that facilitate progress through the stages of treatment adherence

The TTM construes change as progress over time, through a series of stages: precontemplation, contemplation, preparation, action, maintenance, and temptation. Over 35 years of research on a variety of health behaviors have identified processes of change that work best in each stage to facilitate progress.

The Stages of Change

Stage of change is the TTM's central organizing construct. Longitudinal studies of change have found that people move through a series of stages when modifying behavior on their own or with the help of formal interventions (DiClemente & Prochaska, 1982; Prochaska & DiClemente, 1983). In the first stage, *precontemplation*, individuals may deny that they have a problem and thus are resistant to change their behavior, are unaware of the negative consequences of their behavior, believe the consequences are insignificant, or have given up the thought of changing because they are demoralized. They are not intending to take action in the next 6 months. Individuals in the *contemplation* stage are more likely to recognize the benefits of changing their behavior. However, they continue to overestimate the costs of changing and, therefore, are ambivalent and not ready to take action. Those in the *preparation* stage are seriously intending to make a behavior change within the next 30 days and have already begun to take small steps toward the goal. Individuals in the action stage are overtly engaged in modifying their problem behaviors or acquiring new, healthy behaviors. Individuals in the *maintenance* stage have been able to sustain action for at least 6 months and are actively striving to prevent relapse. Individuals in the termination stage are totally confident and feel no temptations to relapse and have made the intended change into an automatic habit. The stages form a simplex pattern in which adjacent stages are more highly correlated with each other than with more distant stages (Prochaska, DiClemente, Velicer, Ginpil, & Norcross, 1985). For most people, the change process is not linear, but spiral, with several relapses to earlier stages before they attain permanent behavior change and finish the change process (Prochaska & DiClemente, 1983, 1986).

Research comparing stage distributions across behaviors and at-risk populations finds that only a minority is in preparation with a majority in precontemplation and contemplation (Laforge, Velicer, Richmond, & Owen, 1999; Velicer et al., 1995). These data suggest that if we offered all individuals action-oriented interventions that assume readiness to participate in treatment adherence, we would be misserving the majority, who are not prepared to take action.

Interventions tailored to stage and related variables can have a greater impact than action-oriented, one-size-fits-all programs by increasing participation and increasing the likelihood that individuals will take action. Stage-matched interventions for smokers more than doubled the smoking cessation rates of the best action-oriented interventions available (Prochaska, DiClemente, Velicer, & Rossi, 1993). TTM-tailored interventions have produced significant impacts across a broad range of behaviors, including exercise acquisition (Marcus et al., 1998; Johnson et al., 2008; Prochaska et al., 2008), dietary behavior (Campbell et al., 1994; Johnson et al., 2008; Prochaska et al., 2008), mammography screening (Rakowski et al., 1998; Prochaska et al., 2005), stress management (Evers et al., 2006; Prochaska et al., 2008), depression prevention (Levesque et al., 2011), and medication adherence (Johnson et al., 2006a, 2006b).

Assessing Stages

Stage of change is generally assessed using a staging algorithm, a set of decision rules that places individuals in one of the five mutually exclusive stage categories based on their responses to a few questions about their intentions, past behavior, and present behavior. This approach to staging is robust across behaviors and populations (e.g., DiClemente et al., 1991; Blissmer et al., 2010; Prochaska et al., 1994). In a study of a TTM computer-tailored intervention (CTI) to improve adherence to antihypertensive medication funded through the Small Business Intervention Research grant mechanism from the National Institutes of Health (NIH), participants were given a staging measure – the definition of taking high blood pressure pills as directed, which included taking the entire dose prescribed by a physician on time every day. A staging item asked, "Do you consistently take all your high blood pressure pills as directed by your doctor?" (Johnson et al., 2006b).

Participants who responded with a "No" to the staging item were asked if they intended to do so in the next 6 months or 30 days, and were staged in precontemplation, contemplation, or preparation based on their responses. Participants who responded with "Yes" to the staging items were asked how long they had been taking their pills as directed and were staged in action (6 months or less) or maintenance (more than 6 months).

Decisional Balance

Change requires the consideration of the potential gains (pros) and losses (cons) associated with a behavior's consequences. The decisional balance inventory (Velicer, DiClemente, Prochaska, & Brandenburg, 1985) consists of two scales, the pros of change and the cons of change. Longitudinal studies have found those measures to be among the best available predictors of future change (e.g., Velicer et al., 1985).

In an integrative report of 12 studies, Prochaska et al. (1994) found that the balance of pros and cons was systematically related to stage of change in all 12 behaviors examined. The cons of changing to a health-promoting behavior outweighed the pros in the precontemplation stage; the pros and cons were tied in the contemplation stage, the pros surpassed the cons in the preparation stage; and the pros outweighed the cons in the action and maintenance stages. From these 12 studies, Prochaska et al. (1994) discovered the degree of change in pros and cons needed to progress across the stages of change: Progression from precontemplation to action involved an increase of 1 standard deviation (SD) in the pros of making the healthy behavior change, and progression from contemplation to action involved a one-half SD decrease in the cons. These results have been replicated in a meta-analysis of 120 studies from 10 countries and found the same pattern of relationships between stages and pros and cons, including the pros increasing exactly 1.00 SD and the cons decreasing by .56 SD (Hall & Rossi, 2008).

The pros of adherence could include the following: makes me feel more in control of my health, can help me live longer, makes me feel more responsible, will help me participate in my healthcare, and could make my loved ones worry less about my health. The cons of adherence often include side effects, costs, hassles, and not feeling any benefit. The effect that such cons have on adherence can depend on which stage the patient is in and their decisional balance. For example, two patients can have the same side effect profile or the same discretionary income. A patient who was in the contemplation stage may have felt pressured by their provider to take a medication. With pros and cons tied, the patient is already ambivalent about taking the medication. Side effects or costs can produce a negative decisional balance, and the patient may decide to discontinue their medication. A patient in the action stage with pros clearly higher than the cons can experience a con such as side effects or costs and still sustain a positive decisional balance while continuing to adhere.

Among individuals not adhering to a treatment regimen, increasing the salience and enhancing the decisional weight of the pros of treatment adherence, and decreasing the cons, can help increase readiness to adhere.

Self-Efficacy

Self-efficacy, or the degree to which an individual believes he or she has the capacity to attain a desired goal, can influence motivation and persistence (Bandura, 1977). Self-efficacy in the TTM has two components that are distinct but related: (1) confidence to make and sustain changes, and (2) temptation to relapse. Like decisional balance, levels of self-efficacy differ systematically across the stages of change, with subjects further along in the stages of change generally experiencing greater confidence and less temptation. Self-efficacy for treatment adherence means having the confidence to practice adherence in a variety of difficult situations (e.g., when one is stressed, has financial difficulties, or has side effects).

Processes of Change

In a comparative analysis of 24 major systems of psychotherapy, Prochaska (1979) distilled a set of 10 fundamental processes by which people change. The set was refined following further theoretical analyses (Prochaska & DiClemente, 1984) and empirical studies (Prochaska & DiClemente, 1985, 1986). These 10 processes describe the basic strategies that can be used to change problem behaviors, affects, cognitions, or interpersonal relationships. The 10 processes most often applied to treatment adherence are defined in the following text, with examples of interventions:

1. *Consciousness raising:* Increasing awareness and information related to treatment adherence. (Screening can make patients aware that they have a high-risk condition, and their provider can inform them that a condition such as hyperlipidemia could be managed by diet and exercise and/or medication.)
2. *Dramatic relief:* Experiencing strong negative emotions that could be relieved by practicing treatment adherence. (Results of screening can produce strong fear that can begin to be relieved by a provider's confidence that behavioral and/or biological medications can reduce or remove the risks.)
3. *Environmental reevaluation:* Realizing the impact that effective treatment adherence could have on other people. (The provider could empathize with the strong emotions and ask who all would benefit from the patient becoming adherent.)
4. *Self-reevaluation:* Emotional and cognitive reappraisal of values and self-image related to treatment adherence. (The provider could ask how you would feel about yourself if you were taking this medication, or if you would like to try a behavior medicine first.)
5. *Self-liberation:* Making and demonstrating a firm commitment to adhere to a treatment regimen. (By giving patients choices, such as behavioral or biological medicines, commitment is strengthened for the choice that is taken.)
6. *Reinforcement management:* Increasing intrinsic and extrinsic rewards for treatment adherence. (The sooner patients receive feedback that their cholesterol profile has improved, the more intrinsic reinforcement they experience, and the more likely they are to adhere.)
7. *Helping relationships:* Seeking and using social support to encourage or help with treatment adherence. (There are some excellent online social network programs where individuals help each other to change.)
8. *Counter conditioning:* Substituting new behaviors and cognitions for old responses to treatment adherence (positive self-statements such as, "I am doing what I chose rather than feeling pressured by my provider").
9. *Stimulus control:* Adding cues or reminders to adhere to the treatment regimen (taking a medication at the same time and same place as an automatic habit such as brushing one's teeth).

10. *Social liberation:* Realizing that society is changing to support treatment adherence (appreciating the increasing number of free or low-cost and easily accessible online evidence-based programs for adherence to behavioral and biological protocols).

An 11th process, healthcare provider helping relationships, can also be important in the adherence area. This process involves calling on medical professionals for assistance with adherence.

The data from our research show that self-changers in different stages rely on different processes of change, naturally integrating change strategies and processes often considered theoretically incompatible. Individuals in the early stages rely more on cognitive, affective, and evaluative processes of change; individuals in the later stages rely more on social support, commitments, and behavior management techniques. Table 4.1 summarizes a common integration of self-changers' patterns of emphasizing particular processes as they progress through the stages (see Prochaska, DiClemente, & Norcross, 1992).

Table 4.1 Integration of the stages, processes, and principles of change.

Precontemplation	*Contemplation*	*Preparation*	*Action*	*Maintenance*
Consciousness raising				
Dramatic relief				
Environmental reevaluation				
	Self-reevaluation			
		Self-liberation		
			Reinforcement management	
			Helping relationships	
			Counter conditioning	
				Stimulus control
Pros of changing increasing				
	Cons of changing decreasing			
			Self-efficacy increasing	

NOTE: Social liberation has been found to not have differentiated emphasis across all five stages.

Table 4.2 Continuum of adherence.

Behavior	*Appropriate Intervention*
Screening	Promote screening so individuals with risk can be identified and treated appropriately
Acquisition	Prepare those in early stages, provide action plans for those in preparation, and provide relapse prevention for those in action
Adherence (continuation/persistence)	Provide action-oriented advice and relapse prevention
Non-adherence	Prepare those in early stages to become more adherent (raise pros, reduce cons, etc.)
Discontinuation	Increase readiness for reacquisition

Continuum of Adherence

We have found that it is important to create interventions that are appropriate for the specific adherence behavior that a patient confronts. The intervention for a patient who has not even been screened for a possible risk factor such as hypertension would be quite different from a patient with hypertension who has discontinued using anti-hypertensives. Table 4.2 outlines a continuum of adherence that we use in developing such interventions.

Screening

Screening is the first phase of intervention that is needed to determine if patients have risk factors that need to be treated. We have already presented examples of how screening can start the change process by raising awareness and emotion. If patients have not been screened for risk factors such as hypertension, hyperlipidemia, depression, stress, or a high-fat diet, then that is the first challenge. A big question is, who is not being adherent, the patient or the professional? If clinical guidelines call for population-based screening, and particular practices are not following the guidelines, then those practices would be having problems with adherence. Medical practices tend to be much more proactive in following such screening guidelines when the risk factors are seen as more biological in nature, such as hypertension and hyperlipidemia. Practices tend to have more problems in being proactive in screening behaviors such as alcohol abuse, depression, diet, sleep, or stress. The difference is due in large part to physicians having more confidence in prescribing medications, such as antihypertensives or statins, than in providing effective assistance for more behavioral risk factors.

In general, patients tend to be passive when it comes to screening. They usually are not feeling sick, in pain or distress for their diet, inactivity, drinking, or smoking.

They tend to take their lead from their provider. If the practitioner does not take the time and make the effort to screen for particular risks, then patients are likely to conclude that such screening is not particularly important. We encourage providers to think of behaviors as silent killers, the way they think of hypertension, and to contemplate being more proactive in screening the way they automatically do for hypertension.

Acquisition

Once screened, the second phase is the patient's acquisition of the prescribed intervention. Here, problems can arise if clinicians have not assessed the patient's readiness to acquire a prescribed intervention. Patients diagnosed with hyperlipidemia, for example, are very likely to be prescribed a medication such as a statin. Clinicians take care to match the appropriate biological treatment to the patient's biological condition that has been assessed. However, clinicians are not likely to recognize that they are prescribing behavior as well as biology. Are patients ready to start on the prescribed medication? Just because the clinicians are ready to prescribe does not mean that all patients are ready to follow the biological prescription. Patients may have entered the office with no intention of starting to take a medication each day for the rest of their lives. Patients in precontemplation are likely to weigh the cons of taking the medication (e.g., costs, side effects, hassles) as clearly outweighing the pros. Their decisional balance is likely to lead them to not even fill their prescription. The clinician has prescribed the correct biological medicine but not the appropriate behavioral medicine.

Continuation

In this phase, patients have started the acquisition process, but the question is, will they continue with the prescription. Patients in the contemplation stage are likely to be very ambivalent about taking a particular pill every day for the rest of their lives. Their clinicians may convince them that the prescription is correct for them. Wanting to be cooperative patients, they may go along with their physician's recommendation initially. So they fill the prescription, take it daily as prescribed, but begin to experience some cons, such as costs, side effects, or doubts about their real risk. As discovered earlier, an ambivalent decisional balance can now shift in a negative direction, with the cons outweighing the pros. These patients are at increased risk of discontinuation. Here again, the clinicians may have provided the appropriate biological medicine but an inappropriately matched behavioral medicine. An excellent adherence opportunity can be met if the behavioral prescription is appropriate for the patient's stage rather than being driven by a provider's unrealistic design to produce immediate action.

Non-adherence

In this phase, the patients are continuing with the prescription but are not taking it as prescribed. They may be cutting their pills in half, taking drug holidays, or missing pills on a repeated basis. Here, the assessment needs to be whether the problem is more of a memory problem, confidence problem, or a decision problem. If lapses are due mainly to memory, then a particular process such as a stimulus control technique can be used to help cure the patient. Pill containers can be of help, as can computerized calls or texting to high-cost patients who need more intensive help. If the problem is due to lowered self-efficacy under tempting situations, such as times of stress or depression, then help may be needed in coping with such conditions. A stress management or mood management program may be part of the solution.

If the problem is more decisional in origin, such as cutting the pills in half as a way to cope with the price, then different help may be needed. Patients may need to be informed of lower-cost options, such as generic medications, if comparable ones exist.

Discontinuation

Once patients discontinue the prescribed biological and/or behavioral prescriptions, then the major challenge is to help them recycle back through the stages to take more effective action. With behavioral discontinuation, such as relapse from smoking cessation or exercise prescription, clinicians can be more optimistic or ambitious. The vast majority (about 85%) will regress only back to the contemplation or preparation stage. There, patients are ready to start contemplating or preparing for another serious action attempt. These patients can be helped to process what they did right and what they need to do next time to be better prepared to sustain the action.

Patients in precontemplation need to be helped to not give up on their abilities to change or to not give up on their prescribed medicine. With behavioral medicine such as smoking cessation or exercise, this challenge holds only for about 15% of patients. With medication, on the other hand, we have found that a much larger percentage of patients may regress all the way back to precontemplation. If these initial results continue to be replicated, then the implication would be that patients may give a particular prescription only one chance in the foreseeable future. If this chance fails, then an important opportunity may be lost. These results would suggest that taking the time and making the effort to prepare patients for the behavioral requirements of their biological medication may be particularly important. Recycling patients who discontinue medications may be much more challenging than recycling patients who discontinue behavioral treatments.

Stage-Matched Interventions Based on the TTM

In addition to providing an assessment framework, the TTM provides a scheme for tailoring programs by matching them to the needs of patients at each stage of change for treatment adherence. The degree of tailoring possible depends directly on the extent of the assessment. The following are descriptions of how one could use TTM for increasing treatment adherence through self-help print materials, provider interventions, or Internet-based programs.

Stage-based manuals or books

Evidence-based self-help materials are one of the most frequently recommended or prescribed treatments by behavior health providers, but not by physical health providers, in part because of a lack of awareness of the efficacy of such help. Later, we will identify some of the most frequently recommended stage-based manuals and books for behavior change. Stage-based manuals or books describe how self-changers progress through each stage of change, and how they recycle if they relapse. These materials teach users about general principles of behavior change, about their particular stage of change, and the processes they can use to progress to the next stage. Appropriate sections are matched to each stage of change, and they provide details on change processes and stage-matched exercises. There are several ways to use the materials. First, they could be read through to get the big picture of how people change. Second, readers could turn to the section for the stage they are in and study that stage for a while. This is a good way to be sure they are heading in the right direction. Finally, users could look ahead to the next stage to learn more about how to move forward.

For example, if a patient in the precontemplation stage for adherence to statins is underestimating the pros of adhering to their medication regimen, that patient could use the section of the manual that describes dozens of documented pros of adhering to one's lipid-lowering medication regimen. The patient would be also encouraged to seek more information about the importance of adherence from the media, their healthcare provider, and their pharmacist.

Because each manual contains sections relevant to each stage of change, readers can refer to the appropriate chapters as they advance or regress through the stages. In addition, the manual underscores that the principles the patient is using to change his or her behavior relating to statin adherence can also be applied to other behavior changes. Individuals are taught that they can systematically use the 15 principles and processes of change to make progress on multiple behaviors simultaneously rather than focusing on only one. Given the generalizability of TTM's principles and the importance of diet and exercise to the treatment of hyperlipidemia, for example, stage-matched guidance of these behaviors is included in the manual to assist patients in making dietary modification and exercise essential parts of their treatment regimen (Johnson et al., 2006a).

Stage-based provider guidance

Healthcare providers could also target interventions to the patient's stage of change for adherence by administering the staging algorithm (e.g., in the waiting room). There are brief, evidence-based, Health Risk Assessments that include staging of patients' health risk behaviors, including adherence. With such assessments, providers could then base brief interventions on processes that are most helpful to a particular stage. For example, precontemplators come in denying or minimizing their problems. They may be unaware of the negative consequences of their unhealthy behavior, or they may be demoralized because of repeated failures in changing their behavior.

The goal for the provider is to engage precontemplators in the change process. Lecture and confrontation will not work, and prescribing action can make things worse. Providers can help precontemplators raise consciousness by teaching them about the stages of change, asking them to name as many benefits of treatment adherence as they can (precontemplators can typically name only two or three), and by providing more information about the treatment protocol to dispel any misconceptions the patient may have.

During the first appointment with precontemplators, providers can ask if they are willing to do any of the following before the next time they meet:

- Read about treatment adherence (e.g., the importance of a particular medication)
- Double their list of the pros of treatment adherence
- Talk with someone who is currently adhering to a similar treatment

Providers should reinforce the notion that their patients have the capacity to be adherent. They should remind their patients that any forward movement (e.g., becoming more open to considering alternatives, becoming more aware) is progress; change does not equal action – change means progressing to the contemplation stage.

Contemplators are thinking about changing but are not yet committed to do so. They are more likely to acknowledge that their behavior needs to be changed, but they substitute thinking about it for acting on it. They recognize the benefits of changing, but overestimate the cons. Contemplators are ambivalent about changing and are often waiting for the magic moment. Providers can assist by acknowledging the ambivalence and work to resolve it by encouraging contemplators to weigh the pros of treatment adherence against the cons. Patients are asked to shrink cons by comparing them to the growing list of pros, by asking how important they are relative to the pros, and by challenging themselves to counter the cons. Interventions in these appointments can be more intensive, including taking small steps toward treatment adherence. Providers can help by using motivational interviewing strategies such as reflective listening to assist contemplators to resolve their ambivalence by working with them to identify the negative consequences on others of continuing not to be adherent, and by providing case examples of people who have been able to change to adhere to the treatment protocol. Helping patients enhance their new self-image is important in contemplation. Providers can encourage patients to ask themselves about their self-image. For example, "How do you think and feel about yourself as someone who doesn't adhere to your treatment regimen? What might it be like if you changed that behavior?"

Patients in preparation assess the pros as more important than the cons, are more confident and less tempted, are developing a plan, and are ideal patients most likely to participate in action-oriented programs. With those in preparation, providers can be like effective coaches who provide encouragement. They need to coach, not lecture, and give praise, support, and recognition for taking small steps; keep interventions short, focused, and action oriented; be available for phone support; focus on developing a plan for treatment adherence; and problem-solve.

Providers can enhance progress by ensuring that patients choose steps that are realistic, concrete, and measurable. Those in preparation should be asked to put treatment adherence plans in writing and to share how they will tell others about their commitment to adhere. It is important to help patients identify sources of support for their new behaviors – family members, coworkers, friends, or online social networks. Providers should encourage patients' to be as specific as possible about the type and amount of support they need, as well as role-play their requests for support. Providers can also help the patients to imagine how they will feel about themselves after they make changes.

Patients in Action are those who have recently begun adhering to the treatment regimen. They are using behavioral processes of change. Their confidence is building but temptation and risk of relapse is a concern. Providers with patients in action need to be facilitators for the behavior change. The focus is on the behavioral processes of change – counter conditioning, stimulus control, and reinforcement management. It is important to also offer guidance for patients to plan ahead to prevent lapses and relapses.

Providers can help by getting patients to identify problematic beliefs and behaviors that inhibit treatment adherence and then by problem solving on positive alternatives that they believe will work for them. People, places, and things that increase the likelihood of not adhering need to be managed when possible. Reminders, in both familiar and unexpected places that support treatment adherence, need to be left around, like a gym bag filled and ready to use, a picture on the desk of relaxing with friends, or pill taking scheduled on their smart phone. Those in action also need to notice the intrinsic rewards of their treatment adherence – better health, more energy, more control of their life. Patients need to reward themselves with positive statements; providers can praise achievements and help patients recognize the benefits of their efforts.

Patients in maintenance have high confidence, and temptations are low. They are at risk primarily in times of distress or atypical temptations. With those in maintenance, the provider needs to be a consultant to provide advice regarding relapse prevention. Providers can do this by helping patients to cope with distress (a major cause of relapse), continuing to refine a relapse prevention plan, being available to provide support, and establishing a support system in the community or online. For many people, maintenance can be a lifelong struggle – it is a dynamic stage, and not a static one. This may be particularly true for areas such as exercise, where the regimen requires daily action and may be associated with ongoing cons. There needs to be work to consolidate gains and increase self-efficacy through increasing coping skills.

Remember, a majority of individuals relapse to earlier stages before reaching permanent maintenance. Well-prepared providers can help many more of their patients to progress toward lives freer from risk by starting with where their patients are at to begin the journey toward adherence as part of a healthier lifestyle.

The good news about adherence is that there are significant numbers of people who reach the termination stage. They take their medication as prescribed at the same time and same place. Their behavior change is now under stimulus control, which is a much more powerful form of behavior control than decisional control. They have developed a health habit that is automatic, just like brushing their teeth. They have total confidence and few temptations about relapsing. They are free to use their increased behavior change competence to enhance other areas of their health and well-being.

Computer-tailored interventions

Lengthier assessments that include each of the constructs of the TTM permit significantly more tailoring but may be impractical in a clinic setting where competing demands limit time. With grants from the National Institutes of Health, we have developed computer-tailored intervention adherence programs that are designed to be easy and engaging for patients to use and can be delivered over Internet platforms, which offer a cost-effective, easily disseminated alternative. The technical basis for these systems relies on the integration of statistical, multimedia, and database software. A system resides either on the Internet or on a web server and can be accessed by anyone who has the appropriate address and password. Once a patient logs onto the program, he or she is asked to complete a TTM treatment adherence assessment that evaluates stage, decisional balance, self-efficacy, and the processes of change. Linn, Vervloet, van Dijk, Smit, and Van Weert (2011) have seen the use of Internet-based interventions to improve medication adherence increasing rapidly during the past decade. From a systematic review of 13 studies, they found that Internet interventions have the potential advantage of tailoring the interventions to the needs and situation of the patient. The work of Noar, Benac, and Harris (2007) and Krebs, Prochaska, & Rossi (2010) explored the extent to which tailoring works and found that tailored messages have outperformed comparison messages in affecting health behavior change. Review of the literature demonstrated that tailored messages are more likely to be read, understood, recalled, rated highly, and perceived as credible (Kreuter Oswald, Bull, & Clarke, 2000).

In developing our treatment adherence programs, a series of multivariate statistical analyses are used to verify empirically the hypothesized relations between the constructs of the TTM (stage, decisional balance, self-efficacy, processes of change) and to determine the programs' empirical decision rules. For each stage, the goal of the analysis is to empirically determine levels of construct use to optimize movement to the next stage. To generate individualized expert system feedback, an individual is assessed on all relevant TTM constructs. The assessment provides the input for the expert system (i.e., the basis for the tailoring and individualization of the intervention materials each participant receives). After a patient completes the assessment for each construct, his or her responses are analyzed by the expert system. The expert system then produces individualized feedback reports that are provided to the patient through text and graphical feedback on his or her computer screen or smartphone.

People could use processes too little or too much, depending on their stage of change. If they are not using a process enough, they would receive negative feedback. An example of the environmental reevaluation process is, "You're not paying enough attention to how your decision not to adhere to your medication regimen affects other people. Remind yourself that you could set a good example for others if you were to take your medication as directed." The decision rules depend on the stage of change. The same process may be involved in more than one stage. For example, increasing an individual's knowledge may be important for those in both precontemplation and contemplation. How much of an increase is necessary for progress may, however, differ at different stages. In a similar manner, the decisional balance and self-efficacy scales represent sensitive change principles for facilitating progress. An example of positive feedback for someone in precontemplation is as follows:

> Great! You seem to be increasingly aware of the pros (benefits) of taking your high blood pressure medication each day. This is a good sign that you're ready to think more seriously about taking them as prescribed. If you want to make more progress, continue to add to your list of pros.

The feedback also includes exercises for the participant to complete (e.g., set a start date, list who can support your efforts and how they can help) and recommended strategies (e.g., how to deal with unexpected temptations, how to make a commitment to change behavior, strategies for building confidence) to help participants move forward. The feedback report (typically two to three printed pages) can be printed out at the end of the session.

During a patient's first use of the program, feedback is based on a comparison of the responses of the individual to a larger comparative sample of successful and unsuccessful individuals making the behavior change to treatment adherence. This feedback relies only on normative comparisons that differ by stages. The initial norms were derived from a naturalistic sample of individuals at risk for treatment adherence. Evaluation of the expert system provides updated norms at periodic intervals. The second and subsequent interactions compare the individual with both the normative group and his or her own previous responses, and provide both ipsative (i.e., self-comparisons) and normative comparisons. The ipsative comparisons require access to the database for the results of the previous contact. The program makes individualized recommendations of change and guides the participants through the behavior change process that meets their individual needs.

The computer-generated feedback also links or refers participants to sections of a stage-matched Personal Activity Center (PAC). Like the stage-matched manual described earlier, the online PAC teaches users about general principles of behavior change as well as their particular stage of change and the processes they can use to progress to the next stage. The individualized feedback reports refer participants (via links) to appropriate sections of the PAC to provide more details on change processes and stage-matched exercises. For example, a participant can link to the PAC where there are testimonials about the effects of stress from people who are now effectively managing their stress, an exercise to learn about what controls one's behavior, a bulletin board listing rewards people give themselves for effectively managing stress, and substitutes for unhealthy stress management that do not involve food, smoking, or alcohol. For a demo of a program designed for stress management, please go to www.prochange.com/stressdemo or check out a full program at www.prochange.com/myhealth.

Conclusion

From a transtheoretical perspective, assessing and increasing treatment adherence is a complex challenge involving multiple variables for multiple behaviors. Fortunately, the same variables are assessed and applied to each behavior on the continuum of adherence. These variables are the stages of change, pros and cons of changing, self-efficacy about changing, and the processes of change. Depending on the depth of the assessment, varying degrees of tailoring are available to intervene on adherence. Once all variables are assessed for a specific adherence behavior (e.g., screening, acquisition, or discontinuation), the assessments can then drive an intervention designed to increase the specific adherence behavior. The intervention can vary from expert provider interventions to expert computers or some combination of each.

The literature to date indicates that the most promising approaches to increasing adherence will be multifaceted interventions on multiple variables for multiple behaviors. The TTM measures and intervention modalities can provide a framework that can systematically, empirically, and practically tailor these complex approaches to enhance adherence for populations at each point of the adherence continuum. We envision a near future where computer-tailored interventions will be to behavior medicine what many pharmaceuticals are to biological medicines – easily accessible, cost-effective treatments that can be delivered by patients at home to enhance the health of large populations, but with minimal side effects.

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Part II

Common Medical Problems

5

Promoting Physical Activity for the Management of Obesity

Tony Morris and Melissa Moore

Introduction

Obesity is rapidly increasing worldwide, as the provision of food increases and people eat more energy-dense food, while patterns of activity decrease in transportation, at work, and with the growth of sedentary leisure in the computer age. The role of sport and exercise has increasing significance for health both in protecting against obesity and in managing overweight. This chapter focuses on sport and exercise among those who are obese, addressing the challenges of participation and then, based on the benefits, examining ways to increase physical activity in obese people.

Definitions

According to current international classification, for adults (18 years and older), normal weight is considered to be a body mass index (BMI) between 18.5 and 24.9; all-inclusive overweight is defined as a BMI of 25 of more ($\text{BMI} \geq 25$); overweight, but not obese, known as pre-obese, is defined as a BMI between 25.0 and 29.9, and a BMI of 30 or more ($\text{BMI} \geq 30$) is considered to be obese (WHO, 2012a).

Physical activity (PA) is a broad term that includes all bodily movement produced by the skeletal muscles that results in energy expenditure (Casperson, Powell,

The Handbook of Behavioral Medicine, First Edition. Edited by David I. Mostofsky.

& Christenson, 1985). PA covers all types of activity that require movement. Common PA sub-types include sport, exercise, active transport, and occupational and lifestyle PA.

Sport involves structured competitive situations that are governed by rules, and can be played at recreational, high school, college, Olympic, and professional levels (Berger, Pargman, & Weinberg, 2007). Sport activities require physical exertion and/or physical skill, and typically have an accompanying focus on winning (Australian Government, 2010). Examples of sport activities include netball, basketball, football, squash, tennis, and soccer.

Exercise involves planned, structured, continuous bouts of activity. People typically take time out of their daily routine to take part in exercise. Exercise activities can be solitary in nature, or performed in a group setting. Like all types of PA, there are numerous reasons why people exercise regularly, including for enjoyment, social reasons, and/or to achieve specific health benefits, such as weight management or physical fitness. Examples of exercise types include swimming, cycling, brisk walking, resistance training (RT), and attending a group exercise class (Casperson et al., 1985).

Lifestyle PA involves two key elements that distinguish it from exercise: lifestyle PA is unstructured, because a person does not need to take time out of their daily routine to be active; and lifestyle PA can be accumulated throughout the day, rather than in one continuous bout. Examples of lifestyle PA include gardening, climbing stairs, active household chores (e.g., mopping the floor), and parking the car a little further from the desired destination and walking the rest of the way. Researchers have demonstrated that achieving the minimum 30 minutes of daily PA via the accumulation of short bouts (e.g., 10 minutes) of moderate-intensity PA can have equivalent health benefits to a continuous bout of exercise (Dunn, Trivedi, Kampert, Clark, & Chambliss, 2005).

Active living (AL) is a broad concept that embraces the full spectrum of PA, and describes it as being an essential part of daily living (NSW Premier's Council for Active Living [NSW PCAL], 2010). The concept AL gives individuals the flexibility to incorporate PA into their daily life in a way that suits their needs, abilities, preferences, and environment. Furthermore, there is no hierarchy of activities, and no value judgments to the relative merits of one PA type compared to another (Swedburg, & Izso, 1994). The main goal of AL is that individuals are attaining the daily PA recommendations, regardless of what PA type/s they engage in to achieve this. Thus, advocating an active lifestyle, rather than encouraging a particular type of PA, may be a more effective approach to combating the current worldwide epidemic of inactivity than trying to persuade people to visit gymnasiums or swimming pools regularly (NSW PCAL, 2010).

Throughout this chapter, the term "PA" is used to describe any bodily movement that increases energy expenditure above basal level. We employ the terms PA, sport, exercise, lifestyle PA, and AL when researchers have used these terms, or if what researchers have described was specifically covered by one of these terms, according to the definitions.

Physical Activity Recommendations

It is clear that PA provides significant physical and psychological health benefits. To achieve health benefits, PA recommendations suggest an accumulation of at least 30 minutes of moderate-intensity PA on most, preferably all, days of the week, or at least 90 minutes a week of vigorous aerobic exercise (American Diabetes Association [ADA], 2007). For effective type 2 diabetes mellitus (T2DM) management, resistance training (RT) (three times per week) is also encouraged among people free of contraindications (ADA, 2007). The PA recommendation for weight loss is the accumulation of at least 60–90 minutes of moderate-intensity PA on most, and preferably all, days of the week. For weight maintenance, the accumulation of approximately 60 minutes per day of moderate-intensity PA is encouraged (NHLBI Obesity Education Initiative Expert Panel, 2000). Furthermore, to experience psychological benefits (e.g., reducing depression across the severity spectrum), the same amount of PA specified for health benefits is also generally suggested. Psychological benefits can be attained, however, in single PA bouts of 10–20 minutes. Additionally, with reference to PA intensity and type for achieving psychological benefits, individual preference is the overriding factor (Berger, 2004). Finally, it should be noted that recommendations for moderate-intensity PA may need to consider individual fitness levels (Lee et al., 2003).

Obesity and Participation in Sport and Exercise

Overweight and obesity

Prevalence Once considered a problem in countries with high personal income, overweight and obesity are now on the rise in low- and middle-income countries, particularly in urban settings. In 2008, the World Health Organization estimated that 1.5 billion adults (20 years and older) were overweight, of which 200 million men and nearly 300 million women were considered obese (WHO, 2012a). Overall, more than 10% of the world's adult population in 2008 was obese (WHO, 2012a). In particular, an increasingly high proportion of the population in Western countries, such as Australia and America, are now considered to be overweight or obese. For example, in Australia, the proportion of adults (aged 18 years or over) classified as obese (24%) or overweight (37%) has increased from 56% in 1995 to 61% in 2007–2008 (Australian Bureau of Statistics [ABS], 2011a). Similarly, in the United States, obesity rates for adults have doubled over the last two decades (National Center for Chronic Disease Prevention and Health Promotion, 2010).

Etiology and risk factors Overweight ($\text{BMI} \geq 25$) is a health problem with multiple etiologies and multiple risk factors, such as genetic, physiological, behavioral, environmental, social, and cultural factors (Brownell & Wadden, 1992). The relative contribution of each risk factor differs for each individual; however, behavioral (i.e., high-calorie diet, physical inactivity) and environmental (e.g., greater access to energy-dense foods, sedentary jobs, labor-saving devices such as escalators, automobiles, and the Internet) factors are considered to be primarily responsible for the dramatic rise in overweight during the past two decades (Racette, Deusinger, & Deusinger, 2003).

Associated health problems An overwhelming literature supports the link between overweight and obesity and adverse health outcomes. Some of the major health problems associated with overweight (BMI ≥ 25) include increased risk of coronary heart disease (CHD), T2DM, several types of cancer, and psychological problems such as depression (Barr et al., 2006). People who are overweight also have an increased risk of mortality, with overweight and obesity being the fifth leading risk for global deaths. At least 2.8 million adults die each year as a result of being overweight or obese (WHO, 2012a).

Health benefits of modest weight loss Even modest weight loss (e.g., 5–10% of initial body weight) can have beneficial outcomes on a number of health parameters and disease outcomes (Stewart, Tikellis, Carrington, Walker, & O'Dea, 2008). Some of the health benefits include (although not limited to) a reduction in T2DM, psychological problems, and a 25–50% reduction in mortality (Stewart et al., 2008).

Treatment Successful treatment of overweight and obesity requires a life-long effort (Medstar Health, 2008) and an individualized, multidimensional approach. Such an approach typically includes the combination of a reduced-calorie diet, regular PA, and behavior modification. Pharmacotherapy is needed to assist some overweight people, and in extreme cases, surgery may also be required (Pi-Sunyer et al., 1998). To achieve long-term health benefits (of weight loss), a 10% weight loss needs to be maintained for at least 1 year (Wing & Hill, 2001). Wing and Hill (2001) estimated that only about one-fifth (21%) of initially overweight people are successful at maintaining this amount of weight loss after 1 year, and longer-term success is generally even lower. Although PA does not produce considerable weight loss when used independently, regular PA (at least 30 minutes daily, and ideally 60 minutes for weight loss/maintenance is considered a key component of effective overweight treatments (Schaar, Moos-Theile, & Platen, 2010; Stewart et al., 2008). Overweight and obese individuals who engage in regular PA can still enjoy the numerous physical and psychological health benefits of PA, regardless of weight loss. Further, in addition to *contributing* to weight loss and weight maintenance (Schaar et al., 2010; Wing & Hill, 2001), regular PA also has a beneficial impact on obesity-associated comorbidities (Scott et al., 1999). In this chapter, we focus on PA participation among overweight and obese adults for health benefits, rather than PA specifically for weight loss. The amount of PA required for weight loss is double the minimum level recommended for health benefits. Thus, unless specified otherwise, the information presented here relates to health benefits that can be obtained from a minimum of 30 minutes of daily moderate-intensity PA.

Benefits of Physical Activity Participation among Overweight or Obese People

Types of physical activity that lead to health benefits

The wide range of physical and psychological health benefits of PA can be achieved via participation in all types of PA, including structured continuous bouts of aerobic exercise (Bernstein, Costanza, & Morabia, 2004), intermittent exercise (Jakicic & Otto, 2005), resistance training (Vincent, Braith, & Vincent, 2006), and yoga and flexibility exercises (Tudor-Locke, Bell, & Myers, 2000). Moreover, health benefits can be achieved from accumulated short bouts of exercise and lifestyle PA (Lutes, Daiss, Barger, Read, Steinbaugh, & Winett, 2012; Murphy, Nevill, A., Nevill, C., Biddle, & Hardman, 2002). Therefore, consistent with the "active living" concept, individuals can meet the minimum recommended PA level and receive the associated health benefits by engaging in the type/s of PA that suit their needs and preference.

Physical health benefits

The favorable effects of regular PA on health are no longer under debate (Proper & Van Mechelen, 2008). A graded linear relationship also exists, with more PA leading to a lower risk of health problems, and maximum health benefits, compared to less PA (Warburton, Nicol, & Bredin, 2006). An encouraging finding for sedentary people wanting to become more physically active is that the greatest health improvements are seen when people who are unfit become physically active (Darren, Warburton, Whitney, & Shannon, 2006). Additionally, regular PA is a key ingredient for weight loss and weight maintenance (Schaar et al., 2010). Outcomes from one study suggested that, for weight loss, exercise intensity is as important as exercise duration (Spees, Scott, & Taylor, 2012). This highlights the need for researchers, practitioners, and individuals to remain attentive to the intensity level of PA when striving for weight loss/maintenance. Although moderate-intensity PA provides some health benefits, it appears vigorous intensity PA is needed to facilitate weight loss (Spees et al., 2012).

Regular PA participation can assist with the primary and secondary prevention of several chronic diseases. These diseases include (although are not limited to) CHD; stroke; some cancers (e.g., colon, breast, and endometrial); muscle, bone, and joint diseases (e.g., osteoporosis); and chronic fatigue syndrome (Pate et al., 1995; Whiting et al., 2001). Additionally, research has demonstrated the key role of PA in

T2DM prevention and management, independent of weight loss (Jeon, Lokken, Hu, & Van Dam, 2007).

Psychological health benefits

Existing literature on the psychological benefits of PA is not as extensive as the plentiful research examining physical health benefits. Nevertheless, since the 1990s, substantial and accumulating evidence has demonstrated a relationship between regular PA and improved psychological health, such as enhanced mood, well-being, and quality of life, and reduced anxiety, depression, and stress (Berger, 2004). Consequently, in 1996, exercise was acknowledged by the Surgeon General's Report to be an effective intervention for depression and anxiety (US Department of Health and Human Services [USDHHS], 1996).

Health benefits independent of weight change

The physical and psychological health benefits of higher levels of aerobic fitness (an outcome of regular PA) have been demonstrated in overweight and morbidly obese adults (Jakicic & Otto, 2006). These health benefits have been shown to counteract the negative influence of excess body weight on health outcomes (Healy, Dunstan, Shaw, Zimmet, & Owen, 2006). Although overweight individuals can achieve health benefits from PA, even those who participate in high levels of PA are still at greater risk of CVD and diabetes than normal-weight individuals who engage in low levels of PA (Fogelholm, 2009). Therefore, weight loss should still be a health priority among overweight and obese populations.

Physical activity is now a central aspect of the treatment of the three major (and often comorbid) chronic illnesses: obesity, CHD, and T2DM (Pi-Sunyer, 2007; Wing & Phelan, 2005). It is important to note, however, that similar to maintaining a 10% initial weight loss, regular PA will only produce the desired health benefits as long as people regularly continue to participate (Praet & van Loon, 2008). Therefore, to experience and sustain health benefits, adherence to regular PA is just as important as initially increasing PA participation (Martinus, Corban, Wacherhage, Atkins, & Singh, 2006).

Impact of Common Comorbidities on Participation in Sport and Exercise

For overweight individuals, particularly those experiencing additional comorbidities (e.g., T2DM, depression), participating in regular PA can be a challenging task, at least in the initial stages of increasing one's PA level. There are health-related factors associated with being overweight and experiencing other comorbidities that impact individuals' participation in sport and exercise. For example, excess body weight may restrict the ability to engage in high-impact/weight-bearing activities, such as jogging or aerobics. Such activities may increase the risk of injury, particularly to feet, ankles, and knees, and place too much stress on the joints. Thus, overweight individuals may need to engage in low-intensity/low-weight-bearing activities, such as swimming and cycling (Broderick, Winter, & Allan, 2006). Additionally, many overweight people, particularly those who have habitually engaged in a low level of PA, have a lower exercise capacity (Ribisl et al., 2007) than the general population. The main risks associated with participating in exercise/sport with a low exercise capacity are the additional stresses placed on the joints of the body, as well as the pressures created for the cardiovascular system (Medstar Health, 2008).

Further, obese individuals need to be aware that although exercise enhances insulin sensitivity, some people with diabetes cannot engage in high-intensity exercise (Scott et al., 1999). For example, vigorous activity should be avoided in the presence of ketosis (Sigal, Kenny, Wasserman, Castaneda-Sceppa, & White, 2006). Thus, for most obese individuals, low-intensity PA and lifestyle PA would be an appropriate choice, at least in the initial stages of increasing PA participation (Sigal et al., 2006). Consistent with these potential health issues and associated PA recommendations is the finding that overweight individuals prefer lower-intensity types of PA (Spees et al., 2012). Lifestyle PA, such as walking, has been found to be a preferred PA type for overweight and obese individuals, because it is low impact, with little risk of injury. Further, higher PA adherence rates have been demonstrated in interventions aimed at increasing lifestyle PA, rather than structured exercise (Marcus et al., 2006).

Depression is a health problem that may inhibit participation in sport or exercise, or prevent participation altogether. This is concerning for overweight or obese individuals because depression is a common comorbidity of obesity, and people with chronic conditions, such as obesity, are typically inactive to start with. Therefore, experiencing depression may make overweight individuals even less likely to become physically active, when they are among those who are most in need of doing adequate physical activity for health. Populations with such chronic illnesses merit particular efforts to encourage them to be physically active. In an exercise/sport context, certain situations or factors may increase the likelihood of depression among overweight or obese individuals. For example, overweight/obese individuals may feel discouraged from exercising in group settings (e.g., gymnasiums, sporting clubs), because exercising around normal-weight and fitter individuals makes them feel "out of place." Such feelings of inferiority (relating to physical appearance and physical ability) may reduce motivation to be active, and impact self-esteem and self-confidence. Consequently, these depressive feelings may prevent obese people from participating in group-based activities altogether (Berger, 2004). Thus, it is important to consider the impact that exercise context (and fellow exercisers) can have on the PA behavior of overweight and obese individuals. Perhaps encouraging PA in supportive contexts with similar people exercising might increase the likelihood that social comparisons will motivate, rather than prevent, PA participation.

Additionally, for overweight and obese individuals, particularly those who are sedentary and in the initial stages of increasing their PA level, exercising requires considerable physical effort. Such effort may result in feelings of physical discomfort, and may be associated with social and/or physique anxiety, particularly when exercising in public settings (Berger, 2004). These feelings of anxiety may increase the individuals' risk of exercise drop out. Physical discomfort from exercise may also be interpreted as pain. Exercise-related "pain" can be worse in people who are overweight or obese since extra body weight can induce joint pain due to the extra force exerted on the joints (Wingo et al., 2011). Further, overweight/obese individuals' interpretations of exercise-induced physical discomfort may lead to fear, which, in turn, may result in exercise avoidance (Wingo et al., 2011). This is important information for researchers and health practitioners aiming to increase PA among this population. Specifically, when tailoring an exercise program to individuals' needs, early recognition of fear-avoidance beliefs may lead to increased self-efficacy and improvements in PA participation and adherence (Wingo et al., 2011).

Stopping an exercise routine, for whatever reason, can also increase the risk of depression. Nevertheless, despite such potential pitfalls impacting on obese individuals' subjective well-being in exercise settings, sufficient data supports the conclusion that carefully designed exercise programs can enhance overweight and obese individuals' well-being and self-esteem, and decrease ongoing stress levels and depressive symptoms (Berger, 2004). Furthermore, it is important to note that obese individuals can and do participate in all types of PA, and across the spectrum of intensities. Thus, obese individuals wanting to increase their PA participation should consider and work with their baseline fitness level, health status, needs, and preferences (Berger, 2004).

Physical Activity Participation Prevalence

Paralleling rising overweight and obesity rates is the increasing number of individuals, globally, particularly in Western countries such as Australia and America, living a sedentary lifestyle and engaging in a low level of PA. For example, globally, around 31% of adults (men 28% and women 34%) aged 15 years or more are insufficiently active (WHO, 2012b). In Australia, nearly three-quarters (72.8%) of adults (aged 15 years or more) are sedentary or engage in a low level of exercise (ABS, 2009). Specific sub-populations are even less likely to engage in PA, including people from culturally and linguistically diverse communities, people with low socio-economic status, dependent children, or lower education levels, and overweight/obese adults (ABS, 2011b). Similarly, a substantially low level of PA participation is reported among American adults, particularly those who are overweight or obese. For example, between 1999 and 2009, at least 80% of American adults aged 18 years or more engaged in an insufficient level of PA. In other words, less than 20% of American adults engaged in a sufficient level of PA during that 10-year period (National Center for Health Statistics, 2011).

Health Problems and Economic Burden Associated with Physical Inactivity

Physical inactivity has been identified as the fourth leading risk factor for global mortality causing an estimated 3.2 million deaths (6%) globally (WHO, 2012b). In Australia, PA is ranked second (behind tobacco smoking) as the most important factor in disease prevention (AIHW, 2004), and physical inactivity is ranked fourth in terms of the leading causes of disease burden (ABS, 2006b). For example, physical inactivity is a significant independent risk factor for (although not limited to) osteoporosis, overweight/obesity, and major chronic diseases, including CVD, cancer (particularly colon and breast), and T2DM (WHO, 2012b). Physical inactivity is also associated with mental health problems such as depression and anxiety (ABS, 2006b; Darren et al., 2006).

Detrimental Effects of Sedentary Behavior on Health

Paralleling research on the negative effects on inactivity are contemporary findings showing the autonomous impact of a sedentary lifestyle on health, independent of PA level. For example, sedentary behavior has been associated with an increased risk of overweight (Healy et al., 2008a; van Uffelen, Watson, Dobson, & Brown, 2010), developing chronic illnesses, such as T2DM and CVD (Dunstan et al., 2007; Hu, Li, Colditz, Willett, & Manson, 2003), and total mortality (Patel et al., 2010). For example, Dunstan et al. (2004) found that, among 8,299 Australian adults aged 25 years or more, those who watched at least 14 hours of television a week had more than double the risk of T2DM than those who watched less than 14 hours a week, independent of the effects of PA. Thus, in addition to identifying successful interventions to increase PA participation and adherence, particularly among populations at high risk of inactivity, such as overweight and obese individuals, strategies are also needed to focus on reducing sedentary behaviors. This suggests that interventions encouraging the accumulation of lifestyle PA throughout the day may help to simultaneously increase PA and reduce daily sedentary time.

Promoting Physical Activity Participation among Obese Individuals

Barriers to and motivation for PA participation among obese individuals

Many factors influence people's PA participation. Some factors facilitate (labeled "motivators") people's efforts to either begin or maintain regular PA participation, while other factors inhibit PA participation and adherence (labeled "barriers"). Knowledge of these factors among the population of interest, in this case overweight or obese individuals, can assist in the development of effective interventions tailored to enhance PA participation for that group. Very limited research has specifically examined motives and/or barriers for certain types of PA, particularly sport or exercise, so in this section, the term "PA" is used to refer to all activity types.

Barriers to physical activity

Several PA barriers appear in research on adults in most populations. These barriers include (perceived) lack of time (Korkiakangas, Alahuhta, & Laitinen, 2009), low exercise self-efficacy (Korkiakangas et al., 2009), low motivation (Jewson et al., 2008), and lack of energy (Jewson et al., 2008). Tiredness or lethargy is another commonly reported PA barrier, particularly among adults with T2DM (Korkiakangas et al., 2009) and people with depression (Craft et al., 2008). Laziness has also been reported by some to prevent PA participation, especially among people who are overweight (Jewson et al., 2008). Enjoyment of sedentary behavior (e.g., reading, watching television) has also been found to contribute to the high number of adults engaging in insufficient PA (Dunstan et al., 2007). Thus, some individuals' preference for sedentary activities may facilitate reporting of other PA barriers, such as lack of time, low motivation, and tiredness.

Other frequently reported barriers include a lack of knowledge about the benefits of PA (Struber, 2004), initial high expectations of the exercise program (Jones, Harris, Waller, & Coggins, 2005), or a negative attitude toward PA (Di Loreto et al., 2003). Also, commonly reported barriers among people who are overweight include feelings of being too fat (Korkiakangas et al., 2009; Struber, 2004), and poor body image (Struber, 2004). Additionally, perceiving oneself to be too old to engage in PA (Struber, 2004), fear of injury (Struber, 2004), and having physical health problems (Korkiakangas et al., 2009; Struber, 2004) prevent PA participation for some adults. Pain is a particular barrier to PA among those who are overweight (Struber, 2004). Furthermore, experiencing depression has consistently been shown to be a barrier to PA behavior (Kyrios, Nankervis, Reddy, & Sorbello, 2006).

External barriers to PA are also commonly reported among adults. Such barriers include insufficient social support (Struber, 2004) or having no exercise partner (Trost et al., 2002). For many people, poor weather (Casey, De Civita, & Dasgupta, 2010), a lack of access to exercise facilities (Casey et al., 2010), and an unsafe neighborhood (Struber, 2004) discourage people from participating. Financial costs related to transportation and/or gymnasium membership fees also inhibit PA participation, particularly for individuals earning a lower income (Korkiakangas et al., 2009). Facility-based exercise programs can create additional barriers for some people, such as scheduled class times that clash with other commitments, and transportation difficulties (Marcus et al., 2006). Furthermore, for some, particularly people at high risk of inactivity, such as overweight individuals with additional health problems, the absence of individualized programs may inhibit their participation.

Motives for physical activity

Certain factors have been shown to facilitate PA behavior. For example, in Bandura's (1986) self-efficacy theory (SET), the belief people have in the capability of performing a specific behavior is a strong motivator of actual behavior (Bandura, 1986). High exercise self-efficacy is consistently reported to be a dominant factor in assisting individuals to begin and maintain regular PA participation (Frederick & Richard, 1993; Moore, 2011; Sweet et al., 2009).

Factors underlying one's motivation also influence PA participation and adherence. For example, enjoyment of engaging in the PA (a type of intrinsic motivation, as defined by Deci and Ryan's [1985] self-determination theory [SDT]) is a commonly reported motivating factor among adults (Sweet et al., 2009; Thogersen-Ntoumani & Ntoumanis, 2006). Additionally, autonomous motivation (Deci & Ryan, 1985) has been shown to influence PA participation and adherence for some adults (Sweet et al., 2009; Thogersen-Ntoumani & Ntoumanis, 2006). Autonomous motivation refers to the perception of being in control of decisions, that is, it is about having free choice. Additionally, among obese individuals, determinants explaining one's intention to engage in PA, namely (higher) perceived behavioral control and anticipated regret (i.e., negative feelings toward the idea of not exercising) have been shown to predict actual behavior (Godin, Amireault, Belanger-Gravel, Vohl, & Perusse, 2009). Support and encouragement to begin and maintain PA, from one's family and friends (Jewson et al., 2008; Moore, 2011), exercise staff (Casey et al., 2010), and physician (Schutzer & Graves, 2004), is another predominant motivating factor for adults in all populations. Some adults are motivated to exercise for social reasons (Jewson et al., 2008), such as to spend time with existing friends or to meet new friends. Additionally, observing others (e.g., modeling) engaging in PA facilitates PA behavior for some individuals (Trost et al., 2002).

The resultant physical and psychological health benefits (Casey et al., 2010) of PA are commonly reported motivators. In particular, engaging in PA for weight loss reasons has been shown to be influential for people who are overweight (Jewson et al., 2008). Other frequently reported motivators of PA include having a positive perception of PA and the associated outcomes (Kirk, Barnett, & Mutrie, 2007), and positive past experiences in PA (Trost et al., 2002). Furthermore, the convenience of home exercise equipment, perceived and actual access to fitness and recreation clubs, and satisfaction with these clubs facilitate PA participation for some individuals. Environmental influences have also been cited as motivating factors for PA participation. These influences include having a safe neighborhood, appealing terrain, and enjoyable scenery (Trost et al., 2002). No two people are the same; so one person's PA barriers and motivators are likely to differ from those of the next person (Lawton et al., 2006). To maximize the effectiveness of interventions aimed at increasing PA participation and adherence, in addition to factors that are prominent in the population of interest, the specific PA barriers and facilitators that are relevant to each individual should also be considered (Sherwood & Jeffery, 2000).

Interventions to Increase Physical Activity Participation among Obese People

Numerous interventions, including structured, pre-determined programs and psychological interventions grounded in theory, have been developed with the aim of promoting PA participation in people who are overweight or obese. Several reviews provide insight into the overall effectiveness of PA interventions, and highlight interventions, strategies, and settings that show promise in increasing PA participation among this high-risk population for inactivity (Marcus et al., 2006). Some reviews also provide recommendations for researchers, practitioners, and individuals, aiming to increase PA in this population (Kirk et al., 2007). In this section, the problem of poor adherence to regular PA is discussed. Then, outcomes are summarized from several reviews examining the impact of interventions, particularly theoretical interventions, on PA behavior among overweight and obese people. Finally, attention is paid to an intervention type (PA Consultation), a technique (objective self-monitoring), and a setting (workplace) that have shown encouraging results in promoting PA in people who are overweight or obese.

Poor adherence to regular PA

It is apparent that getting people initially active is challenging. Studies have shown that PA interventions, particularly those in supervised settings, are more successful in getting people to begin exercise compared to no intervention, at least in the short term – for example, 6 months (Dishman & Buckworth, 1996). For example, Dishman and Buckworth's (1996) meta-analysis revealed that interventions for increasing PA can improve success from the typical rate of 50% without intervention to between 70% and 88%. In addition to getting people to *begin* PA, ensuring people *adhere* to regular PA is an equally arduous task (Martinus et al., 2006; Sherwood & Jeffery, 2000). Marcus and colleagues (2006) reported dropout rates from structured exercise programs ranging from 9% to 87% (mean 45%). Thus, it seems that exercise is not unlike other health-related behaviors, in that, typically, around half of the people who begin a PA program will not sustain their participation for more than 6 months (Marcus et al., 2006).

Intervention effectiveness among overweight and obese individuals

The problem of poor adherence, particularly from pre-determined, structured exercise interventions, has been noted in almost all populations, including people who are overweight or obese (Dunstan et al., 2005), and those with chronic illnesses such as T2DM (Dunstan et al., 2006; Kirk et al., 2007) and depression (Richardson, Avripas, Neal, & Marcus, 2005). For example, in a 12-month randomized control trial (RCT), Dunstan and colleagues (2005) assigned 36 sedentary overweight men and women with T2DM aged 60–80 years at random to either the intervention group (high-intensity resistance training [RT] plus moderate weight loss), or the control group (moderate weight loss plus a control program of flexibility exercises). In the first 6 months (phase 1), participants in the intervention group attended three weekly sessions of supervised, gymnasium-based, high-intensity progressive RT. During the 6-month follow-up (phase 2), participants were encouraged to continue their RT (intervention group) or stretching (control group) in an unsupervised setting, either at home or in a gymnasium. In the intervention group, adherence to the supervised gymnasium-based program was 88% (phase 1); however, during the follow-up period (phase 2), adherence reduced to 72.6%. Furthermore, of those who reported maintaining their PA behavior during the follow-up period, their PA frequency and volume had reduced (Dunstan et al., 2005). Poor adherence to PA is problematic, because health benefits from PA are only experienced while PA participation is maintained. Thus, different approaches to promote adherence to regular PA are needed.

Gourlan, Trouilloud, and Sarrazin (2011) conducted a meta-analysis, including 46 quasi-experimental and RCT studies, to determine the global effect that interventions promoting PA among obese populations (including children, adolescents, and adults) had on their PA behavior. Outcomes showed that interventions globally had an impact on PA behavior for obese populations. This finding is important because it suggests that programs promoting PA may be an effective strategy for helping obese populations to adopt more active lifestyles. Nevertheless, results also showed a large level of variability in efficacy between interventions, and most interventions involved low sample sizes, so study samples may not have been representative of the obese population. Furthermore, Gourlan et al. revealed that interventions of less than 6 months showed significantly larger effects than longer interventions. However, relatively few studies addressed this issue ($n = 9$). Future research should include longer programs (>6 months) and integrate multiple regular assessments to determine the PA evolution of obese participations during long interventions (Gourlan et al., 2011).

Based on outcomes from contemporary research, interventions need to be theoretically driven, include psychological strategies/techniques, and promote “active living” (e.g., encouraging PA types the individual prefers), rather than participation in a prescribed type of exercise or sport. Belanger-Gravel, Godin, Vezina-Im, Amireault, and Poirer (2011) conducted a systematic review to investigate the long-term effectiveness of theory-based interventions for increasing PA. They aimed to identify the most effective techniques for behavior change among overweight/obese individuals. Of the studies in which researchers observed a significant short- or long-term effect of time on behavior, the theoretical frameworks most often (83% of studies) applied were the traditional behavioral model and Bandura’s (1986) social learning/cognitive theory (SL/CT), either alone or in combination with other theories. In particular, stages and processes of change were targeted in almost all interventions partially or exclusively based on the transtheoretical model (Prochaska & DiClemente, 1982). Main theoretical techniques used in these studies were providing opportunities for social comparison, providing instructions, and self-monitoring. Additionally, the techniques that distinguished or characterized the experimental groups from the control groups were prompting practice, barrier identification, and prompting intention formation. Although a combination of these three techniques appears successful, the long-term impact of theory-based interventions remains ambiguous. The number and type of theoretical techniques used varied substantially across studies, even though the interventions referred to the same theoretical background. Furthermore, self-efficacy has been shown to be an important mediator of interventions aiming to increase PA participation (Belanger-Gravel et al., 2011), which provides support for Bandura's (1986) social cognitive theory.

In their review of outcomes, Belanger-Grave and coworkers (2011) showed that the long-term effectiveness of theory-based interventions to increase the level of PA among overweight/obese people was only weakly supported because very few studies observed a superior effect of their experimental conditions. Additionally, no clear conclusion could be drawn from this systematic review regarding the most effective theories or components, as well as the most effective combination of these to promote a long-term PA pattern among overweight/obese individuals. This lack of information impacts on the possibility of developing evidence-based interventions for overweight/obese individuals to increase PA. To gain this valuable and needed information, Belanger-Gravel et al. recommended that more evaluation studies of the long-term effect of interventions are needed to gain clearer insight into the long-term efficacy of modifying PA. They also highlighted the need for researchers to isolate targeted theoretical constructs, and more importantly, techniques in their experimental conditions to evaluate the specific contribution of these variables. Furthermore, Belanger-Gravel et al. suggested that researchers should pay particular attention to carefully selecting and describing the theoretical techniques adopted to change key theoretical constructs – for example, by using taxonomies developed by Abraham and Michie (2008).

Acknowledging the need for further research examining the most effective intervention strategies for promoting PA in people who are overweight or obese, evidence to date does indicate that, compared to pre-determined structured (formal) exercise interventions, psychological interventions that promote the accumulation of lifestyle PA (active living) may be more successful at initiating and promoting adherence to PA among adults, particularly those who are overweight or obese (Kirk et al., 2007). For overweight ($\mathrm{BMI} \geq 25$) individuals, in addition to lower intensity/lifestyle PA being an ideal type of PA from a health perspective, it is likely to be easier for inactive individuals to make long-term changes to increase PA level by accumulating these everyday behaviors, than to establish new formal exercise/sport activities (Grave, Calugi, Centis, Ghoch, & Marchesini, 2010). Encouraging findings from a recent study showed that advocating small changes in diet and PA can result in modest, but sustained, clinically significant weight loss across a 9-month period (Lutes et al., 2012). Additionally, Berger (2004) suggested that, to facilitate PA adherence in obese populations, it is important to change the perception of exercise from "should" to "want." Psychological interventions that encourage active living (i.e., participation in PA that the person enjoys), rather than a pre-determined PA type or intensity, are likely to be more successful in changing people's perception that they want to exercise. Such interventions are more likely to result in PA participation and adherence, particularly for overweight or obese individuals (Berger, 2004).

Additional support for interventions advocating lifestyle PA comes from medical recommendations which now indicate that around 30 minutes of accumulated moderate-intensity PA on most days is enough to produce general health benefits (Pate et al., 1995). Consequently, there has been an expansion in the development of theory-based, psychological interventions advocating active living/lifestyle PA (Kirk et al., 2007). Psychological interventions have been shown to be effective among individuals who are overweight or obese (Andersen et al., 1999), people with T2DM (Krug, Haire-Joshu, & Heady, 1991), people with CHD (Rogerson, 2009), depressed individuals (Richardson et al., 2005), and previously sedentary individuals (Dunn et al., 1999).

Regardless of the intervention, however, to enhance dissemination, there is a need for close collaboration between researchers and community organizations when translating research into practice (Goode, Owen, Reeves, & Eakin, 2012). Goode et al. suggested that researchers need to be closely involved in the translation process, to advocate for translation, and to support necessary adaptations to ensure fidelity with the original program and the relevant evidence (Goode et al., 2012).

Intervention Type: Physical Activity Consultation

One type of psychological intervention aimed at increasing active living/lifestyle PA is PA consultation, originally labeled "exercise consultation" (Loughlan & Mutrie, 1995). PA consultation combines key techniques from a number of psychological models and principles with the aim of encouraging people to identify their own lifestyle changes that will increase PA. For example, the style of consultation is based on motivational interviewing (Miller & Rollnick, 2002), a technique that has been successful in promoting health behavior change by guiding people to make their own decisions about the need for them to change their behavior and how they will do it. PA consultation is also based on the transtheoretical model (TTM; Prochaska & DiClemente, 1982). The essence of TTM is that people at different stages of the behavior change process need different kinds of support to make progress. Matching the kind of support process with the stage of change is the key to promoting behavior change, according to Prochaska and DiClemente. Another key to the success of PA consultation is the inclusion of self-efficacy. People tend to choose to do things for which their self-efficacy is high, they have more confidence about doing them, so they persevere longer, especially in the face of initial failure (Bandura, 1997).

Increasing self-efficacy is a key component of PA consultation. It is usually based on the provision of mastery experiences, which depend on setting meaningful, but readily attainable goals.

Numerous studies, including RCTs, and review articles have provided support for the use of PA consultation for successfully increasing the adoption of, and adherence to, PA among various groups, including people with CHD (Hughes et al., 2002), depression (Seime & Vickers, 2006), and T2DM (Kirk et al., 2007). Additionally, researchers have conducted qualitative studies showing the potential effectiveness of PA consultation for increasing PA among individuals with depression *and* chronic illness, including individuals with depression and CHD (Rogerson, 2009), and overweight or obese women with T2DM and depression (Moore, 2011). For example, Kirk and coworkers (2003) conducted an RCT to evaluate the effect of an exercise consultation intervention, the original term describing the intervention, modified to "PAC" more recently, on "PA participation" (assessed using an accelerometer, and the 7-day PA recall), and the resultant physiological and biochemical changes at 6 and 12 months. A total of 70 inactive adults (50% female, 94.3% overweight; mean age of 57.6 years) with T2DM were randomized to either an exercise consultation ($n = 35$) or a control condition ($n = 35$). Consultations, using the exercise consultation approach, were delivered at baseline and after 6 months, with follow-up phone calls after 1, 3, 6, and 9 months. Results showed that individuals receiving the intervention had increased levels of PA from baseline to 6 months, with no decrease from 6 to 12 months. In the control condition, weekly accelerometer counts decreased from baseline to 12 months. Furthermore, compared to the control condition, participants in the exercise consultation condition had improved glycemic control, and reduced CVD risk factors (Kirk et al., 2003).

Moore (2011) implemented a 12-week PA consultation intervention, involving a one-off consultation in week 1, and two follow-up phone calls in weeks 8 and 12, based on the guidelines of Kirk, Barnett, and Mutrie (2007), to increase PA participation and adherence among six overweight women with T2DM and depression. Using a case-study design, the purpose of this study was to explore the individual experiences of these six women, particularly in relation to the effectiveness of the intervention on their self-reported PA and mood, especially depression, over a 24-week period (i.e., 12-week intervention and 12-week follow-up). Individual differences were evident in participants' experiences, particularly regarding their PA and mood changes during the follow-up period. All women found the intervention beneficial in increasing their psychological readiness (e.g., PA awareness, motivation, intention), and most also increased their self-reported PA participation. The intervention appeared particularly useful in increasing PA participation for women who were contemplating or preparing to increase their PA. It appeared, however, that women experiencing a high level of depression may require additional assistance with adoption and maintenance of PA (Moore, 2011). Strategies that were identified in this study as being particularly useful in assisting overweight women with their PA behavior were those that directly and indirectly facilitated participants' intrinsic motivation (e.g., enjoyment) and PA self-efficacy (i.e., confidence in the ability to initiate and maintain specific types of PA). Such strategies included education; identifying and overcoming barriers; goal setting and re-assessment, and ensuring goals are realistic and broken down into smaller tasks; identifying and encouraging suitable activities they enjoyed; self-monitoring strategies (e.g., PA log); and providing verbal support. These findings provide support for theory-based interventions and strategies for assisting overweight women suffering from T2DM and depression with successful behavior change. Moreover, the impact of PA consultation on self-efficacy supports previous research and reviews (e.g., Belanger-Grave et al., 2011). The findings are particularly relevant for health professionals aiming to increase PA in overweight women with T2DM and depression. Consistent with the recommendations of Belanger-Grave and coworkers (2011), more research is needed to identify appropriate and effective ways to engage individuals in PA who are overweight or obese, including those with multiple health complications.

Technique: Objective Monitoring of PA

As mentioned, intervention strategies and techniques to improve adherence with sufficient doses of PA are needed to enhance long-term PA maintenance to sustain health outcomes, such as improved cardiovascular fitness, psychological well-being, and weight loss, among overweight people. Self-monitoring techniques, such as accelerometers and pedometers have been demonstrated to be an effective and valuable inclusion in interventions aimed at increasing PA participation and adherence in various populations (Bravata et al., 2007), including overweight and obese individuals (Pal et al., 2009; Schneider, Bassett, Thompson, Pronk, & Bielak, 2006) and individuals with chronic illness (Ruppar & Conn, 2010). Ruppar and Conn's meta-analysis outcomes indicated that strategies involving self-monitoring (such as accelerometers and pedometers) significantly improved the effectiveness of interventions aimed at promoting PA in people with chronic illness, such as T2DM, regardless of other strategies employed (Ruppar & Conn, 2010). Pedometers are a type of self-monitoring tool that provides feedback about the number of steps a person accumulates. This information has been shown to prompt activity as it raises awareness of current walking behaviors (Bravata et al., 2007; Pal et al., 2009). According to the outcomes of a meta-analysis by Bravata el al. (2007), pedometer use is associated with significant increases in PA, adding approximately 2,000 steps, equivalent to around 1 mile of walking per day. Moreover, pedometer use has been associated with clinically relevant reductions in weight and blood pressure (Bravata et al., 2007).

Findings from independent studies involving overweight and obese individuals further support the potential value of pedometers in psychological interventions aimed at increasing PA (Bravata et al, 2006; Pal et al., 2009). Pal et al. (2009) conducted a study to evaluate whether the daily use of pedometers could increase PA in sedentary, middle-aged, overweight and obese women. Results showed that pedometer use significantly increased the number of steps/day women achieved after

6 and 12 weeks. One explanation for the positive impact of pedometers on PA behavior may be because of the immediate feedback that pedometers provide, enabling individuals to set realistic PA goals, and/or that pedometers act as an environmental cue to be active and raise awareness of current behaviors. Thus, the inclusion in PA interventions of self-monitoring techniques, such as objective monitoring devices, may promote increase in PA among overweight and obese individuals, at least in the short term (Jakicic, Davis, Garcia, Verba, & Pellegrini, 2010).

Intervention Setting: Workplace

Many aspects of modern living promote an inactive lifestyle through factors including sedentary jobs, motorized transport, and labor-saving devices (Brownson, Boehmer, & Luke, 2005). Additionally, for working individuals, a large proportion of their time is spent at the workplace. Therefore, numerous studies and reviews have examined the effectiveness of PA interventions at the workplace for promoting PA behavior (e.g., Marcus et al., 2006; Proper & Van Mechelen, 2008). Recent reviews of research of high methodological quality show strong evidence for the impact of worksite interventions for increasing PA behavior, and some relevant health risk factors, including blood cholesterol level and body composition (Marcus et al., 2006; Proper & Van Mechelen, 2008).

Review outcomes suggest that workplace programs offering fitness facilities, or referrals to worksite fitness programs, show little efficacy, and are typically attended by people who were already exercising or highly motivated to do so (Marcus et al., 2006). Consistent with the support for theoretical interventions, there is stronger evidence supporting individually tailored motivational programs guided by behavior change theory, and for programs that used strategically placed prompts, such as signs encouraging use of stairs. Successful interventions typically increased short-term PA behavior (Marcus et al., 2006). Thus, workplace interventions have shown favorable outcomes on PA behavior, especially when they have used individually tailored, theory-based materials and/or environmental prompts (Marcus et al., 2006). Few studies have included an evaluation of the economic benefits of PA programs in workplace settings. Based on review outcomes, Proper and Van Michelen (2008) predicted that increases in PA participation via worksite PA and/or diet interventions may produce a reduction of 0.45% on total healthcare costs, and a reduction of 0.53% on total indirect costs, that is, around 1%, which they considered to be a significant saving in the larger context.

There is some evidence to suggest that workplace interventions may be effective for promoting PA behavior in overweight and obese adults. Dinesh et al. (2011) conducted a 9-month study to determine if a treadmill-workstation (TMWS) increased PA and influenced anthropometric, body composition, cardiovascular, and metabolic variables in 12 (mean age 46.2 years) overweight and obese office workers (mean BMI: 33.9 kg m^2), who volunteered to participate in this study. During the 9-month study, participants were asked to maintain the same PA and dietary habits outside of work that they followed before the TMWS installation. Results revealed significant increases between baseline and 9 months in median standing and stepping time, and total steps/day. Correspondingly, the median time spent sitting/lying decreased. On the whole, this study demonstrated that sedentary office workers can increase PA and reduce sedentary time by using a TMWS. Dinesh et al. argued that TMWS provides one option for being more active at work, rather than solely relying on leisure time PA.

Conclusion

Substantial progress has been made in recent years related to the identification of effective ways to encourage people who are overweight or obese to become more physically active and, importantly, to *stay* active. For example, evidence to date reveals that interventions are effective in increasing PA participation in overweight and obese individuals, at least in the short term. Theoretical interventions (e.g., those based on the behavioral model, social learning/cognitive theory, and the transtheoretical model), particularly those that promote active living/lifestyle PA (such as PA consultation), are more effective in assisting overweight and obese individuals to begin and maintain PA than structured, pre-determined PA programs. Strategies and techniques that are effective in promoting PA participation in people who are overweight or obese include those that increase self-efficacy, intrinsic motivation, and provide opportunities for social comparison and self-monitoring.

Nevertheless, as demonstrated by the continued rise in overweight or obesity and physical inactivity in many countries, identifying effective interventions and strategies to promote PA participation and adherence continues to challenge researchers and practitioners alike. Thus, to build on the progress made to date, more research is needed, particularly RCTs with long follow-up periods ($\geq$6 months), to examine the long-term impact of interventions (particularly those grounded in theory, such as PA consultation) on PA initiation and adherence; to identify specific strategies and techniques, such as self-monitoring techniques, and those that enhance self-efficacy and intrinsic motivation; and to target different intervention settings (e.g., workplace) and delivery modes (e.g., face-to-face, email, phone). The benefits to be gained from continued research could be far reaching. For example, this may result in higher PA levels and improved (physical and psychological) health for people who are overweight or obese, which would translate into improved health, enhanced quality of life, and reduced financial costs for individuals and society.

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6

Cancer-related Fatigue

Benjamin J. Hassan and Maíra P. O. Campos

> Cancer-related fatigue is a distressing persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning.
>
> National Comprehensive Cancer Network, Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Cancer-Related Fatigue v.1.2012

Fatigue is likely the most common, distressing, and overlooked symptom related to cancer and its treatment. It is not relieved by rest or sleep, in contrast to the exhaustion that results from physical exertion or a viral illness. Patients with cancer-related fatigue (CRF) avoid physical activity even as their attempts to rest are not rewarded by recovery; this vicious cycle of impaired activity, declining physical conditioning, and worsening fatigue may cause patients to feel helpless (Horneber, Fischer, Dimeo, Ruffer, & Weis, 2012).

The physical aspects of CRF are only one dimension of a multidimensional process. Mood disturbance, impaired social function, and impaired cognition or mental fatigue often accompany the lack of physical energy, resulting in a profound impact on all aspects of quality of life (QoL) as well as productivity and self-worth. Fatigued patients are less able to participate in leisure activities alone or with their families and friends, less able to work, and more dependent on others (Morrow, 2007; Mustian et al., 2007). According to Hofman and colleagues, over 90% of patients with CRF report that their fatigue interferes with their daily activities and QoL (2007).

Factors that contribute to the development of CRF, in addition to cancer or any of its treatments, are comorbid medical conditions, pain, mood and sleep disturbances, poor coping skills, decreased social function, and employment problems

The Handbook of Behavioral Medicine, First Edition. Edited by David I. Mostofsky.

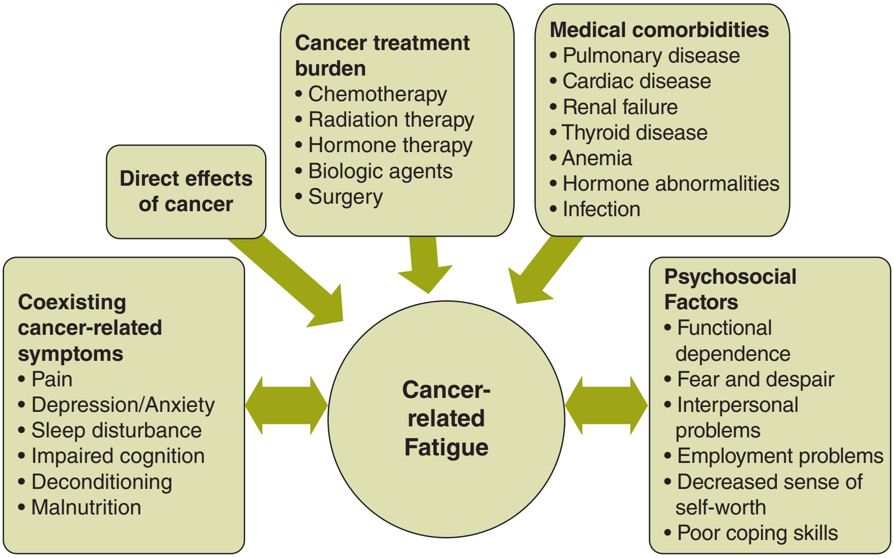

Figure 6.1 Causes and contributing factors. Adapted from Mustian et al. (2007) and Wagner and Cella (2004).

(Figure 6.1). Mood and sleep disturbances are strongly associated with CRF (Hofman et al., 2007) and may more often be a result than a cause of fatigue, as improvement in fatigue has been shown to result in decreased levels of anxiety and depression (Tchekmedyian, Kallich, McDermott, Fayers, & Erder, 2003).

Patients may experience fatigue at any time during the course of illness, although it usually begins early—at or before diagnosis or near the start of anticancer therapy. Fatigue often intensifies throughout active treatment, a trend that may be superimposed by brief periods of rapid intensification and reduction corresponding to each dose of chemotherapy or round of radiation. Fatigue usually subsides gradually after treatment and especially upon remission or cure, but a proportion of patients continue to experience fatigue long after treatment has completed or even years after their cancer has been cured (Horneber et al., 2012; Wagner & Cella, 2004). Patients' experience of fatigue and its relative makeup (physical, mental, emotional, and social aspects) also depends on the type of cancer and the phase and type of treatment.

Most striking among all of its consequences is that CRF may impact survival. In 1588 breast cancer patients followed over a median of 13 years by Groenvold and colleagues, lower levels of fatigue was a significant and independent predictor of progression-free survival (2007). CRF was also shown to be a marker of poor survival in patients with esophageal cancer (Stauder et al., 2012).

Barriers to the identification of CRF exist on the parts of both patients and physicians. Physicians may not understand the severity of the symptom and the impairment that it causes, and may wrongly relate patients' CRF to their own personal experience with tiredness. They may also simply fail to assess fatigue systematically, hindered by the idea that it is an expected part of cancer or its treatment, and by the absence of an objective diagnostic study that can reliably demonstrate it. Patients likewise may see fatigue as an expected, unavoidable, and irremediable consequence of their disease or treatment. They may also fear that it heralds a recurrence of their cancer or that reporting the symptom might incite a change toward less aggressive treatment or a delay in their treatment (Campos, Hassan, Riechelmann, & Del Giglio, 2011; Horneber et al., 2012).

Prevalence of CRF

Estimates of the prevalence of CRF fall across a wide range and depend on the population studied, the type of cancer, and the diagnostic criteria used. It has been accepted by many reviewers that 60–90% of cancer patients experience fatigue at some point, and over 80% report fatigue during treatment with chemotherapy or radiation (Hofman et al., 2007). These estimates do not identify the proportion of patients who have persistent fatigue that interferes with QoL and functioning, meets formal diagnostic criteria, and would benefit most from a specific intervention. To illustrate, Curt and colleagues found that, among 379 cancer patients, 76% experienced fatigue at least a few days each month, while 30% reported fatigue on a daily basis (2000).

The prevalence of fatigue in patients actively undergoing radiation therapy is exceedingly high, but chemotherapy seems to have a more prolonged impact, sometimes lasting years after treatment. Fatigue has been reported in 40% of patients with biochemically controlled prostate cancer on long-term androgen deprivation therapy (Storey et al., 2012), in 30% of survivors of Hodgkin disease 16 years after cure (Hjermstad et al., 2005), and in up to a third of breast cancer survivors 10 years after cure (Reinertsen et al., 2010).

CRF also may be present in 50–100% of pediatric cancer patients according to Mooney-Doyle (2006), although it has not been well studied in this population, and researchers usually query the parents' perception of their children's energy levels instead of surveying the patients themselves.

Mechanisms of Fatigue

Fatigue is a complex biological process involving alterations in multiple body systems. The following proposed mechanisms have been described by Ryan and colleagues in an exhaustive review (2007).

- *Serotonin (5-HT) dysregulation.* Selective serotonin reuptake inhibitors (SSRIs) have been studied in CRF trials with the hypothesis that correcting mood disturbance might lead to improvements in fatigue, and the results have been disappointing. The reasons may be two-fold: (1) there is no clear causative relationship between CRF and depression, and (2) fatigue has been associated with *increased*, not decreased, levels of central 5-HT.

Tryptophan, the precursor to 5-HT, increases during exercise and results in increased levels of 5-HT, which may give rise to central fatigue when levels become high enough. Baseline tryptophan levels have been shown to increase in chronic fatigue syndrome (CFS) such that further exercise-induced increases may more easily result in fatigue. 5-HT may also activate peripheral afferent nerves and cause production of other neuromediators such as prostaglandins. Further, the interaction between the HPA axis and the serotonergic system may become disrupted, and 5-HT levels may also be increased by proinflammatory cytokines. 5-HT receptors may eventually be upregulated, exaggerating the serotonergic response to several stimuli.

- *Dysregulation of inflammatory cytokines.* Increased levels of several cytokines have been associated with cancer and its treatment, as well as with lethargy, anorexia, fatigue, and the body's "sickness behavior." Interest in IL-6 and TNF-α was sparked by studies that demonstrated their increased levels in CFS. A quantitative review on CRF-specific studies showed significant correlations between CRF and IL-6, IL-1ra, and neopterin, but not TNF-α (Schubert, Hong, Natarajan, Mills, & Dimsdale, 2007).
- *Disturbances of the HPA axis.* In response to stress, corticotropin-releasing hormone (CRH) is secreted from the hypothalamus, which in turn acts on the pituitary to cause adrenocorticotropic hormone (ACTH) release. ACTH stimulates the adrenal glands to release cortisol, which, in addition to having many regulatory biologic effects, provides negative feedback to the hypothalamus and pituitary.

  While stress increases hypothalamic CRH, chronic inflammation reduces it. Low cortisol levels have been found in several chronic diseases including CFS, rheumatoid arthritis, and cancer, but a causal relationship between HPA axis dysfunction and fatigue is unclear. In one study of breast cancer survivors, women who were fatigued had lower levels of cortisol than those who were not fatigued (Bower, Ganz, Aziz, & Fahey, 2002).
- *Circadian rhythm disturbances.* Alterations in diurnal endocrine rhythms, metabolism, immune function, and rest–activity patterns all have been demonstrated in patients with cancer. Diminished diurnal cortisol variation has been particularly associated with fatigue in cancer survivors, and patients with CRF have been shown to have diminished activity levels during the day and more restless sleep at night. The causal relationship between CRF, sleep disturbance, and HPA alterations is not clear.
- *Peripheral fatigue.* It has been hypothesized that the experience of fatigue may relate in part to a reduced contractile capacity of the muscles themselves. Most exploratory hypotheses are based on the impairments in ATP synthesis and oxidative muscle metabolism that have been found in CFS, but this mechanism has not yet been investigated in CRF. Moreover, although reduced physical

functioning has been confirmed objectively in CRF patients, studies using electromyography have failed to demonstrate a true peripheral mechanism (Yavuzsen et al., 2009).

- *Vagal nerve activation.* The vagal afferent nerve hypothesis is borne out of animal models and has yet to be substantiated in humans. It holds that cancer or its treatment results in the release of neuroactive agents that activate vagal afferent nerves, which then suppress somatic muscle activity and stimulate production of peripheral cytokines. This process may mediate the induction of "sickness behavior," the symptoms of which include malaise, poor concentration, subjectively impaired memory, sleep disturbance, decreased appetite, and fatigue.
- *Sex hormone alterations.* Anticancer therapy can result in both menopause in women and andropause in men, the effects of which are particularly augmented by androgen deprivation therapy for prostate cancer and by hormone therapy for breast cancer.
- *Comorbid conditions and other contributors.* Anemia, cachexia, mood disturbances, sleep disorders, hypothyroidism, pain, electrolyte and metabolic disturbances, and organ dysfunction such as heart failure, lung disease, or myopathy, all may contribute to fatigue (Escalante, Kallen, Valdres, Morrow, & Manzullo, 2010). These potentially reversible or treatable conditions should be identified and treated separately based on established guidelines.

Diagnostic Criteria

The 10th revision of the International Statistical Classification of Diseases (ICD-10) includes diagnostic criteria for CRF. Although the visual analog scale (VAS) or brief fatigue inventory (BFI) can be used more conveniently as a rapid assessment tool, and the ICD-10 criteria cannot be used to assess fatigue severity, it has good internal consistency and may reliably diagnose fatigue that is likely to be impairing and warrant further evaluation and management (Van Belle et al., 2005). According to these criteria, significant fatigue and five or more of 10 associated symptoms (including alterations in sleep, interest, emotional reactivity, concentration, motivation, short-term memory, and task completion) must have been present for at least 2 weeks in the past month and lead to impairment in at least one functional domain. Fatigue also must be due primarily to cancer or cancer treatment and must not be a consequence of comorbid psychiatric disorders (Cella, Davis, Breitbart, & Curt, 2001).

Clinical Evaluation and Management

Overview

The evaluation and management of CRF is approached using a biopsychosocial model in which the multiple dimensions of CRF are taken into account. The

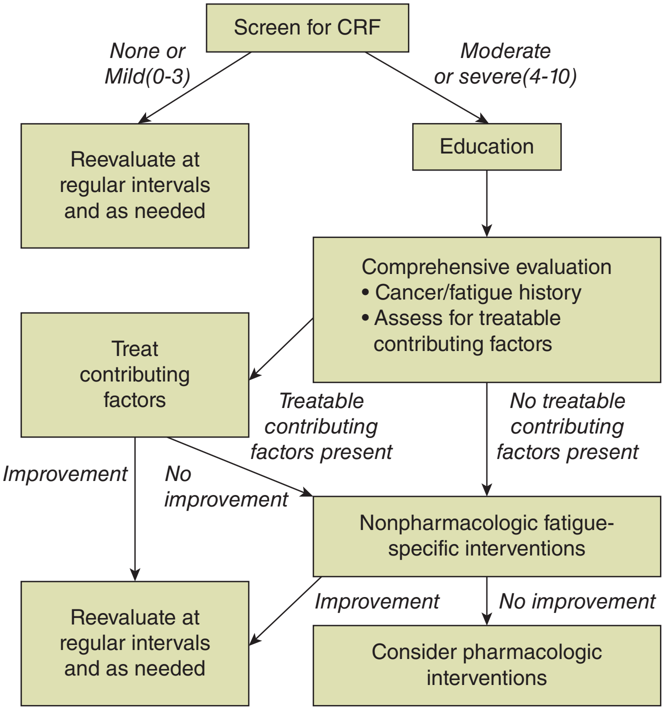

Figure 6.2 Algorithm for the evaluation and treatment of cancer-related fatigue.

following key points are discussed further in the sections that follow and are based to a large extent on the National Comprehensive Cancer Network® (NCCN®) guidelines on CRF (2012) (Figure 6.2).

1. Screen for fatigue at the initial visit and at regular intervals thereafter, particularly upon changes in cancer stage or treatment.
2. Identify and treat potentially reversible contributing factors such as sleep disorders, mood disturbance, pain, medication effects or interactions, anemia, or other major medical comorbidities.
3. Educate patients and caregivers on CRF.
4. Devise an individualized treatment plan while harnessing the patient's strengths and resources and activating the patient's social support network.
5. Use non-pharmacologic treatments first. Exercise is the most beneficial non-pharmacologic treatment, followed by energy conservation and psychosocial interventions such as cognitive behavioral therapy.
6. Choose methylphenidate or dexmethylphenidate as the first pharmacologic choice in select patients.
7. Reserve erythropoiesis-stimulating agents (ESAs) for patients with symptomatic anemia.

Screen for fatigue The NCCN® recommends that patients of all ages be screened for CRF at their initial visit and at regular intervals thereafter. The authors of this chapter feel that the following are indications for rescreening:

- Changes in cancer-associated factors such as advances in stage or the identification of recurrence or metastasis
- Changes in patient factors such as new comorbid medical conditions, mood disturbance, cachexia, or decline in performance status
- Initiation of anticancer therapy, major changes in therapy, and at regular intervals during therapy
- Appearance of any new symptoms or signs to suggest the presence of CRF

Escalante and colleagues (2010) and the NCCN® recommend that patients over 12 years of age be screened initially by being asked to rate their fatigue over the last 7 days on a 0–10 scale, in which 10 is the worst fatigue imaginable. Scores indicating mild, moderate, and severe fatigue are 1–3, 4–6, and 7–10, respectively. For children aged 7–12, a simpler 1–5 scale is recommended, in which 4–5 is severe and 3 indicates moderate fatigue. Children aged 6 or younger may be screened simply by being asked if they are "tired" or "not tired."

Two unidimensional tools are better studied than the 1–10 scale discussed in the preceding text, yet remain relatively easy to use. The VAS is an extremely simple visual representation in which the patient indicates fatigue severity on an unmarked 10-cm horizontal line. The BFI is a well-validated tool for the assessment of the presence and severity of fatigue in which a score from 1 to 10 is derived from a one-page, nine-item questionnaire (Mendoza et al., 1999).

Many longer, multidimensional tools possessing excellent test characteristics exist, such as the European Organisation for Research and Treatment of Cancer–Quality of Life Questionnaire–Q30 (EORTC-QLQ-C30), and the Multidimensional Fatigue Symptom Inventory (MFSI). The Functional Assessment in Chronic Illness Therapy-Fatigue scale (FACIT-F) is not generally considered multidimensional, but it has been validated in many languages and includes subscales in fatigue and in physical, social/family, emotional, and functional well-being. Its robust psychometric properties made it the preferred instrument in a review of 22 fatigue scales conducted by Minton and Stone (2009), and though its subscales are not independently validated, they still may help to guide individualized treatment. A pediatric version of the FACIT-F demonstrated good internal consistency in a study of 159 pediatric patients as well (Lai et al., 2007). The FACIT-F is available at www.facit.org.

In clinical practice, however, screening using a 1–10 scale, the VAS, or the BFI is practical and reliable.

Conduct a comprehensive evaluation In patients with moderate to severe fatigue (4–10 on the one-item scale or the BFI, or 3–5 in children aged 7–12), the initial evaluation should first involve an in-depth fatigue history in which the onset, pattern, and duration of fatigue is ascertained, as well as any changes over time, associated or alleviating factors, interference with physical, cognitive, emotional, and social domains of function, and the availability of actual or potential caregivers and a social support network. It is important to determine what a patient's daily life is like, including activity levels and patterns, sleep habits, health habits, and personal goals and expectations. Thorough assessment of the patient's cognitive and functional status cannot be overemphasized. When appropriate, referrals should be made for assistance with activities of daily living, instrumental activities of daily living, and medication administration.

A focused history should also be taken to include ascertainment of the patient's treatment type and duration, response to treatment, disease status, and whether or not the fatigue underlies a change in this status (such as recurrence or metastasis). Medication lists should be reviewed thoroughly, with particular attention to side effects or interactions. Finally, the evaluator should perform a review of systems, physical exam, and appropriate diagnostic workup in order to rule out treatable contributing factors (see below).

Educate patients and caregivers The healthcare team should provide comprehensive education on CRF to patients and caregivers. Patients who are undergoing active treatment may not know that their exhaustion, while a not unexpected side effect of the treatment, still warrants fatigue-specific interventions that may provide relief. They may also need reassurance that their fatigue does not herald treatment failure. Education ideally should start before treatment begins.

Disease-free cancer survivors may be unable to comprehend why they still feel fatigued long after they have been cured. Some may fear that their fatigue indicates a recurrence and avoid calling attention to the symptom. The opportunity to provide appropriate reassurance will then be missed unless patients are actively screened for fatigue.

Expectations must be managed early. It is important for providers to explain the expected timeline of fatigue to patients, which will vary by cancer type and phase of treatment, and not to mislead patients into thinking they will be cured of their fatigue. Patients should also be encouraged to ask for help from their friends and family when needed, and to understand that it is appropriate to delegate tasks. Even when they are reluctant to ask for help themselves, they may welcome the opportunity to bring their families into the office and feel unburdened when clinical staff offer to educate their families on CRF (Escalante & Manzullo, 2009).

Education, as an intervention itself, may reduce fatigue levels. In a trial published by Yun and colleagues of 273 disease-free cancer survivors randomized to a web-based 12-week education program based on the NCCN guidelines or a waiting-list control, the intervention group showed significant improvements in fatigue as well as in levels of anxiety, global QoL, and functioning (2012).

Address treatable contributing factors Fatigue often does not occur by itself, and commonly coexists with depression or anxiety, pain, or sleep disturbance in a multisymptom cluster. Adequate treatment of pain is essential to QoL, and patients with

Table 6.1 Treatable contributing factors in CRF.

Categories	*Examples*
Medication side effects	Antihypertensives including beta blockers, diuretics, and clonidine, antipsychotics, antidepressants, antiepileptics, opiate analgesics, antiemetics, antihistamines
Pain	Related to cancer itself, invasive procedures, or chronic/ preexisting conditions
Mood disturbance	Anxiety, depression
Sleep disturbance	Obstructive sleep apnea, restless leg syndrome, narcolepsy, circadian rhythm disturbance
Nutritional/	Cachexia, rapid weight/caloric intake changes, volume metabolic imbalance, depletion, electrolyte imbalances
Functional status changes	New or preexisting decline in activity level or conditioning
Substance abuse	Alcohol, prescribed analgesics/anxiolytics/sleep aids, illicit substances
Medical comorbidities	Heart failure, coronary artery disease, climacterium, androgen deficiency, adrenal insufficiency, hypothyroidism, vitamin D deficiency, hepatic dysfunction, renal dysfunction, lung disease, infection, neurologic impairment, anemia

Source: Adapted from the 2012 NCCN guidelines.

pain that is complex or difficult to manage may benefit from referral to a pain specialist. Patients should also be screened for mood disturbances and referred for treatment when appropriate. Sleep disturbance is common in patients with cancer and may be related to the disease itself, its treatment, medications, mood disturbance, medical comorbidities, or sleep-related breathing disorders such as obstructive sleep apnea. These conditions should be evaluated and treated separately, when possible (see Table 6.1).

Many cancer patients develop anemia as a consequence of their malignancy, its treatment, or coexisting comorbidities. When present, efforts should be taken to identify correctable causes such as iron deficiency, B12 or folate deficiency, blood loss, or hemolysis. When none is found, blood transfusions or ESAs should be considered, the latter to be used with extreme caution and only in patients undergoing chemotherapy without curative intent. For blood transfusions, the NCCN guidelines on cancer- and chemotherapy-induced anemia recommend a target hemoglobin of 7–9 g/dL for asymptomatic anemia and 8–10 g/dL for symptomatic anemia (v1.2013).

Other treatable factors include organ dysfunction, endocrine abnormalities, electrolyte and metabolic disturbances, and side effects of medications, and should be addressed comprehensively. Unfortunately, many patients remain fatigued even after optimal treatment of these factors, and fatigue is more often directly associated with cancer or its treatment than with a treatable condition. If moderate to severe fatigue remains despite these efforts, or if no contributing factor is found, treatment should involve further targeted interventions, discussed in the following text (Mustian et al., 2007).

Specific guidelines for the treatment of cancer-related pain, emotional distress, and anemia have been developed by the NCCN and are available at www.nccn.org.

Individualized treatment of CRF Both pharmacologic and non-pharmacologic interventions exist that are supported by evidence from CRF-specific clinical trials. It is recommended that non-pharmacologic interventions be initiated first as the evidence for these therapies is greater, the magnitude of the effect size tends to be larger, and the risk for adverse outcomes is minimal.

Non-pharmacologic treatment

Exercise. Regular exercise increases functional capacity, reducing the effort needed to carry out daily activities, and it improves patients' sense of well-being and self-worth. Cochrane systematic reviews of exercise for CRF have included 56 trials of 4,826 participants undergoing active treatment (Mishra et al., 2012) and 40 trials of 3,694 cancer survivors (Mishra et al., 2012), both encompassing a wide range of cancers and cancer treatments. Improvements in fatigue and QoL were shown to be significant in both groups and accompanied by improvements across emotional, social, and functional domains. In another meta-analysis of 44 studies, CRF levels improved consistently, and the effect seemed to be greater when resistance exercise, rather than aerobic exercise, was used (Brown et al., 2011).

Exercise should be recommended to all patients unless a contraindication is present such as symptomatic anemia, severe thrombocytopenia, fever or active infection, or bone metastasis. While, according to Horneber and colleagues, a balance of endurance and resistance exercise totaling 30–45 minutes on most days of the week is ideal (2012), the choice of exercise should be based primarily on patient preference, as patients are more likely to continue with activities they enjoy. Severely deconditioned patients may benefit from referral to a physical therapist to build conditioning to acceptable levels before a regular exercise program is undertaken (Escalante et al., 2010). For those who have never been accustomed to exercising or have no specific preference, a walking program makes an excellent starting point. The recommended maximum heart rate for more vigorous endurance exercise, once initiated, is 180 minus the age in the acute care setting and 220 minutes the age in the rehabilitation phase (Horneber et al., 2012).

As patients with CRF experience fatigue even with regular activity, clinicians must work to convince them that an exercise program will be beneficial. At the same time, they must advise patients not to overexert themselves in ways that will severely exacerbate exhaustion or pain, and might discourage them from returning to the activity in subsequent sessions.

Psychosocial interventions. In another Cochrane systematic review of 27 studies with over 3,000 participants, limited evidence was found for the benefit of psychosocial interventions in reducing CRF during treatment. The effect was greatest for interventions specifically focused on fatigue; general interventions aimed at psychological distress, mood, and physical symptoms tended not to be effective (Goedendorp, Gielissen, Verhagen, & Bleijenberg, 2009). The effective interventions were generally brief and provided by trained nurses over several sessions in which participants were educated and taught self-care or coping techniques and activity management. The magnitude of the benefit of behavioral techniques is less than that of exercise (Duijts, Faber, Oldenburg, van Beurden, & Aaronson, 2011).

A strategy of energy conservation and activity management (ECAM) was studied by Barsevick and colleagues in 396 fatigued cancer patients initiating chemotherapy or radiotherapy. Patients were randomly assigned to spend similar nursing orientation time focused on either diet and nutrition (the control intervention) or strategies to conserve energy, and monitor the association of various activities with fatigue levels. A modest benefit in CRF was seen in the treatment group (2004). In ECAM, patients are taught to economize their physical resources by pacing and prioritizing their activities, delegating less essential tasks, resting at intervals, and planning pleasant leisure activities that distract them from their symptoms.

While evidence exists for the benefit of individual psychotherapy provided over long periods of time, long and time-consuming interventions may not be optimal for patients who are already spending large amounts of time in the clinic or hospital undergoing intensive treatment. For these patients, ECAM, psychoeducational sessions, or cognitive behavioral symptoms management programs delivered over 2–8 weeks by a nurse in the primary oncology team, in which each individual session is kept brief, will be most effective. Conversely, in cancer survivors in whom CRF is more lasting and inexplicable, ongoing and more in-depth CBT sessions with a trained psychologist may be beneficial.

Sleep interventions. While sleep disturbance is exceedingly common in patients with cancer and the NCCN recommends CBT for sleep in the post-treatment setting, randomized controlled studies are generally lacking, and the existing observational studies and uncontrolled trials should be viewed as hypothesis-generating only. In one important randomized trial of 219 breast cancer patients assigned to behavioral therapy or a healthy eating control, the intervention group experienced significant improvement in sleep quality but not in fatigue outcomes (Berger et al., 2009). It is therefore clear that behavioral interventions aimed at improving sleep may be successful in their primary aim, but their impact on CRF is less evident.

Even in the absence of trial evidence, sleep disturbance that impairs QoL merits, at the very least, education. According to the 2012 NCCN guidelines, the administration of sleep-related counseling should involve the following techniques:

Stimulus control: Going to bed only when sleepy and at the same time every night; establishing a regular rising time

Sleep restriction: Avoiding long daytime naps and limiting time in bed
Sleep hygiene: Avoiding stimulants after noon and establishing a good sleeping environment

Complementary and alternative medicine. Although complementary therapies seem intuitively appealing in their potential to improve the sense of well-being and decrease fatigue, most clinical trials have been small, open-label, or even non-randomized. The marked placebo effect in CRF trials is well known (de la Cruz, Hui, Parsons, & Bruera, 2010) and related to the subjective nature of the outcome. Massage, art therapy, music therapy, polarity therapy, Qigong, Reiki, yoga, and acupuncture all may prove beneficial to individual patients if carefully chosen according to cultural and spiritual contexts and preferences, but they cannot be recommended based on currently available evidence. Yoga (Bower et al., 2012) and acupuncture (Molassiotis, Sylt, & Diggins, 2007) have shown promise in small randomized controlled trials, the results of which must be interpreted with extreme caution.

Pharmacologic treatment

While evidence exists supporting the use of some pharmacologic therapies, the effect sizes in the randomized controlled trials tend to be small, and over half of controlled CRF trials have a significant placebo response (de la Cruz et al., 2010) that often is greater in magnitude than the difference between the intervention and placebo groups. Patients with moderate-to-severe fatigue that impairs QoL may be considered candidates for pharmacologic therapy as a supplement to, rather than a substitute for, non-pharmacologic treatment, especially when fatigue does not improve with other modalities. Table 6.2 summarizes the currently accepted pharmacologic options and includes indications, dosing recommendations, and further information.

The psychostimulants methylphenidate and dexmethylphenidate have shown promise in the adjunctive treatment of CRF. Though the majority of individual randomized trials have been small and produced negative results, a meta-analysis demonstrated a benefit in FACIT-F scores with a moderate effect size (Minton, Richardson, Sharpe, Hotopf, & Stone, 2010). The benefit of modafinil has only been demonstrated in severely fatigued patients within a post-hoc subgroup analysis of a single randomized controlled trial. The effect size was small (Jean-Pierre et al., 2010).

In trials using ESAs specifically for the treatment of CRF, the beneficial impact on fatigue has been marginal. In addition, there is important clinical trial evidence that ESAs are associated with increased risk for thromboembolic events, higher mortality, and shorter locoregional progression-free survival. While many of these trials targeted a hemoglobin concentration of >12 g/dL and were conducted in patients not receiving chemotherapy, the risk of harm resulting even from lower

Table 6.2 Pharmacologic therapies for CRF.

Medication	*Dosing*	*Indication*	*Benefit*	*Risks*	*Evidence*	*Placebo-controlled Trials*
Methylphenidate (MP)	Start 5 mg BID, titrate to 10 mg BID. Alternative: 5 mg every 2 hours as needed. Maximum 40 mg/day.	Moderate to severe fatigue on or off active treatment	Moderate, shown over 1–12 weeks	Tachycardia, increased blood pressure, arrhythmia, MI, stroke, serious allergic reaction, dependence	Fair	4 individual RCTs of MP (n = 385); none reached significance. 1 RCTof DMP (n = 152); effect size (ES) −0.37.[1] Cochrane meta-analysis: included the DMP trial and 3 of the 4 MP trials and showed moderate benefit with ES of −0.28[2]; all used FACT-F. The MP trial not included in the Cochrane analysis used long- acting MP up to 50 mg/day in divided doses and showed improvements in BFI only in patients with severe fatigue or advanced cancer in a post-hoc subgroup analysis that must be interpreted with caution.[3]
Dexmethylphenidate (DMP)	Start 5 mg BID, titrate to 10 mg BID. Maximum 20 mg/day.					

(*Continued*)

Table 6.2 (*Continued*)

Medication	*Dosing*	*Indication*	*Benefit*	*Risks*	*Evidence*	*Placebo-controlled Trials*
Modafinil	200 mg daily	Only severe fatigue on chemotherapy	Small, over 3 cycles of chemotherapy	Serious allergic reactions, increased blood pressure, arrhythmia	Poor	1RCT of 877 fatigued patients on chemotherapy. Randomization was compromised by significant drop-out: 631 patients provided data. No benefit in BFI scores was seen. In a post-hoc subgroup analysis, the 438 patients with severe fatigue benefited significantly from modafinil over placebo; ES was small.[4]
Erythropoietin Darbepoietin	40,000 units weekly or 150 units/kg 3 times weekly 2.25–4.5 mcg/kg weekly or 300–500 meg every 3 weeks	Only fatigue associated with symptomatic anemia	Moderate, shown over 12 weeks	Thromboembolic events, possible increase in cancer progression and mortality	Fair	6 erythropoietin RCTs were included in a Cochrane meta-analysis (n = 1333); ES was significant and moderate at −0.28.[2] Since then, a large RCT of 1379 patients showed no benefit in EORTC or MFI-20 scores.[5] All trials used FACT-F or FACT-An fatigue subscale. 4 darbepoietin RCTs (n = 999) were included in the above meta-analysis; ES was borderline significant and small (−0.13).

Source: Lower et al., 2009[1]; Minton et al., 2010[2]; Moraska et al., 2010[3]; Jean-Pierre et al., 2010[4]; Engert et al., 2010[5].

hemoglobin targets cannot be excluded. The benefits of ESAs – avoiding transfusions and associated risks such as transfusion reactions, virus transmission, heart failure, and iron overload – must be weighed carefully against these risks. ESAs therefore are only recommended by the NCCN to treat symptomatic anemia or asymptomatic anemia with hemoglobin concentration of <7 g/dL in patients receiving myelosuppressive chemotherapy without curative intent and in cancer patients with anemia due to chronic kidney disease. Current guidelines dictate that ESAs, when given, should be administered at the lowest dose possible and should increase the hemoglobin only to the point of transfusion avoidance. The previous target hemoglobin concentration of 10 g/dL is not supported by current data (Rizzo et al., 2010).

Other agents have been investigated in CRF but do not have convincing evidence to support recommending their use. The NCCN suggests that corticosteroids may be appropriate for short-term palliation in terminally ill cancer patients, but clinical trials do not exist to support this approach. Antidepressants, multivitamins (de Souza Fede et al., 2007), donepezil (Bruera et al., 2007), and progestational steroids (Minton et al., 2010) have not been found to have beneficial effects on fatigue. A single crossover RCT of guarana (*Paullinia cupana*) in breast cancer patients undergoing chemotherapy suggested its potential as a natural pharmacologic alternative (de Oliveira Campos et al., 2011).

A multidisciplinary approach

CRF consists of physical and mental exhaustion that is highly prevalent in cancer patients, significantly affects QoL and functioning, and encompasses the physical, cognitive, emotional, and social domains.

Non-pharmacologic therapies, including education and an exercise program, should be instituted in all patients with moderate to severe fatigue. Pharmacologic treatments should be reserved for fatigued patients actively undergoing anticancer treatment; this recommendation is based on the short duration of clinical trials of these therapies, the potential toxicities, the makeup of the trial populations, and the usually transient nature of fatigue during active treatment. The use of psychostimulants in cancer survivors with chronic fatigue is not supported by sufficient evidence of benefit to counter the potential long-term risks of these medications.

Some patients may benefit from a multidisciplinary approach in the setting of a dedicated CRF clinic that utilizes a standardized, objective, and comprehensive evaluation and the development of an individualized treatment plan. Such is the experience reported by Escalante and colleagues at the University of Texas M.D. Anderson Cancer Center (2010). Their CRF clinic assesses fatigue systematically, educates patients, families, and other healthcare providers, and uses non-pharmacologic and pharmacologic treatments. The most common interventions employed have been energy conservation (98.5%), sleep hygiene (97%), exercise (95%), relaxation (27%), antidepressants (27%), analgesics (25%), stimulants (22%), anxiolytics (17%), and nutritional counseling (10%). Most patients who attended follow-up achieved significant reductions in fatigue levels.

Although most centers do not have the resources for a dedicated CRF clinic, a multidisciplinary approach is nearly always feasible. Patients may be referred to physical therapists or exercise specialists, nurse educators, nutritionists, or psychologists. In addition, the marked placebo effect seen in trials of pharmacologic therapies underscores the value of regular contact with clinical staff. Perhaps the patients' knowledge that their fatigue is being explored and addressed provides comfort and reassurance, which, in turn, contributes to improvements in fatigue and in quality of life.

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7

Transition from Pediatric- to Adult-focused Healthcare in Young Adults with Chronic Medical Conditions

Michele Herzer Maddux, Hillary VanSlyke,
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Healthcare Transition Defined

The Society for Adolescent Medicine defines transition to adult medical care as the "purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems" (Blum et al., 1993). It refers to two closely related processes – transition and transfer. During the transition process, disease-related responsibilities are gradually re-allocated between adolescents and caregivers, and the responsibility for managing healthcare demands shifts from the caregiver to the young adult. Adolescents take on greater responsibility for their self-care and medical needs, which can include taking medications independently, calling in prescription refills, and scheduling doctor visits, while caregivers shift their role from primary health managers to a more supportive role that encourages autonomous decision-making and self-care on the part of the youth. During the transfer process, youth with special healthcare needs (YSHCN) move from their pediatric providers to an adult provider who will assume primary responsibility for the youth's medical needs thereafter. As part of this move, youth are intended to retain medical care in a manner that is uninterrupted, comprehensive, accessible, and individualized (American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians–American Society of Internal Medicine, 2002; Blum et al., 1993).

Healthcare transition applies to all YSHCN. According to the National Initiative for Children's Healthcare Quality, YSHCN are those at "increased risk for chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type or amount beyond that required of children generally"

The Handbook of Behavioral Medicine, First Edition. Edited by David I. Mostofsky.

(Quality, 2011). This includes (but is not limited to) conditions such as asthma, diabetes, cancer, attention deficit hyperactivity disorder, depression, and anxiety. It is estimated that over 20% of adolescents in the United States meet this criterion, with 750,000 of these adolescents reaching transition age yearly in the United States (Scal & Ireland, 2005).

Established Guidelines and Recommendations for Transition

As more and more adolescents and young adults with chronic medical conditions survive into adulthood, transition has evolved into an important healthcare issue. The importance of transition was first highlighted in the Surgeon General's 1989 report, "Growing Up and Getting Medical Care: Youth with Special Health Care Needs" (Koop, 1989). This detailed a national agenda focused on training, research, and program development, and was aimed at establishing a healthcare system that would allow YSHCN to move successfully from pediatric to adult-centered services.

Over one decade later, in 2001, the US Department of Health and Human Services Maternal and Child Health Bureau sponsored a national meeting of leaders from primary and subspecialty care, multidisciplinary professionals, and parents of youth with disabilities. This resulted in the development of a consensus statement titled "A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs," coauthored by the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians – American Society of Internal Medicine (American Academy of Pediatrics et al., 2002). The goal of this statement was to ensure that, by 2010, all physicians who provide care to YSHCN: (1) understand the rationale behind transitioning young patients from pediatric- to adult-focused healthcare; (2) have the knowledge and skills needed to provide transition-related support that is developmentally appropriate; and (3) should know if, when, and how transfer of care is warranted.

Guidelines for ensuring successful transition and transfer to adult-focused healthcare have been proposed. The American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians – American Society of Internal Medicine all endorse the following proposed guidelines for ensuring successful transition: (a) assigning specific healthcare professionals the responsibility of ensuring transition and healthcare planning; (b) teaching clinical providers the necessary skills to provide developmentally appropriate healthcare transition; (c) developing portable medical summaries to facilitate collaboration of care among providers; (d) creating a written transition plan that is individually tailored to meet the needs of each patient and family; and (e) making sure that continuous health coverage is maintained throughout the transition and transfer process (American Academy of Pediatrics et al., 2002). Such clinical guidelines share the goal of ensuring transition to adult-focused healthcare that is patient- and family-centered, continuous, comprehensive, and coordinated.

Despite efforts by the American Academy of Pediatrics (AAP) to provide clinical practice recommendations for transition and transfer, there is high variability in practices across pediatric medical centers and few pediatric centers provide transition planning as part of standard care. A study of 58 pediatric dialysis centers in North America and Europe (Bell, 2007) found variability in the age at which transition is initiated (mean age = 19.9 years, range: 17–22 years). Moreover, only a third of these centers had formal transition programs. Among pediatric dialysis centers without a transition program, 74% endorsed a need for formal transition practices. In addition, at the time of transfer, only a small proportion (20%) of young adults were perceived as functioning independently for specific aspects of their care (e.g., filling prescriptions, scheduling appointments) (Bell, 2007). A recent national survey conducted by the American Academy of Pediatrics (Pediatrics, 2009) confirms that few pediatric practices provide routine transition-related support services or initiate transition planning early in adolescence. The broader pediatric literature similarly documents a high degree of variability in transition practices across sites (Burke, Spoerri, Price, Cardosi, & Flanagan, 2008; McLaughlin et al., 2008).

Barriers to Successful Transition of Care

Several barriers to standardized transition planning and successful transition of care have been identified (see Table 7.1).

System-specific factors. There is widespread recognition that transition planning should be a standard part of care for all YSHCN. Yet, several barriers make the goal of transition planning as a standard of care difficult to attain. Lack of manpower and resources to develop and implement transition-related support have been identified as primary barriers noted by pediatric providers, along with lack of resources to provide staff with developmentally appropriate training in transition planning, and lack of reimbursement to fund transition-related services in clinical care. The aforementioned survey conducted by the American Academy of Pediatrics revealed that, among the 600 pediatricians surveyed, few have the resources, skills, and the staff to carry out transition planning (Pediatrics, 2009). Others cite the lack of developmentally appropriate and validated transition readiness screening tools as another significant impediment to successful transition of care. These are essential for gauging a patient's skill set and readiness to transition, and for subsequently guiding educational interventions to support transition and transfer. Among available checklists and screening tools, many rely on Yes/No answer formats, which provide little information on the extent to which a young patient can complete various disease management tasks (e.g., filling prescriptions, scheduling appointments, understanding their treatments, answering questions about their medical history) (Sawicki et al., 2011). Available tools also take a "one size fits all" approach and give little consideration to developmental differences during adolescence and young adulthood; that is, patients in early adolescence are screened no differently

Table 7.1 Common barriers to successful transition of care.

System-specific factors	• Lack of resources, staff, and skills to develop and implement transition planning and support in clinical care • Lack of resources to provide staff with appropriate training in transition planning • Lack of developmentally appropriate and validated transition readiness screening tools • Potential loss of insurance coverage for patients under parental plan or Medicaid • Lack of reimbursement for transition-related clinical care
Patient- and family-specific factors	• Reluctance to leave familiarity of pediatric setting and develop relationships with new providers • Reluctance to bring adult provider "up to speed" on medical condition and treatment, particularly if this involves a long medical history • Fear of unforeseeable changes to patient's treatment regimen following transfer • Discomfort with perceived differences between pediatric and adult healthcare; shift from family-centered care to disease-centered care • Distrust that adult provider will match the training and experience of the pediatric provider • Cognitive or developmental impairment in either patient or caregiver
Provider-specific factors	• Reluctance by pediatric providers to let go of longstanding relationships with patients • Limited knowledge of available adult providers to transfer patients to • Limited availability of adult providers to transfer patients to, dependent on subspecialty • Adult providers feel ill-equipped to care for young adults because they lack training and expertise in childhood-onset diseases • Adult providers feel ill-equipped to care for young adults because they have little knowledge of adolescent development • Lack of communication between pediatric and adult provider at time of transfer • Unsuccessful or incomplete transfer of patient medical chart from pediatric to adult provider

than patients in late adolescence. In the absence of such measures, routine assessment of patient readiness to transition is severely impeded.

Issues related to insurance coverage have also been identified as constraints on transition of care among YSHCN. While healthcare reform provisions and the Affordable Care Act provide relief for young adults, they are still expected to seek new coverage if they have been covered under parental plans or Medicaid. This barrier is paramount, particularly as approximately 36% of YSHCN are covered under public insurance such as Medicaid or Children's Health Insurance Program (CHIP) (National Survey of Children with Special Health Care Needs, NS-CSHCN 2009/10, 2010). In addition, young adults have been identified as a group at high risk of being uninsured, with almost 30% of individuals aged 18–24 lacking health insurance coverage (Cohen & Bloom, 2010). In either case, the transfer from pediatric to adult care causes inherent changes to the type and level of healthcare coverage, and many young adults are left with the responsibility of finding new insurance coverage.

Patient- and family-specific factors. Patient- and family-specific factors can also impact successful transfer of care. Patients and families are often reluctant to leave the familiarity of the pediatric setting, especially if they have developed long-standing relationships with providers. They also may not want to educate a new provider on their medical condition, particularly if it is accompanied by a long medical history (Reiss, Gibson, & Walker, 2005; Tuchman, Slap, & Britto, 2008). Patients and families are also fearful of the unknown – of unforeseeable changes that may occur in the patient's treatment regimen following transfer of care. They often voice concerns regarding the change from family-centered care to patient-centered care, including finding an adult provider with similar training and experience as their pediatric provider, and one who is familiar with the young adult's medical condition. Reiss et al. (2005) conducted focus groups and interviews with young adults, caregivers, and providers, and found that pediatric providers were perceived as more organized, more readily available for questions and support, more involved in patient care, and more family-oriented. Differences between pediatric and adult healthcare have been cited by many as a primary barrier to successful transfer of care (Patterson & Lanier, 1999; Rutishauser, Akre, & Suris, 2011; Tuchman et al., 2008).

Provider-specific factors. Last but not least, provider-specific factors can render the successful transfer of care from pediatric to adult healthcare settings difficult. The aforementioned survey by the American Academy of Pediatrics (Pediatrics, 2009) revealed that few pediatricians have adult providers to transfer patients to. In some cases, pediatric providers lack knowledge of adult providers who may be able to take over patient care. Or, depending on the patient population served or medical subspecialty, there may be limited availability of suitable adult providers to take over the medical care of a young patient entering into the adult medical system. Often, adult providers feel ill-equipped to care for young adults because they lack training and expertise in childhood-onset diseases and have little knowledge of adolescent development (Hait et al., 2009). Yet another factor that further impedes successful transfer of care is lack of communication between pediatric and adult providers during the time of transfer. Collaboration between providers has been deemed a central tenet of transition (Leung, Heyman, & Mahadevan, 2011), yet this rarely occurs as part of routine care for YSHCN, and few pediatric and adult providers collaborate on patient care before and during transfer of care (Burke et al., 2008;

Suris, Akre, & Rutishauser, 2009). This likely contributes to the fact that many adult providers receive inadequate or incomplete medical records from pediatric providers, and many receive none at all (Hait et al., 2009).

While many of the barriers reviewed here occur at the individual level, they underscore systemic deficits in transition planning for YSHCN. A commitment to transition planning at the hospital, state, and national level is needed. This is crucial for setting the foundation for resources that ensure transition program development and evaluation, communication between pediatric and adult providers, training for healthcare providers, and support services for families.

Consequences of Failed Transition

Without support and planning for transition, YSHCN are at significant risk of experiencing difficulty meeting the demands incurred by the transfer of care and enduring adverse health outcomes. In fact, many consider transfer of care as the most challenging and arduous times in the care of young adults. This often comes at a time when young adults are coping with the novelty and stress that comes with maturing into adulthood, and often coincides with other important life milestones such as high school graduation and the start of college.

Non-adherence. Poor adherence to prescribed treatment regimen has been associated with transfer. Studies among adolescent transplant patients have shown significant decreases in adherence to oral medication after transfer into adult care, which places patients at risk of serious health complications including death (Annunziato et al., 2007). In fact, research suggests that transfer from pediatric to adult settings is associated with increased variability in self-management and adherence (Cadario et al., 2009). Data on hospital admission rates among young adults with congestive heart disease also shows that the proportion of patients admitted to the emergency department nearly doubled at the time of transfer to adult care (Gurvitz et al., 2007). Other groups of YSHCN (e.g., diabetes) have similarly shown a consistent pattern of increased hospitalization rates both during and after transfer of care.

Loss to follow-up. Some have cited loss to follow-up as a consequence of failed transition into adult care. Yet, little is known about the prevalence of loss to follow-up among young adults making the transfer out of pediatric care into an adult care system. Research into this area is largely dominated by pediatric cardiology, with findings documenting loss to follow-up rates as high as 53% among patients aged 18 and older (Goossens et al., 2011; Reid et al., 2004). This suggests that a large proportion of young adults are at risk of experiencing delays in their receipt of appropriate medical care during the first few years after leaving pediatric care, and consequent adverse health outcomes. It is plausible to assume that the aforementioned barriers to transition, such as lack of collaboration and communication between the pediatric provider and the receiving adult provider, can increase the likelihood that a young adult patient may be lost to follow-up, and never makes first contact with the receiving provider.

To date, no large-scale study has evaluated the efficacy of a transition program. Yet, preliminary evidence suggests that the presence of transition planning is associated with improved outcomes among YSHCN. McDonagh and colleagues developed a transition program following a needs-based approach, and found significant improvements in the quality of life of young adult patients with juvenile arthritis and their parents (McDonagh, Southwood, & Shaw, 2007). Others have similarly shown that providing young adult patients with a structured process that includes ongoing support from medical providers, education on transition, and/or education on the medical disease and treatment can improve adherence to prescribed treatments (Annunziato et al., 2008; Holmes-Walker, Llewellyn, & Farrell, 2007). Additional benefits of transition care planning include an increased sense of partnership with medical providers, decreased worry and frustration, enhanced self-management skills, and improved health outcomes (McAllister, Presler, & Cooley, 2007). All in all, this data suggests that providing young adult patients with transition-related planning, support, and guidance holds great promise for improving overall health and well-being.

Best Practices: Key Elements of Transition Planning

Several models of transitional care have been posited. For example, the Shared Management Model (Kieckhefer & Trahms, 2000) emphasizes a strong alliance between the patient, parents, and medical professionals to support YSHCN in developing into independent managers of their health. This model also highlights the gradual shift in responsibility between all players, such that leadership for care is shifted from health professionals to the parent, then to the youth. This gradual process occurs in a planned and developmentally appropriate manner. Other models (e.g., direct transition, sequential transition, developmental transition, professional transition) have similarly been noted (McDonagh, 2005). All of these models differ in the degree of transition-related support and preparation provided to young adults, and the extent to which pediatric and adult health providers communicate about a particular patient. Yet, all models share an overlapping goal – to provide a transition process that supports young adults in becoming successful managers of their healthcare, is tailored to each patient's unique needs, and ensures continuity of healthcare that is uninterrupted and comprehensive. In order to ensure that the transition needs of young adults with special healthcare needs are met, several critical factors must be taken into consideration, and are outlined in the following text (Table 7.2).

Start early. Though opinions differ on the best age to begin transition planning, there is widespread recognition that this process should begin early. In fact, the American Academy of Pediatrics recommends that the first step in the healthcare transition planning process should begin at age 12. This allows ample time to adequately prepare patients, families, and providers before the patient reaches legal adult age at 18, and targets a developmental stage when most adolescents are capable

Table 7.2 Key elements of transition planning.

- Start early
  - First step in healthcare transition-planning process should begin at age 12.
  - Depending on patient cognitive/developmental function, developmental age (not chronological age) should be used to determine best time to start transition planning.
  - Focus on transition (i.e., gradual reallocation of disease-management tasks between caregivers and patients) *and* transfer (i.e., physical moving of healthcare services from pediatric to adult medical setting).
- Routine transition readiness screening
  - Useful for identifying type and level of transition planning needed to achieve skills acquisition and mastery before transfer of care.
  - Focus on evaluating patient knowledge/ability across disease management and self-care.
- One size does not fill all
  - Transition planning should be individually tailored based on specific patient needs.
  - Individualized approach toward when to initiate transition, the type of preparation that is required, and the level of the young patient's involvement in transition planning.
- Parental involvement
  - Transition planning must address challenges experienced by parents.
  - Transition planning must provide education and information to parents about their role in the transition process.
- Anticipatory guidance regarding pediatric versus adult healthcare models
  - Focus on differences in treatment approaches or disease management, any differences in the composition of the medical team, and the changing role of patients and caregivers.
- Knowledge of adult healthcare resources
  - Focus on identifying availability of potential adult providers to transfer patients to.
  - Focus on identifying any gaps in adult healthcare services and alternative resources.
  - Can direct anticipatory guidance provided to patients and families regarding differences between pediatric and adult healthcare models.
- Collaboration between pediatric and adult provider
  - Ensures that needs and expectations of pediatric and adult providers are met.
  - Ensures that appropriate medical documentation is passed to receiving adult providers.
  - Facilitates co-management of care while patient becomes established within adult healthcare setting.
  - Directs anticipatory guidance/preparation provided to patients before transfer of care.
- Transition: A positive life event
  - Focus of reframing transition and transfer, by highlighting positive changes of entering adulthood and adult medical settings.

of participating in their healthcare (Cooley & Sagerman, 2011). Targeting patients early also gives providers ample time to normalize the transition process, engage patients and families in the process, address any anxieties or worries, and teach patients the needed skills to independently and successfully meet daily living skills, even beyond those imparted by their healthcare needs. For most young patients, chronological age can be used to determine the best time to initiate transition planning; however, some patients (e.g., those with developmental or cognitive impairments) may require that the timing of transition planning be based on developmental age, not chronological age (Herzer, Goebel, & Cortina, 2010).

Assuming the start of transition planning at age 12, equal consideration should be given to the interrelated processes of transition and transfer. As mentioned previously, transition refers to the gradual reallocation of disease-management tasks between caregivers and patients; that is, adolescents gradually assume greater responsibility for their own healthcare and eventually become independent managers, while caregivers gradually shift their role from primary decision-maker to a more supportive role. In contrast, transfer refers to the physical move of healthcare services from pediatric to adult medical setting. Focus on transition and transfer can occur along a continuum, similar to suggestions from the AAP (Cooley & Sagerman, 2011). Between ages 12 and 14 (phase one), focus should be given to orienting patients and families to office transition practices, assessing patient transition readiness, and mapping out the expectations of patients, caregivers, and medical providers along each phase of transition planning. During this phase, the sharing of disease management tasks between caregivers and adolescents should be initiated, and education provided as needed to facilitate adolescents' increasing self-management. Between ages 15 and 17 (phase two), reallocation of disease management tasks continues, with the adolescent patient assuming primary responsibility for all tasks. Education regarding the disease, treatment, and/or disease management tasks continues, and strategies such as modeling and behavioral rehearsal are used to facilitate the acquisition of self-management skills. Patients and families also begin to consider options for transfer of care, and education is initiated regarding differences between pediatric and adult systems. Once phase 3 (ages 18+) is reached, patients are likely capable of meeting illness demands independently. Strong emphasis is given to planning the eventual transfer of care, including identification of potential adult providers, preparation of documentation (e.g., medical records) necessary for transfer of care, and collaboration between pediatric and adult health providers to ensure continuity of care.

Routine transition readiness screening. Routine screening of patient readiness for transition is crucial during transition planning. Yet, developmentally appropriate and validated transition readiness screening tools are lacking. This results in significant difficulty in gauging patient knowledge, understanding, and ability across disease management tasks and healthcare management. Without well-validated assessment tools, clinical providers are also limited in their ability to identify the type and level of transition support needed by a patient to achieve skills acquisition and mastery before transfer of care. Various checklists are available, yet many of these assess readiness to transition via a Yes/No format, thereby precluding any conclusions on the level or degree of patient readiness along a continuum. Available checklists also do not distinguish between early-, mid-, and late-adolescence, and expectations of transition readiness remain the same regardless of patient age. This is a significant limitation since a patient's skill level and understanding of healthcare management has been shown to increase with age (Sawicki et al., 2011). In the recent past, measures of readiness for transition from pediatric to adult healthcare for YSHCN have emerged (e.g., Transition Readiness Assessment Questionnaire [TRAQ; Sawicki et al., 2011], TRxANSITION Scale [Ferris et al., 2012]); information on the psychometric properties (e.g., reliability and validity) is still preliminary.

Despite their shortcomings, available readiness checklists are an important component in transition planning. To supplement these, clinical providers are encouraged to have open dialogues with patients and family regarding any barriers (e.g., financial, psychosocial) that may impede successful transition or require a lengthened transition process. Patient readiness can also be gauged by evaluating the manner in which disease management tasks are allocated between the patient and caregivers, and the degree to which a patient can complete tasks independently (e.g., taking medication, scheduling appointments, calling in prescription refills, maintaining health records). This multidimensional approach is likely to accurately capture patient readiness to transition and facilitate successful transfer of care to adulthood.

Individualized tailoring of transition planning. There is widespread agreement that the transfer of care should be individualized to meet the specific needs of each patient and family (American Academy of Pediatrics et al., 2002). One size does not fit all in transition planning – factors described previously such as developmental and cognitive status, and readiness, may render one transition plan successful with a particular patient and family, while another family may struggle with the same plan. Clinicians are thus encouraged to individualize the transition process to the specific needs and skill set of a particular patient, as there is likely to be great variability. The age of the patient at which to initiate transition planning, the type of preparation that is required, and the level of the patient's involvement in transition planning should be based on factors such as the patient's chronological age, cognitive and developmental functioning, as well as the family's sociodemographic characteristics and psychosocial resources (Bell et al., 2008).

Parental involvement. A primary focus of transition is the gradual increase in patient responsibility, decision-making, and ability to manage their own care. Yet, the role and involvement of parents and other caregivers is paramount during this process. Just as the patient's role is evolving, parents undergo significant role changes as transition planning progresses, which can be very stressful and overwhelming. Research documents some of the challenges experienced by caregivers as YSHCN enter adulthood, including distrust that adult providers can match the expertise of pediatric providers (Reiss et al., 2005), lack of information about the adult specialist (Rutishauser et al., 2011), and having few to no discussions about transition with the child's pediatric provider (Scal & Ireland, 2005). These challenges are primary impediments to successful transition, particularly since parents and caregivers are instrumental in preparing and supporting adolescents for their emerging adult role in healthcare.

Transition planning must anticipate and address challenges experienced by parents, and their needs and perspectives must be considered. It is also imperative for healthcare professionals to engage and involve caregivers throughout transition planning, and provide education and information about their role in the transition process. This education should include information about how the healthcare environment changes when the youth legally becomes an adult at 18 years of age, as well as differences between pediatric and adult medicine models, and the manner in which their role is likely to change (Cooley & Sagerman, 2011).

Anticipatory guidance regarding pediatric versus adult healthcare models. Pediatric and adult healthcare systems have been described as dissimilar systems and cultures of care that serve different populations with different healthcare needs (Betz & Redcay, 2005). As highlighted earlier, the transfer from a pediatric to an adult provider can be an overwhelming and frightening experience for patients and caregivers alike. These difficulties are likely amplified if families have not received adequate education and anticipatory guidance regarding differences between pediatric and adult healthcare models. For young adults with special healthcare needs and their caregivers, such education is likely to address any differences in treatment approaches or disease management, any differences in the composition of the medical team, and the changing role of patients and caregivers. For example, pediatric healthcare has been described as family centered, with significant parental involvement within a multidisciplinary team that often includes social work, psychology, and/or nutrition. In contrast, adult healthcare is patient centered and often operates without the resources of a multidisciplinary team (Fleming, Carter, & Gillibrand, 2002; Leung et al., 2011). If patients and caregivers have not been sufficiently prepared for these changes, they may be dissatisfied with the adult care provided and perceive these changes as disrespectful or unfriendly.

Knowledge of adult healthcare resources. Successful transfer of care cannot occur if there is no receiving provider. As such, becoming familiar with the characteristics of adult healthcare resources is one of the most important tasks for pediatric providers. The survey conducted by the American Academy of Pediatrics (Pediatrics, 2009) highlights the need for pediatric specialists to identify potential adult providers to transfer patient care to. If the availability of qualified adult subspecialists is limited, pediatric providers may need to consider transfer of care to a general family practitioner, or extending pediatric care into adulthood. In either case, understanding adult healthcare resources carries several advantages. First, this assists patients and families in identifying available and appropriate adult care providers. Second, this facilitates communication between pediatric and adult providers about a patient's care, health needs after transfer, as well as the needs and expectations of the receiving provider. Third, if adult resources are not sufficient or available to meet the full range of healthcare needs of a young adult patient, pediatric providers can assist patients in addressing gaps in healthcare services and seeking out alternative resources. Last but not least, knowledge of adult healthcare resources, and the strengths and limitations of these, can direct the anticipatory guidance provided to patients and families regarding differences between pediatric and adult healthcare models.

Collaboration between pediatric and adult providers. Collaboration between pediatric and adult medical providers is essential to facilitate continuity of care, and it is the responsibility of the pediatric provider to ensure appropriate communication of any and all medical needs to the receiving provider (Cooley & Sagerman, 2011). It is also the next step after identifying available and appropriate adult healthcare resources. For YSHCN, direct communication between pediatric and adult providers is essential for many reasons. First, adult professionals may be unfamiliar with certain pediatric conditions or with adolescent development. Under such circumstances, pediatric providers can be key agents of change in providing education and guidance. Second, collaboration is one of the best ways to meet the needs and expectations of pediatric and adult providers. For example, a recent survey of adult gastroenterologists revealed that adult providers have certain expectations of pediatric providers and young adult patients. Adult providers expected patients to be knowledgeable of their medications (including name, dose, and side effects), prior medical history, and the impact of unhealthy lifestyle behaviors (e.g., smoking, drugs, and alcohol) on their health (Hait et al., 2009). With such knowledge gained during collaboration, pediatric providers can appropriately prepare patients. Communication between providers can also ensure that appropriate medical documentation is passed to the receiving medical professionals, further improving continuity of care.

Healthcare transition does not necessarily end with transfer. This lends further support to the importance of communication between pediatric and adult providers. Pediatric providers are often sought out by receiving providers for information or assistance during the immediate post-transfer period. Co-management of care while a young adult patient is becoming established within an adult healthcare setting has also been identified as an essential component for successful transition (Cooley & Sagerman, 2011). This can be implemented by having patients meet with the adult provider before the actual transfer of care, having medical visits with both pediatric and adult professionals present, and assigning different aspects of patient care to the pediatric and adult provider. Inevitably, such co-management of care can only occur with ongoing communication between medical professionals, and a shared goal that the adult provider will ultimately take over all aspects of patient care.

Transition: A positive life event. Leaving the familiar setting of the pediatric environment can undoubtedly be an overwhelming and stressful experience for young adults with special healthcare needs. While such growing pains and anticipatory distress must be addressed with young patients, equal emphasis should be given to the positive changes and advantages incurred by entering adulthood and adult medical settings. Focus group data among young adults with special healthcare needs has found that, after transfer of care, many young patients report greater independence and control over medical decision-making, greater awareness of important health-related issues, and feelings of empowerment from being treated as a mature young adult and being trusted with increased responsibility for self-management skills (Tuchman et al., 2008). Others report feeling more comfortable discussing intimate topics (e.g., drugs, alcohol, sexual activity) in the adult setting that they felt reluctant to discuss in the presence of their parents during visits to pediatric providers (McCurdy et al., 2006). The positive aspects of transition and transfer can further be highlighted by discussing adult-onset comorbidities (e.g., cancer, pregnancy, fertility), which an adult provider may be better suited to address, compared to pediatric counterparts.

All in all, the aforementioned key elements to transition planning are meant as a guide for clinical providers working with young patients with special healthcare needs. They represent a multifaceted approach to transition planning, which has been recognized as key for ensuring successful transition and transfer of care.

Special Considerations

Although one of the ultimate goals of transition planning is transfer of care in young adulthood, this process demands flexibility and individual tailoring to each young patient and family. In some cases, transition planning may extend into adulthood, and some YSHCN may never achieve the task of becoming independent managers of their healthcare and daily living.

The transition process of some adolescents and young adults with special healthcare needs may be complicated by cognitive impairment. Cognitive sequela is common among young patients with various chronic illnesses, such as those with sickle cell disease, diabetes, and epilepsy. Compared to medically healthy peers, many of these youth demonstrate significantly lower IQ scores (Berkelhammer et al., 2007), significant impairment in math and reading skills (Duquette, Hooper, Wetherington, Icard, & Gipson, 2007), as well as deficits in concentration, memory, and executive function (Hamiwka & Wirrell, 2009). Such deficits can limit the ability to independently manage healthcare, understand disease/treatment-related information, as well as follow prescribed medical regimens (Sanchez, Chronis, & Hunter, 2006).

For chronically ill youth with cognitive impairments, the transition into adult healthcare can be quite challenging. In fact, the available literature suggests that adolescents with cognitive impairment experience more difficulty finding adult providers who are willing to work collaboratively with them, their family, and their pediatric providers (Reiss et al., 2005). The 2001 Surgeon General's report also states that youth with "mental retardation" experience more negative health outcomes and have greater difficulty finding, accessing, and paying for appropriate healthcare (US Department of Health and Human Services, Public Health Service, & General, 2002). Pediatric medical providers are also presented with unique challenges, particularly assessing patient readiness and capacity for transition, and developing transition plans tailored to the needs of the individual patient. And, in the absence of standard transition practices, cognitively impaired adolescents with special healthcare needs are vulnerable not only to the risks already imposed by their cognitive impairments (e.g., poor decision-making and self-management), but also because those cognitive risk factors occur in the context of often limited (or absent) practices for ensuring successful transition to adult care.

In some of our previous work on transition (Herzer et al., 2010), we outline a clinical case presentation and offer recommendations for clinical providers involved in transition planning with young adults with comorbid medical illness and cognitive impairments. These include: (a) obtaining a neuropsychological evaluation of cognitive, developmental, and adaptive functioning that can ultimately be used to draw conclusions about the patient's capacity for daily living skills, decision-making, communication, and information processing; (b) taking a multidisciplinary approach that involves collaboration between pediatric medical providers, social workers, psychologists, adult medical providers, the patient, and primary caregivers; (c) understanding that, while the standard goal is transition from pediatric- to adult-oriented care in late adolescence, these patients may require a lengthened transition planning process that spans into adulthood; (d) identifying a caregiver capable of taking responsibility for overseeing the patient's transition to adult care, particularly since parents may become appointed legal guardians, may remain heavily involved in decision-making and daily living, and may continue to care for their young adult child for the remainder of their lifespan; and (e) providing transition planning and preparation in a developmentally appropriate manner that is congruent with the patient's level of functioning (see Herzer et al., 2010, for further details).

Youth with mental health or other disabilities may also require a lengthened transition process. Currently, approximately 2 million YSHCN suffer from moderate or severe attention deficit hyperactivity disorder (ADHD-ADD), 1 million suffer from moderate or severe anxiety as well as behavioral or conduct problems, and 0.5 million suffer from moderate or severe depression. In addition, 12.3% of YSHCN experience significant difficulty communicating and being understood, 6.6% experience difficulty with self-care (e.g., dressing, bathing), and 17.6% experience developmental delays that affect the child's ability to learn (National Survey of Children with Special Health Care Needs, NS-CSHCN 2009/10, 2010). This suggests that many youth may remain dependent on caregivers when they enter adulthood, and transition planning may include individuals from other sectors, including schools and mental health providers.

Conclusion

Among families and YSHCN, transition can be an overwhelming and frightening experience. Patients and families are often capable of pursuing the transition process but may need support from healthcare providers to carry out this process in a successful manner. It is essential for transition planning to be part of standard clinical care for these patients, beginning at age 12. This process should be gradual, developmentally appropriate, individually tailored to each family's unique needs, and solicit active participation from patients, parents, as well as pediatric and adult medical professionals. Pediatric healthcare providers have an obligation to prepare their patients and families with knowledge, access to resources, and coordination of care in order to successfully transition from the pediatric healthcare setting to the adult healthcare setting.

Yet, current practice falls short of ensuring successful transition planning and transfer from pediatric to adult care. At both state and national levels, resources are needed to provide early training for medical residents in providing developmentally appropriate transition planning, to provide funding and institutional support for transition program development and evaluation, to facilitate partnerships between pediatric and adult providers, and to offer patients and families a multidisciplinary approach to transition planning as part of standard clinical care.

Provider-Focused Transition Resources

Good2Go – hospital for sick children

https://www.sickkids.ca/Good2Go/index.html

- Provides resources including the Good2Go transition program's toolkit, MyHealth Passport (a portable medical summary), readiness checklists, and links to patient educational materials (e.g., communicating with providers, the first appointment).
- Provides educational and national resources and links to various transition programs.
- Topics covered include: secondary education issues, sexuality, medication management, and independent living.

Got transition

http://www.gottransition.org/home

- Provides resources for healthcare professionals, patients, parents, and policy-makers.
- Provides educational materials for clinical providers, including webcasts and webinars.
- Provides links to research articles and useful resources for youth and families to navigate the transition process.

Center for children with special health needs – Seattle children's

http://cshcn.org

- Provides printable tracking forms (e.g., medication, hospitalizations, health providers).
- Provides resources for patients including differences between pediatric and adult healthcare, insurance 101, and tips for keeping track of medical information.

Adolescent health transition project

http://depts.washington.edu/healthtr

- Provides family/patient-centered resources including planning for emergencies at home, sexual/reproductive health, technology/mobility devices, and tips on scheduling and communicating with healthcare providers during a visit.
- Provides materials for school-based accommodations, including transition-specific individualized education plans (IEPs) and resources for school nurses.
- Provides tools for medical providers such as links to national transition websites and articles that address transition needs for various medical, developmental, and behavioral diagnoses.

JaxHATS

http://www.jaxhats.ufl.edu/index.php

- Provides tools for medical providers including a resource guide for transitioning children with special healthcare needs, clinical screening tool for health and psychosocial issues, and transition readiness checklists.
- Videos are available for patients on scheduling a medical appointment, completing paperwork during a medical visit, and bringing medications to an appointment.
- Provides healthcare transition workbooks, which engage patients and families in planning for independence in health management and daily living. Available in English and Spanish.
- Provides links to online training for healthcare professionals (as well as families): The professionals' course describes healthcare transition practices and "identifies legal, educational, social, and developmental issues that should be taken into consideration when helping youth and families develop and implement their healthcare transition plan." This is a 4-hour course, and CME credit is available for Florida providers.

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8

Assessment and Non-pharmacological Management of Pain in Children with Burns

Narisa Damanhuri and Stuart Enoch

Introduction

Burn injuries continue to remain a significant clinical problem globally, encountered by diverse medical and nursing practitioners worldwide. Although the majority of small burns can be managed by family physicians and in a primary care setting, some complex burns and all major burns warrant specialist care and a skilled multidisciplinary approach for successful clinical outcome. Burn injuries are common among the younger age group, with approximately 36% of cases accounting for children less than 10 years of age; scalds account for the majority of burn injuries in children (Figures 8.1 and 8.2). Other important causes include contact burns such as from the glass front of gas fireplaces and domestic radiators (Figure 8.3), and flame burns.

Pain and distress are strongly associated with burns in children. Monitoring and reporting of pain in children with burns has generally been poor. For example, the potential for anticipatory pain before procedures, such as dressing changes, is high, and little has been reported in the literature about chronic pain following a burn injury. Monitoring of pain is complicated by the traumatic nature of the initial injury and reaction to distress after a burn.

Pain has adverse physiological and emotional effects, and adequate pain control is an important factor in improving outcomes. Key to successful treatment is the continuous and accurate assessment of pain and the response to therapy. Pain management should be a multidisciplinary approach involving varying professionals such as the burn surgeon, pediatrician, pain specialist (usually anesthetist), nurse,

The Handbook of Behavioral Medicine, First Edition. Edited by David I. Mostofsky.

Figure 8.1 Scald from boiled water from a kettle. The child pulled the kettle with water over his head, resulting in the classical "pull-over" scald.

Figure 8.2 Deep burn in the palm of a young child from scald.

occupational therapist, physiotherapist, psychologist, play therapist, as well as the family. This chapter discusses the essential aspects of the pathophysiology of pediatric burns and the management of pain in children with such injuries. The emphasis will be on the various assessment tools available to evaluate pain and the non-pharmacological options available in managing pain.

Figure 8.3 Contact burn on the palm from a domestic radiator. This is a partial thickness burn.

Pain in Burns

All children with burns will experience pain, regardless of the cause, size, or depth of the burn. Undertreated pain can result in non-compliance with treatment and, consequently, protracted healing times. This can disrupt care and increase the risk of post-traumatic stress disorders. It is possible to ensure better pain management by trying to understand the child's experience rather than just acknowledging the pain. Thus, the most fruitful approach would seem to be frequent assessment of pain with readiness to try alternative or additional measure when relief seems inadequate.

Multidisciplinary assessment helps to integrate pharmacological and psychological pain relieving interventions to reduce physical, emotional, and family distress. Special attention should be paid to the child's environmental conditions. For instance, a parent's or legal guardian's presence and participation during the procedure can be highly beneficial.

Children with burns have background pain and procedural pain, and it is important to distinguish between the two. Background pain, once assessed and evaluated, can be managed pharmacologically with regular analgesia, whereas procedural pain requires stronger analgesia (i.e., bolus dose). However, procedural pain is difficult to evaluate and is therefore frequently undertreated. Poor management of pain can lead to anticipatory anxiety before future procedures and, consequently, a lower pain tolerance threshold.

Chronic pain has multiple and often unclear origins. Neuropathic pain is one of the reasons for this, and it develops secondary to nerve damage, abnormalities in nerve regeneration, and reprogramming of the central nervous system. It can be

Figure 8.4 Healing wounds from a flame burn on the back of a child. However, it requires frequent dressing changes, which can result in pain.

frustratingly unresponsive to conventional treatment modalities. Adjuvant therapies such as clonidine and anticonvulsants are effective in the treatment of sympathetically mediated pain. Psychological therapies to boost coping strategies and aid relaxation should be added.

Management of pain is important during all stages of treatment including in the emergency department, during procedures such as dressing changes and after discharge when complex neuropathic pain syndromes may develop. Pain is an important issue not just during the acute stages but also once the burns begin to heal (Figure 8.4), requiring frequent dressing changes.

Management of Minor Burns

Various guidelines exist to aid management of minor burns in the community setting – those not requiring specialist referral. It is widely recommended that a burn should be cleansed with soap and water (or a dilute water-based disinfectant) to remove loose skin including open blisters (Figure 8.5). The clinical evidence for management of blisters is, however, poor; nevertheless, without removing the blister, it is impossible to assess the depth of the burn, and it is therefore recommended to be de-roofed. Isolated lax blisters $<1\,\text{cm}^2$ in size can be left alone. Simple non-adhesive dressing, such as a paraffin gauze (e.g., Jelonet®) or a soft

Figure 8.5 Blisters on the back of a child from scald.

Figure 8.6 Biobrane being used on a burn wound.

silicone dressing (e.g., Mepitel®) padded by gauze, is effective in most superficial burns (small area). Dressings should be examined at 48 hours for re-assessment of depth. Further dressings may be left for 3–5 days, provided there are no signs or symptoms to suggest infection. There is high-level evidence from comprehensive meta-analyses that biological dressings (e.g., Biobrane™) (Figure 8.6) are better than simple dressings for superficial partial thickness burns, particularly for children, as they reduce pain, and the wound bed can be inspected through the translucent sheet.

Pain Assessment in Children

Pain assessment tools

Pain evaluation and management in children pose unique challenges, as they require consideration of various factors such as the child's age and the corresponding developmental level, cognitive and communication skills, previous pain experiences, and associated beliefs. Additionally, the ability of the healthcare professional in correctly assessing and interpreting information conveyed by the child also needs to be considered.

Although accurate pain measurements in children are difficult to achieve, the pursuit toward better understanding of the child's pain experience rather than merely acknowledging pain is key to successful overall treatment. The frequent assessment of pain and response to therapy during all stages of treatment, beginning from admission until after discharge, is important so as to effectively address both acute and possibly chronic pain. Chronic pain in this context may develop secondary to nerve damage.

Three main methods are currently used to measure pain intensity in children. These include:

- Self-reporting
- Behavioral measures
- Physiological measures

Self-reporting measures are the most valid form of assessment. It is most suitable when used in children who have the capability to describe pain. However, this method, particularly for younger children, to a certain extent, is reliant on the healthcare professional completing the report in view of the level of cognitive and language development of the child.

For younger age groups, such as infants and neonates, where communication is difficult, *behavioral measures* are employed. These consist of physical observation – for example, assessment of crying, facial expressions, body postures, and movements.

Physiological measures include assessment of pulse rate, blood pressure, respiratory rate, oxygen saturation, palmer sweating, and neuroendocrine responses. Generally, this method is used in combination with behavioral and, where applicable, self-report measures, as physiological responses are usually valid only for a short duration of acute pain. It may also be difficult to distinguish if the physiological response is solely due to acute pain or secondary to other stressors.

Various measurement tools have been established to aid assessment of pain in children, as summarized in Table 8.1. These tools vary according to the age group, so as to adapt to the developmental level of the child.

Table 8.1 Pain assessment scales.

Age Group	*Scales*	*Indicators*
Preterm to full-term infants	Premature Infant Pain Profile (PIPP)	Gestational age, behavioral state before painful stimulus, change in heart rate during stimulus, change in oxygen saturation, brow bulge, eye squeeze, and nasolabial furrow
Preterm to full-term infants	Neonatal Facial Coding System (NFCS)	Brow bulge, eye squeeze, nasolabial furrow, open lips, stretched mouth (horizontal or vertical), lip purse, tout tongue, and chin quiver
Preterm to full-term infants	Neonatal Infant Pain Scale (NIPS)	Face, cry, breathing pattern, arms, legs, and state of arousal
32–60 weeks	Crying Requires Increased Vital Signs Expression Sleeplessness (CRIES)	Crying, increased oxygen requirements, expression, vital signs, and sleeping
Infants	Maximally discriminate facial movement coding system (MAX)	Brow, eye, and mouth movement
Infancy to 7 years	The Faces Legs Activity Cry Consolability Scale (FLACC)	Face, legs, activity, cry, and consolability
1–4 years	Observational Pain Scale	Facial expression, cry, breathing, torso, arms and fingers, legs and toes, and states of arousal
1–5 years	Toddler–Preschooler Postoperative Pain Scale (TPPPS)	Vocal pain expression, facial pain expression, and bodily pain expression
1–6 years	Child Facial Coding System (CFCS)	Facial actions: brow lower, squint, eye squeeze, blink, flared nostril, nose wrinkle, nasolabial furrow, cheek raiser, open lips, upper lip raise, lip corner puller, vertical mouth stretch, and horizontal mouth stretch
1–7 years	Children's Hospital of Eastern Ontario Pain Scale (CHEOPS)	Cry, facial, child verbal, torso, touch, and legs
3–7 years	COMFORT Scale	Calmness/agitation, respiratory response, physical movement, blood pressure, heart rate, muscle tone, and facial tension
3–13 years	The Observational Scale of Behavioral Distress (OSBD)	Eleven behaviors related to pain and/or anxiety

(*Continued*)

Table 8.1 (*Continued*)

Age Group	*Scales*	*Indicators*
≥4 years	Faces Pain Scale	Pain intensity "faces" correspond to pain intensity
4–13 years	Poker Chip Tool	Pain intensity poker chips represent "pieces of pain"
≥5 years	Oucher Scale	Pain intensity 'faces' correspond to pain intensity
7 years	Visual Analog Scale (VAS)	Pain intensity (numeric, color)
8–17 years	Pediatric Pain Questionnaire	Information seeking, problem solving, seeking social support, positive self-statements, behavioral distraction, cognitive distraction, and externalizing/internalizing
8–17 years	Adolescent Pediatric Pain Tool (APPT)	Intensity, location, and quality of pain

Non-pharmacological management of pain in children

Non-pharmacological management along with psychological strategies are helpful adjuncts to conventional medical treatment in providing optimal analgesia for children with burn pain. A child-centered approach should be employed, whereby the child is encouraged to be fully involved and given the freedom to ask questions and voice out simple preferences prior to performing a particular procedure. This helps children control their anxiety cognitively, thus helping them gain a level of pain relief. Family members or parents (or legal guardians) are also guided to act as positive assistants rather than negative restraints during painful procedures.

Distraction techniques are also useful in drawing children's attention away from the painful stimuli. It is most effective when adapted to the developmental level of the child, and has been proven to be more economical than using certain analgesics. Distraction techniques can be divided into:

Active distraction, whereby health professionals provide a good understanding of the procedure to the child and encourages the child's participation in the activities during the procedure

Passive distraction, by which the child is requested to remain quiet and still while the healthcare professional is actively distracting the child (i.e., by talking, singing, reading a book, praying, describing photographs, listening to music, or playing games)

Table 8.2 illustrates various forms of distraction that are proven effective with different age groups.

Table 8.2 Forms of distractions among different age groups.

Age group	*Description*
Neonates and infants	Distraction techniques appropriate for this age group are mostly passive. Cognitive strategies used include visual or auditory interventions – for example, showing pictures, putting on cartoons/music, singing lullabies, or letting child play with mobile phones and mirrors. Behavioral strategies that promote a peaceful and calming effect – for example, non-nutritive sucking, skin-to-skin contact, rocking, soothing, and swaddling the infant may be used as well.
Toddlers and preschoolers	Both active and passive forms of distraction may be used. For younger children, procedures should be explained in an age-appropriate manner, and the child should be given opportunities to ask questions. In older children, initiating distracting conversations (e.g., “Who is your favorite superhero?”) and deep breathing exercises are helpful.
School-aged children	Apart from providing a better understanding of the procedure and its indications, giving the child a choice (i.e., sitting/lying down, right or left arm) helps them to feel in control, and thus encourage voluntary participation. Active techniques include singing songs, squeezing balls, and playing with electronic devices.
Adolescents	Ensuring a private setting is particularly important for this age group as they tend to deny pain in front of others. Letting them decide on the type of distraction and the presence of friends or family members proves to be useful.

Apart from age-specific strategies, there are other forms of interventions that may be used to minimize pain in children. These include cognitive and behavioral categories, as described in Table 8.3.

Conclusion

Pain is strongly associated with burn injuries in children. It can have adverse physiological and emotional effects, and thus adequate pain control throughout the treatment process is important in improving outcomes. Key to successful healing of burn injuries is the continuous and accurate assessment of pain, using any of the various pain assessment tools, and the response to therapy. Pain management should

Table 8.3 Cognitive and behavioral interventions.

Intervention	*Cognitive*	*Behavioral*
Age group	Commonly used among older children	Often used among younger children
Description/ examples	Imagery Child is asked to imagine a happy moment or experience	Breathing exercises Child is given party blowers or asked to practice blowing bubbles
	Preparation/education/ information Child is thoroughly explained the current condition/procedure in an age-appropriate manner Clear instructions are given to encourage participation and help them understand what to expect	Modeling positive coping behaviors Child is asked to watch another child undergoing a similar procedure (maybe shown using a video), whereby positive coping behaviors are rehearsed and suggested to be applied during the actual procedure
	Coping statements Positive thoughts are reinforced, i.e., "I am doing well, I can do this!"	Desensitization The procedure is introduced in a step-by-step manner and by effectively dealing with easier tasks before moving on to the next one
	Parental training Parents are taught one of the preceding interventions to decrease their stress, in turn minimizing the child's level of stress as well	(d) Positive reinforcement – The child is rewarded with praises, constructive comments, and concrete gifts after successfully completing the painful procedure
	Audio/visual distractions Used to direct child's attention away thus alleviating pain during procedures	(e) Parent coaching Parents are guided to enthusiastically encourage the child to use one of the preceding strategies

be a multidisciplinary approach, and it is the responsibility of the healthcare professional to institute appropriate therapies to manage pain – be it pharmacological or non-pharmacological. Acknowledging the significance of pain associated with burn injuries and being aware of the various treatment options available is crucial in achieving a satisfactory outcomes.

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9

Cognitive Behavioral Interventions in Children with Functional Abdominal Pain and Irritable Bowel Syndrome

Julie Snyder and Samuel Nurko

Introduction

Functional gastrointestinal disorders, often characterized by abdominal pain and uncomfortable variations in stool patterns, affect anywhere between 4 and 25% of school-aged children (Huertas-Ceballos, Logan, Bennett, & Macarthur, 2008). These disorders frequently result in an increased amount of pediatrician visits per year and account for approximately 25% of new patient referrals to specialty gastroenterology clinics (Crushell et al., 2003). During the elementary school years, boys and girls are equally affected by functional GI disorders; however, as children age, higher rates of these diagnoses are found in girls (Schulte, Petermann, & Noeker, 2010).

Given that the symptoms in children with FGID are not explained by structural or biochemical abnormalities, specific symptom-based criteria for the proper diagnosis of these disorders have been developed. Now in its third revision, the Rome criteria outline the diagnostic requirements and exclusions for the various functional gastrointestinal disorders, including functional abdominal pain and irritable bowel syndrome in children.

Per the Rome III pediatric criteria, pediatric functional abdominal pain is characterized primarily by abdominal pain that may be persistent or episodic and that occurs at least once per week for a period of at least 2 months. The pain cannot be better explained by another functional gastrointestinal disorder, and it must occur in the absence of an identified organic process. Irritable bowel syndrome, according to Rome III criteria, is characterized by abdominal pain or discomfort that is accompanied at least 25% of the time by two or more of the following symptoms: the pain

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or discomfort is relieved with defecation, the onset is associated with changes in stooling frequency, and/or the onset is associated with changes in the appearance in stool form. Similar to functional abdominal pain, patients with irritable bowel syndrome must experience this constellation of symptoms in the absence of an identified organic process, and the symptoms must occur at least once per week for at least a 2-month period (Rasquin et al., 2006).

While a large number of patients meeting criteria for functional abdominal pain or irritable bowel syndrome improve over time, studies have consistently indicated that children and adolescents may continue to report symptoms of the same or additional functional disorders years after the diagnosis (Walker, Garber, Van Slyke, & Greene, 1995), as well as into adulthood (Dengler-Crish, Horst, & Walker, 2011). Moreover, these diagnoses often result in significant functional impairments for pediatric patients. These may include difficulties with attending school on a regular basis and declining grades (Logan, Simons, Stein, & Chastain, 2008), decreased peer socialization and peer victimization (Greco, Freeman, & Dufton, 2007), and the termination of participation in sports or other extracurricular activities. Higher rates of internalizing disorders, such as anxiety or depression, have also been reported in this population when compared to controls (DiLorenzo et al., 2005). Families also suffer both emotionally and financially due to schedule disruptions associated with frequent medical visits, high costs associated with these visits, and an increase in missed, and potentially unpaid, work days (Guite, Lobato, Shalon, Plante, & Kao 2007; Palermo, 2000).

Biopsychosocial Approach to Diagnostic Formulation and Treatment

Functional gastrointestinal disorders are now conceptualized and treated in accordance with a biopsychosocial framework. This particular model is based on the premise that individuals have a genetic make-up that makes them more vulnerable to functional disorders, and that early biological or environmental life events may influence perception, gastrointestinal physiology, and motility later on in life, thereby impacting the development of disorders such as functional abdominal pain or irritable bowel syndrome. Psychological factors, including mood symptoms as well as the way individuals react, think about, and cope with pain-related symptoms, largely influence disease maintenance, exacerbation, or improvement. Social and environmental factors, such as supportive or unsupportive family relationships, academic or emotional stressors, and overall daily functioning, further contribute to patients' disease experience and prognosis.

An updated review of the information regarding the biological and gastrointestinal factors proposed to potentially be playing a role in functional disorders can be found in a recent article published by Chiou & Nurko (2010). With regards to the contribution of psychological factors, research has consistently shown that patients with functional abdominal pain actually experience an increased prevalence of internalizing disorders, such as anxiety or depression (Dorn et al., 2003; Campo et al., 2004). This has resulted in some experts beginning to question whether mood disorders and functional abdominal pain are simply highly comorbid or whether the two diagnoses combined actually represent one specific disorder. For example, Dufton, Dunn, and Compas (2009) compared a sample of patients diagnosed with functional abdominal pain to a sample of patients previously diagnosed with an anxiety disorder as well as to a sample of "healthy" controls. The results indicated that over half (67%) of the functional abdominal pain patients met the diagnostic criteria for an anxiety disorder, and that approximately one-third of the anxiety group met the criteria for functional abdominal pain. Further research on this topic would be invaluable for those working with this specific population of patients, particularly given the relationship between heightened autonomic system arousal, anxiety, and pain perception (Zeltzer, & Blackett Schlank, 2005).

An additional psychological factor that may contribute to the development, exacerbation, and maintenance of functional gastrointestinal disorders is coping style. More specifically, pediatric patients who demonstrate passive coping strategies and tendencies, including disengagement from social and academic activities, isolation, an external locus of control, and catastrophic thinking (e.g., "There is nothing that I can do to reduce my pain"), are at significant risk of experiencing an increase in pain and mood symptoms as well as greater functional disability (Walker, Smith, Garber, & Van Slyke, 1997; Walker, Smith, Garber, & Claar, 2005; Compas et al., 2006). On the other hand, patients who demonstrate adequate problem-solving abilities and who successfully utilize distraction strategies while maintaining an internal locus of control tend to experience decreased pain and may be able to continue on with or resume activities at a quicker pace (Thompson, Gil, Burbach, Keith, & Kinney, 1993; Harding-Thomsen et al., 2002).

In considering how social and environmental factors contribute to the diagnosis and course of functional abdominal pain or irritable bowel syndrome, research has demonstrated a relationship between disease maintenance and factors such as life stress, parent–child relationships, and family dynamics and communication patterns. For example, there is some evidence to support a time relationship between a stressful life event and the onset of a functional gastrointestinal disorder (Robinson, Alvarez, & Dodge, 1990); more daily social and home-related stressors have also been documented in children diagnosed with functional abdominal pain as compared to controls (Walker, Garber, Smith, Van Slyke, & Claar, 2001). Moreover, consistent with social learning theory principles and the theory of operant conditioning, research has also demonstrated that parental responses to their child's pain largely influences disease exacerbation and maintenance. Children and adolescents whose parents attend to pain symptoms by engaging in behaviors such as apologizing, persistently inquiring about pain intensity and severity, permitting school absences, or granting special privileges and offering gifts tend to experience an exacerbation of gastrointestinal symptoms (Walker, Garber, & Greene, 1993; Walker et al., 2006). Additionally, because higher rates of functional gastrointestinal disorders have been found in parents of children diagnosed with FAP or IBS

(Buonavolonta et al., 2010), children may actually come to model their parents if they have watched them engage in illness-related behaviors of their own, such as repeatedly missing work when symptoms occur (Levy et al., 2004). Thus, the best course of action is for parents' to engage in opposite behaviors, such as suggesting the utilization of active coping strategies and recommending paced, yet consistent attendance at school so as to positively influence their child's progress and symptom improvement over time.

Given the significance and relevance of the preceding information, it therefore becomes important to be mindful of these factors during the assessment process and to then review some of these factors as well as the biopsychosocial approach when discussing diagnostic formulation and treatment planning with patients and families. By doing so, families may experience less frustration and confusion and may be more likely to follow-through with both medical and psychological interventions if viewed as part of a multidisciplinary treatment package (Schurman & Friesen, 2010). Additionally, research has provided evidence to support that explaining a functional gastrointestinal disorder in accordance with a biopsychosocial approach results in reduced maternal anxiety and increased satisfaction with medical providers and the overall clinical evaluation (Williams, Smith, Bruehl, Gigante, & Walker, 2009).

Approach to Treatment

Success in treating patients with FAP or IBS begins with the establishment of an effective patient–physician relationship. The physician should provide reassurance that the positive diagnosis of FAP or IBS is not a failure to identify an organic illness, while educating the patient and family about the pathophysiology of visceral pain and associated complaints. A confident diagnosis, confirmation, and explanation of pain experience and reassurance can by itself be therapeutic (Levy et al., 2006). The physician should adopt an "active listening approach" and an enthusiastic, positive, and encouraging attitude toward treatment (Hyams, 2004). The physician should elicit any patient concerns or fears as well as provide reassurance that a positive diagnosis of FAP or IBS is not a failure to identify an underlying illness. Setting up an expectation for normal results to laboratory testing or investigations, when appropriate, may assist in establishing acceptance of a functional disorder diagnosis. Explaining the pathophysiology of visceral pain and associated complaints in the context of a brain–gut axis can be helpful, but symptoms should be validated as real. It is also important to make clear that treatment response is often gradual, and to set realistic goals such as improved coping with symptoms and maintenance of normal daily living activities, rather than expectation of a prompt cure. Overall, management should be multidisciplinary and tailored to the patient's specific symptoms and identifiable triggers. Cognitive behavioral therapies (CBTs) are an important aspect of this multidisciplinary care. The present chapter will focus solely on CBT interventions.

Cognitive Behavioral Therapies

Psychological assessment and intervention

Psychological assessment and intervention serves as one of the core components of a multidisciplinary, biopsychosocial treatment approach for the management of pediatric functional abdominal pain.

The assessment process, which may be completed in conjunction with a gastroenterology visit or at another time, provides key information regarding pain history and the overall functioning of a patient in developmental, social, emotional, and academic domains. This information can be utilized and considered when determining goals to address during psychological treatment for symptom management. It may be helpful to gather some of the information listed in Table 9.1 when conducting a psychological assessment for pediatric patients experiencing chronic gastrointestinal symptoms:

Table 9.1 Psychological assessment of functional GI disorders.

Assessment Topics	*Information to Gather*
Current symptoms	• Frequency, duration, and intensity (0–10 pain scale) of symptoms • Verbal description of GI symptoms (e.g., cramping, burning, squeezing feelings) • Symptom triggers (e.g., food, constipation, poor sleep, increased/decreased movement, stress) • Current strategies to cope with/manage symptoms (e.g., medications, active or passive coping strategies) • Functional impairments (e.g., reduced participation in academic, social, or extracurricular activities) • Current feelings about and perceptions of symptoms
Symptom history	• Symptom onset and potential triggers (e.g., physical injury, virus or illness, psychological stressor) • Symptom course since initial onset • Previous evaluations conducted, recommendations made, and usefulness of these recommendations
Early developmental history/ medical history	• Pregnancy/delivery complications • Achievement of developmental milestones/need for early intervention • History of other gastrointestinal problems • History of other medical problems, including other pain-related problems

(*Continued*)

Table 9.1 (*Continued*)

Assessment Topics	*Information to Gather*
Mental health history/current review of symptoms	• Past mental health diagnoses • Past or current involvement in mental health treatment • Past or current psychotropic medications • Assessment of depressive symptoms • Assessment of anxiety symptoms, which include symptoms specific to GI disorders (e.g., worry about pain getting worse in certain situations, worry about not being able to make it to the bathroom on time or not having a bathroom available, worry about frequent bathroom use and peers picking up on this) • Assessment of substance use/abuse • Assessment of trauma/abuse • Assessment of body image/risk for developing eating disorder (e.g., overuse of prescribed laxatives, increased worry about bloating, restrictive eating to prevent symptoms but also to lose weight)
Academic/social history	• Academic functioning and progress • Implementation of 504 plan given GI symptoms • Current or past IEP (individualized education plan) • History of weaknesses in learning/diagnosed learning disabilities • Daily activity schedule (if not attending school because of pain) • Peer relationships (e.g., presence of solid peer group, current or past problems with bullying) • Participation in extracurricular activities • Involvement in romantic relationships
Family history	• Family history of gastrointestinal symptoms • Family mental health history • Family reactions to and beliefs about symptoms

Following a thorough assessment, discussions can be held with the family regarding applicable and potential psychological treatment strategies. Research examining the effectiveness of interventions for the management of functional gastrointestinal disorders has consistently provided evidence to support the utilization of specific types of psychological treatments. This includes CBT, which frequently incorporates different self-regulation strategies such as relaxation, hypnosis, and biofeedback (Sprenger, Gerhards, & Goldbeck, 2011; Brent, Lobato, & LeLeiko, 2008a; Huertas-Ceballos et al., 2008). Treatments such as these provide patients with active tools that they can utilize to cope with and to reduce symptoms. This is often a crucial point to emphasize when reviewing the rationale for learning these strategies, particularly because many patients diagnosed with functional abdominal pain report feelings of helplessness with regards to their ability to self-manage symptoms.

CBT: empirical support

CBT is one of the most common types of treatment for the management of functional gastrointestinal disorders in children and adolescents. Although the focus of many CBT sessions is on teaching the patient specific skills and strategies, parents are also frequently included in treatment to provide instruction on how to best assist and respond to the patient when he or she is experiencing pain.

Studies examining the role of CBT in the management of pediatric functional abdominal pain have consistently generated promising results. Sanders et al. (1989) randomly assigned 16 children diagnosed with recurrent abdominal pain and their parents to a CBT intervention or wait-list control group. Those assigned to the CBT group received eight therapy sessions addressing parental reactions and responses to pain and patient instruction in relaxation, distraction, and positive self-talk. Assessments of pain intensity and pain-related behaviors were completed at baseline, at the conclusion of treatment, and 3 months post-treatment. While both groups reported a reduction in their pain, these results were reported sooner for the patients assigned to the CBT intervention group. Moreover, 87.5% of patients in the intervention group reported complete elimination of their pain at 3 months, as compared to only 37.5% in the wait-list control group. In 1994, Sanders and colleagues (Sanders, Shepherd, Cleghorn, & Woolford, 1994) expanded on this initial research study by randomly assigning a group of 44 children and their parents to either a six-session CBT family intervention or standard medical care. At the conclusion of treatment as well as at 6-months follow-up, children in the CBT intervention group were more likely to report complete elimination of pain. The parents also observed this. Additionally, when compared to the standard medical care group, the children and families in the CBT intervention reported less functional impairments and lower levels of relapse at the 12-month follow-up.

In an effort to provide further support for the effectiveness of CBT in the treatment of functional abdominal pain, Robins, Smith, Glutting, and Bishop (2005) examined the benefit of CBT plus standard medical care compared to standard medical care alone. The 40 children and parents in the CBT group reported significantly lower scores on a measure of abdominal pain following a five-session treatment intervention as well as at a 6-month to 1-year follow-up. These participants also had significantly less missed school days when compared to the standard medical care group. Significant differences between groups were not found for somatization, functional disability, and frequency of contact made with the child's physician. A similar randomized control study conducted by Duarte et al. (2006) found that participants in a four-session CBT + standard medical care intervention reported significantly less episodes of abdominal pain as compared to the group receiving routine medical care. Reports of pain intensity did not, however, differ between the treatment and control groups.

A more recent study conducted by Levy and colleagues in 2010 evaluated the effectiveness of a three-session CBT intervention that placed particular emphasis on parental responses to their child's reports of abdominal pain in addition to the overall coping abilities of the child. Parental assessments indicated that children in the CBT intervention demonstrated significantly less pain and decreased severity of gastrointestinal symptoms at the conclusion of treatment as well as at a follow-up time point. Additionally, parents in the treatment intervention reported significantly less solicitous verbalizations in response to their child's pain as compared to parents in the control group.

Components of CBT

CBT specifically targets the interplay between thoughts, feelings, and behaviors. Children and adolescents are encouraged to play an active role in treatment, meaning that they work together with the clinician to determine what they can do on their own to cope with and manage their gastrointestinal symptoms.

Some of the CBT interventions most commonly taught and implemented for the management of chronic abdominal pain, irritable bowel syndrome, and other functional gastrointestinal symptoms include:

Psychoeducation: This component is introduced at the beginning of treatment. Psychoeducation may focus on reviewing the biopsychosocial treatment model, providing reassurance regarding the diagnosis of a functional GI disorder, and educating both the patient and family about the specific techniques they will learn over the course of treatment. It is also important to ensure that patients and families understand that the treatment team acknowledges and believes that the pain is real and that psychological strategies, such as CBT, is recommended in an effort to help the patient to better cope with his or her pain.

Cognitive restructuring: Patients who experience chronic abdominal pain and IBS-related symptoms oftentimes experience many negative thoughts related to this symptom and their ability to function. As a result, they may experience both increased pain and psychological distress (Walker et al., 2005). The cognitive component of a CBT intervention assists patients in first recognizing these negative thought patterns and understanding how these thoughts can influence pain perception. Once patients are able to identify these thoughts, treatment proceeds to working on challenging and altering these patterns in thinking to include more helpful coping statements. For example, after a physical education teacher assigns the class to run laps around the gymnasium, a patient who thinks, "This will be torture! I will definitely experience a worsening of my pain! I will probably never be able to run again!" may begin to experience increased worry and possibly increased pain prior to even starting to run. In turn, the patient may verbalize that he cannot participate in the assigned activity and may miss out on the ability to socialize with friends during gym class. In this case, the goal would be to help the patient to identify and to recognize thinking errors and to restructure cognitions to statements that may help to increase the chances of him successfully participating in the assigned activity (i.e., "I can cope with this. Just because this happened once doesn't mean it will always be this way. Maybe I can set the goal to try to at least complete half of the assigned laps"). With repeated practice and use of these cognitive skills, patients develop an increased amount of confidence that they will be able to successfully cope in a situation, thereby reducing psychological distress.

Self-regulation strategies: Instruction in self-regulation strategies assists patients in changing their perception and experience of pain by decreasing the anxiety and physiological reactions to symptoms. It is important to recall that there is evidence to support the notion that pediatric and adult patients diagnosed with functional GI disorders may experience autonomic nervous system dysfunction (Chelminsky, Boyle, Tusing, & Chelminsky, 2001; Sowder, Gevirtz, Shapiro, & Ebert, 2010). The presence of anxiety can also contribute to this dysfunction. This results in a chronic state of over-arousal, which in turn may exacerbate these patients' abdominal pain or IBS-related symptoms. The utilization of self-regulation strategies assists patients in reducing this over-arousal, which in turn can reduce the intensity of the pain or other symptoms.

The most frequently implemented self-regulation strategies for pain management include relaxation techniques such as diaphragmatic breathing, progressive muscle relaxation, and guided imagery. Self-hypnosis and biofeedback have also been frequently utilized as adjunctive treatments to CBT. Regardless of which strategy is used, it is important that the patient understands the importance of practicing these techniques on a regular basis. It may be helpful to provide an analogy of the frequency of fire drills throughout the school year (i.e. that the fire drills are done so that you know exactly what to do if there is a fire). The same concept applies to practicing these interventions, as patients need to become experts at the appropriate utilization of these skills, so that they can quickly and effectively utilize them during times when they are experiencing an exacerbation of symptoms or to prevent symptom triggers (i.e. stress or anxiety).

Diaphragmatic breathing: This is perhaps one of the simplest strategies for patients to learn. It is helpful for children and adolescents to recognize how their breathing patterns may change in response to an episode of pain. For example, they may begin to take shallow breaths and may tense their muscles. Unfortunately, this can result in further exacerbation of the abdominal pain. With diaphragmatic or "belly" breathing, patients are instructed to breathe solely from their diaphragm. As they inhale through the nose, they should think about filling the stomach up with air, similar to what happens when blowing up a balloon. On the exhale, patients are instructed to breathe out slowly through pursed lips. As this occurs, the abdomen will slowly contract (this can be compared to air slowly leaking out of a balloon). It is helpful to find a pace that works for each individual child and to encourage daily practice of this skill. Younger patients may benefit from placing an object on their abdomen to ensure that they are breathing from the diaphragm. Older patients may be instructed to place one hand on the stomach and one hand on the chest in order to make sure that they are only feeling the hand on the stomach move.

Progressive muscle relaxation: This technique assists patients in learning to recognize the difference between muscle tension and relaxation. The goal is to reduce overall muscle tension, given that it can result in pain amplification. Children and adolescents are taught to tense different muscle groups for a short period of time (approximately 5 seconds), followed by gradual relaxation of these muscles. One example of a progressive muscle relaxation script for children is provided in an article by Koeppen (1974).

Guided imagery: Guided imagery involves the use of one's own imagination to create calming and relaxing mental images. The rationale behind the utilization of guided imagery for chronic pain is that the images that are created and imagined are incompatible with a patient's experience of pain, discomfort, or distress (Brent, Lobato, & LeLeiko, 2008b). It is often helpful to explain to patients that, just like it is impossible to be in two places at once, it is also quite difficult to experience both pain and relaxation at the same time.

When using guided imagery, it is sometimes beneficial to ask the patient about an image that he or she deems calming or to offer a few choices of potentially relaxing images. This provides an opportunity for the patient to play an active role in this intervention and ensures that the image that is being used is actually one that the patient feels is relaxing. When creating the image, the therapist may ask the patient to think about what they would hear, taste, touch, see, and smell. This information can then be incorporated into the imagery that the therapist creates for the patient. Once these steps are completed, the therapist can begin the guided imagery intervention. Patients are first instructed to make themselves as comfortable as possible. Next, the therapist may instruct the patient in either diaphragmatic breathing or an abbreviated form of progressive muscle relaxation to further elicit a relaxation response. Once this is achieved, the session can progress to introducing the imagery that was decided upon by the therapist and the patient. Following the guided imagery exercise, the therapist may find it helpful to elicit feedback from the patient about the exercise and to problem-solve regarding anything that the patient found difficult about the exercise or disliked. The imagery exercise can also be recorded and then provided to the patient so that he or she can begin to practice and utilize it in the home environment.

A few studies have evaluated the particular benefits of incorporating guided imagery into a CBT treatment protocol. Ball, Shapiro, Monheim, and Weydert (2003) conducted an initial pilot study examining the effectiveness of a four-session guided imagery protocol for 10 patients diagnosed with recurrent abdominal pain.

While a 67% decrease in pain was reported, a major limitation of this preliminary study was the absence of a control group. Weydert and colleagues initiated a follow-up study in 2006. In this particular study, 22 patients diagnosed with functional abdominal pain were randomly assigned to either four sessions of guided imagery plus progressive muscle relaxation or breathing strategies alone. Patients assigned to the guided imagery group demonstrated a significant decrease in pain and missing out on scheduled activities as compared to the breathing group.

A more recent study by van Tilburg et al. (2009) evaluated the effectiveness of a primarily home-based guided imagery intervention for the management of functional abdominal pain. A total of 34 patients were randomly assigned to standard medical care plus guided imagery or standard medical care alone. Patients in the guided imagery group were asked to listen to a set of imagery CDs multiple times per week over the course of 2 months. Measures were completed at baseline and at a 6-month follow-up period. When compared to the standard medical-care-only group, patients in the guided imagery plus standard medical care group demonstrated a significant reduction in pain, functional disability, and medical visits immediately after treatment as well as at the 6-month follow-up time point.

Hypnosis: Clinical hypnosis involves assisting a patient in entering a state of increased focus and awareness. The therapist offers suggestions while a patient is in this trance-like state, with the overarching goal being to assist the patient in reducing symptoms (e.g., pain, worry, etc). During hypnosis, the patient is in complete control and actively participates in the treatment session; the role of the practitioner is to guide the patient through this experience, offering different strategies and suggestions that the patient may find helpful to visualize and to use after the session is completed to manage symptoms.

There are different stages in a clinical hypnosis encounter. As with any type of therapeutic intervention, it is essential for the practitioner to first spend time developing rapport with the child or adolescent. During this stage, it is helpful to obtain information pertaining to treatment goals as well as the patient's interests and strengths, so that this material can be incorporated into the hypnosis session. Moreover, it is important to obtain a better understanding of the patient's developmental level, their experiences with reported symptoms, previous participation in hypnosis or alternative treatments, and feelings about utilizing hypnosis for symptom management. All of this information combined can assist the practitioner in tailoring a hypnosis session specifically to the patient's needs. The goal of the next phase, termed the *induction phase*, is to assist the patient in beginning to focus their attention and awareness. Previously learned relaxation methods, such as breathing and progressive muscle relaxation, may be incorporated during this phase. The third phase, or intensification, continues to focus on enhancing the patient's awareness. Following this, the practitioner may begin to offer suggestions for symptom management (phase four) and may then offer additional suggestions (phase five) for how the patient can continue to take control over symptoms in the following days. The reorientation or closure phase assists the patient in becoming more alert and is followed by a debriefing phase where the patient is afforded the opportunity to discuss their hypnosis experience and provide feedback to the practitioner.

There are a multitude of suggestions that can be offered to patients who are experiencing abdominal pain or other functional GI symptoms. For patients experiencing increased pain or discomfort, the following may be helpful (Brann, 2012; Kohen, 2001; Olness & Kohen, 1996):

- Distancing from pain by suggesting that patients visualize themselves present in their favorite place
- Eliciting anesthesia by suggesting the creation of numbness in the hand and transferring this numbness to the abdomen
- Incorporating the concept of a pain switch or dial and making suggestions for the patient to actively turn down their pain or discomfort by manipulating this switch or dial
- Inviting patients to create an image of their pain or discomfort and then making the suggestion that this image can be changed to something more pleasant
- Increasing feelings that are generally incongruent with symptom experiences by offering suggestions for increased comfort or relaxation

Numerous research studies have documented the successful utilization of clinical hypnosis for the treatment of irritable bowel syndrome and other functional GI disorders in adult patients. While research targeting the pediatric population is more limited, a handful of studies have documented the usefulness of this particular intervention for the management of functional abdominal pain and irritable bowel syndrome in children and adolescents.

In 2001, Anbar conducted a case study examining the effects of hypnosis on five patients diagnosed with functional abdominal pain. Four of the five patients reported no symptoms within weeks of a single hypnosis session. Of note, the patients were asked to practice self-hypnosis on their own following the one hypnosis session. In 2007, Vlieger and colleagues (Vlieger, Menko-Frankenhuis, Wolfkamp, Tromp, & Benninga, 2007) conducted the first randomized controlled trial comparing the effectiveness of clinical hypnosis to standard medical care. The study group included 53 children and adolescents, all of whom were previously diagnosed with either functional abdominal pain or irritable bowel syndrome. The patients in the hypnosis group underwent six sessions of hypnosis. The sessions were individualized for each patient, and all participants were asked to continue practicing their self-hypnosis in between sessions. The control group received standard medical care plus six sessions of supportive therapy. At the 1-year follow-up mark, both groups reported a decrease in both pain frequency and intensity; however, these reductions were significantly greater in the hypnosis group. Moreover, treatment was deemed successful in 85% of the hypnosis group as compared to only 25% in the control group.

Most recently, Vlieger, Menko-Frankenhuis, Wolfkamp, Tromp, and Benninga (2012) conducted a follow-up study to determine the long-term effects of hypnosis in pediatric patients diagnosed with functional GI disorders. The study sample consisted of 49 of the 53 patients who participated in the 2007 study. The results indicated that, at nearly 5 years post-treatment, 68% of the participants in the hypnosis group continued to report symptom remission, as compared to 20% in the standard medical care group. Additionally, pain frequency and intensity scores continued to be significantly lower in the hypnosis group. Interestingly, the patients in the hypnosis group were also found to have significantly lower somatization scores at follow-up when compared to the control group.

Biofeedback: Biofeedback involves the utilization of electronic equipment to first analyze and process physiological activity and then to "feedback" this information to patients. The information that is provided during a biofeedback session helps patients to further comprehend the mind–body connection by assisting them in understanding how their bodies react when in a state of arousal as compared to a state of relaxation. Common bodily functions that are often measured include heart rate, muscle tension, and skin temperature. Self-regulation strategies, such as the ones mentioned earlier, are often paired with biofeedback to assist patients in directly changing bodily functions that are typically associated with increased stress and sympathetic nervous system arousal (Schurman, Wu, Grayson, & Friesen, 2010). For example, through the use of regulated diaphragmatic breathing, progressive muscle relaxation, or guided imagery and hypnosis, patients may be able to directly see a decrease in heart rate and muscle tension and an increase in skin temperature on the biofeedback screen.

Studies examining the incorporation of biofeedback into the self-regulation component of a CBT treatment protocol for pediatric functional abdominal pain and irritable bowel syndrome in particular have been scarce. Nevertheless, a few studies published within the last few years have provided support for the effectiveness of biofeedback as an adjunctive treatment method for this particular population. In 2010, Schurman and colleagues conducted a pilot study to examine the benefits of biofeedback-assisted relaxation training plus medication versus medication alone. Twenty patients were randomly assigned to one of the two groups. The biofeedback group received 10 sessions of biofeedback that focused primarily on muscle tension, skin temperature, skin conductance, and breathing rate. The self-regulation strategies taught to the patients included diaphragmatic breathing, progressive muscle relaxation, and autogenic hand warming. Results indicated that participants receiving biofeedback plus medication demonstrated declines in pain intensity and duration at a steeper rate when compared to the medication-only group.

Through the use of biofeedback, Sowder's group (2010) recently sought to determine whether autonomic nervous system dysregulation, a factor identified in the literature as potentially contributing to the development of IBS in adult patients, could also be playing a role in pediatric patients diagnosed with functional GI disorders. One way of measuring autonomic nervous system functioning is via the monitoring of one's heart rate variability (HRV), or the change in heart rate from one beat to the next. An increased HRV is indicative of prime ANS stability, meaning that the body is able to achieve homeostasis following a fight-or-flight response.

Sowder's group hypothesized that a group of 20 children diagnosed with FAP would display lower HRV (and therefore ANS dysregulation) at baseline as compared to a control group of 10 healthy participants. This study also sought to determine whether instruction in 6 weeks of HRV biofeedback could decrease pain symptoms in the FAP group. Results provided support for both hypotheses; however, causation could not be determined, given the absence of a control group for the HRV biofeedback intervention. Nevertheless, this study provides helpful information regarding the potential relationship between ANS dysregulation and pediatric FAP as well as the potential efficacy of HRV biofeedback for the management of pain symptoms in this subset of pediatric patients.

Parental participation: As previously discussed, parental responses to pain complaints can significantly influence a child or adolescent's ability to cope, as well as their overall pain experience (Walker & Zeman, 1992). Thus, the parent component of a CBT intervention includes assisting parents in learning ways to help their child when he or she is pain. This is to be done in the absence of providing reinforcement of illness-related behaviors via actions such as continuously asking the child if he or she is in pain, apologizing when the child verbalizes pain, permitting the child to miss school or other activities, or offering gifts or special privileges (van Tilburg et al., 2009). It is beneficial to assist parents in understanding that the goal of these types of interventions is not to take away their ability to help their child; rather, the intent is to offer strategies so that parents can appropriately acknowledge the pain and then offer suggestions for pain management. For example, parents can say something similar to "I see that you don't feel well right now" instead of saying "I'm sorry" when a child verbalizes pain. This can be followed by the suggestion for the child to use one of the coping strategies that has been taught in treatment or the utilization of a distracting activity (such as taking a walk or playing a game).

In certain circumstances, children and adolescents diagnosed with functional GI disorders may become considerably debilitated by their pain. As a result, they may begin to miss a significant number of school days and may withdraw themselves from social or extracurricular activities. Oftentimes, the thought of returning to these activities and the possibility of experiencing increased gastrointestinal discomfort while doing so results in increased distress. When this occurs, parental participation becomes a crucial component of a CBT treatment package in order to assist in school reintegration, goal setting, exposure, and activity scheduling, all of which are discussed in the following text.

School reintegration: For some children, the thought of attending school while experiencing pain can be overwhelming, which in turn may result in repeat absences (Logan et al., 2008). Unfortunately, excessive absences from school can also result in feelings of sadness or anxiety, given that the child or adolescent is left with having to make up a significant amount of coursework upon their return to school. It is therefore important to establish a school reintegration plan as soon as possible for patients identified as having missed a large number of school days.

When creating a reintegration plan, it is crucial to involve the family and school officials as well as the patient. If a patient has been out of school completely for weeks or months, a gradual reentry plan is usually recommended. This plan typically incorporates operant conditioning strategies (i.e., positive reinforcement for meeting daily academic goals or consequences for not following through) and the creation of a hierarchy related to increasing attendance at school. For example, for a child who has not been attending school for weeks, steps in the hierarchy might include attending school for 1–2 hours each day for the first week and then increasing the number of hours attended in every week thereafter. While it would be ideal for the child to return directly to the classroom, some children who experience increased anxiety may have to begin by completing work in the library or guidance office and then transitioning to the classroom in later weeks. Parental participation is crucial during the implementation of a school reintegration plan, in order to provide motivation and incentive for the child and to address any concerns with school personnel. Educating parents about how to respond to school refusal and how to prompt the utilization of learned coping strategies is also important.

Specific accommodations to assist a child in feeling more confident about making the return to school or continuing to attend school even when experiencing increased gastrointestinal symptoms are frequently included in school reintegration plans. For example, these accommodations may include permitting the child to utilize the bathroom without asking, allowing for short breaks in the nurse's office or another quiet place to practice learned self-regulation strategies, and granting permission to use a private restroom at school. Oftentimes, schools will require that these accommodations be documented formally in what is called a Section 504 Plan, under the "Other Health Impairments" category. Some students may also be able to receive accommodations under an Individualized Education Program (IEP).

Research on the implementation of school reintegration plans for children diagnosed with GI or other pain-related conditions is lacking and therefore needs to be conducted in order to better understand the effectiveness of this intervention.

Goal setting and exposure: Functional gastrointestinal symptoms, including chronic abdominal pain and variable stool patterns, can result in some patients significantly restricting their extracurricular activities. This may be done in an effort to prevent pain exacerbation or to prevent embarrassing symptoms from occurring in the context of a social event or sports-related function. Unfortunately, the restriction of extracurricular activities oftentimes results in pain maintenance and may result in patients experiencing increased feelings of sadness and disappointment if they are no longer able to engage in something that they previously enjoyed. In order to prevent this, it is recommended that families and the multidisciplinary team assist patients in setting up a series of graduated tasks and smaller goals to assist them in returning to previous activities.

For example, a patient diagnosed with irritable bowel syndrome may experience increased anxiety and worry about the possibility of experiencing increased pain or not being able to make it to the bathroom in time during a basketball game. If this results in the patient quitting the sport, the intervention would be focused on setting up small goals to assist him or her in returning to basketball. These goals could include activities such as shooting hoops with family members, participating in daily skill drills, or running the length of a basketball court. The patient would be encouraged to utilize coping strategies taught during CBT sessions, including self-regulation skills and positive coping statements, while moving up the devised goal hierarchy. The main purpose of including this type of intervention is to assist patients in developing increased confidence about their ability to participate in previously enjoyed activities despite their symptoms.

Activity scheduling: It may also be important to devise a daily activity schedule for patients who become considerably disabled by their gastrointestinal symptoms, particularly if they are spending hours or full days out of school at the beginning of treatment. Clinicians can work with families to determine a schedule of events that patients can participate in throughout the day, including waking up at the same time each morning, performing school-related tasks, and exercising. It is also helpful to incorporate more pleasurable activities into patients' daily schedules, such as spending time with friends or engaging in a favorite hobby. The scheduling of pleasant activities is a core component of many CBT interventions, given that it promotes functioning and may contribute to an increase in positive feelings (Friedberg & McClure, 2002).

Summary and Future Directions

Functional abdominal pain and irritable bowel syndrome are frequently diagnosed in pediatric gastroenterology clinics. Symptoms associated with these diagnoses may result in temporary or chronic impairments in the daily functioning of both children and adolescents, in addition to more frequent, and often unnecessary, medical procedures and clinic visits. A multidisciplinary, biopsychosocial approach is often used in the diagnosis and treatment of both disorders, given that it provides a comprehensive overview of factors considered to influence symptom presentation, intensity, and outcomes.

While medical interventions are often incorporated into the treatment plan to reduce or eliminate symptom triggers, the inclusion of non-pharmacological approaches have also proven effective in assisting patients with being better equipped to cope with and to reduce symptom severity on a daily basis. One specific psychological intervention, CBT, has been deemed promising for the management of functional abdominal pain and irritable bowel syndrome. Continued research on this intervention is, however, necessary in order to better understand which aspects of this treatment approach are most helpful and how exactly they affect the nature and course of a patient's symptoms. Moreover, given that pediatric patients are largely influenced by the people and institutions that exist around them, additional studies are needed to confirm or dismiss the effectiveness of interventions, such as school reintegration plans, and parental/caregiver involvement in strategies such as gradual exposure to situations that may exacerbate pain as well as re-involvement in previously enjoyed activities.

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Part III

Doctors and Patients

10

Patients' Perceived Control over Their Disorder

Amir Al-Dabagh and Steven R. Feldman

For some acute conditions, such as most bacterial infections, cures can be achieved. However, for most chronic diseases, a cure is often not an option. The primary outcome of chronic disease management is adequate control of the condition. For a few chronic conditions, success is realized by achieving some numeric score on an objectively measurable value, for example, a blood pressure in the case of hypertension or an HgbA1c level in the case of diabetes. Nevertheless, for most chronic, symptomatic conditions, success is achieved when patients feel subjectively satisfied with how they are doing.

Achieving subjective control of disease is not completely divorced from objective clinical findings. Physicians have a wide array of treatment options to offer patients to control the underlying pathophysiological determinants that cause disease, thereby improving objective signs and symptoms. However, patients' subjective impression of their condition is not solely a function of their objective disease symptoms. Patients' perceptions of their conditions are shaped by a host of psychological factors. In this chapter, we examine one of these factors, *perceived control*, and discuss how physicians can use perceived control to affect patients' subjective impression of their disease. We will define perceived control, describe behavioral research studies that have examined the concept, review studies that have looked at the effect of perceived control on workers, and then describe how the concept of perceived control can be used to improve patients' treatment outcomes.

Defining Perceived Control

Perceived control is the belief that a situation is completely controllable, that a person has the skills, opportunities, and resources to achieve positive outcomes or

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avoid any negative effects through his own actions (Thompson & Schlehofer, 2008). By having control, a patient can determine his own internal states and behavior, affect his environment, and bring about any desired medical outcomes (Wallston, Wallston, Smith, & Dobbins, 1987). Perceived control has two fundamental features: *contingency* and *competence* (Weisz, 1986). Contingency refers to the degree by which the patient believes that the outcome is controllable, whether or not his or her actions can affect his or her clinical symptoms. Personal competence, then, is a patient's perception of how capable he or she is of completing the desired, or suppressing the undesired, outcome. Contingency and competence are needed for a patient to have a sense of control. Without this sense of control, hopelessness and despair can occur and diminish patients' quality of life.

Control is a fundamental need of human psychology. Humans have a desire to be effective in their relations within a social and physical context (White 1959). Often referred to as a need for competence or mastery, this viewpoint hypothesizes that people are internally motivated to produce effects, to make things happen (Elliot & Dweck, 2005; Elliot et al., 2002; Koestner & McClelland, 1990). The underlying motive is to provide energy and direction for discovering how the world functions, and, in doing so, people are stimulated to develop a range of actual competencies to create desired, and prevent any undesired, outcomes (Skinner & Greene, 2008). From an evolutionary standpoint, this motivation is valuable, since species that invest energy and time into learning how to be effective in its environment will develop a repertoire of actions as well as the knowledge about what opportunities and restrictions exist in its environment. As tribulations come, a human or other animal can utilize its competence to overcome adversities, whether extrinsic or intrinsic.

The sense of control does not require patients to actually have control over their condition; perceived control is the relevant psychological factor. The perception of control has been correlated with reduced physiological impact of stressors, enhanced ability to cope with stress, emotional well-being, improved performance, less pain, and a greater ability to make difficult changes in behavior (Thompson & Schlehofer, 2008). Perceived control is an adaptive tool that physicians can use to give patients improved subjective treatment outcomes.

Differing from objective control, perceived control focuses on the subjective evaluation of the patient. It is about the reality in patients' minds rather than external reality. The two realities may, but do not always, overlap. If the person believes he or she is in control but is not, this phenomenon is called an *illusion of control* (Tennen & Sharp, 1983; Langer, 1975; Langer & Roth, 1975). The overestimation of personal control is not necessarily detrimental (Langer, 1983). Choice, familiarity with the situation, and involvement are associated with a greater impression of control over outcome. The perception of control, accurate or not, influences a patient's behavior and emotions to a greater degree than actual control.

In addition to influencing emotions, perceived control is a valuable predictor of a patient's health behavior. Feelings of self-efficacy help patients make behavior changes. Without believing in their ability to commit to or change particular habits (i.e., apply topical medications or stop smoking), patients are unlikely to put forth an adequate effort. Both humans and animals decrease their attempts to change their situation when feelings of helplessness prevail, regardless of whether effective action or necessary resources are available (Seligman, 1975). As the contingency for control is lost, so too are patient's efforts, even though available treatments have the potential to clear the signs and symptoms of disease.

Behavioral Research on the Effects of Perceived Control

A lack of perceived control can result in learned helplessness that can be triggered by past experiences of a lack of control. Studies have examined this phenomenon in dogs (Overmier & Seligman, 1967; Seligman & Maier, 1967). Dogs were placed in harnesses, so that they could not escape, and administered small electric shocks. These dogs, as well as control dogs who were not subjected to earlier shocks, were placed in shuttle boxes with a barrier separating two sides of the box (Figure 10.1). When shocks were administered via the electric grids on one side of the barrier, control dogs howled, urinated, and ran around until they jumped the barrier to avoid the electric shocks. Consequent trials lead to faster escapes until avoidance was observed. In contrast, the dogs pretreated with inescapable shock initially howled, ran around, and acted like naïve dogs but would then passively accept the electric shocks and succumb to the pain, laying down and whimpering (Seligman, 1972). These dogs continued to endure the shock as long as the experimenter gave it. If pretreated dogs happened to jump the barrier or fall out of the shuttle box by chance, they did not repeat this behavior in consecutive trials. Once they sensed a loss of control, these dogs learned helplessness and no longer escaped even though it was possible.

Humans may exhibit similar behavior. However, past experiences are not necessary for people as an assertion by a physician or fellow individual that control is limited can result in a helpless attitude. Studies using obnoxious noise, instead of electric shock, were used to investigate similarities between human behavior and learned helplessness of the dogs (Hiroto, 1974). Subjects were randomized into three groups: one group heard 30 bursts of loud, obnoxious noise without a means to stop

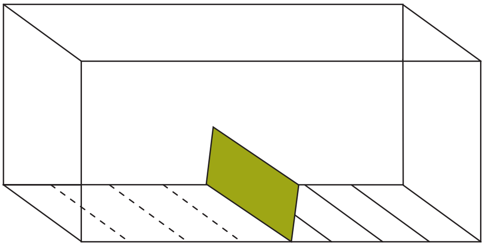

Figure 10.1 Shuttle box is depicted here. The hatched lines represent the electric grid on the metal floor. The barrier separates the electrified side from the safe side.

it, one group could control the noise by pressing a button, and the last group heard no noise. After completing the initial phase, the same groups were exposed to another series of bursts of noise preceded by a red warning light. However, this time all groups had the ability to prevent the noise if they quickly pushed a lever. They were not told whether the lever should be pushed to the right or left. Before this phase began, the researchers told half the subjects that their success was based on their skill, while the other half were told that avoiding the noise was a matter of chance. Individuals who were pretreated with inescapable noise failed to control the noise four times more than those in the other groups; the contingency of control, accurate or not, played a role in their behavior. Those participants who expected skill to control the noise were significantly more likely to exert control over the noise than those told that chance determined the outcome of the trials. Thus, like the dogs in the shuttle box, humans tend to exert less effort to control their environments when past experiences suggest that those efforts are useless, but unlike animals, humans only need to be told that they are powerless or lack control in order to cause the same effect. Another intriguing feature of human helplessness, not seen in animals, is vicarious learning or modeling, in which people learn helplessness by observing others encountering uncontrollable situations (Bandura, 1986).

Similar effects have been seen in nursing home studies (Langer & Rodin, 1976). Elderly adults in a nursing home were given a sense of control and responsibility over a living entity (plant) in order to overcome their helpless feelings. This was not the case in the control group, where staff support was emphasized over self-support. After 18 months, half as many elderly died in the responsibility-induced group (7/47) than the control group (13/44) who relied on staff for support. Having a sense of control had a life-sustaining effect.

Perceived Control in the Workplace

Helplessness can also be learned in group settings (Simkin, Lederer, & Seligman, 1983), including the workplace. Humans only need to be told they lack control to breed helplessness. Explicit labels that suggest inferiority to another person can result in the same outcome as workers lose autonomy. During phase 1 of an experiment involving 102 high school students, all participants were initially successful at completing a task. They were then assigned either the label "worker" or "assistant" (as opposed to the "boss"), or no label at all, and performed an entirely different task. The last part of the experiment involved all subjects engaging in the same task they completed during the first phase. Despite their earlier success on the same task, students given the intervening dependency and diminished autonomy demonstrated a decrease in performance relative to the control group. Thus, while explaining the pathology and treatment plans with patients, physicians should be aware of how labels may affect patient psychology.

Generally, the more helpless an employee feels, the less effective their work performance becomes (Carlson & Kacmar 1994). Productivity, job involvement, and satisfaction are three important outcomes that can potentially suffer due to individual helplessness. Workers who lack helplessness and who perceive control in their work are more likely to be productive because they recognize that efforts produce outcomes, learn from their mistakes, and tend not to internalize their failures (Carlson & Kacmar, 1994). On the other extreme, those workers with a great potential to learn helplessness will most likely be the least productive. Because they fail to see how their efforts are tied to their performance, helpless employees will eventually quit exerting an effort or apply improper methods to solve issues (Abramson et al., 1978; Wortman & Brehm 1975). In addition, as job involvement increases, workers sincerely care about their work and have fewer absences and lower resignation rates (Blau and Boal, 1987). Since learned helplessness often leads cognitive and behavioral deficits and emotional withdrawal, these individuals are expected to have lower job involvement (Seligman, 1975, 1981). And lastly, employee satisfaction is important to organizations as dissatisfaction has been related to lower performance, turnover, and other negative consequences (Organ 1977; Mobley, Griffith, Hand, & Meglino 1979).

In addition to productivity, job involvement, and satisfaction, workers with a perception of control are more adaptive to organizational change, feel empowered and autonomous in the workplace, and have fewer conflicts with their superiors (Liu, Spector, Liu & Shi, 2011; Hornung & Rousseau, 2007). Workers who have autonomy and perceive control in their workplace are the most satisfied with their jobs. They understand the connection between their efforts and the organization's mission and, as a result, feel satisfied. Without making this critical association, workers feel their efforts have no impact and begin to feel inadequate and incapable of performing. Their future expectations are low, limiting the satisfaction they can grasp from working their jobs (Seligman 1991).

Without a sense of control at the workplace and in groups, social and professional organizations suffer from helplessness and endure great losses to their overall performance and goals. Patients are an essential part of a medical team, and, once they are helpless, decreased productivity in taking medications, less involvement in their medical care, and lower satisfaction with treatment plans may be some of the unwanted consequences.

Perceived Control in Medicine

Medicine is not immune from the psychological repercussions of learned helplessness. Ideally, physicians give patients control, but when this fails, patients are given a "psychological button" to press when help is needed. The perception of control can have the same, if not a greater, impact on the patient's psychology.

Patients may encounter feelings of vulnerability and powerlessness at any stage of their medical experience (Figure 10.2). The lack of a clear diagnosis is one way this problem can develop. A young individual may become frustrated with the constant, idiopathic pain that throbs in their back. Parents may feel hopeless with

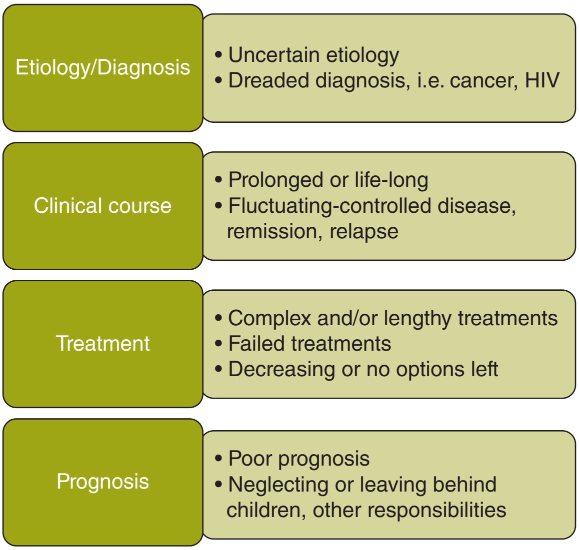

Figure 10.2 At every stage of a patient's medical experience, the patient can encounter issues that can result in a perceived loss of control and feeling of helplessness.

failed efforts to understand the skin lesions or the decline in platelet counts of their infant. Yet, a clear, understandable diagnosis does not necessarily prevent helplessness. Any chronic disease, by definition one that is not curable, can cause patients to lose hope. Hearing the word "cancer" may represent a straight path to the grave for some patients rather than a disease that may be controlled or cured with treatment. Treatment options and the clinical course of a disease can also play a critical role in the psychology of the patient. More complex and lengthy treatment may reduce patients' sense of both contingency and competence. Maintaining a sense of control is often more difficult when the clinical course of disease is prolonged or fluctuating between relapse and remission.

When patients perceive no control and become helpless, even effective treatment options may become ineffective due to poor adherence. Just as the dogs in the shuttle box passively accepted the shocks and no longer jumped the barrier, there is the potential for patients to have a solution to their problems but not use it. And lastly, prognosis is just as important as the diagnosis given to the patient and the treatment options available. We have all heard of scenarios where patients are given a period of time before death is expected. Yet, more mild cases can cause the same level of helplessness. With skin lesions of psoriasis, a patient with a high degree of self-awareness can view life as lackluster as they are embarrassed to become intimate with partners or appear at pools and other public facilities. A physician carries a great responsibility when working with the patient to revive or maintain a high level of control in order to avoid helplessness and any decline in quality of life. Sometimes no changes in treatment plans are necessary; all that is required may be educating the patient about his or her current situation.

Education and easing escalating stress can assist in giving patients' control. When etiology is unclear, physicians can explain what is known and what remains unknown to the patient, as well as the next necessary steps. By knowing, the patient will relax and feel a sense of direction, that, with the tests and visits they have endured, some outcome has emerged. The disease has not been labeled with a diagnosis, but care and consideration are guiding the patient toward a diagnosis. Helplessness is avoided as the patient grasps on the information with control. The burden of a dreaded diagnosis or poor prognosis can also be lifted with knowledge of the disease and treatment options. Wherever knowledge is given, hope is achieved and control is perceived.

When control is hindered or unachievable, the physician can modify the perception the patient holds. The physician can utilize a few psychological tools, ranging from simple encouragement and motivation to make a lifestyle change or take a medication daily, to more concentrated methods of complete situational reframing. As we have seen earlier, hopelessness can surface with disease, and in order to overcome this, control must be perceived again. Remember, perception of control weighs more in an individual's psyche than their actual control.

Physicians can use the *idea* of available treatment options before actually using those medications. When patients acknowledge more potent medications exist, an escape from this calamity is secured. Like having an insurance plan, a patient feels safe knowing the any treatment failure or unexpected progress can be alleviated with tangible options. For example, a physician can prescribe a short-acting beta agonist as needed for a child suffering from asthma. While this rescue medication may initially be adequate, the physician can offer information and pamphlets to the individual with information regarding treatments further down the algorithm such as inhaled corticosteroids and long-acting beta agonists.

The physician can clarify that "the asthma can be controlled with other medications *if we have to* use something stronger." The patient leaves with newfound information, but more importantly, with new hope of control. "If we have to" becomes their new insurance policy. Similarly, an algorithm exists for the treatment of diabetes. Diet and exercise may be enough to lower the patient's weight and HbA1C levels, and these are followed by metformin, sulfonylureas, and insulin for more severe diabetes. Letting patients know that "a stronger medicine is available if we have to" is an approach that can help them avoid hopelessness and improve the subjective quality of life while avoiding poor adherence and the resulting poor treatment outcomes. While stronger therapy may need to be employed for some patients, other patients may be satisfied by just knowing that the stronger treatment exists, giving them the perception of control of their condition.

Conclusions

The approach to treating chronic illnesses differs from that used for acute diseases. Surgery and other treatments are usually adequate for curing acute episodes;

achieving control is the goal with chronic illnesses. While objective clinical findings are essential to monitor the disease, a patient's subjective impression of their state is influenced by a host of psychological factors.

Perceived control, or at times the illusion of control, is one of these. The patient avoids learned helplessness and its negative repercussions targeting the patient's psychology and efforts to better their situation. Both dogs and humans alike suffer from helplessness. Dogs no longer jump over the barrier to avoid the painful stimuli. Humans, on the other hand, fail to avoid obnoxious noise and fail to complete tasks they have successfully finished beforehand. Nursing home tenants were more likely to die when they lost hope. Productivity, job involvement, and satisfaction were only some of the repercussions workers suffered if control was not perceived.

Vulnerability and helplessness can be observed at any stage of a patient's medical experience. An illusive diagnosis can be as trying to an individual as a dreaded one, a failed therapy, or even a poor prognosis. Physicians can utilize education to give patients a better sense of control; however, actual control may not be an option. Through the utilization of key phrases and reframing of the circumstances surrounding the patient's disease, physicians can give patients' perceived control and empower them toward an improved quality of life.

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11

Anger Control and Cardiovascular Disease

Ari Haukkala

This chapter examines how anger and related concepts are linked to cardiovascular disease and the possible mechanisms of that relationship. First, different anger concepts are presented. The concept of anger control will be used as an example of the emotion regulation model of anger. Then, the association between anger and cardiovascular disease, which has been illustrated through prospective studies, will be presented relative to different dimensions of anger. I will examine how especially anger control approach may have implications for interventions to prevent the negative effects of anger on cardiovascular health.

Anger and Related Concepts

What were the circumstances when you were angry the last time? When you think back to that situation, you might find different reasons for being angry. Furthermore, you may realize that the strength of your anger and the way you expressed this anger may have been different, depending on the context of that situation. Anger is a normal, functional emotion that we need to express within our social behavior to adjust our relations and our own well-being (Averill, 1982). How can this become a health problem? Anger is an emotion that has more physiological responses than many other basic emotions. In addition to characteristic facial expression, anger activates one's body by increasing one's breathing, pulse, and blood pressure. This offers a plausible mechanism for how mental states could have effects on health. As early as in the sixteenth century, William Harvey proposed that emotions play a significant role in heart disease. Since that time, there has been a

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long tradition of research attempting to explain how anger may cause especially cardiovascular disease.

Within the context of behavioral medicine, the concepts anger and hostility are used as interchangeable terms. Both of these include three dimensions: (1) an affective dimension, including feelings of anger; (2) a cognitive dimension of hostility, including negative attitudes toward others, and cynicism, the belief that other people are motivated only by selfish concerns; and (3) a behavioral dimension that includes behavioral and verbal expressions. These three dimensions are also referred to as AHA syndrome (anger, hostility, and aggression). One common definition of the affective dimension of anger is "an emotional state that varies from mild irritation to fury and rage" (C. Spielberger, Krasner, & Solomon, 1988). In experimental studies, experimenters try to create situations where people become very angry, in order to examine what kind of physiological consequences this emotion has. In addition to treating anger as such a *state* variable, there are stable individual differences (*trait* approach). Some people may get angry more easily than others; in other words, they can be said to have a higher tendency to become angry. Treating anger as a personality trait, it refers to the tendency to experience frequent and pronounced episodes of anger.

The cognitive aspect of anger is called *hostility*. Hostile cognitions mean that, in our thinking, we may have hostile and cynical attitudes toward others and their intentions. These thoughts may have consequences for our social interactions and behavior because we may not trust other people.

The behavioral aspect of anger is sometimes referred to as *aggression*, but there are several ways to express anger. The psychoanalytic tradition proposed a hypothesis that suppressed anger not only causes uncontrolled aggression but also health problems. This tradition was examined in relation to blood pressure, both in experimental and cross-sectional population-based studies, but it was found in later studies that both anger-suppression- and anger-expression-related measures have only modest effects on blood pressure (Schum, Jorgensen, Verhaeghen, Sauro, & Thibodeau, 2003).

Anger is labeled as a negative emotion. Another example of negative emotion is anxiety. Emotions should be differentiated from moods: an emotion is usually shorter in duration than a mood, of which depression is one example. However, in behavioral medicine, these concepts are all studied under the concept of negative affect. Positive affects, such as joy and happiness, and dispositional traits, such as optimism and resilience, are usually concepts that differ in effect from their negative counterparts, such as pessimism. They seem to have independent effects on health above negative affects such as a depressive mood (Chida & Steptoe, 2008).

Another psychosocial concept that is related to anger is *stress*. It is important to differentiate between a stressor that may cause stress, and an appraisal of a stressor that may cause an experience of stress. If a situation is experienced as stressful, people conduct a secondary appraisal, in which they examine what kind of resources they may have to cope with the stressor (Lazarus & Folkman, 1984). Anger may be a consequence of a stress experience, or it may increase stress in social interaction (Smith & Frohm, 1985). Stress offers one possible mechanism between anger and cardiovascular disease. Smith, Glazer, Ruiz, and Gallo (2004) and Wranik and Scherer (2010) give more detailed descriptions of the different aspects of anger.

In addition to variation in the theoretical concepts, there are different ways to assess anger. Anger measures have included both interview ratings by others and self-report measures, which seem to correlate only moderately with each other (Dembroski, MacDougall, Williams, Haney, & Blumenthal, 1985). The different anger and hostility scales have been addressed thoroughly in some earlier reviews (Miller, Jenkins, Kaplan, & Salonen, 1995), and details are not covered here. This chapter will focus on the emotional aspect of anger and the expression of that emotion. Charles Spielberger et al. (1985) developed a scale that would assess the different aspects of anger: the State–Trait Anger Expression Inventory (STAXI). Questions related to the state anger dimension assess current state and intensity of angry emotions, while trait anger includes 10 items that evaluate how easily a person may become angry. The anger expression scale was expected to be a one-dimensional, bipolar measure of anger, ranging from expression to suppression. Later, Spielberger (C. Spielberger et al., 1988) found that the opposite of expressing anger (Anger Out) was not its suppression (Anger In), but rather the control of anger. While the Anger Out dimension included items such as "I express my anger," the Anger Control dimension included eight items such as "I control my temper." The correlations between different dimensions in the STAXI scale have been nearly identical in different samples; those with high Trait Anger scores had low Anger Control and high Anger Out scores but only moderate associations with Anger In scores, respectively; Anger Control and Anger Out have a high negative correlation, but both of these correlate only moderately or not all with Anger In (Bleil, McCaffery, Muldoon, Sutton-Tyrrell, & Manuck, 2004; Haukkala, Konttinen, Laatikainen, Kawachi, & Uutela, 2010). Deffenbacher, Oetting, Lynch, and Morris (1996) and Linden et al. (2003) have subsequently noted that expression of anger is more multidimensional than the three dimensions described in the STAXI scale.

Compared to some other psychosocial measures such as depression, anger is not clearly defined as a psychiatric diagnosis despite its part in the diagnosis for some mental health problems. Anger scales do not have any clinical cut-off points or other standards to assess the prevalence of the anger problem either. Anger is one of the most frequent emotions that people experience in everyday life (Averill, 1982; Scherer, Wranik, Sangsue, Tran, & Scherer, 2004). The STAXI scale enables evaluating the way people report how they express anger themselves on average. Compared with other anger expression styles, Anger Control was the most frequently reported in response to situations in which respondents were angered. Anger Out was even less frequently reported by participants than Anger In in a Finnish-population-based study (Haukkala, 2002). Martin et al. reported that Anger In was associated with a general tendency for being emotionally inexpressive, whereas Anger Out was more specifically related to the expression of angry emotions (Martin et al., 1999). However, in another study, Anger Out was not associated with angry behavior reported in diaries (Martin & Watson, 1997). The former were able to validate the Anger In and Anger Control dimensions, but items from the Anger Out scale loaded to different anger expression style factors. Respondents' own evaluations and spousal evaluations of their partner's anger expression style have shown only moderate correlations, between 0.34 and 0.49 (Romanov, Koskenvuo, & Kaprio, 1991).

Anger and Emotion Regulation

Anger is an example of an emotion that people try to regulate in social situations. This far, I have mostly discussed the aspects that have been concerned with experiencing and expressing anger. However, in emotion regulation, there are phases before the emotion has evolved. According to the emotion regulation model by Gross, there are four phases in emotion: situation, attention, appraisal, and response (Gross, 1998). For each phase, there are different processes of regulating emotions. People can regulate emotions just by selecting or avoiding certain situations. Within a given situation, they can focus their attention on the aspects that do not increase their emotions as much as other aspects. The location of Anger Control measure in this continuum is in the last phase, response modulation. The anger expression scale starts with the statement "When I am angry . . ." and is followed by a list of ways to express anger and how often that kind of response is used. In emotion regulation (Gross & John, 2003), there are two main processes. First, in the appraisal phase, cognitive change (i.e. reappraisal) is measured by "I control my emotions by changing the way I think about the situation." Then, suppression at the response level is indicated by "I control my emotions by not expressing them." Similar items in the Anger In dimension of the STAXI scale are coded as emotion suppression as a regulation strategy, and this strategy has been found to relate to higher psychopathology meta-analyses (Aldao, Nolen-Hoeksema, & Schweizer, 2010). This does not, however, imply that anger expression (Anger Out) is a suitable response in all situations. Moreover, traditional anger measures do not indicate the positive outcomes on expressing anger when anger expression has negative outcomes. For this purpose, measures should assess what kind of specific adaptive regulation strategy, such as problem-solving or reappraisal of acceptance, is followed by anger experiences. Different psychotherapies have been found to be effective in resolving anger problems (Del Vecchio & O'Leary, 2004). Compared with the process model of emotion regulation strategies, anger management is focused on cognitive change and response modulation, while the three preceding regulation processes receive less attention. Mauss, Evers, Wilhelm, and Gross (2006) found that the preceding implicit evaluation of emotion regulation was related to successful down-regulation of anger in anger-provoking situations. A further advantage of using a wider emotion regulation approach is that different emotion regulation processes are not evaluated as good or bad per se, but outcomes are dependent on the context of emotion regulation processes (Gross & John, 2003).

Anger and Social Position

Spicer and Chamberlain (1996) argue that the definition of anger as a trait leads to individualistic interpretations that omit particularly the social causes for anger. Spielberger's definition was compared with another where anger has the function of adjusting social behavior when someone has violated the rules of behavior (Oatley & Jenkins, 1996). Anderson and Armstead (1995) give an example of the latter definition when they argue that higher hostility scores among Afro-Americans, compared to the white majority in the United States, is an adaptive coping response to a more threatening environment. Schieman (2000) proposes two different approaches: (1) anger as a consequence of stratification, where angry emotions are highest among the oppressed and powerless, and (2) education as an indicator of power to express anger more freely. From the US General Social Survey, it was found that well-educated people were less likely to display their anger but perceived the appropriateness of anger more positively than the less educated (Schieman, 2000). In one study, the strongest association with SES indicators had cognitive aspects of anger measured with the cynical distrust scale (Haukkala, 2002). There were no differences in trait anger and ways to express anger, but subjects in higher SES positions were more likely to express Anger Out when they were angry (Haukkala, 2002). Hence, high Anger Out scores in surveys could indicate higher self-confidence in expressing anger when there is a reason to be angry, not necessarily indicating problems with regulating emotions in personal interactions. However, in the US General Social Survey, the more educated respondents more likely used active coping styles to change the situation when they were angry (Schieman, 2010).

Evidence of a Relationship between Anger and Cardiovascular Disease

The potential adverse effect of anger on cardiovascular health has been one of the earliest and most extensively examined topics in psychosomatic medicine. Cardiovascular diseases refer to diseases that affect the cardiovascular system. Coronary heart disease (CHD) is the most common form of cardiovascular disease. CHD could include sudden death, myocardial infarction (MI), or angina pectoris. In the field of cardiovascular epidemiology, anger has been studied as a broad psychological construct that includes emotional and behavioral aspects as well as a cognitive aspect of hostility. Empirical evidence of the association between anger and cardiovascular disease (CVD) has been accumulated from three different kinds of studies. In prospective studies, anger is assessed at baseline in a large sample of people who do not have CVD yet, and these people are followed for a long time period to examine whether those with higher anger are at greater risk of having cardiovascular disease at follow-up. Another method is to study people who already have CVD or have had a heart attack and examine whether people who have higher anger scores are more likely to have a new CVD incident. Finally, in secondary prevention studies, patients who have had a non-fatal infarction are randomized to either normal treatment or an intervention, in which the aim is to diminish anger scores. If the intervention successfully diminishes anger scores, the likelihood of having a second CVD incident would also decrease.

There are many excellent reviews of these studies in which several original studies examined the effect of anger on cardiovascular disease or all-cause mortality (Suls & Bunde, 2005; Low, 2010). A recent meta-analysis estimated how strong this effect is. Based on 25 selected prospective studies, Chida and Steptoe conclude that people in healthy populations who have higher anger scores have a 20% higher risk for CVD (Chida & Steptoe, 2009). They included 18 studies where the effect of anger was examined among those who had already had an incident of CVD, and, in those studies, subjects with higher anger also had a 22% higher risk for having a second incident of CVD.

Suls and Bunde (2005) drew a distinction among the anger measures between cynical hostility, anger, and anger expression. In their review, they found that seven of 11 studies showed a positive association between cynical hostility and CVD. Barefoot, Dahlstrom, and Williams (1983) found that Cook–Medley hostility scores among medical students predicted CVD 25 years later. The hostility scale was from a study where Cook and Medley (1954) examined what items from the Minnesota Multiphasic Personality Inventory (MMPI) discriminated good teachers from bad teachers. Items that indicated bad teachers revealed types of individuals who disliked and distrusted others (Cook & Medley, 1954). Since the MMPI was one of the most widely used personality measures, the Cook–Medley scale became an extensively used hostility scale in health research. Despite later studies which revealed that Cook–Medley hostility is more about cynical mistrust than anger or aggression, hostility has remained the label for this scale in health-related studies. In another study conducted among males, cynical distrust was related to a higher risk for CVD mortality and acute myocardial infarction incidents, but this was explained mostly by other risk factors (Everson et al., 1997). One large-scale study reported no associations between cynical hostility and cardiovascular outcomes but found an association with total mortality among men (Surtees et al., 2005), as did another study among women (Tindle et al., 2009). These recent studies challenge Suls and Bunde's review's conclusion that hostility-related measures would have the strongest association with CVD. It could be that cynical hostility is a more distal indicator of anger than other dimensions and is not necessarily related to progression of CVD-related outcomes but rather to all-cause mortality.

For the second dimension in Suls and Bunde's review, the association between trait anger and CVD outcomes were mixed in three studies. The Trait Anger scale measures the intensity and frequency of angry emotions. Subjects in Normative aging study with high Trait Anger scores had a higher risk for CVD events in a US study (J. E. Williams et al., 2000). Kawachi, Sparrow, Spiro, Vokonas, and Weiss (1996) found that the Anger Content scale, including anger items similar to the Trait Anger scale, was a significant predictor for CVD and angina pectoris except when the outcome was restricted to CVD events. Moreover, three items that overlap with Trait Anger items did not predict ischemic heart disease (IHD) events, but they did have an association with cardiovascular mortality among males after a 3-year follow-up (Koskenvuo et al., 1988). If people who are likely to become more angry in different situations do not have higher risk for cardiovascular disease, could it then be that the way you *express* anger makes a difference?

The third dimension, anger expression, was described in five studies that reported a positive association with CVD outcomes, two studies that found such a relationship in only some subsamples, and two studies that showed no association (Suls & Bunde, 2005). Anger expression was included in studies that used antagonistic responses from the Interpersonal Hostility Assessment Technique as well as Anger Out and Anger In scales from Spielberger's STAXI scale. Anger Out scores were not related to CVD outcomes in a study conducted among American male health professionals (Eng, Fitzmaurice, Kubzansky, Rimm, & Kawachi, 2003). Anger In has not been used in healthy samples, but three anger suppression items from the Framingham Anger scale predicted IHD among British males (Gallacher, Yarnell, Sweetnam, Elwood, & Stansfeld, 1999). A study in Finland had the rare opportunity to compare five different anger measures: cynical hostility, trait anger, and three different dimensions of anger expression (Haukkala et al., 2010). Nearly 8,000 males and females aged 25–74 years from two national risk factors cohorts were followed for 10–15 years. Over 400 subjects who had already had cardiovascular diagnosis before the baseline were excluded. During the follow-up, there were 399 cardiovascular events and 219 first IHD events. Higher cynical hostility predicted both CVD and IHD incidents after adjusting for age, but after adjusting for marital status and education this association disappeared. Trait Anger had a nearly significant age-adjusted risk ratio with CVD still after age, marital status, education and gender, but after adding cardiovascular risk factors, the association diminished. Only one dimension, namely low Anger Control, predicted CVD events in both sexes after adjusting sociodemographic factors, cardiovascular risk factors, other anger-related measures, and depressive symptoms that were also found to be significant predictors for CVD in earlier studies with same subjects (Haukkala, Konttinen, Uutela, Kawachi, & Laatikainen, 2009). However, anger control predicted IHD events only in women after adjustment for sociodemographic factors, other cardiovascular risk factors, and depressive symptoms. Although this is a single study and these results need confirmation from other studies, this gives us an interesting opportunity to think about how to target anger in intervention studies to prevent cardiovascular incidents. Before the discussion of prevention, let us first have a discussion about the mechanism between anger and cardiovascular disease.

Anger and Progression of Atherosclerosis

Atherosclerosis is a major cause for CHD as it creates plaques on the inner walls of the arteries. Some recent studies have examined how anger scales are associated with carotid atherosclerosis using intima medial thickness (IMT) to measure this process. Julkunen, Salonen, Kaplan, Chesney, and Salonen (1994) compared Cynical Hostility, Anger In, and Anger Control, and found that only Cynical Hostility predicted the progression of carotid atherosclerosis among middle-aged men after a 2-year follow-up. Bleil et al. (2004) observed that Trait Anger and Anger Out, but not Anger In or Anger Control, were related to IMT in a cross-sectional study among hypertensive men. By contrast, Stewart, Janicki, Muldoon, Sutton-Tyrrell, and Kamarck (2007) showed in a 3-year follow-up among middle-aged men and women that cynical hostility and the four anger-related dimensions from the STAXI scale were unrelated to IMT progression. These studies do not give clear answer to the question of which dimension is related to the progression of atherosclerosis.

What Is the Proposed Mechanism between Anger and Cardiovascular Disease?

It is not clear what dimension of anger is related to cardiovascular disease. There could be different mechanisms related to the emotional, cognitive, or behavioral aspects of anger. The mechanisms for how anger is related to cardiovascular disease are usually categorized by five models. The first is labeled the *physiological reactivity* model. Anger, as well as its negative effects, contributes to CVD by increased physiological responses to stressors (R. B. Williams, Barefoot, & Shekelle, 1985). Frequent episodes of anger create adverse cardiovascular and neuroendocrine responses. More detailed experimental studies have found that social situations may moderate this association. Men who were high in hostility had larger increases in blood pressure, heart rate, and cortisol levels during the problem-solving task only in situations when they were harassed during the task (Suarez, Kuhn, Schanberg, Williams Jr., & Zimmermann, 1998). According to the second model, the *psychosocial vulnerability* model, people with higher anger have lower levels of social support, more depression, and stressful life events (Smith, 1992) that in turn have deleterious effects on health mainly through stress process. The *transactional* model integrates the reactivity and psychosocial models and suggests that hostile individuals whose mistrust to others leads to negative behavior that produces interpersonal conflict and heightened cardiovascular reactivity to be more frequent and prolonged (Smith et al., 2004). The *constitutional* *vulnerability* model (Krantz & Durel, 1983) speculates that biological factors such as a hyper-responsive sympathetic nervous system may cause both manifestations of anger and vulnerability to CVD. Modern genome-based studies could test this hypothesis, but it must be borne in mind that both the phenotype of anger and the health outcome cardiovascular disease are really multifactorial, and so there could be hundreds of different genes contributing to both outcomes. However, there are some preliminary studies on how genetic polymorphism could moderate cardiovascular responses to psychological stress (Brummett, Siegler, Ashley-Koch, & Williams, 2011).

Anger Control and Health Behaviors

The *health behavior* model suggests that anger is associated with unhealthy lifestyle factors that contribute to poor physical health. Similarly, all dimensions of anger could relate to health behavior. Higher cynical hostility has been found to relate to higher body mass index, waist-to-hip ratio, insulin resistance, lipid ratio, triglycerides, and glucose in a meta-analysis (Bunde & Suls, 2006). Most of these studies were cross-sectional, and it is not possible to address the direction of the association. In a 3-year follow-up study, cynical hostility did not predict weight gain or weight loss, while depressive symptoms predicted both weight gain and loss (Haukkala, Uutela, & Salomaa, 2001). In addition to these indicators that are related to obesity and type 2 diabetes, cynical hostility was related to higher alcohol consumption and smoking (Bunde & Suls, 2006). There are no reviews on the relationship between other dimensions of anger and health behaviors, but smoking and smoking cessation demonstrate how complicated this association could be. Some experiments have shown that smoking may reduce mood fluctuation, including aggression, under stressful situations. Male smokers with high trait irritability displayed aggressive behavior in a nicotine deprivation situation while smokers with low trait irritability did not change their aggressive behavior in response to nicotine deprivation (D. J. Parrott & Zeichner, 2001). Furthermore, nicotine patch treatment reduced the reports of anger compared to placebo treatment among participants with high hostility scores (Jamner, Shapiro, & Jarvik, 1999). In another 24-hour monitoring study that measured moods and smoking behavior, both men and women were more likely to smoke when they were angry, but smoking calmed anger only among men (Delfino, Jamner, & Whalen, 2001).

The reduction in negative affect achieved by smoking is not necessarily caused only by the pharmacological effects of nicotine, but also by a learned response through secondary reinforcement to situations when smoking is especially rewarding (Kassel, Stroud, & Paronis, 2003). However, Parrott (2000) has argued that smoking does not reduce negative affect per se but rather helps dependent smokers to remain feeling normal. Abstinence from cigarettes, however, seems to lead to negative affectivity. The most prevalent withdrawal symptoms in the first week following cessation are negative emotions such as anger. These negative emotions also predict relapse into smoking (Kassel et al., 2003). Whether feeling angry increases the likelihood of smoking or the abstinence from smoking leads to increased hostility, awareness of these emotions in relation to smoking can be useful in understanding the smoking cessation process.

Anger Control and Prevention of Cardiovascular Disease

The reason for researching predictors for cardiovascular disease is that, by reducing these risk factors, we can prevent new CVD events. Different national and international guidelines for CVD prevention target only the main risk factors: (1) preventing smoking initiation and supporting smoking cessation, and (2) lowering blood pressure and cholesterol through lifestyle changes, or, in some cases, by medication. These are prevention targets where theory and evidence from behavioral medicine offer great help in achieving these goals. Increasingly prevalent, type 2 diabetes is a significant cause of death, but all major targets to prevent type 2 diabetes also help prevent CVD incidents. Currently, there are no interventions on psychosocial factors in primary prevention although assessing depressive symptoms among risk groups and patients is recommended (Lichtman et al., 2008). The first secondary prevention study in relation to anger was type A behavior prevention study. The type A coronary-prone behavior pattern (TABP) was invented by two cardiologists, Friedman and Rosenman, during the 1950s. They found that heart disease patients were more likely to have a competitive orientation, time urgency and impatience, and aggressive and hostile behavior when compared to healthy males (Friedman & Rosenman, 1974). Early prospective studies (Haynes, Feinleib, & Kannel, 1980; Rosenman et al., 1975) had promising results on the association between TABP and cardiovascular disease (CVD), and type A behavior was named as a risk factor (Cooper, Detre, & Weiss, 1981). However, when the first negative findings appeared (Shekelle, Gale, Ostfeld, & Paul, 1983), researchers became aware of the multidimensional nature and methodological problems with TAPB and shifted to studying cynical hostility (Dembroski & MacDougall, 1983). A type A secondary prevention study that included over 800 males with MI were randomized to three groups where, in one group, patients also received counseling to diminish type A behavior patterns (Friedman et al., 1986). They were able to diminish type A behavior pattern in the intervention group and recurrent infraction was also less likely in that group. During the following years, several secondary intervention studies have addressed psychological factors in their intervention. Linden et al. included 43 randomized trials in their meta-analysis and found that psychological treatments for cardiac patients reduced mortality by 27% and reduced event recurrence by 43%. However, the mortality benefits appeared only in men. They also found that studies which recruited cardiac patients immediately did not have effects, and only those interventions that were able to reduce distress were able to show benefits. However, the largest intervention for secondary prevention, ENRICHD study, was targeted to those patients who have depressive symptoms and little social support (Berkman et al., 2003). This study was able to diminish depression, but the risk for recurrent events was the same as in the control group.

One recent intervention study that also addressed anger was a Swedish study that was done among men and women who had suffered acute MI (Gulliksson et al., 2011). They were randomly allocated to traditional care and intervention groups that included both traditional care and cognitive behavioral therapy. This therapy was delivered in 20 sessions, each of 2 hours duration, with a focus on stress reduction and management, time urgency, and hostility. This program had five key methods to achieve these aims: education, self-monitoring, skills training, cognitive restructuring, and spiritual development. In skills training, the goal was to reduce negative affect and to learn to act constructively in different situations. Subjects were asked to do daily exercises and to keep track of how they succeeded in those exercises. Other skills that were trained included problem-solving and communication. In cognitive restructuring, the goal was to diminish hostility, worries, and self-defeating attitudes. This was trained by self-monitoring of attitudes and interpretations, and by examining attributions of what or who has caused or is in charge of different social situations. The intervention was delivered as a group format, which gave opportunities for modeling and other group processes for development of coping skills. During an average 8-year follow-up period, there were 40% less fatal and non-fatal recurrent CVD events in the intervention group (Gulliksson et al., 2011).

In the preceding text, I have tried to show that anger is related to cardiovascular disease, and that addressing anger in secondary prevention programs may prevent recurrent cardiac events. Although I have addressed anger specifically, I think it is only one example of an emotion. Current progress in emotion regulation studies could offer interesting new techniques to address not only the negative effects but also increasing positive effects.

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12

Using Evidence-Based Practice to Improve Healthcare Quality and Patient Outcomes

Bernadette Mazurek Melnyk and
Lynn Gallagher-Ford

The Importance of Evidence-Based Practice

The state of the American healthcare system is in a critical condition, with a tripling of costs over the past two decades, poor-quality services, wasteful spending, and a rise in medical errors (Hader, 2010; McGinty & Anderson, 2008; Melnyk, 2012a). Half of the United States' hospitals are functioning in deficit, and there are up to 200,000 unintended patient deaths every year (American Hospital Association, 2007). We are living in an era in which patients receive only a portion of the care they should receive when they enter the healthcare system and clinicians do not consistently follow evidence-based recommendations and guidelines (Melnyk, Grossman et al., 2012). Further, there continues to be a major time lag (of several years) to translate findings from research into clinical settings to improve patient care and outcomes. In addition to these disconcerting issues, the American healthcare system is facing the most severe shortage of health professionals that it has ever encountered.

Because of the need to address the most pressing problems in healthcare and improve the health of Americans, a landmark summit on health professions education was sponsored by the Institute of Medicine (IOM). From this summit, it was recommended that all health professional educational programs include five competencies: (a) providing patient centered care, (b) applying quality improvement principles, (c) working in interprofessional teams, (d) using evidence-based practices, and (e) using health information technologies (Institute of Medicine, 2003). Evidence-based practice (EBP) also has become the driver of transformation for the six national priorities and goals developed by the national priorities partnership, a

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group of 48 organizations that are assuming a critical role in creating strategies for achieving more affordable, better care, and healthy people and communities (National Priorities Partnership, 2008). Unless radical solutions are implemented and there is a more consistent use of the best EBPs, the United States will not achieve the Institute of Medicine's goal that 90 percent of healthcare decisions be evidence-based by 2020 (Institute of Medicine, 2008), and it will continue to spend an exorbitant amount of money on healthcare practices that does not lead to the best health outcomes for the American people.

Definition of EBP

EBP is a conscientious, problem-solving approach to the delivery of healthcare that integrates the best evidence from well-designed studies with a clinician's expertise and a patient's values and preferences (Sackett, Rosenberg, Gray, Haynes & Richardson, 1996). When EBP is delivered in a culture and environment that supports it, the best clinical decisions and highest quality of patient outcomes are achieved (Melnyk & Fineout-Overholt, 2011), as shown in Figure 12.1.

There are two types of evidence that should be included in clinical decision-making. External evidence that results from a synthesis of well-designed research studies and internal evidence that is derived from a patient's history, assessments,

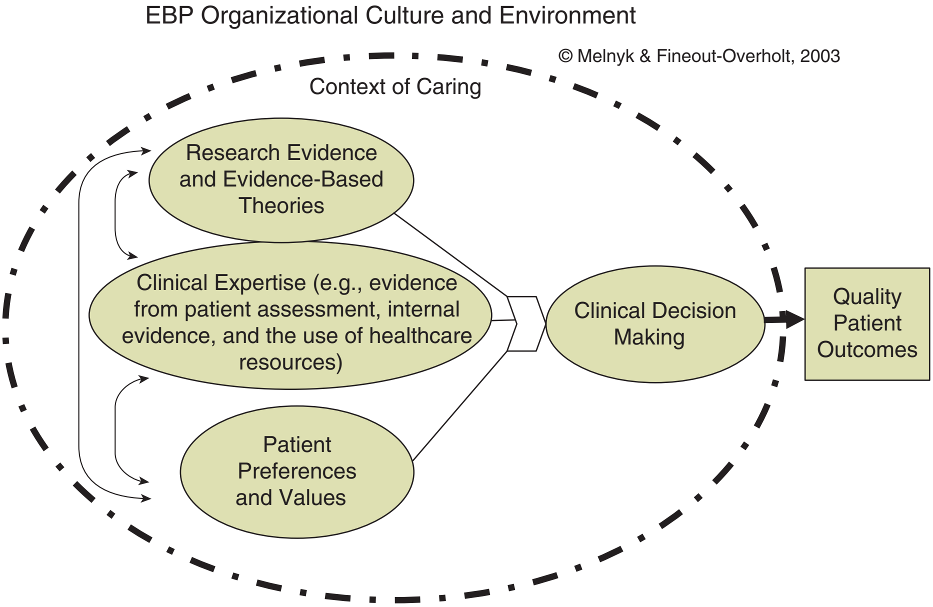

Figure 12.1 The core elements of EBP within a supportive EBP culture and environment lead to the best clinical decisions and quality patient outcomes. © Melnyk & Fineout-Overholt, 2003.

and objective findings, as well as data gathered internally from quality improvement and outcomes management projects in the organization, all of which contribute to a clinician's expertise (Melnyk & Fineout-Overholt). It is only when clinicians engage in thoughtful integration of the three EBP components (i.e., evidence, clinical expertise, and patient preferences and values) that the best care is attainable for individuals and populations. In the current healthcare environment, which is focused on quality and safety, best practice is no longer possible when one relies on inferior knowledge, outdated sources (e.g., tradition, trial and error, textbooks), and keeping current by means of traditional continuing education. Instead, best practice requires the integration of the best available evidence into clinical decision-making, as well as implementation of EBPs, measurement of the outcomes of EBPs, and dissemination of findings to further inform healthcare practices. This process requires that clinicians have the specific skills, resources, and time needed to formulate searchable questions; search electronic databases for evidence; critically appraise evidence for validity, reliability, and applicability to practice; and effectively plan, implement, and measure EBP changes.

Barriers to and Facilitators of EBP

Although the United States Preventive Services Task Force (USPSTF) and other professional organizations have long published evidence-based guidelines, clinicians have faced difficulties in implementing them in real-world practice settings. These challenges have been related to less-than-adequate rigor in methodological approaches in development of the guidelines, which can lead to conflicting or inconsistent recommendations (Melnyk, Grossman et al., 2012). In addition, the complexity of the health problem or recommendations being addressed in the particular guideline, the mechanism by which the guideline is disseminated, and even the format and layout of the guideline have been cited as characteristics that can affect clinical guideline uptake by clinicians (Davis & Taylor-Vaisey, 1997; Grol & Grimshaw, 2003). These variations in clinical practice guideline development and implementation lead to poor-quality care and wasteful healthcare spending. Other barriers in the healthcare system also deter the use of EBP by clinicians. These barriers include: (a) misperceptions that EBP takes too much time, (b) inadequate knowledge and skills, (b) lack of access to EBP mentors, (c) insufficient resources and tools to support EBP, (d) administrators and leaders who do not support or role-model EBP, (e) peer, leader, and nurse manager resistance, and (f) environments and cultures that are steeped in tradition with outdated policies and procedures (Beckette et al., 2011; Majid et al., 2008; Melnyk, Fineout-Overholt, Gallagher-Ford & Kaplan, 2012).

Conversely, studies have supported a variety of facilitators that enhance a clinician's ability to deliver evidence-based care, including: (a) sufficient EBP knowledge and skills, (b) beliefs in the value of EBP and the ability to implement it, (c) access to mentors skilled in the EBP process and promoting behavior change,

(d) skills-based EBP training and access to tools that enhance implementation, and (e) organizational cultures that provide EBP resources and administrative support (Ayers & Griffith, 2007; Melnyk, Grossman et al., 2008; Melnyk, Fineout-Overholt, Giggleman & Cruz, 2010). In 2003, Grol and Grimshaw examined barriers and facilitators of best practice implementation and framed them as occurring at six levels: (1) the innovation or change itself (feasibility, complexity), (2) the individual professional (knowledge, skills, motivation), (3) the patient (motivation, compliance), (4) the social context (interest of colleagues, authorities, and level of teamwork), (5) the organizational context (management support, staff-support, staffing, and tools), and (6) the economic and political context (financial, regulatory, health insurance).

In spite of the barriers, the necessity to integrate evidence into practice to deliver the best care persists. Individual health professionals as well as healthcare organizations must take actions to promote best EBPs on behalf of their patients, communities, and the society at large.

The Steps of EBP

There are seven steps involved in EBP (see Table 12.1).

Step 0 of the EBP process

Step 0 of the EBP process is to cultivate a spirit of inquiry and an EBP culture. A spirit of inquiry is defined as "a consistently questioning attitude toward practice" (Melnyk & Fineout-Overholt, 2011, p. 11). It is imperative that organizations cultivate and promote environments where EBP can flourish, and that environments encourage and recognize ongoing clinical inquiry. Only in organizations where curiosity about practice is invited, enhanced, supported, and celebrated (e.g., "why do we do it this way?", "is there a better way?") can EBP thrive.

Melnyk and Fineout-Overholt (2011) describe the critical components of an EBP culture as:

Table 12.1 The seven steps of EBP.

0. Cultivate a spirit of inquiry and EBP culture.
1. Ask the burning clinical question in PICOT format.
2. Search for and collect the most relevant best evidence.
3. Critically appraise the evidence (i.e., rapid critical appraisal, evaluation, and synthesis).
4. Integrate the best evidence with one's clinical expertise and patient preferences and values in making a practice decision or change.
5. Evaluate outcomes of the practice decision or change based on evidence.
6. Disseminate the outcomes of the EBP decision or change.

- A philosophy, mission and commitment to EBP: there must be organizational commitment to advance EBP
- A spirit of inquiry: all health professionals/students are encouraged to question their current practices
- A cadre of EBP mentors: people who have in depth knowledge and skills in EBP, mentoring others, and overcoming barriers to individual and organizational change
- Administrative role-modeling and support: leaders who value and model EBP as well as provide the needed resources to sustain it
- Infrastructure: tools and resources that enhance EBP across the organization, such as computers for searching and up-to-date databases
- Recognition: individuals and units are rewarded regularly for EBP

There is an emerging body of evidence that describes what individuals and organizations must do to promote and sustain EBP. Organizational cultures where EBP is a reality must be deliberately created and sustained with vision and persistence because they do not happen by chance.

> Often we feel powerless, like tiny cogs in a giant machine. But we can acquire power by challenging things we doubt or know to be untrue. Each intelligent question helps. It strengthens the individual. It humanizes the process.
>
> Albert Einstein

Step 1 of the EBP process

Step 1 of the EBP process is to formulate a focused, searchable (PICOT) question. The purpose of creating focused searchable questions is to enable the clinician to find the most relevant and best evidence to answer questions that arise out of clinical inquiry in the most time-efficient manner. By framing questions in a systematic way with the PICOT format, the clinician can efficiently and effectively search computer databases to find the answer to his or her question. Clinical questions should be formulated using the PICOT format where: P = patient population; I = intervention or issue of interest; C = comparison intervention or group; O = outcome(s), and T = timeframe (Melnyk & Fineout-Overholt, 2011). An example of a well-formed PICOT question is: “In depressed adolescents (P), how does cognitive behavioral therapy (I) versus interpersonal therapy (C) affect depressive symptoms (O) 6 months after treatment (T)?” It is not uncommon for clinicians to describe their clinical inquiry with a great deal of detail, using a multitude of diffuse terms. Although detailed descriptions of clinical scenarios are useful when one is attempting to understand the context of a situation and/or question, such descriptions are problematic when attempting to conduct a focused, effective search in an electronic database. By formulating questions with the PICOT format, the question lends itself to the most effective means of searching because all elements of the inquiry being addressed are included in the search, the volume of the results of the search is likely to be a manageable amount, and the clinician saves precious time.

Step 2 of the EBP process

Step 2 of the EBP process is to search for the best evidence. There are many sources of information that can inform a practice question, and finding the best information to answer a particular question involves several considerations.

- The clinician must be prepared to systematically seek information from multiple sources. These sources include external evidence (such as research articles and evidence-based clinical practice guidelines) as well as internal evidence (such as quality and outcomes data from within an organization).
- The clinician must recognize that external evidence is available to clinicians in many forms, including:
  - *Pre-appraised literature* in which the evidence has already been critically appraised by an author for the quality of methodology and reliability of findings.
  - *Primary research*, where the individual clinician is responsible for conducting the critical appraisal of the quality of methodology and reliability of findings. Examples of primary research evidence include systematic reviews, single research studies, literature reviews, and expert opinions.
  - *Clinical practice guidelines*, where the evidence is "a grouping of practice recommendations derived from a methodologically rigorous review of the best evidence on a specific topic" (Melnyk & Fineout-Overholt, 2011, p. 13). Guidelines typically summarize best care and/or recommendations for patients/families related to a particular disease or recommendations on preventive screening or behavioral counseling that are based on the best evidence, such as those developed by the USPSTF. Examples of clinical practice recommendations and guidelines can be found at the USPSTF website (http://www.uspreventiveservicestaskforce.org) and at the National Guideline Clearinghouse website (http://www.guideline.gov).

Clinicians must recognize that, although all evidence gathered to answer a particular question is useful, there are certain types of studies that will provide the *best* evidence to answer a particular question. The best evidence to answer a particular question is based on the type of question being asked (i.e., intervention or treatment question, meaning question, etc.). For example, if a clinician asks a question about the best intervention to provide in a particular clinical situation (i.e., an intervention PICOT question), a systematic review or meta-analysis of randomized controlled trials would be the *best* evidence (strongest level of evidence) to answer the question. On the other hand, if the clinical question is about what patients or families experience in a particular situation (meaning PICOT question), a randomized controlled trial would, most likely, not be available because it would not be an appropriate type of study to describe a lived experience. Instead, the clinician should look for research from the qualitative literature, such as a phenomenological study, to best answer the meaning question. The clinician needs to seek out all of the evidence available (the body of evidence), and sort the evidence into types based on the strength of the study methodology. Once this is accomplished, the clinician can move on to the next step in the EBP process, which is critical appraisal of the evidence.

Stillwell, Fineout-Overholt, Melnyk, and Williamson (2010) describe five steps for searching for best evidence to answer a clinical question. The steps are:

1. Identify the type of PICOT question.
2. Determine the level of evidence that best answers the question.
3. Select relevant databases to search (PubMed, CINAHL, ERIC, DARE).
4. Use keywords from the PICOT question to search the databases.
5. Streamline the search with the following strategies:
   Use database-controlled vocabulary (such as "MeSH terms")
   Combine searches by using Boolean connectors ("AND" and "OR")
   Limit the final search by selecting defining parameters (such as "humans" or "English")

Identify the type of PICOT question Knowing the type of question being asked helps to determine the best, most rigorous study design to search for in order to answer the question. If the clinician is asking a question to determine the best intervention or therapy to implement for a particular patient population (an intervention question), the types of studies that would best answer that question would be different than if the question being asked is about the lived experience of a particular situation (a meaning question). For answering an intervention question, a quantitative systematic review of multiple randomized clinical trials (RCTs) would be the best fit for answering the questions, whereas a qualitative phenomenological study would be the best fit for answering a meaning question.

Determine the level of evidence that best answers the question Research evidence is often framed in a hierarchy to represent the rigor of the methodology of various types of studies. At the top of the evidence hierarchy are the most rigorous studies (systematic reviews and meta-analyses of RCTs). These are considered the best external evidence and provide the most reliable information for clinical decision-making. As one moves down the hierarchy, the rigor of methodologies diminishes, and the evidence is considered less reliable. It is critical to remember that the research methodology that provides the best evidence for a particular clinical question differs depending on the type of question being asked.

The hierarchical level of any research evidence is not the only aspect for the clinician to consider. The quality of the work must also be evaluated and is addressed in Step 3 of the EBP process, which is critical appraisal of the evidence.

Select relevant databases to search Clinicians need to become efficient at searching for evidence to support practice, and knowing the best place to begin the search for reliable evidence is critically important. Searching for evidence in synthesized resources (e.g., the Cochrane Database of Systematic Reviews) is the first step. Searching in authoritative bibliographic databases that index scholarly peer-reviewed research (e.g., PubMed, which includes MEDLINE, and CINAHL, the Cumulative Index to Nursing and Allied Health Literature) is the next step. If the question to be answered is focused on an issue that may not be thoroughly addressed in the healthcare databases, the clinician needs to search in databases from other disciplines, such as education (ERIC, Educational Resources Information Center) and business (ABI, Business Abstracts). If clinicians wish to explore what other evidence is available, an exploration of web-based resources (such as Google Scholar) can be considered. Although these sources can provide interesting additional information, the clinician must not rely on these sources exclusively, and must carefully evaluate and consider the information retrieved. Another critical step in effective searching for evidence is to reach out to expert colleagues, particularly healthcare librarians. Librarians are immensely helpful to clinicians at any point in the evidence search process; however, they can be especially helpful when the clinician has attempted to find evidence to answer a question and has not been successful. Collaboration with a healthcare librarian can be one of the most effective and rewarding activities a clinician can engage in to become more proficient in EBP work.

Use keywords from the PICOT question to search the databases Databases can be searched using keywords or controlled vocabulary. In keyword searching, the simple language (terms) identified in the PICOT question are entered into the database, and the database looks for the occurrence of the term(s) in the indexed titles and/or abstracts. The challenge of keyword searching is that all of the possible synonyms of a particular term must be included in the search, or evidence will be missed. For example, in the search for evidence to answer the PICOT question previously formulated ("In depressed adolescents (P), how does cognitive behavioral therapy (I) versus interpersonal therapy (C) affect depressive symptoms (O) 6 months after treatment (T)?"), when doing the keyword search for the population of interest (P, depressed adolescents), one would need to also search with terms that are synonymous with the term "adolescents" (such as teenagers and teens). By searching for synonymous key terms, all of the studies that were written with the terms "teen" or "teenagers" in the title as opposed to the term "adolescents" will be found, rendering a much more comprehensive search. In addition, in order to achieve a complete and thorough search, different spellings of the same word (such as "organization" and "organisation"), as well as both the singular and plural forms of the same word, need to need to be included in keyword searches (such as "attitude" and "attitudes").

Streamline the search with the following strategies Several scholarly databases have developed alternative searching mechanisms in an attempt to ease the burden of the searching process on the clinician as well as to enhance the retrieval of evidence. The mechanisms developed are referred to as *controlled vocabulary* (or subject headings, thesaurus, and/or taxonomy) searching. In controlled vocabulary, keywords related to the content of an article are assigned to a category or subject heading that it falls under. For example, the keywords of tumor, mass, and neoplasm would all be assigned to the subject heading of cancer. No matter which one of the keywords the searcher enters into the database (tumor, mass, or neoplasm), the database would "map" them to the subject heading of cancer and provide the searcher with all of the articles under the cancer subject heading. Controlled vocabulary searching prevents the searcher from needing to know every possible synonym for the key terms before the search begins, automatically includes variations of spelling as well as plural and singular versions of keywords, and expands the search to include terms that the searcher might not have thought of. Developing skills in both keyword and controlled vocabulary searching is critical to being successful in navigating databases and the EBP process.

One of the important features of developing the PICOT question is to select succinct terms that represent the inquiry. In the searching step of the EBP process, each of the PICOT terms is searched in the database individually. It is quite likely that each of the individual terms will render a large number of results. For example, in the search for evidence to answer our preceding PICOT question, the search of the key term "depressed adolescents" in PubMed resulted in 7,887 articles; the search of the key word "cognitive behavioral therapy" in PubMed resulted in 48,113 articles; the search of the key word "interpersonal therapy" in PubMed resulted in 20,940 articles; and the search of the key word "depressive symptoms" in PubMed resulted in 258,991 articles. Clearly, it would be impossible to read, appraise, and synthesize all of this information. However, when the searches from each of the key words are combined, the yield is a small number of studies that is more manageable because each article retrieved in the combined search contains all of the keywords from the PICOT question. When the searches from the four keywords were combined using the Boolean connector "AND" (depressed adolescents AND cognitive behavioral therapy AND interpersonal therapy AND depressive symptoms), the search yielded a very manageable 28 articles.

A final step in refining the combined search is to place limits on the search to eliminate any other articles that might be irrelevant to answering the clinical question. Limits that are commonly selected include the languages that the searcher is able to read and studies with humans as the subjects (as opposed to laboratory animals). There are many other limits available in the databases that can be imposed on a search (e.g., the type of study, RCTs only, or the age of the subjects in the studies). However, as more limits are placed on the search, fewer articles will be retrieved, and the scope of the body of evidence gathered is diminished.

Step 3 of the EBP process

Step 3 of the EBP process is critical appraisal of the evidence. Critical appraisal is a process that includes examining and appraising research evidence (findings) from a study to determine their worth or value and relevance for clinical decision-making. Critical appraisal is different from critique in that it a purposeful process intended to find the value that the research evidence brings to a particular question. The first step in the critical appraisal process is to determine the type of study that is being appraised. Once the type of study is determined, the clinician is able to assign a "level" of evidence using an evidence hierarchy, which is merely a rating scale based on methodological rigor. There are many variations of evidence hierarchies. However, the top of the hierarchy (Level 1 or Level A) holds the most rigorous studies, and, as the levels descend (Level 2, 3, 4, 5 or B, C, D, E), the methodological rigor weakens. The strongest level of evidence is systematic reviews of RCTs, and the lowest level of evidence is expert opinion and consensus statements. Once the level of evidence is determined, the clinician must then proceed to appraise the quality of the study. There are three key questions that are used in this step of the critical appraisal process:

1. Is this study valid? In critical appraisal, validity refers to whether the results of the study are as close to the truth as possible. The validity question is answered through critical appraisal of the rigor and quality of the research methodology utilized in a study.
2. Is this study reliable? In critical appraisal, reliability refers to how important the results of the study are, and what the effect was of the intervention/treatment. The reliability question is answered through critical appraisal of the findings of the study, including statistical significance, clinical significance, and magnitude of the effect(s) studied.
3. Is this study applicable or generalizable? In critical appraisal, generalizability refers to whether the findings of the study will help the clinician take care of their particular patients. The generalizability question is answered through critical appraisal of the feasibility of providing the particular intervention/treatment, the risks and benefits of the particular intervention/treatment, and consideration of the individual patient's/family's values and expectations related to the particular intervention/treatment.

Critical appraisal of a body of studies can be organized by placing the individual studies into a comprehensive summary or evaluation table. Once the studies are organized, it is easier to see the findings across studies in order to synthesize what the body of evidence gathered has revealed related to the clinical question. Once the critical appraisal questions are critically answered, the clinician is able to integrate the evidence with his clinical expertise and the patient's preferences and values to make the best decision about patient care. The strength of the evidence (e.g., Level 1, 2, 3) plus the quality of the evidence determined by critical appraisal gives clinicians the confidence to change practice.

Step 4 of the EBP process

Step 4 of the EBP process is to integrate the evidence with clinical expertise and patient preferences to make the best clinical decision/implement the EBP change. Once the evidence has been synthesized, the clinician must then apply his or her clinical experience and expertise as well as the preferences of the patient(s) in order to make a decision and plan for implementing the EBP change in the real-world practice setting. There are many contextual and cultural considerations involved in planning practice changes in any type of organization. The unique environment and culture, the clinicians involved, and the patient population must be considered. A comprehensive assessment of an organization's readiness for EBP as well as the capacity for change should be conducted. Regardless of the size and/or complexity of the practice setting, change is a multidimensional transition process that requires planning and patience, and there are many change models/frameworks that can be utilized to support and promote successful change. Barriers, key stakeholders, facilitators, organizational complexity, leadership styles, transdisciplinary relationships, and communication patterns will all have an impact on any EBP change trajectory. Careful planning, clear delineation of expected outcomes, and engaged leadership are critical to implementing and sustaining EBP changes.

Step 5 of the EBP process

Step 5 of the EBP process is to evaluate the outcomes of the EBP change. Once an EBP change has been implemented, it is critical to measure the outcomes of the practice change. This is only possible if a plan for measuring outcomes was developed early in the EBP change implementation process. Outcomes must be clearly defined and measurable, and the data must be available. A simple approach to developing outcomes is to use the SMART approach where S = specific; M = measurable; A = attainable; R = realistic; and T = timely. In defining the outcomes to be measured, it is especially critical to include outcomes that resonate with key stakeholders. Obviously, patients/families who will be affected by the EBP change are stakeholders, and therefore patient outcomes are a first priority; however, that is not the end of the outcomes to be measured story. It is extremely important to consider "so what outcome factors" (Melnyk & Morrison-Beedy, 2012), such as cost, which will be important to other key stakeholders including administrators, regulatory bodies, and third-party payers, all of whom have significant impact on organizational priorities and decision-making. Any EBP change project that is implemented should include an outcome (or several) that address the "*So* what outcome factor(s)" and the bottom line impact of the practice change.

Step 6 of the EBP process

The final step in the EBP process is disseminating the outcomes of the evidence-based change. Quite often, EBP change projects render interesting, powerful, and important outcomes. When evidence is translated into various practice settings, sometimes the outcomes replicate study findings that informed the EBP change, and yet sometimes the outcomes are quite different from those obtained in research. In addition, it is important to realize that whether the outcomes of an EBP change project are subtle or stunning, the results are nevertheless important. EBP change outcomes inform clinical practice and, through dissemination, the impact of the EBP work is exponentially increased.

Strategies for Moving Evidence-Based Guidelines and Recommendations into Clinical Practice

An important strategy to enhance implementation of EBP and the uptake of evidence-based guidelines in practice, especially for those that involve behavioral interventions, is skills-based training and access to tools that assist with implementation (Brown, Bratton, Cabana, Kaciroti, & Clark, 2004; Cabana et al., 2006; Lustig et al., 2001). Clinicians who have not implemented EBP routinely will need moderate to intense skills-based training to change their practice behaviors, as it is well known that passive dissemination of evidence-based guidelines and didactic education alone does not usually lead to behavior change (Melnyk, Grossman et al., 2012). Interactive skills-building sessions with individualized feedback and audit have been successful in promoting consistent use of EBP (Schectman et al., 2003).

Studies have indicated that a clinician's practice environment or organization influences the use of evidence-based guidelines and recommendations (O'Connor et al., 2006). Without an EBP culture and environment, clinicians' EBP efforts are unlikely to sustain. An organization that desires to build this type of culture and environment so that its clinicians can consistently implement evidence-based care must have a philosophy, mission, and commitment to EBP that should be made visible throughout the organization, its policies, and reward system. The culture also should be one where clinicians are consistently encouraged to question their clinical practices, and there is access to mentors who have expertise in EBP. These EBP mentors must also be skilled in how to work with individuals on behavior change strategies, since many clinicians in the current healthcare system did not "grow up" with EBP and are still practicing the way they were taught in their educational programs years ago. Findings from research have indicated that mentors who are available to work with clinicians on implementation of EBP facilitate positive patient outcomes (Melnyk, 2007; Melnyk, Fineout-Overholt, Giggleman & Cruz, 2010). Administrative role modeling and support is also a critical component of building an EBP culture. Administrators and leaders must "walk the talk" by supporting their own decisions with evidence if they expect clinicians in their organization to deliver care based on the best evidence. In addition to modifying their own practice approaches, administrators are responsible for creating environments that support EBP. This can be achieved in some relatively easy ways through the provision of resources to help clinicians engage in EBP, such as: computers, databases, educational sessions, EBP mentors, and library/librarian support. However, some other barriers to creation of an EBP culture that must be attended to by administrators are much more challenging, such as overwhelming workloads and lack of manager support for EBP. Although these issues are extremely complex and challenging, they must, nevertheless, be addressed for EBP to become a day-to-day reality in clinical practices. Finally, recognition must be built into an organization striving to consistently deliver evidence-based care where clinicians are routinely valued and rewarded for their efforts.

The provision of a consistent set of clinical guidelines by competing health plans also improve the delivery of recommended services by clinicians, and therefore is a good strategy to employ to promote evidence-based care (Ayers & Griffith, 2007). In addition, since clinicians are typically pressured with rapid-pace high-volume practices and workloads, implementation of best practices should be made easy. Electronic health records that build in reminders and evidence-based guidelines also can be useful in assisting clinicians to deliver evidence-based care (Melnyk, 2012b).

> I have an almost complete disregard of precedent, and a faith in the possibility of something better. It irritates me to be told how things have always been done. I go for anything new that might improve the past.
>
> Clara Barton

An Example of Actions to Employ When Insufficient Evidence Exists to Guide Best Practices: The COPE Program for Depressed and Anxious Adolescents

Unfortunately, there are many areas of healthcare that do not have a strong body of evidence to guide best practices in real-world clinical settings. For example, the USPSTF recommends screening of adolescents (12–18 years of age) for major depressive disorder (MDD) when systems are in place to ensure accurate diagnosis, psychotherapy (cognitive behavioral or interpersonal), and follow-up (USPSTF, 2009). However, many pediatric primary care practices across the nation do not screen teens routinely for depression, usually rationalizing that they have no system in place to deliver psychotherapy to affected youth, often due to the shortage of mental health providers. Further, although there is strong evidence to support cognitive behavior therapy (CBT) as an effective first-line treatment for depressed and anxious teens (March, 2009; Williams, O'Connor, Eder, and Whitlock, 2009), few teens receive it. In fact, adolescents are usually placed on long wait lists for care when they need to have access to timely evidence-based treatment (Jaycox et al., 2006).

After an extensive evidence search to answer the PICOT question "In depressed adolescents (P), how do primary care delivered CBT interventions (I) versus other types of interventions (C) affect depressive symptoms (O) 6 months after treatment (T)" revealed no systematic reviews or full-scale randomized controlled trials testing the delivery of a brief CBT intervention specifically targeted to teens in primary care settings, and in an attempt to bring more needed treatment to adolescents with elevated depressive symptoms, the seven-session COPE (Creating Opportunities for Personal Empowerment) program was developed, based on the 12 principles of CBT (Beck, 2011). The COPE program was designed and manualized so that it was feasible for delivery by primary care providers in seven brief, weekly, 20–30-minute sessions. These seven sessions are the first phase of a 15-session cognitive behavioral skills building healthy lifestyle intervention for high school adolescents (i.e., COPE Healthy Lifestyles TEEN [Thinking, Emotions, Exercise and Nutrition] Program) currently being evaluated with 779 adolescents in high schools located in the

Table 12.2 Content of the COPE TEEN 15-session program.

Session 1	The Thinking–Feeling–Behaving triangle
Session 2	Self-esteem and positive thinking, self-talk
Session 3	Goal-setting and problem-solving
Session 4	Stress and coping
Session 5	Emotional and behavioral regulation
Session 6	Effective communication, personality and communication styles
Session 7	Barriers to goal progression and overcoming barriers
	Energy balance; ways to increase physical activity and benefits
Session 8	Heart rate; stretching
Session 9	Food groups and a healthy body; stoplight diet (red, yellow, green)
Session 10	Nutrients to build a healthy body: reading labels, media and advertising effects on food choices
Session 11	Portion sizes; "supersize," influences of feelings on eating
Session 12	Social eating: strategies for eating during parties, holidays, and vacations
Session 13	Snacks and eating out
Session 14	Integrate skills and knowledge to develop a healthy lifestyle plan
Session 15	Putting it all together; review of course content

Southwest region of the country (Melnyk, Jacobson et al., 2013). Findings from pilot tests of the program in primary care as well as community mental health and school-based settings have not only indicated decreases in depression and anxiety levels with COPE, but improvements in self-esteem and healthy lifestyle behaviors as well as the prevention of obesity (Melnyk, Jacobson et al., 2009, 2013; Lusk & Melnyk, 2011). This case is an example of how clinicians can create solutions to pressing problems when little evidence exists to guide practice. Even if rigorous clinical trials are not available to guide practice, internal evidence can be generated by clinicians through outcomes management, quality improvement, and pilot projects with their own patients as some evidence is typically better than care that is steeped in tradition or the philosophy of "that is the way we have always done it here."

It is important to recognize that EBP is growing incrementally in healthcare. The incremental nature of EBP is twofold: (1) for many clinicians, EBP is a new concept that requires new learning and skills development, and (2) there are wide variations in the amount and quality of evidence available to answer clinical questions. For some clinical questions, there is an abundance of high-level rigorous research available, yet for other questions, there is very little evidence available to guide best practice. Even when there is only a limited amount of quality evidence available to inform clinical practice, clinicians should integrate it into their clinical decision-making because practice based in evidence is better for patients than practice devoid of evidence and based solely on anecdotes and tradition.

Summary

Clinicians from all disciplines, by virtue of their professional license to practice, accept the responsibility of providing the best care possible for their patients. The burden of this obligation can be met when clinicians become evidence-based practitioners, because EBP enhances the quality and reliability of healthcare, improves patient outcomes, and decreases costs. EBP is a problem-solving approach to the delivery of care that combines the best evidence with a clinician's expertise, along with patients' preferences and values, to drive conscientious, caring decision-making and, ultimately, best practice.

EBP will only become a reality in healthcare when every clinician embraces his or her personal and professional obligation to be evidence-based *and* when every practice setting/organization meets its responsibility to provide work environments that support EBP. The steps of EBP are facilitated by the work of both clinicians and organizations as they move along the EBP paradigm shift continuum. Clinicians must gain knowledge and skills in EBP and believe in the value of EBP. Further, organizations must provide EBP skills training, high-quality evidence-based guidelines, available mentorship, support from managers and leaders, resources and tools, and a culture and environment that support EBP. Only when these circumstances happen will the United States meet the 2020 IOM goal that 90 percent of practice decisions be evidence-based.

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Part IV

Behavioral Technologies in Theory and Treatment

13

Cognitive Behavioral Treatment of Sleep Disorders in Children and Adolescents

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Introduction

Sleep is recognized as an essential part of daily life that is necessary for a child's health, well-being, and overall growth. In fact, sleep is considered the primary activity of the brain during early development; by the age of 2, children will have spent approximately 10,000 hours asleep and 7,500 hours awake, and will have shown marked maturational advances in numerous areas of development (Anders, Goodlin-Jones, & Sadeh, 2000). Researchers now understand that sleep, arousal, affect, and attention are closely interrelated in a dynamic regulatory system, opposing the common image of sleep as "simply rest" (Dahl, 1996). Children's sleep patterns change dramatically over time, with newborns requiring approximately 16–17 hours of sleep per day, 1-year-olds requiring 13 hours plus a 2-hour nap, and adolescents requiring 9–10 hours. Furthermore, biological sleep patterns shift toward later bed and wake times in adolescence (Carskadon, et al., 1980; Anders & Eiben, 1997). Although numerous studies have documented the importance of regular and sufficient sleep patterns, many children and adolescents get less sleep than needed.

Approximately 25% of children and adolescents experience sleep difficulties of some kind (Archbold, Pituch, Pahanhi, & Chervin, 2002; Owens, Spirito, McGuinn, & Nobile, 2000). Inadequate sleep is associated with a range of difficulties in children, including inattention, impulsivity, daytime sleepiness, disruptive behavior, impaired cognitive functioning, poorer academic performance, and social difficulties (Dahl, 1996; Fallone, Owens, & Deane, 2002; Mindell, Owens, & Carskadon, 1999). Insufficient sleep can also negatively affect the immune system and metabolic processes, and has been associated with lower health-related quality of life in

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children (Hart, Palermo, & Rosen, 2005). When left untreated, children's difficulties sleeping tend to persist over time. In fact, research suggests that 84% of children exhibiting sleep disturbances in early childhood demonstrate the same sleep problems 3 years later (Mindell, 1993). While the majority of infants and young children exhibit transient sleep problems as part of their natural development (Mindell, Owens, & Carskadon, 1999), most of these sleep problems tend to dissipate on their own and do not necessitate treatment. However, for a subset of children, sleep problems persist. Numerous studies have suggested that persistent, disrupted sleep likely contributes to physiological and emotional dysregulation in children, which may then increase vulnerability to later psychopathology (e.g., Dahl, 1996). Thus, enduring or severe sleep disturbance warrants intervention at its earliest stages.

This chapter has several aims. In the first section, the major sleep disorders affecting pediatric populations will be described, including a review of the various types of dyssomnias and parasomnias. Next, we will review research highlighting the associations between mental health problems and sleep disorders in youth, given that there is likely a bidirectional relationship between sleep disorders and various forms of childhood psychopathology. Following this review, we will describe the various cognitive behavioral strategies that can be utilized to treat a number of sleep disorders in youth. The chapter will close with a case example illustrating the use of these techniques to effectively treat a child with behavioral insomnia.

Overview of Pediatric Sleep Disorders

Sleep problems are common concerns for children and adolescents. Up to 37% of school-aged children experience sleep-related difficulties such as bedtime resistance, sleep anxiety, or daytime sleepiness (Owens et al., 2000). Recent estimates suggest that 3.7% of youth seen in primary care settings meet criteria for a sleep disorder (Meltzer, Johnson, Crosette, Ramos, & Mindell, 2010). Sleep disorders are more common in young children, with prevalence rates decreasing across development (Meltzer et al., 2010; Petit, Touchette, Tremblay, Boivin, & Montplaisir, 2007). Pediatric sleep problems can become chronic if left untreated (Byars, Yolton, Rausch, Lanphear, & Beebe, 2012); however, sleep disorders are notoriously under-recognized and under-diagnosed in youth (e.g., Blunden et al., 2004; Chervin, Archbold, Panahi, & Pituch, 2001; Meltzer et al., 2010).

The International Classification of Sleep Disorders, Version 2 (ICSD-2), identifies 85 distinct sleep disorders. Sleep disorders that occur independently of mental, neurologic, or medical conditions may be categorized as either dyssomnias or parasomnias. Dyssomnias are sleep disorders characterized either by difficulties initiating or maintaining sleep or by excessive sleepiness, contributing to abnormalities in the amount, quality, or timing of sleep (ICSD-2; American Academy of Sleep Medicine, 2005). Parasomnias are sleep disorders in which ongoing sleep is disrupted by undesirable behaviors or physiological events that occur during either specific stages of sleep or sleep–wake transitions (Anders & Eiben, 1997; ICSD-2, AASM, 2005). The characteristics of some of the more common ICSD-2 dyssomnias and parasomnias affecting youth are discussed in the following text.

Dyssomnias

Obstructive sleep apnea syndrome. Obstructive sleep apnea syndrome (OSAS) is characterized by repeated episodes of upper airway obstruction during sleep, typically presenting as snoring punctuated by 20–30-second periods, during which breathing ceases. In children, associated features of OSAS may include loud snoring, excessive daytime sleepiness, inattention or hyperactivity, open-mouth breathing, chest retraction during sleep, and nocturnal enuresis (ICSD-2; AASM, 2005). OSAS is considered an intrinsic dyssomnia, meaning that it is assumed to originate from causes within the body rather than from the external environment (ICSD-2; AASM, 2005). OSAS in children may be related to enlarged tonsils and adenoids obstructing the airway, craniofacial abnormalities, such as a large tongue or abnormal palette, premature birth, and obesity (Anders & Eiben, 1997; Meltzer & Mindell, 2009). Many adults with OSAS report a history of snoring during childhood, and thus snoring in pediatric populations may be considered a risk factor for the later development of OSAS; however, this warning sign is often overlooked by pediatricians and parents (Byars et al., 2012). Prevalence rates for the disorder in childhood range from 1% to 3.7%, but studies indicate that 12–20% of children between the ages of 1 and 3 snore several nights per week, placing them at an increased risk for OSAS (Katz & Marcus, 2005; Meltzer et al., 2010; Owens et al., 2000).

Narcolepsy. Narcolepsy is an intrinsic dyssomnia characterized by excessive daytime sleepiness, repeated lapses into sleep, and cataplexy, or the abrupt loss of muscle tone following the experience of strong emotion. Lapses into sleep for short periods of time, often referred to as *sleep attacks*, can last from 10 to 40 minutes, after which the patient feels revitalized for the following 2–3 hours, at which point the cycle repeats itself (Anders & Eiben, 1997; ICSD-2; AASM, 2005). Associated features of narcolepsy may also include sleep paralysis and hypnagogic hallucinations, or vivid and realistic perceptual experiences that occur at sleep onset or offset, and nocturnal sleep disruption (ICSD-2; AASM, 2005). Narcolepsy in children is relatively uncommon, with prevalence estimates ranging anywhere from 0.003% to 0.7% (Anders & Eiben, 1997; Meltzer et al., 2010). The onset of narcolepsy is most likely to occur during adolescence or early adulthood, with the peak age of onset at age 14 (ICSD-2; AASM, 2005); it tends to be a chronic condition, affecting individuals for a lifetime (Anders & Eiben, 1997).

Restless legs syndrome. Restless legs syndrome (RLS) is an intrinsic dyssomnia in which individuals report unpleasant sensations in their legs prior to sleep onset that is alleviated by leg movement, thus interfering with normal sleep patterns. Sensations are described in a variety of ways, including “tingling,” “aching,” “creeping,” and “itching” (ICSD-2; AASM, 2005). As the peak age of onset for RLS is middle age (ICSD-2; AASM, 2005), this disorder is less common than others in childhood.

In a sample of over 100,000 children and adolescents seen in primary care settings, Meltzer and colleagues (2010) found prevalence rates of 0.02% for the disorder. Research suggests that RLS may be more common among females (Laberge, Tremblay, Vitaro, & Montplaisir, 2000). The most common cause of the disorder in childhood is low levels of ferritin, a protein that absorbs and releases iron. As a result, treatment of RLS in children often involves the administration of iron supplements (Meltzer & Mindell, 2009).

Limit-setting sleep disorder. Limit-setting sleep disorder is categorized by the ICSD-2 as an extrinsic dyssomnia, indicating that it is due to causes outside of the body rather than within (ICSD-2; AASM, 2005). Limit-setting sleep disorder is considered a behavioral insomnia of childhood and is characterized by insufficient enforcement of bedtime routines by caregivers and child stalling, resistance, or refusal to follow appropriate bedtime routines. Once sleep is initiated, however, it is typically of normal quality and duration (ICSD-2; AASM, 2005), although if bedtime resistance significantly cuts into overall sleep time, daytime sleepiness may occur. The disorder typically emerges in early childhood, a time in development when limits are being tested and children have gained sufficient verbal abilities to protest or argue about bedtime routines (Meltzer & Mindell, 2009). If limits around bedtime are absent or inconsistent, when caregivers do attempt to set limits, they are often unable to enforce them in the face of childhood resistance (Mindell & Meltzer, 2008). Bedtime resistance and stalling may involve multiple requests by the child to go to the bathroom, get a drink of water, hear an additional bedtime story, or requests for caregiver comfort in the face of bedtime fears. Refusal of such requests often results in crying, pleading, and tantrums. Limit-setting sleep disorder is common among children, occurring in 10–30% of toddlers and preschoolers and 5–10% of all children (ICSD-2; AASM, 2005; Meltzer & Mindell, 2009).

Sleep onset association disorder. Sleep onset association disorder is diagnosed when normal sleep is achieved only when certain conditions are present, such as using a bottle, watching television, or being rocked by parents (ICSD-2; AASM, 2005). In the absence of these conditions, however, sleep onset is difficult to achieve. Nighttime wakings are also common among children with the disorder, and upon waking the associations must be reestablished in order for the child to resume sleep (Mindell & Meltzer, 2008). In the absence of the required conditions, children and their caregivers likely experience sleep deprivation, with accompanying irritability and excessive daytime sleepiness. This disorder is most common in infants and young children (Mindell & Meltzer, 2008), with 15–20% of infants and toddlers meeting criteria prior to age 3 years, after which the prevalence rates decrease significantly (ICSD-2; AASM, 2005).

Parasomnias

Sleepwalking. Sleepwalking, also known as *somnambulism*, is an arousal disorder characterized by complex motor behaviors such as sitting up in bed or walking around the house while asleep (ICSD-2; AASM, 2005). As with other arousal disorders, sleepwalking takes place during transitions between slow-wave sleep and other phases of sleep, typically during the first third of the night (Kotagal, 2009). Inappropriate or dangerous behaviors may occur during sleepwalking episodes, such as urinating in an inappropriate place or becoming agitated and trying to "escape" the home. During sleepwalking episodes, children may appear to be awake but are typically non-responsive to others and demonstrate confusion when awakened. There is typically no memory of the episode the following morning. Children who sleepwalk are more likely to experience confusional arousals, sleep-talking, and night terrors (Laberge et al., 2000), with confusional arousals and sleep-talking often co-occurring with sleepwalking episodes (Sheldon, 2004). Sleepwalking is more common among children than adolescents and adults, with the first episode most likely to occur between ages 5 and 10 (Kotagal, 2009). About 15–40% of children experience at least one episode of sleepwalking (Mindell & Owens, 2003), and 14.5% of children between ages 2 and 6 meet the criteria for the disorder (Petit et al., 2007). Although sleepwalking is generally benign and tends to decrease spontaneously by adolescence, children who sleepwalk are at risk for injuring themselves or others. Thus, maintaining the child's safety is a primary concern associated with this disorder.

Sleep terror disorder. Sleep terror disorder is an arousal disorder characterized by repeated episodes of sudden arousal from sleep, accompanied by a piercing scream and behavior suggesting the experience of intense fear. Sleep terrors are accompanied by several physiological symptoms, including accelerated heart rate, rapid breathing, profuse sweating, increased muscle tone, and pupil dilation (ICSD-2; AASM, 2005). Despite the appearance of being awake, the child is unresponsive to attempts to calm or comfort them, and exhibits confusion and disorientation when awakened. Occasionally, the child attempts to escape or fight during an episode, which may result in injury to the child or caregivers. Children are often unaware of their night terrors, as there is typically amnesia for the event the following morning. As with sleepwalking, sleep terrors occur during slow-wave sleep and are most common during the first third of the night. Thus, sleep terrors should be differentiated from nightmares, the content of which the child can typically recall vividly and which tend to occur during the last third of the night. Sleep terrors vary in frequency in children, from two to three times per week to two to three times per month (Kotagal, 2009). Most sleep terrors occur between ages 4 and 12 and are more common in early childhood, with nearly 40% of children aged 2–6 meeting the criteria for the disorder (Petit et al., 2007), and 17% of children aged 3–13 meeting the criteria (Laberge et al., 2000). Sleep terrors tend to remit naturally by adolescence (Laberge et al., 2000).

Nightmares. Nightmares are parasomnias involving frightening dreams that occur during REM sleep, typically during the second half of the night. In contrast to sleep terrors, the nightmare typically awakens the sleeper, who is then fully alert and able to recall the dream, often experiencing a delay in returning to sleep (ICSD-2; AASM, 2005). Nightmares are very common in childhood, with 10–50% of children between ages 3 and 6 experiencing episodic nightmares (Anders & Eiben, 1997). The content of nightmares becomes increasingly complex as children develop, evolving from those commonly involving monsters or other fantasy creatures in early childhood to those involving real-life violence, death, or separation from loved ones, or upsetting experiences at home or school (Kotagal, 2009; Stores, 2009). Although nightmares tend to decrease in frequency across development, they can occur at any age, and half of adults report that they experience occasional nightmares (ICSD-2; AASM, 2005). Sporadic nightmares in childhood tend not to require treatment and may be managed through reassurance and education (Sheldon, 2004). However, a small subset of children experience frequent nightmares contributing to clinically significant distress or impairment in daily functioning, particularly in the context of anxiety disorders or post-traumatic stress disorder (Stores, 2009). If nightmares become frequent, persistent, and impairing, the underlying psychological or medical causes should be investigated (Sheldon, 2004).

Sleep enuresis. Recurrent sleep enuresis, or bed-wetting, is part of normal development between infancy and preschool-age, and between 4% and 15% of school-aged children experience occasional bed-wetting (Kotagal, 2009). After age 5, however, the repeated involuntary passage of urine during sleep is considered a parasomnia (ICSD-2; AASM, 2005). In primary sleep enuresis, the child has never experienced nights without involuntary urination, while in secondary sleep enuresis, the child has a history of 3–6 months of dry nights (Anders & Eiben, 1997). Primary enuresis accounts for the vast majority of cases of sleep enuresis (i.e. 70–90%; ICSD-2; AASM, 2005). For children and adolescents with sleep enuresis, bladder control is typically normal during the day. Urination can occur during any stage of sleep, although it typically occurs during the first third of the night. Research indicates that 1.2% of youth between ages 4 and 18 meet criteria for sleep enuresis (Meltzer et al., 2010), and that the disorder is seen more frequently in boys than girls prior to the onset of puberty (Laberge et al., 2000; Kotagal, 2009). Sleep enuresis is most common in early childhood, with 16.1% of 6-year-olds meeting the criteria for the disorder (Petit et al., 2007). Prevalence rates for sleep enuresis decrease by 14–16% every year between ages 5 and 19 (ICSD-2; AASM, 2005).

Associations between Sleep and Mental Health in Youth

There is growing awareness of the strong connection between sleep disturbance and psychopathology in children and adolescents. Extended periods of inadequate sleep are associated with a range of behavioral problems in children (Grover, Ginsburg, & Ialongo, 2007; Mindell et al., 1999), and persistent sleep-related problems in early childhood predict future psychopathology, including anxiety and depression (Gregory, Eley, O'Connor, & Plomin, 2004; Gregory & O'Connor, 2002; Ong, Wickramaratne, Tang, & Weissman, 2006; Touchette et al., 2012). Inadequate sleep is also associated with a range of other difficulties in children, including inattention, hyperactivity, disruptive behavior, impaired cognitive functioning, and poorer academic performance (Aronen, Paavonen, Fjällberg, Soininen, & Törrönen, 2000; Dahl, 1996; Fallone, Owens, & Deane, 2002; Fredriksen, Rhodes, Reddy, & Way, 2004; Jansen et al., 2011; Mindell, 1999; Wolfson & Carskadon, 1998). There is likely a bidirectional relationship, whereby psychological symptoms contribute to poor sleep quality, and poor sleep exacerbates emotional, behavioral, and cognitive impairment. Next, we will review the most current research findings to date in the areas of sleep and mental health in youth.

Sleep and anxiety disorders

Sleep-related problems are a common occurrence among anxious youth (Alfano, Ginsburg, & Kingery, 2007) and researchers have proposed a reciprocal relationship whereby disturbed sleep increases a child's vulnerability to developing anxiety, and anxiety, in turn, interferes with sleep (Dahl, 1996). Notably, several studies have found a stronger association between early sleep-related problems and anxiety as compared to other psychiatric problems (Gregory et al., 2004; Gregory & O'Connor, 2002; Johnson, Chilcoat, & Breslau, 2000).

In a recent study examining sleep-related problems in anxious youth, 54% of the children in the sample reported trouble sleeping overall, while parent-reports of children's sleep difficulties reached 85% (Alfano et al., 2010). In a similar study investigating sleep-related problems in anxious youth, Alfano and colleagues (2007) found that 88% of a sample of 128 anxious children, 6–17 years of age, experienced at least one sleep-related problem, and 55% experienced three or more. The most common sleep-related problems among anxious children and adolescents are insomnia, reluctance or refusal to sleep alone, and nightmares. Clinically anxious youth also report later bedtimes on school nights, which may be associated with bedtime resistance or nighttime worry related to school (Hudson, Gradisar, Gamble, Schniering, & Rebelo, 2009). While sleep-related problems are common across the anxiety disorders, research indicates that the type, frequency, and severity may vary by age and diagnosis. Younger children reportedly experience more nightmares and are more likely to refuse to sleep alone than older children (Alfano et al., 2007). In a recent study, Alfano and colleagues (2010) found that younger children were reported to have greater sleep disturbance overall, along with higher levels of bedtime resistance, sleep anxiety, and parasomnias.

Overall, children diagnosed with generalized anxiety disorder (GAD) and separation anxiety disorder (SAD) have been found to experience more sleep-related problems than those with other anxiety disorders (Alfano et al., 2007, 2010). GAD is marked by excessive anxiety and worry about a variety of situations that is difficult to control and leads to significant distress or impairment in daily functioning. Insomnia is commonly endorsed by individuals with GAD and is considered a core symptom of the disorder (American Psychiatric Association, 2000). Sleep problems are also common in children with SAD, a disorder characterized by excessive anxiety about being away from home or from one's parents or caregivers. Fears of separation often manifest at bedtime, with persistent reluctance or refusal to sleep alone and recurrent nightmares about separation (American Psychiatric Association, 2000). Sleep-related problems are also commonly experienced by youth with other anxiety disorders, including social phobia and obsessive–compulsive disorder (OCD) (Alfano et al., 2007, 2010); however, the mechanisms may differ. For instance, it has been theorized that obsessions and compulsive rituals may delay bedtime and increase anxiety about going to sleep in youth with OCD (Chorney, Detweiler, Morris, & Kuhn, 2007).

Sleep and mood disorders

Poor sleep quality or significant changes in sleep are common across all mood disorders (American Psychiatric Association, 2000). Both hypersomnia and insomnia are considered core symptoms of depression and are included in the diagnostic criteria for major depressive disorder (American Psychiatric Association, 2000). Epidemiological data, along with studies utilizing both objective and subjective measures of sleep, further support that sleep disturbance is prevalent among depressed adults (Armitage, 2007; Ford & Kamerow, 1989; Hatzinger, Hemmeter, Brand, Ising, & Holsboer-Trachsler, 2004). Laboratory research has detected differences in the sleep patterns of individuals with depression, including differences in sleep duration, sleep onset, and rapid eye movement (REM) latency (Goetz et al., 1987; Kutcher, Williamson, Marton, & Szalai, 1992). There is some evidence that sleep disturbance may also predict the initial onset of depression (Breslau, Roth, Rosenthal, & Andreski, 1996) and depression relapse (Perlis, Giles, Buysse, Tu, & Kupfer, 1997).

Similar to adults, there appears to be a strong association between sleep and depression in youth (Gregory, Rijsdijk, Dahl, McGuffin, & Eley, 2006; Ivanenko, Crabtree, & Gozal, 2004; Morrison, McGee, & Stanton, 1992; Roberts, Lewinsohn, & Seeley, 1995; Roberts, Roberts, & Chen, 2001; Wolfson and Carskadon 1998). Depressed youth report later bedtimes, more daytime sleepiness, and experience greater sleep disturbance overall compared to healthy controls (Jin-Ding, Tungb, Yu-Hsin & Fu-Gong, 2011; Moore et al., 2009; Murray, Murphy, Palermo, & Clarke, 2012). The relationship between sleep and depression seems to grow stronger in adolescence (Alfano, Zakem, Costa, Taylor, & Weems, 2009), and some evidence suggests that sleep disturbance in early childhood is a predictor of future depressive episodes (Ong et al., 2006). Liu and colleagues (2007) found that children who experienced sleep-related problems and higher levels of depression were also more likely to have a comorbid anxiety disorder than those without sleep problems. Although the association between sleep disturbance, anxiety, and depression is not well understood, some evidence suggests that a pathway exists from anxiety to disturbed sleep, which is followed by the onset of depression (Dahl & Harvey, 2007; Johnson, Roth, & Breslau, 2006).

Sleep disturbance is also a common feature of pediatric bipolar disorder (see review in Harvey, 2009). Bipolar disorder is characterized by distinct periods of elevated, expansive, or irritable mood, often preceded or followed by periods of depression (American Psychiatric Association, 2000). Research with pediatric populations is limited, but sleep-related symptoms appear to be a prominent feature of bipolar disorder in youth. Decreased need for sleep, in particular, has been identified as a symptom that is more strongly associated with bipolar disorder than other forms of child psychopathology (Geller et al., 2002). There is also some evidence from studies including objective measures of sleep that youth with bipolar disorder have reduced REM sleep, lower sleep efficiency, increased sleep onset latency, increased nocturnal activity, and longer slow wave sleep compared to healthy controls (Faedda & Teicher, 2005; Mehl et al., 2006). While sleep disturbance is common across many forms of psychopathology, research has begun to distinguish sleep patterns uniquely associated with bipolar disorder. Longitudinal research indicates that depressed patients who go on to develop bipolar disorder, compared to those who follow a unipolar course, exhibit increased stage one sleep and decreased stage four sleep (Dahl & Puig-Antich, 1990). Evidence also suggests that sleep disturbance may be an early marker for bipolar disorder in youth. Decreased need for sleep, shorter sleep latency, and poorer sleep quality are more common among high-risk children of parents with bipolar disorder than children of control parents (Faedda, Baldessarini, Glovinsky, & Austin, 2004; Jones, Tai, Evershed, Knowles, & Bentall, 2006). Retrospective studies also indicate that sleep disturbance is one of the first symptoms to emerge in early-onset bipolar disorder (Duffy, Alda, Crawford, Milin, & Grof, 2007; Shaw, Egeland, Endicott, Allen, & Hostetter, 2005). Taken together, these findings suggest that thoroughly assessing sleep may be useful in the early detection of bipolar disorder.

Sleep, inattention, and behavioral problems

Disturbed or inadequate sleep is associated with a range of behavioral problems in children, including inattention, impulsivity, and disruptive behavior (Aronen et al., 2000; Dahl, 1996; Fallone et al., 2002; Fredriksen et al., 2004; Mindell, 1999; Sadeh, Gruber, & Raviv, 2002; Stein, Mendelsohn, Obermeyer, Amromin & Benca, 2001; Minde et al., 1993; Richman, Stevenson, & Graham, 1982). Research indicates that sleep-related problems, including daytime sleepiness, sleep-disordered breathing, restless legs syndrome (RLS), and periodic leg movements during sleep (PLMS), are associated with inattention, hyperactivity, oppositionality, and conduct problems (Chervin & Archbold, 2001; Chervin, Dillon, Archbold, & Ruzicka, 2003; Chervin, Dillon, Bassetti, Ganoczy, & Pituch, 1997; Corkum, Tannock, Moldofsky, Hogg-Johnson, & Humphries, 2001; Crabtree, Ivanenko, & Gozal, 2003; Konofal, Lecendreux, Bouvard, & Mouren-Simeoni, 2001; Shur-Fen Gua, 2006). There is likely a bidirectional relationship in which children's behavioral problems result in sleep-related difficulties, and poor sleep impairs daytime functioning.

A common manifestation of behavioral problems around sleep is bedtime noncompliance. Resisting bedtime and waking in the morning are particularly common among children with attention-deficit hyperactivity disorder (ADHD) and oppositional defiant disorder (ODD) (Corkum, Moldofsky, Hogg-Johnson, Humphries, & Tannock, 1999). Conversely, sleep disturbance or inadequate sleep may cause or exacerbate daytime behavioral problems. Many children with sleep disorders such as obstructive sleep apnea, RLS, and PLMS exhibit daytime sleepiness, inattention, hyperactivity, and aggression, which often improve with treatment of the sleep disorder (Ali, Pitson, & Stradling, 1993 Chervin & Archbold, 2001; Chervin et al., 1997; Guilleminault, Korobkin, & Winkle, 1981; Picchietti & Walters, 1996; Walters et al., 2000).

ADHD is the most commonly reported problem among children and adolescents who present for mental health services, with an estimated prevalence rate ranging from 3% to 7% in school-age children (American Psychiatric Association, 2000). Core symptoms of the disorder include a persistent pattern of inattention and/or hyperactivity and impulsivity since early childhood. In addition to these core symptoms, ADHD is often associated with a range of other problems, including temper outbursts and low frustration tolerance, peer rejection, academic difficulties, and sleep disturbance (American Psychiatric Association, 2000). Additionally, ADHD has a high rate of comorbidity with other childhood disorders, including ODD, conduct disorder, learning disorders, anxiety, and depression (Barkley, 2005; Biederman et al., 1996; Biederman, Newcorn, & Sprich, 1991; Faraone, Biederman Weber, & Russell, 1998; Jensen, Shervette, Xenakis, & Richters, 1993; MTA Cooperative and Group; 1999; Wilens et al., 2002).

Among youth diagnosed with ADHD, both parent- and child-reported sleep-related problems are common, with more than 50% of youth diagnosed with ADHD subjectively reporting significant sleep difficulties (Dahl & Puig-Antich, 1990; Owens, Maxim, Nobile, McGuinn, & Msall, 2000; Trommer, Hoeppner, Rosenberg, Armstrong, & Rothstein, 1988). The most frequently reported problems include bedtime resistance, difficulty initiating sleep, restless sleep, greater daytime sleepiness, and nightmares (Ball, Tiernan, Janusz, & Furr, 1997; Chervin et al., 1997; Corkum et al., 2001; Hvolby, Jørgensen, & Bilenberg, 2009; LeBourgeois, Avis, Mixon, Olmi, & Harsh, 2004; Ring et al., 1998). Studies including subjective and objective measures of sleep have revealed several differences in the sleep patterns of children with ADHD compared to children with other psychiatric disorders or healthy controls. The most prominent differences include longer sleep onset latency, increased movement during sleep, more variability in their sleep patterns, longer REM sleep duration, more sleep cycles, and higher levels of daytime sleepiness among ADHD youth (Golan, Shahar, Ravid, & Pillar, 2004; Gruber, Sadeh, & Raviv, 2000; Hvolby, Jørgensen, & Bilenberg, 2008; Kirov et al., 2004). However, differences may be less robust after accounting for confounding variables, such as comorbidity and medication status. Cortese and colleagues (2006) conducted a systematic review of the literature on sleep in children with ADHD and found that, after controlling for confounding factors, the only significant differences were increased movement during sleep, higher levels of daytime sleepiness, and higher apnea–hypopnea index scores. There were no differences in other objective or subjective sleep measures, such as sleep onset latency, bedtime resistance, REM sleep, or sleep efficiency. A similar meta-analysis found no differences in children with ADHD compared to controls, other than higher prevalence of PLMS and periodic limb movement disorder (PLMD; Sadeh, Pergamin, & Bar-Haim, 2006). Lastly, there is some evidence that sleep disturbance varies by ADHD subtype. Children with ADHD, predominantly the inattentive type, report higher levels of daytime sleepiness, while those with ADHD, combined type, exhibit poorer sleep efficiency, more fragmented sleep, and increased movement during sleep (Corkum et al., 1999; Dickerson Mayes et al., 2009; Lecendreux, Konofal, Bouvard, Falissard, & Mouren-Simeoni, 2000; Ramos Platon, Vela Bueno, Espinar Sierra, & Kales, 1990).

Sleep, learning, and cognitive impairment

Sleep is widely recognized as a behavior that serves multiple important functions, including the optimization of learning processes and memory consolidation (Benington 2000; Hobson & Pace-Schott, 2002; Krueger & Obal, 2003; Siegel, 2009; Smith, 2001). Sleep deprivation studies have revealed that inadequate sleep has a significant impact on cognitive functioning in adults (Durmer & Dinges, 2005; Pilcher & Huffcutt, 1996; Van Dongen, Maislin, Mullington & Dinges, 2003). Although the data is more limited, these findings seem to apply to children as well. Youth who undergo sleep restriction in lab settings exhibit significant impairments in a number of areas, including executive functioning, concentration, verbal creativity, abstract thinking, and working memory (Carskadon, Harvey, & Dement, 1981; Randazzo, Muehlbach, Schweitzer, & Walsh, 1998).

Children and adolescents who experience persistent sleep problems are at increased risk of cognitive, academic, and learning problems. There is an established connection between sleep quality and academic performance (Carskadon, 1990; Dahl, 1996; Shin, Kim, Lee, Ahn, & Joo, 2003; Wolfson & Carskadon, 1998), and parent-reported sleep problems are more common among children with learning disorders than healthy controls (Marcotte et al., 1998). Evidence suggests that inadequate sleep and other sleep-related problems, including insomnia, daytime fatigue, and poor sleep quality, are associated with lower grade point averages (GPAs) and higher school failure rates (Blum et al., 1990; Dewald, Meijer, Oort, Kerkhof, & Bögels, 2010; Kahn, Van de Merck, & Rebuffat, 1989; Link & Ancoli-Israel, 1995; Millman, 2005; Paavonen et al, 2000; Shin et al., 2003; Wolfson & Carskadon, 1998). This is likely related to the cognitive impairments associated with extended periods of inadequate sleep that may interfere with learning (Kahn et al., 1989; Sadeh, Gruber, & Raviv, 2002; Steenari et al., 2003; Walker & Stickgold, 2006). Conversely, students with better sleep hygiene and more consistent sleep schedules perform better in school and report higher GPAs (Link & Ancoli-Israel, 1995; Gray & Watson, 2002).

Cognitive Behavioral Techniques Applied to Sleep Disorders in Youth

There are numerous cognitive behavioral techniques that can be helpful for treating sleep disorders in youth. In the next section, we will review a number of these techniques, present their empirical support, and describe the ways in which they can be utilized in children with sleep disorders and their families.

Operant-based procedures/contingency management

Operant-based procedures are based on the premise that, for behavioral change to occur, environmental and reward structures must be modified. Through operant conditioning, behaviors are altered by the consequences that follow them (Kazdin, 1975). For example, operant theorists suggest that fearful or disruptive behaviors increase because a parent or other significant person selectively attends to and rewards them. This model calls for an assessment of the positive and negative reinforcing stimuli that produce or maintain behaviors (Ayllon, Smith, & Rogers, 1970; Hersen, 1970). Derived from this model, treatment procedures for limit-setting sleep disorders focus on modifying environmental contingencies and reward structures by training parents to ignore oppositional or fearful behavior at nighttime, for example, and reward alternative, non-oppositional, non-fearful behaviors. Numerous studies have utilized operant strategies such as reinforcement, verbal praise, and bravery sticker incentives as an effective component of a treatment package for improving children's behavioral insomnia and for reducing nighttime fear complaints (Graziano, DeGiovanni & Garcia, 1979; Giebenhain & O'Dell, 1984, Pincus, Weiner & Friedman, 2012). Operant strategies have also been utilized successfully when treating children with nighttime enuresis, whereby the child is rewarded for attaining "dry nights" using stickers or a point system (also referred to as "dry bed training").

Differential reinforcement

Based on operant principles, parents are often taught to reward appropriate behaviors and to ignore inappropriate behaviors in the context of nighttime. Parents might be instructed to first determine the most salient types of reinforcers for their particular child (e.g., stickers, tokens, praise, physical affection) and to utilize these reinforcers to attend to positive behaviors that parents would like to see increase. Parents are also taught appropriate ways to ignore inappropriate behavior, so that this behavior is not reinforced. This skill is often part of the parenting component for treatment packages for numerous types of sleep disorders, including behavioral insomnia of childhood (limit-setting type), as well as for children's nighttime fears (Pincus et al., 2012).

Progressive muscle relaxation (PMR) training

This procedure is aimed at reducing muscle tension, as a therapist teaches the child to tense and relax opposing sets of muscles to produce a cumulative effect of relaxation. A number of studies provide support for the efficacy of relaxation training even with young children (Barbasz, 1973; Van Hasselt et al., 1979; Friedman & Ollendick, 1989; Pincus et al., 2012). PMR is typically used in cognitive behavioral interventions for internalizing disorders, but has also been used in several studies as part of a cognitive behavioral "skills package" for helping children fall asleep at night (Friedman & Ollendick, 1989; Pincus et al., 2012). The therapist can perform PMR with the child or adolescent by teaching him or her to systematically tense and release different muscles in the body (e.g., Clarke, Lewinsohn, Hops, & Andrew, 1990; Kendall & Hedtke, 2006). When working with younger children, imagery may facilitate the child's use of PMR. For example, when tensing and releasing muscles in the hand, the child can imagine squeezing a lemon and then dropping it. Children are encouraged to practice using this technique to achieve a more relaxed physiological state when falling asleep, or during nighttime waking.

Cognitive strategies

Cognitive-based interventions are treatment approaches that attempt to modify behavior and emotion by restructuring faulty, maladaptive, underlying cognitions. It is assumed that maladaptive thinking leads to maladaptive behavior, and thus, by changing a child's distorted cognitions or "negative self talk", he or she can learn to replace debilitating self-statements at nighttime (e.g., "Monsters might get me in the dark," "I can't take care of myself when I am alone") with more facilitative, competence-related verbal coping responses (e.g., "I am a brave boy [girl]" or "I can take care of myself"). Such verbal coping skills have been shown to be more effective in treating children who are fearful of the dark than either neutral statements ("Mary had a little lamb") or statements focusing on reducing the aversive qualities of the situation (e.g., "The dark is a fun place to be" or "There are many good things in the dark") (Kanfer, Karoly & Newman, 1975). In addition to verbal self-instruction training using competence-related cognitive self statements, cognitive restructuring techniques are also utilized in treatments for insomnia to help children assess the validity of their dysfunctional beliefs and attitudes about sleep (e.g., "If I don't get eight hours of sleep I will fail and won't be able to function," or "I won't be able to fall asleep tonight"). These thoughts can cause "performance anxiety" about sleep that interferes with the child's ability to fall asleep. Children are taught to gather evidence regarding whether their thoughts are true or not true, to evaluate this evidence, and finally to generate alternative thoughts that are more consistent with the real "facts." The therapist may provide information to the child about a person's ability to compensate for lost sleep to help reduce the patient's worry about falling asleep. Cognitive techniques are core components of numerous treatment packages for children coping with nighttime anxiety, depression, or insomnia.

Stimulus control techniques

An important component of treatment for dyssomnias such as sleep onset association disorder is to establish more stimulus control over the bedroom environment. This includes modifying activities so that the bedroom is a stimulus associated with sleep and sleepiness, not with activity. Thus, parents are instructed to implement measures to improve their child's "sleep hygiene" by having the child go to bed when sleepy and get out of bed when unable to fall asleep, preventing non-sleep activities such as television watching in the bedroom, eliminating caffeine or excessive exercise before bedtime, setting up the bedroom to be a peaceful and restful space, and instructing the child to get up at the same time every morning. Patients are often instructed to use a sleep diary to keep track of their sleep and wake times, as well as their sleep hygiene, to increase awareness of the importance of these activities.

Exposure-based techniques

Exposure-based techniques are frequently employed with children suffering from fears or anxieties that interfere with the nighttime routine and disrupt sleep. Parents are typically instructed to expose their child gradually to the feared stimulus while offering support and encouragement. Parents are also instructed to prevent children's attempts at "escape" through avoidance behaviors. Parents might create a "bravery ladder," which lists previously avoided situations that the child can gradually enter. Exposure-based techniques are frequently combined with operant procedures such that children are reinforced for entering previously avoided situations (e.g., children might receive praise from parents for sleeping on their own through the night without waking up parents).

Graduated extinction

Graduated extinction is typically employed to help children with sleep onset association disorder or limit-setting sleep disorder. If the child cries out at night, parents are instructed to check on the child briefly and then leave the room; the parents continue to wait for progressively longer periods of time before checking on the child, until the child falls asleep on his or her own. By using this technique, children are allowed time to develop the necessary sleep associations and self-soothing techniques to help them to fall asleep on their own, without the aid of parents, pacifiers, lights, or other external comforts.

Scheduled awakenings

Scheduled awakenings are considered one of the most effective treatments for sleep terrors in youth. Durand and Mindell (1999) showed that if children with sleep terrors were awakened 30 minutes prior to a typical episode, sleep terrors could be eliminated in just a few weeks. Thus, parents are often instructed to first keep a record of the timing of these sleep terrors, and then to plan to wake up the child 30 minutes prior until the sleep terrors are extinguished.

Classical conditioning interventions

One of the standard interventions for nighttime enuresis, the "bell and pad" technique, is based on classical conditioning principles. Using this technique, a moisture sensor snaps into a child's underwear, with a small alarm attached to the child's pajama top. A slight drop of urine causes the alarm to sound, and the child tenses and stops urinating. The child is then taken to the bathroom to finish urinating. Parents are instructed not to give children any attention when they wake up, but simply to reset the alarm and bring the child back to bed. Within 4–6 weeks, the child will gain bladder control and no longer require the alarm. This technique is now recommended as a front-line treatment for nighttime enuresis (Fritz, Rockney, & the Work Force on Quality Issues, 2004).

Case Example: Sienna, 9-Year-Old Child with Limit-setting Sleep Disorder

Presenting problem

Sienna, age 9, reported to a university-based, outpatient mental health clinic due to her difficulties in falling asleep at night. Her mother, Mrs. A, stated that Sienna had difficulty falling asleep alone and problems staying asleep during the night. Mrs. A reported that Sienna required her mother to lie next to her when she falls asleep. If she woke up and her mother was not by her side, she would scream and protest until her mother returned. Mrs. A expressed that she dreaded nighttime and wished that Sienna could simply fall asleep and stay asleep. She reported that Sienna's sleep problems had disrupted the entire family.

Background information

Mrs. A reported that Sienna had always had difficulty going to sleep on her own. During Sienna's infancy, Mrs. A remembered nursing her to sleep every night. Sienna would wake up crying in the middle of the night, and Mrs. A would nurse her back to sleep and quiet her down. During Sienna's toddler years, her sleep difficulties persisted, with nighttime waking and screaming occurring almost daily. Due to these sleep problems, Mrs. A often let Sienna stay up "as late as she wants" to ensure that she was exhausted by the time she went to bed. Mrs. A stated that Sienna refused to go to bed every night. She would often have tantrums, and Mrs. A typically had to "yell" before Sienna would eventually go upstairs. Sienna usually refused to sleep in her own bed unless her mother was right next to her. Mrs. A stated that she had tried various strategies to get her daughter to fall asleep by herself, such as "bribing" her with candy and extra television time or giving her a nightlight, but they had not been successful. Mr. A, Sienna's father, confirmed that Sienna's sleep problems were interfering in her life, and that they were also troubling the entire family. For example, he stated that he rarely saw his wife due to the fact that she spent so much energy putting Sienna to sleep at night. Sienna's younger siblings were reportedly upset because they did not have any time with their mother at night.

In an interview with Sienna, she reported that she was fearful of the dark and worried if her mother was not right next to her. She stated that she had seen a frightening news report about an intruder and had been fearful at nighttime and in the dark ever since. She was reportedly afraid that an intruder might come to her house, and, thus, she insisted that her mother stay by her side. Sienna lived in a safe neighborhood and did not report any previous trauma history.

Academic functioning

Sienna's fourth grade teacher reported that Sienna had seemed inattentive and often appeared sleepy at school. She had not been completing classwork assignments on time, and often did not complete her homework assignments. Recent cognitive testing indicated that Sienna was of above-average intelligence.

Social functioning

According to Sienna's teacher and her mother, she had numerous friends at school. She was well-liked by her peers, and she was often invited to have play dates with new friends. However, Sienna refused to go on sleepovers because she was afraid that she would not be able to fall asleep by herself. She had also refused to go to some sleepover birthday parties because of her nighttime fears.

Assessment

In addition to interviews conducted with Sienna, her mother, and her teacher, numerous other measures were administered to assess aspects of her functioning.

Sienna's mother was instructed to use a sleep diary for 1 week to record data about Sienna's nighttime behavior, including the time Sienna went upstairs, the exact time she fell asleep, frequency of nighttime awakenings, and time of morning rising. She was also asked to record their current nighttime routine. Sienna's mother completed the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001), a general measure of psychopathology in youth. Results of the CBCL indicated that Sienna's internalizing and externalizing levels of psychopathology were both clinically significant (t-score above 65). Sienna's mother completed the Children's Sleep Habits Questionnaire (CSHQ; Owens, Spirito, & McGuinn, 2000), a 48-item parent report measure designed to assess children's sleep habits. Sienna showed elevated scores on the following subscales: bedtime resistance, sleep onset delay, sleep anxiety, night wakings, and daytime sleepiness. Her total sleep problem score was 48, which is indicative of clinically significant sleep disturbance.

Diagnosis

Based on the interview and initial testing data, Sienna was assigned a diagnosis of behavioral insomnia of childhood, limit-setting sleep disorder. She was also diagnosed with a specific phobia of the dark.

Treatment

A number of cognitive behavioral treatment strategies were employed to help Sienna and her family. Sienna's parents were instructed to continue utilizing a daily sleep diary throughout the course of treatment as one means of tracking Sienna's progress. This also served as a form of self-monitoring. There were both parent and child components of Sienna's treatment.

Parent component. In the parent component, parents were provided with psychoeducation about the importance of sleep, guidelines about good sleep hygiene for children (stimulus control technique), and the importance of developing a consistent, calm, nighttime routine. Sienna's parents were instructed to list each step of the sleep routine and to place it in a visible place in the home so that Sienna could follow the routine each night. Her parents were then instructed to complete a "bravery record form," which enabled them to conduct daily behavioral monitoring of Sienna's sleep behaviors as well as to conduct contingency management. Sienna's parents listed five behaviors that they wanted to see Sienna accomplish each night, including: (1) going to bed promptly, within a reasonable period (5 minutes) after being told, (2) going to bed without complaining, arguing, or crying, (3) sleeping in her own bed with all sources of light and noise turned off, (4) falling asleep and sleeping through the night without getting out of bed or calling out, and (5) falling asleep by herself. Parents were instructed to complete this form each morning and to give Sienna a check mark and sticker for each goal she was able to accomplish.

If Sienna was successfully able to accomplish all five behavioral goals in one night, she earned a special “brave night” sticker to place on a “bravery calendar” designed so her parents could record Sienna’s successes. Sienna and her parents were instructed that if Sienna was able to earn 10 “brave nights” in a row, she would earn a pizza party at the clinic for her and her family. Parents were also taught to employ skills such as differential reinforcement of Sienna’s behavior, as well as how to employ the concept of graduated extinction in the context of Sienna’s nighttime crying episodes. Specifically, Sienna’s parents learned how to reinforce brave, appropriate, nighttime behaviors while actively ignoring inappropriate protests at nighttime. Her parents were instructed to follow the sleep routine consistently and to bring Sienna to bed at 8:30 pm each night to begin the brief nighttime routine. Mrs. A was instructed not to fall asleep with Sienna, and she was taught that her presence was interfering with Sienna learning to develop some of her own tools for self-soothing at bedtime.

Child component. Sienna was taught several cognitive behavioral tools in her portion of the treatment. She was taught cognitive techniques, such as how to examine her anxious thoughts, and was also taught how to restructure some of her fears about bedtime. As a result of this cognitive restructuring, Sienna learned that many of her worries about nighttime and the dark had never occurred and were very unlikely, and, thus, that her level of worry was disproportionate to the situation. Sienna was also taught some relaxation strategies to use at nighttime – particularly, she was taught to use progressive muscle relaxation techniques to help her learn how to elicit a physical state of relaxation prior to bedtime. Sienna was also taught how to eliminate “safety behaviors,” such as sleeping with her mom, in order to truly face her fears in a graduated way. She and her therapist developed a plan for how she would use gradual exposure to tackle her nighttime fears. Sienna made a plan to progressively use the dimmer on her light to gradually make the room darker and darker each night. In order to continue to face her nighttime fears, she made a plan to sleep at her grandparents’ house (without her mother), and once she accomplished this, she made a plan to sleep at a friend’s house who lived nearby. Gradually, Sienna felt confident enough to sleep at a friend’s house who lived further away, and finally, she was able to attend a sleepover party with other same aged peers.

Case outcome

Sienna and her parents showed a very positive response to the cognitive behavioral techniques they were taught in treatment. Sienna’s parents reported that, within 6 weeks of consistently implementing the skills, Sienna had accomplished her goal of falling asleep alone and sleeping through the night by herself, without crying or calling out for help, and with all sources of light/noise turned off. After 8 weeks, Sienna had reached her goal of attaining 10 “brave nights” in a row, and thus, she was rewarded with a pizza party at the clinic. Evaluation of Sienna’s post-treatment assessment data indicated that Sienna’s scores on both the CBCL and CSHQ had returned to non-clinical levels. Sienna's parents reported that Sienna's improved sleep also seemed to translate to better academic functioning at school. Sienna's teacher reported that she was much more alert and engaged at school since she completed treatment. Sienna's parents also reported that their stress level had decreased as a result of treatment, and that there were significantly fewer negative parent–child interactions in the home. Sienna reported that she felt increased confidence in herself as a result of her accomplishments, and that she was most proud of herself for being able to fall asleep alone and for her ability to now attend sleepovers with peers. Parents were instructed to continue to reinforce the consistent nighttime routine they had created, while continuing to adhere to the sleep hygiene recommendations provided by the therapist. At Sienna's post-treatment evaluation, she no longer met clinical criteria for the diagnosis of limit-setting sleep disorder or for specific phobia of the dark.

Conclusion

As this case summary illustrates, children who have sleep problems often experience comorbid mental health issues. Sleep problems during childhood are associated with significant impairment in numerous domains, including social, academic, family, and emotional functioning. Cognitive behavioral treatments have offered great promise for those children who are coping with sleep disorders and their sequelae. Operant techniques, exposure-based techniques, cognitive techniques, stimulus control procedures, graduated extinction, progressive muscle relaxation, self-monitoring techniques, classical conditioning interventions, and differential reinforcement strategies are all examples of cognitive behavioral techniques that can be used to improve the functioning of children and adolescents with sleep disorders. Continued research is needed to advance our knowledge of effective ways to integrate these interventions into settings that regularly provide treatments for youth with sleep disorders.

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14

50 Years of Hypnosis in Healthcare

Mark B. Weisberg

Hypnosis is being used increasingly in hospitals, primary care, and specialty care clinics, as well as in psychotherapy practice. There is now a substantial body of research supporting the efficacy of hypnosis as part of treatment for many medical and dental conditions, including ones that traditional medicine has found hard to treat (Stewart, 2005). The research on hypnosis has led to more detailed expectations about its beneficial effects for health conditions. It is also known now that hypnosis can not only lead to increased comfort and reduced anxiety about health conditions and diagnostic procedures, but can also lead to specifically altered physiological parameters.

What is hypnosis? The following definition of hypnosis was produced by a committee of eminent hypnosis researchers representing Division 30 (Psychological Hypnosis) of the American Psychological Association:

> Hypnosis typically involves an introduction to the procedure during which the subject is told that suggestions for imaginative experiences will be presented. The hypnotic induction is an extended initial suggestion for using one's imagination, and may contain further elaborations of the introduction. A hypnotic procedure is used to encourage and evaluate responses to suggestions. When using hypnosis, one person (the subject) is guided by another (the hypnotist) to respond to suggestions for changes in subjective experience, alterations in perception, sensation, emotion, thought or behavior. Persons can also learn self-hypnosis, which is the act of administering hypnotic procedures on one's own. If the subject responds to hypnotic suggestions, it is generally inferred that hypnosis has been induced. Many believe that hypnotic responses and experiences are characteristic of a hypnotic state. While some think that it is not necessary to use the word "hypnosis" as part of the hypnotic induction, others

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> view it as essential. Details of hypnotic procedures and suggestions will differ depending on the goals of the practitioner and the purposes of the clinical or research endeavor. Procedures traditionally involve suggestions to relax, though relaxation is not necessary for hypnosis and a wide variety of suggestions can be used including those to become more alert. Suggestions that permit the extent of hypnosis to be assessed by comparing responses to standardized scales can be used in both clinical and research settings. While the majority of individuals are responsive to at least some suggestions, scores on standardized scales range from high to negligible. Traditionally, scores are grouped into low, medium, and high categories. As is the case with other positively scaled measures of psychological constructs such as attention and awareness, the salience of evidence for having achieved hypnosis increases with the individual's score.
>
> (Green et al., 2005)

Another way of understanding the hypnotic experience is that it is characterized by three primary features: suggestibility, absorption, and dissociation (Cardena & Spiegel, 1991). These are everyday phenomena that people experience regularly. In clinical hypnosis, these phenomena are specifically elicited for the goals of symptom reduction and improved functioning. Suggestibility means that the person in the hypnotic state is more likely to accept and experience suggestions for changes in sensation, emotion, thought, behavior, and physiology than someone not in a trance state. Dissociation means that the mental functioning of a person becomes compartmentalized, and one part can be experienced in isolation from the others. An example of this could be sitting in an academic lecture while simultaneously experiencing the thoughts, images, and emotions pertaining to a recent ski trip in the Colorado Rockies. Absorption refers to the experience of highly focused attention on something, to the exclusion of everything else. Suggestibility, dissociation, and absorption enable a hypnotic subject to experience suggested thoughts, emotions, and sensations as though they are real, leading to actual physiological and psychological changes.

How useful is hypnosis for healthcare applications? A partial list of health conditions for which clinical hypnosis has been shown to be effective is given in Table 14.1.

Table 14.1 A partial compendium of health conditions and medical/dental procedures where there is support in peer-reviewed scientific literature for treatment with clinical hypnosis.

Acute Pain (Patterson, 2009)
Allergies (Junko et al., 1994; Langewitza et al., 2005)
Asthma (Brown, 2007; Ewer & Stewart, 1986)
Autoimmune disorders (Horton-Hausknecht et al., 2000; Torem, 2007)
Analgesia for invasive medical procedures (Lang et al., 2000)
Burns (Ewin, 1986; Ewin, 1992; Wiechman-Askay et al., 2007)

Table 14.1 (*Continued*)

- Cancer, including diagnostic and treatment phases, as well as managing emotional sequelae of treatment (Hurley et al., 2005; Jensen et al., 2012; Lang et al., 2006; Montgomery et al., 2007; Richardson et al., 2007)
- Cardiovascular disease (Diamond et al., 2006)
- Chronic fatigue syndrome (Hammond, 2001; Wailes, 2004)
- Chronic pain, including:
  - Chronic pelvic pain (Weisberg, 2000)
  - Complex regional pain syndrome (Ghai & Dureja, 2004)
  - Fibromyalgia (Castel et al., 2007)
  - Headaches (Hammond, 2007)
  - Loin pain hematuria (Elkins et al., 2012)
  - Low back pain (Tan et al., 2009)
  - Neck pain (De Jong, et al., 2008)
  - Osteoarthritis (Gay et al., 2002)
- Diabetes (Xu & Cardena, 2008)
- Dental disorders and issues, including:
  - Dental anesthesia (Huet et al., 2012)
  - Dental pain (Clavel & Weisberg, 1997)
  - Temporomandibular disorders (TMD) (Nash & Tasso, 2012; Simon & Lewis, 2000; Weisberg & Clavel, 1999)
- Digestive problems, including:
  - Functional dyspepsia (Calvert et al., 2002)
  - Gastric emptying disorders (Chiarioni et al., 2006)
  - Gastroesophageal reflux disease (Zlotogorski & Anixter, 1983)
  - Inflammatory bowel diseases (Mawdsley et al., 2008)
  - Irritable bowel syndrome (Plotnikoff & Weisberg, 2009; Palsson, 2008)
- Dermatological conditions (Shenefelt, 2000)
- Fertility problems (Levitas et al., 2006)
- Hot flashes (Elkins et al., 2010)
- Human papilloma virus (HPV) (Ewin, 2012)
- Immune regulation during periods of stress (Kiecolt-Glaser et al., 2001; Wood et al., 2003)
- Multiple sclerosis (Jensen et al., 2012)
- Obstetrics, labor, and delivery (Brown & Hammond, 2007; Marc et al., 2008)
- Pediatrics (Kohen & Olness, 2011; Liossi et al., 2009; Olness et al., 1987)
- Preparation for invasive diagnostic and interventional radiology procedures including biopsies, endoscopy, and colonoscopy (Cadranel et al., 1994; Conlong & Rees, 1999; Flory et al. 2007; Lang et al., 2000; Neron & Stephenson, 2007; Saadat et al., 2006; Slack et al., 2009)
- Posttraumatic stress disorder (Cardena et al., 2000)
- Preparation for surgery (Hammond, 2008; Lew et al., 2012)
- Sleep disorders (Graci & Hardie, 2007)
- Smoking and smoking cessation (Green et al., 2008)
- Somatoform disorders (Chaves, 1996; Hagenaars et al., 2007)
- Stuttering (Kaya & Alladin, 2012)
- Tinnitus (Ross et al., 2007)
- Urinary and bladder dysfunction (Smith et al., 2006)

Given the evidence suggesting the usefulness of clinical hypnosis for a number of challenging health problems, why has there been such historical hesitation and reluctance by both clinicians and patients to use hypnosis? And why has there been increasing acceptance and broadened utilization of clinical hypnosis in healthcare in more recent years?

Consideration of cultural, scientific, and technological developments in the last half-century provides some clues to this conundrum. This chapter will review salient developments in the healthcare environment over the last 50 years that have influenced how hypnosis is utilized today. This lays the groundwork for an exploration of current uses of clinical hypnosis for a broad variety of physical health conditions.

Hypnosis in Context: Developments in the Healthcare Environment in the Last 50 Years

Numerous cultural and technological transitions shaped the ways hypnosis has been understood and applied in healthcare settings. Discussion of some of these transitions was originally published in the American Society of Clinical Hypnosis, Volume 51, Number 2 (reprinted with permission of the American Society of Clinical Hypnosis). These include the rapid growth of technological medicine in the 1950s, the AIDS epidemic and subsequent development of psychoneuroimmunology, groundbreaking developments in genetics and neuroimaging technology, and the progression from alternative to integrative medicine. A review of some of these salient developments will help put the contemporary use of hypnosis in healthcare in its proper context.

Technological and pharmaceutical advances in the 1950s

The mid-1950s was an auspicious time for medicine and healthcare. Several medical breakthroughs occurred within a very short period of time (Le Fanu, 1999). Some of the first antibiotic medications were discovered, including streptomycin (used to treat tuberculosis). The first reports linking tobacco and lung cancer were published. Concurrently, chlorpromazine emerged as a historic new medicine to manage symptoms of schizophrenia. Many anti-inflammatory drugs were developed during this time, starting with the discovery of cortisone.

In addition to pharmaceuticals, new technologies were developed during this period of time that led to significant advances in patient care. Some of these included kidney transplants, hip replacements, open-heart surgery, and the advent of the intensive care unit in hospitals. These developments both saved and improved the quality of millions of lives.

Another momentous achievement affecting medicine and healthcare occurred in April 1953, when James Watson and Francis Crick described the double helix structure of DNA. This discovery won them the Nobel Prize. With this development came an accelerated search for genetic roots of disease, and with it, the hope for genetically based cures.

As this explosion in technological discoveries and treatments continued, the field of medicine seemed to shun "low-tech" treatments, suggesting that many previous attempts at healing were nothing more than quackery. Modalities such as physical manipulation, massage, dietary advice, and taking time to reassure patients about their conditions were viewed by many as anachronistic, unscientific, and extraneous. This is ironic, since attention to diet, exercise, and the doctor–patient relationship were hallmarks of traditional medicine dating back to Hippocrates, known as the father of Western medicine (Plotnikoff & Weisberg, in press).

"Alternative therapies" versus traditional medicine

It is understandable then that these seemingly "unscientific" treatments started to be embraced by alternative practitioners. A dramatic expansion in the growth of what was previously known as "alternative therapies" started in the late 1950s. This field developed initially as being completely disconnected from the developments of mainstream medicine. Not surprisingly then, alternative medicine was dismissed by mainstream practitioners as being ineffective, unethical, and fraudulent. Meanwhile, patients and consumers learned that if they wanted to avail themselves of both traditional and alternative treatments, they had to do it secretly to avoid confusion and criticism from allopathic practitioners. This is significant because, amidst this cultural and professional backdrop, clinical hypnosis reemerged as a valid medical treatment. The successful applications of hypnosis in the treatment of war casualties in World War II led to renewed attention starting in the postwar years of the 1950s (Upshaw, 2006). The Society for Clinical and Experimental Hypnosis was founded in 1949, and the American Society of Clinical Hypnosis was founded in 1958. The American and Canadian Medical Associations endorsed hypnosis as a valid medical therapy that same year. Shortly thereafter, the American Psychological Association and the British Medical Association offered similar endorsement.

Nonetheless, hypnosis would not yet enjoy wider utilization by health professionals. Dental, medical, and psychology graduate programs still largely ignored this subject. As the health field in general struggled with the question of traditional versus non-traditional treatments and who should deliver them, the field of hypnosis struggled with similar competing factors. With so few physicians, psychologists, and dentists available to train others in hypnosis, the private lay hypnotherapy movement developed to fill in the gap. National schools of lay hypnosis cropped up by the early 1960s, and the resulting tension between lay hypnotists and health professionals trained in hypnosis has remained. Professional hypnosis organizations that represent physicians, psychologists, and dentists have tried to restrict the practice of hypnosis by non-health professionals, especially in regard to "entertainment hypnosis" or "stage hypnosis" that is often seen at parties and business conventions.

However, efforts to curtail lay hypnotists and stage hypnotists have been curtailed by state regulatory bodies, as it was considered unfair restraint of free trade (McKinney, 2007).

Curiously, the hesitation of medicine, psychology, dentistry, and other professional fields to more fully integrate hypnotic treatments into practice had little to do with its efficacy. The therapeutic effects of hypnosis have rarely been disputed (Upshaw, 2006). Rather, when hypnosis has been ignored or rejected by health professionals, it has usually been due to religious concerns or supernatural characterizations, lack of access to scientific explanations, the availability of alternative viable treatments, negative media coverage, or concerns about hypnosis and the fallibility of memory.

From the mid-1970s through the 1980s, another series of professional and cultural events yet again affected to acceptance of hypnosis within healthcare disciplines.

Hypnosis and fallibility of memory

In the early 1980s, new controversies about hypnosis and memory emerged that once again brought the scientific validity and clinical utility of hypnosis into question. The American Medical Association (AMA) brought together a panel to investigate the validity of refreshing a person's recollection with hypnosis. In 1985, the AMA Council on Scientific Affairs released their conclusions. Among them was released the conclusion that recollections obtained during hypnosis had the potential to cause confabulations and pseudomemories.

Questions raised by the APA report tarnished the perception of the medical value of hypnosis. This had the effect of slowing down the growth of hypnotic applications in healthcare settings. However, it also provided impetus for researchers within the hypnosis field to clarify their understanding of hypnosis and memory, and to refine their recommendations for utilizing hypnosis responsibly (Brown et al., 1998).

The Human Genome Project

Another development would set the stage for ultimately investigating whether hypnosis had the potential to affect genetics. The US Genome Project was established as a multi-year effort to find all the genes on every chromosome in the human body to determine their biochemical nature. Ultimately, the goal of the Human Genome Project was to determine the sequence of chemical base pairs that make up DNA, and to identify the more than 20,000 genes of the human genome (International Human Genome Sequencing Consortium, 2001. This invariably led to a torrent of new questions. Would we now view an individual as merely a product of their interacting genes? How would this information shape our definitions of normality, abnormality, and disability? Several reminders that genes cannot be understood outside of the context of environmental factors that enhance or inhibit the expression of a particular gene have been published (e.g. Moore, 2001. Therefore, perhaps hypnosis could modulate gene expression. Later, writers such as Rossi (2002) explored this topic in greater detail.

AIDS, immunology, and psychoneuroimmunology

Another set of cultural and scientific developments would lead to important new discoveries and applications of clinical hypnosis. The late 1970s to early 1980s heralded the beginning of the AIDS crisis in the United States. The rapid expansion in AIDS research enabled scientists to learn much more about the human immune system's function. It is important to keep a historical context – i.e., prior to this time, our scientific understanding of immunology was relatively more limited. These breakthroughs in understanding the immune system paved the way for important new treatments and discoveries.

One such discovery occurred in the laboratory of a research psychologist at the University of Rochester in New York, Dr. Robert Ader, who performed a study that unintentionally led him to recognize that the brain, nervous system, and immune system might be connected in ways not previously thought possible. His study suggested that the immune system could be modified by classical conditioning (Ader & Cohen, 1975). This experiment marked the beginning of the field of psychoneuroimmunology (PNI) (Ader, 2000). This spurred a new interdisciplinary science, capitalizing on the recent developments in neuroscience research and technology, to investigate the interconnectedness of the nervous system, endocrine system, and immune system. Evidence emerged suggesting that communication between these and other physiological systems was facilitated by means of neuropeptide messenger molecules, and that the behavior of these neuropeptide messenger molecules were significantly affected by emotional expression (Pert, 1986).

The ramifications stemming from PNI research were profound (Weisberg, 2008). Researchers were increasingly able to identify components of the intricate communication networks that existed between these various physiological systems and the brain. Disruption of these communication networks in any way, whether inherited or through drugs, toxic substances, surgery, or chronic emotional stresses, could exacerbate the diseases that these systems attempt to guard against.

Hypnosis and psychoneuroimmunology

In the not-too-distant past, physiological ailments were viewed as being either "physical" or "psychosomatic." This artificial distinction between what is considered physical and psychological has hampered our treatment of many conditions, particularly chronic conditions (Plotnikoff & Weisberg, in press). However, it was becoming increasingly recognized that physiological phenomena led to psychological reactions, and that psychological reactions could lead to changes in physiology. Also recognized was that stress not only caused people to "feel bad," but might also lead to profound physiological shifts that affect disease progression and healing. It was shown that psychological experiences such as anxiety, depression, and stress could influence immune function (e.g., Kiecolt-Glaser et al., 2001).

With these new developments, research investigating hypnosis and its role in altering psychophysiological and neuroimmune parameters expanded. Hypnosis was linked to significantly increased levels of CD4 cells (Ruzyla Smith et al., 1995), a specialized type of T-cell that recognizes virus-infected cells and helps destroy them. Taylor (1995) demonstrated that hypnosis, combined with techniques for relaxation and autonomic regulation, induced an increase in T-cells in HIV-positive subjects with low T-cell counts. Hypnosis was shown as being able to modulate the degree of cellular immune dysregulation occurring during periods of acute stress (Kiecolt-Glaser et al., 2001). Davidson and his colleagues (2003) demonstrated direct correlations between relaxation, imagery, and changes in immune function. Hypnotic intervention was shown to alter T-cell activity in healthy subjects (Wood et al., 2003). These and other data were increasingly informing clinical practice. Rossi, integrating some of these findings, postulated the neurobiological pathways by which mind–body healing occurs (1993). Later, interweaving newly discovered data from the Human Genome Project, Rossi discussed ways to creatively facilitate what he called the "psychodynamics of gene expression, neurogenesis, and healing in therapeutic hypnosis" (2002).

"Decade of the Brain": The decline of "low-tech" treatments?

The momentum of converging developments in technology and neuroscience throughout the 1980s led president George H. W. Bush to designate the decade beginning with 1990 as the "Decade of the Brain." This was part of a larger effort, including the National Institute of Mental Health division of the National Institutes of Health, to enhance public awareness of the benefits to be derived from brain research. Many practitioners were excited by the possibility that previously misunderstood conditions could be broken down to their genetic and biochemical foundations and treated effectively. Meanwhile, other practitioners were anticipating that the new conventional wisdom regarding all mental and physical disorders would be reduced to neurons, neurotransmitters, and neurohormones. They feared a devaluation of treatments such as clinical hypnosis and psychotherapy that seemed to be less technological.

Meanwhile, new emerging technologies helped us to understand brain structure and function to a far greater degree than was previously possible. Not long before this, the feasibility of mapping specific regions of the brain in relation to their functional roles seemed remote. By the 1980s, remarkable advances occurred in radiologic technology, including the first magnetic resonance imaging (MRI) scanners. The development of the positron emission tomography (PET) scan and functional magnetic resonance imaging (fMRI) followed soon after. Now the activity of the human brain during mental activity could be measured and visualized. It now became possible to monitor the activity of neurons within complex neural networks during discrete behaviors. Ironically, these new technologies would prove to be a boon to the fields of hypnosis, behavioral medicine, and psychotherapy. For example, it was now possible to observe PET scans showing increased limbic blood flow after interpersonal psychotherapy, but not after administration of the antidepressant medication venlafaxine (Martin et al., 2001). This also allowed clinicians to benefit from neuroscience-informed interventions. Van der Kolk's (1994) work on the neurobiology of posttraumatic stress reflected a growing body of research suggesting that traditional emotional abreaction approaches to treating trauma may actually be at least ineffective and possibly even harmful. Brain scans of traumatized patients revealed that, while speech and language centers in the left frontal lobe were suppressed, other structures in the right frontal lobe and limbic system were more highly activated. Therefore, there was a growing interest in therapeutic approaches that emphasized a shift from verbal insight to non-verbal, experiential modulation (Plotnikoff & Weisberg, in press; Rossi, 2002). This revised information helped practitioners update their understanding on how to use hypnosis differently, to treat many conditions more effectively (e.g., Cardena et al., 2000; Elkins et al., 2007; Jensen et al., 2012).

Hypnosis research and practice benefited greatly in other ways from these new technologies. Rapidly, new information emerged regarding how the physiology of the brain responds and changes, even to *different types* of hypnotic suggestion. For example, Rainville and his colleagues (1997) were able to use PET scanning to demonstrate significant changes in the anterior cingulate cortex in reaction to pain, consistent with the encoding of perceived unpleasantness, whereas primary somatosensory cortex activation was unaltered. This provided important empirical evidence linking the frontal lobe and limbic activity in humans with pain affect. These technologies also helped elucidate the process of neurogenic inflammation, which is now known to trigger and exacerbate migraine headache (Weisberg & Clavel, 1999). Later, Raz and colleagues (2005) utilized fMRI and event-related potentials to demonstrate that properly crafted hypnotic suggestions could *differentially* affect the activity of the anterior cingulate cortex, but only in highly hypnotizable subjects. Feldman (2004) reviewed the overlapping brain structures affecting the processing of pain and emotions as well as their relationship to autonomic arousal. This has furthered the understanding of differences in reactivity to pain, emotions, and stress, and how this affects the development and relief of chronic pain.

The importance of pain control is ubiquitous throughout medicine. Pain is by far the most common complaint leading patients to seek the services of the health system. These studies, as well as others, had groundbreaking ramifications for the practice of hypnosis in pain treatment. They showed that hypnosis could be used to help certain patients regulate their experience of pain and override certain autonomic processes in beneficial ways. Suggestions made for *pain reduction* were shown to affect different brain structures than, for example, suggestions for relieving the *negative emotions* associated with pain.

Increasing support for hypnosis becoming a mainstream treatment for pain and insomnia

The National Institute of Health (NIH) established a Technology Assessment Conference in 1996. This meeting produced an official position paper entitled "Integration of Behavioral & Relaxation Approaches into the Treatment of Chronic Pain & Insomnia." This extensive report included a section on the then-existing research regarding hypnosis and chronic pain. It concluded, "The evidence supporting the effectiveness of hypnosis in alleviating chronic pain associated with cancer seems strong." This panel also reported data suggesting the effectiveness of hypnosis in treatment of other chronic pain conditions including irritable bowel syndrome, oral mucositis, temporomandibular disorders (TMD), and tension headaches (NIH, 1996). Along with other empirical findings, this facilitated the acceptance of hypnosis as a covered therapeutic modality by an increasing number of insurance payors, including Medicare.

The evidence for the efficacy of hypnosis in pain treatment was further supplemented by a meta-analysis of several well-controlled empirical studies analyzing the effectiveness of hypnosis as part of a pain-treatment regimen (Patterson & Jensen, 2003). It was found that utilizing hypnosis in pain treatment led to significant reductions in pain intensity, need for analgesics and sedation, nausea and vomiting, and length of hospital stays. Patterson and Jensen concluded that hypnotic techniques for relief of acute pain may be superior to standard care, and are often better than other recognized treatments for pain.

Hypnosis as an "alternative" versus "conventional" treatment: The evolution of integrative medicine

Until recently, hypnosis had been viewed by many as an "alternative" treatment, which led to skepticism among both patients and clinicians, as well as restricted the application of this modality. As the empirical support for hypnosis has grown, this has changed. An understanding of the evolution of what is now called "integrative medicine" is another important component in conceptualizing the increased utilization of hypnosis in health settings.

The popularity of different modalities of diagnosis and treatment had become increasingly noticed in traditional medical settings. Dating back to 1993, Eisenberg and his colleagues discussed the substantial rise in what they called "unconventional" medical practices, with over $13 billion spent annually in the United States at that time. Hypnosis was, at that time, considered one of these "unconventional" treatments. Despite the controversies generated by this issue, the amount spent by health consumers had grown to almost $34 billion by 2007 (Nahin et al., 2009). As a result, hospitals and clinics became more interested in how and why so many patients were seeking these services and paying primarily out-of-pocket for them. The federal government eventually took notice of this groundswell and started funding well-designed and controlled empirical studies. NIH first conducted these studies through the Office of Alternative Medicine, but years later this body was renamed the National Center for Complementary and Alternative Medicine (NCCAM), and began to fund research in this burgeoning field. Part of the controversy and misunderstanding of this paradigm shift related to the terminology used to describe these different models of understanding health and illness. "Alternative" medicine denoted a treatment that would be used instead of a traditional modality. An example of this was when Laetrile was recommended instead of conventional cancer treatment. Subsequently, the term "complimentary medicine" emerged to describe the growing group of diagnostic and therapeutic disciplines that were used in conjunction with conventional medicine. An example of this would be the use of acupuncture or meditation to help lessen a patient's discomfort after surgery. Eventually, a new term was introduced: "integrative medicine." This model proposed a more holistic, cybernetic combination of different paradigms. Instead of regarding unconventional modalities as an alternative to traditional practice, or adding them as a supplement to traditional treatment, this model emphasized integration of traditional and previously unconventional modalities, based on empirical evidence of their efficacy.

Mistakenly, many patients and clinicians determine whether or not a treatment is integrative based on which modality is used. For example, "acupuncture is integrative and medication is traditional." This is an outdated understanding, as the integrative paradigm also advocates a different model of understanding health and illness. This paradigm proposes that a synergistic combination of biological, psychological, social and spiritual factors are what lead to health as well as to the onset, maintenance, or exacerbation of illness. The roots of this conceptualization can be found in ancient models of medicine dating back thousands of years to China, India, and Japan. George Engel's biopsychosocial paradigm is a descendent of this view as well. This paradigm also recognized the innate human capacity for self-healing, the importance of the clinician–patient relationship, and the value of a collaborative approach to patient care. Once again, these developments affected hypnosis research and practice. There developed increased interest in the hypnosis community regarding the nature of the therapeutic relationship and its effect on the efficacy of hypnotic interventions in health settings.

The question of whether hypnosis in healthcare is an alternative, complimentary, or integrative treatment is less controversial now than it was 20 years ago, in part due to the robust research base supporting its efficacy (Covino, 2008). However, even today, the question still generates some confusion among insurers, clinicians, and patients. The answer depends partially on how health and healing is conceptualized. If one ascribes to the "physiology as machine" metaphor and considers illness to be strictly derived from disordered biology, hypnosis will be viewed and utilized in an ancillary, mechanistic, and less effective manner. On the other hand, if one is informed by PNI and conceptualizes health and illness as a cybernetic system affected by multiple interactive factors, then clinical hypnosis can be viewed as one of many ways to intervene in that system from an integrative perspective. For example, if hypnosis were used as the sole treatment for smoking cessation (as is often the case in "hypnosis shops" found in the Yellow Pages), its utilization would be considered alternative. However, if hypnosis is combined carefully and methodically with consideration of the patient's capacity to tolerate negative emotions, attention to stress management, dietary changes and management of comorbid conditions, then it would be considered an integrative treatment, more effective than if it was used in isolation (Jeffrey et al., 1985).

Current Applications of Clinical Hypnosis in Healthcare Settings

Transition and innovation in cultural, technological, and scientific realms have helped clinical hypnosis evolve to its current status as a frequently used treatment modality in a number of health settings. What follows here are selected examples of how clinical hypnosis is applied for some of the most common problems that present in medicine and dentistry: pain, digestive disorders, diabetes, somatization, and preparation for diagnostic and invasive procedures. There is also some review of a PNI-informed context for introducing hypnosis to patients, which allows for better understanding, improved patient compliance and ongoing participation in self-care.

Whether hypnosis is utilized in the hospital, primary care clinic, specialty care clinic or dental clinic setting, great care must be taken to explain to patients, practitioners, and health systems how and why hypnosis is effective. Responsible use of hypnosis should be informed by research findings, including those from the field of psychoneuroimmunology (PNI). This is because many patients have learned in the traditional health system that all symptoms should be viewed as either "real physical disease" or else "psychosomatic and psychogenic." Most patients with chronic illness fall between the cracks of this outdated dichotomy. This orientation leads most patients to be defensive and resistant to recognizing the rich synergistic interaction of genetics and physiology, emotions, behavior, cognition, and imagery that is central in the development of both disease and healing. This is especially true when understanding the bi-directional relationship between emotions and physical symptoms. Patients find it useful and enlightening to learn about the role of neuropeptides as messenger molecules communicating between multiple levels of brain and body. Patients with pain find it compelling to discover, for example, that a structure in the limbic brain (the thalamus) that serves as a relay station for all incoming sensory information is related anatomically to another structure (the amygdala) that assigns emotional significance to the same sensory information and can activate powerful autonomic reactions that heighten or reduce pain. When patients are educated about the scientific foundations of mind–body interactions, they feel empowered, better understood, more receptive to using hypnosis, and generally more motivated to take an active role in their own healing.

Acute and chronic pain treatment

Pain is the most common complaint causing patients to seek medical care. Unrelieved pain has been increasingly recognized as a serious health problem worldwide, but especially in the United States. When treating pain conditions, use of strictly biological treatments can be associated with limited improvement and occasionally serious side effects. Hypnosis offers one of the most promising clinical approaches for pain control (Chou & Huffman, 2007; Patterson, 2010).

In pain medicine, a distinction is made between nociception (the actually pain signals transmitted through neural pathways) and suffering (all the responses that occur in reaction to pain, including autonomic dysregulation, muscle tension, depression, anxiety, change in identity, despair, and pain behaviors). Hypnosis can be used to address both aspects of this pain equation. For example, hypnosis can reduce the actual nociceptive pain signal (Famonville et al., 2006) as well as the intrusiveness of pain sensations (Elkins et al., 2007; Jensen et al., 2012). Utilizing techniques that work by means of eliciting hypnotic phenomena such as dissociation and time distortion, as well as activating other coping resources, may accomplish this. Another type of hypnotic technique works for reducing pain by directing a certain type of focused attention directly on the pain symptoms. This serves the important function of reducing secondary reactivity in a way that likely activates internal healing resources (Weisberg 2000; Plotnikoff & Weisberg, in press). Hypnosis can be crucial for relaxation training and reducing autonomic hyperarousal or dysregulation. It can also be used to identify and reduce other affective triggers to pain (e.g., for some sufferers, emotions regarding a difficult work environment or stressful relationship may be enough to exacerbate pre-existing pain symptoms). This is crucial in almost every type of pain problem, because we all have a natural reflex to tighten and brace around painful areas. This in turn can increase pain levels.

Hypnosis can be used to reduce dysfunctional behavioral, postural, and muscle habits that worsen pain disorders as well as a variety of other physical conditions. These include slumping, muscle clenching, restricted breathing, poor body mechanics, and tooth grinding (bruxism). This is useful in the treatment of multiple conditions including temporomandibular disorder (Nash & Tasso, 2010; Clavel & Weisberg, 1997), headaches, neck and facial pain (Castel et al., 2007; Hammond, 2007), low back pain (Tan et al., 2009), and even ringing in the ears (tinnitus) (Ross et al., 2007).

As the Institute of Medicine reported at their recent 2010 conference, the American health system excels in the treatment of acute illness but does much less well in the treatment of chronic conditions. This is true partially because health providers often fail to motivate patients to get more actively involved in self-care activities such as dieting, relaxation practice, monitoring times of clenching or other parafunctional behaviors, or engaging in regular exercise. Hypnosis can be indispensible for enhancing motivation for self-care, as well as identifying and reducing ambivalence to full participation in one's rehabilitation (Rossi, 1993; Weisberg, 2000).

Digestive disorders

There are a number of common digestive disorders where hypnosis has been shown to be helpful in treatment. For example, irritable bowel syndrome (IBS) is a common intestinal condition characterized by abdominal pain and cramps; changes in bowel movements (diarrhea, constipation, or both); gassiness; bloating; nausea; and heightened abdominal pain sensation. It is sometimes considered a diagnosis by exclusion. In other words, when a patient presents with digestive distress, and physical examination has ruled out other more serious conditions such as cancer and inflammatory bowel disease (IBD), then a diagnosis of IBS may often be made. IBS is a very common condition (Saito et al., 2002), affecting around 15–20% of the US population, and constituting approximately 33–45% of all patient visits to gastroenterologists. Hypnosis has been empirically demonstrated to be so effective (Barabasz, & Barabasz, 2006; Palsson et al., 1997; Tan et al., 2005) that it is arguably part of the treatment of choice for this disorder. Some clinicians use standardized protocols for hypnotic treatment of IBS, such as those developed by Whorwell (Gonsalkorale et al., 2002) or Palsson (2008). Other clinicians take a more individualized approach to hypnotic treatment, and some will combine aspects of standardized and individualized treatment. Many patients with IBS have severe secondary reactivity in response to sensations of abdominal pain and pressure. Hypnosis can be invaluable in teaching patients to reduce their reactivity to pain sensations, learning how to reframe their IBS symptoms as a useful barometer of important psychophysiological information (Plotnikoff & Weisberg, in press).

Gastroesophageal reflux disease (GERD) is a chronic digestive disease that occurs when stomach acid or, occasionally, bile flows back (refluxes) into the esophagus. The backwash of acid irritates the lining of the esophagus and causes GERD signs and symptoms. Signs and symptoms of GERD include acid reflux and heartburn, occurring at least twice a week. Common treatments include medications to reduce the production of stomach acid. It is estimated that 25% of all Americans suffer from GERD-related symptoms at least once per week (Moyaaedi & Talley, 2006).

Most people can manage the discomfort of heartburn with lifestyle changes and over-the-counter medications. However, for people with GERD, these remedies may offer only temporary relief. People with GERD may need stronger medications, even surgery, to reduce symptoms. Hypnosis in combination with relaxation training and other behavioral treatments have been shown in some studies to reduce GERD symptoms and reduce the need for GERD medications (McDonald-Halle et al., 1994; Zlotogorski & Anixter, 1983).

Inflammatory bowel disease (IBD) as a category includes several chronic disorders of the gastrointestinal tract. Two of the more commonly known forms of IBD are Crohn's disease and ulcerative colitis. Unlike IBS, where there are no pathophysiologic changes in the colon, IBD is characterized by inflammation of the intestine resulting in abdominal cramping and persistent diarrhea. These conditions can range from mild to severe and can be life threatening when the inflammation becomes sufficiently advanced and widespread. Common treatments include medications to reduce inflammation and suppress the immune system. Surgery is sometimes required to remove portions of the intestines damaged by inflammation. Hypnosis has been shown to be a useful adjunctive treatment for IBD, reducing pain and inflammation, and sometimes reducing the amount of steroidal or other medications needed (Mawdsley et al., 2008; Miller & Whorwell, 2008).

Diabetes

Diabetes mellitus refers to two related illnesses that affect how a person metabolizes glucose. In type I diabetes, the pancreas stops producing insulin, likely due to some form of autoimmune process. Type I diabetics need to carefully monitor insulin replacement therapy in order to survive. In type II diabetes, insulin receptor cells have ceased to function (also known as insulin resistance), regardless of whether the pancreas is producing enough insulin. The liver may also be affected, producing more glucose than the body needs. Type II diabetes is associated with high-glycemic, high-fat, high-calorie diets, obesity, and lack of exercise (Alberti & Zimmet, 1998).

Diabetes is a ubiquitous problem that has major ramifications for our health system, costing billions of dollars per year. Patients with diabetes are at higher risk for cardiovascular disease, compromised vision, kidney disease, and circulatory problems.

Hypnosis has been shown to be a valuable adjunctive treatment for the treatment of diabetes. Stress reduction is a vital part of diabetes management, especially in type II diabetes where it appears to lower blood glucose directly (Surwit et al., 2002). Hypnosis is helpful also by improving compliance behaviors, as well as perhaps directly affecting the balance of glucose and stress hormones such as cortisol (Ratner et al., 1990). Both depression and anxiety can worsen glycemic control both directly and indirectly through unhealthy behaviors. Depression and anxiety can be improved through the use of hypnosis (Stewart, 2005). Also, several categories of diabetes self-care behavior and compliance can be improved through the use of hypnosis (Wichowski & Kubsch, 1999; Xu & Cardena, 2008).

Somatization

Somatization is a crucial yet often overlooked topic across all health settings. Traditionally, somatization has been thought of as the presence of physical symptoms in the absence of organic findings. In fact, it is better understood as a far more frequent phenomenon: namely, physical symptoms that are heightened or amplified by unresolved emotional conflicts. Some studies suggest that the percentage of patients presenting in primary care medical settings with somatization may be as high as 20–23 % (Fink et al., 1999). Somatizers are high utilizers of medical services, seeking frequent evaluation and treatment of their symptoms and yet experiencing little relief. This leads to great distress and frustration on the part of both patients and health providers. Hypnosis can be an essential part of treatment for somatization (Chaves, 1996; Wickramasekera, 1995) by helping to improve patients' willingness and ability to tolerate negative emotions associated with their physical symptoms.

Preparation for invasive medical and dental procedures

Advances in medical technologies such as biopsy, endoscopy, colonoscopy, and interventional radiology have saved countless lives through early detection and treatment of disease. However, patients undergoing these procedures may struggle with severe anxiety regarding these procedures, and may also have difficulty with pain management related to the procedures.

Hypnosis can reduce anxiety, increase the ability to tolerate procedures, improve satisfaction, speed healing, and reduce the need for analgesic medication and sedation in patients undergoing many medical procedures. Clinical hypnosis has been shown to be very useful for reducing distress and ensuring better results from the procedure (Flory et al., 2007). Patients who undergo hypnotic preparation for colonoscopy reported less pre-procedural anxiety and less need for analgesic pain medications (Cadranel et al., 1994). Many patients who utilize hypnosis in preparation for endoscopy require less intravenous sedation (Conlong & Rees, 1999). Lang and her colleagues (2006) demonstrated that women undergoing large-core breast biopsy coped far better and experienced less pain when they were taught a simple self-hypnosis technique to practice. Neron and Stephenson (2007) found that hypnosis was very helpful for reducing many of the most troubling symptoms that people undergo as part of the surgical experience: nausea, vomiting, analgesia, and reduction of pain and anxiety.

Dental procedures include cleaning, repair, and extraction of teeth, treating infections of teeth and gums, replacing damaged teeth, as well as treating and repairing underlying bone. Approximately 25% of all patients have dental anxiety severe enough to cause them to delay needed treatment (Eitner et al., 2006b). Hypnosis has been shown to reduce dental anxiety (Hammarstrand et al., 1995). Hypnosis can contribute to controlling the reflexive gag response, thus facilitating procedures (Eitner et al., 2005). Additionally, clinical hypnosis has been shown to positively affect neurophysiological parameters during dental implant surgery, thereby improving outcomes (Eitner et al., 2006a).

Conclusion

A substantial body of research demonstrates the efficacy of hypnosis as part of the integrative treatment of many of the most common conditions presenting in primary care and specialty care medicine, such as chronic and acute pain, cardiovascular disease, cancer, digestive disorders, and diabetes. Hypnosis is often particularly valuable in the treatment of some conditions that traditional medicine has found difficult to treat. In certain conditions (such as IBS), the evidence for the efficacy of hypnosis is so robust that it could be argued that it is unethical not to inform patients about this treatment modality. Better evidence now exists supporting the use of hypnosis to relieve discomfort associated with many diagnostic and invasive procedures. The emergence of the psychoneuroimmunology (PNI) literature informs us that modalities such as (but not limited to) hypnosis not only enhance comfort but may also alter physiological parameters in many conditions. The advent of increasingly sophisticated brain scanning technology has revealed new insights about how various types of hypnotic suggestions change the activity of specific brain structures.

From an integrative medicine perspective, it is important to utilize therapeutic modalities that are backed by solid empirical evidence. By this criterion, clinical hypnosis has demonstrated its value for relieving suffering and improving outcomes in a number of health conditions.

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15

Neurofeedback and Brain–Computer Interfaces

Sarah Wyckoff and Niels Birbaumer

Neurofeedback and Brain – Computer Interfaces

Biofeedback is a form of behavior therapy in which biological information such as heart rate, respiration rate, skin conductance, hand temperature, muscle activity, and brain activity are recorded and fed back to an individual in real-time to promote learned control or self-regulation of specific parameters. Since the 1960s, the application of various biofeedback modalities has been investigated. In an early publication, Schaefer and Engel (1973) provided a comprehensive bibliography of the first decade of biofeedback studies on instrumental and operant learning of autonomically controlled responses in human and animal subjects. At that time, only a handful of studies investigated the therapeutic application of biofeedback. These early studies focused on the application of heart-related feedback for the treatment of essential hypertension, cardiac arrhythmias, and premature ventricular contractions; muscle activity feedback for the treatment of tension headache, neck injuries, and myofascial pain dysfunction syndrome of the temporomandibular joint; and respiration feedback to reduce anxiety (Schaefer & Engel, 1973). Although instrumental and operant learning of electroencephalographic (EEG) parameters were included in this bibliography, the therapeutic application of "neurofeedback" or "EEG biofeedback" modalities was not investigated until after its publication. The feasibility and practicality of utilizing EEG-based brain signals for human–machine communication was first proposed by Vidal (1973), with an expanded definition of brain–computer interface (BCI) established by Wolpaw, Birbaumer, McFarland, Pfurtscheller, and Vaughan (2002).

Neurofeedback is the process of providing an individual with real-time information of their central nervous system (CNS) activity, including EEG, event related

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potentials (ERP), slow cortical potentials (SCP), blood oxygenation level-dependent (BOLD), and near-infrared spectroscopy (NIRS) signals of cortical or subcortical origin, in an operant conditioning paradigm. Sterman and Friar (1972) published the first neurofeedback case study supporting the application of EEG feedback training of the sensorimotor rhythm (SMR) to suppress seizure activity. These findings spurred the investigation of neurofeedback for the treatment of psychiatric and general medical conditions and led to the emergence of several feedback methods and parameters. Although the majority of studies have focused on the treatment of psychiatric disorders such as attention-deficit/hyperactivity disorder, autism spectrum disorders, anxiety spectrum disorders, learning disabilities, mood disorders, and substance abuse disorders, successful treatment outcomes have been reported for a variety of general medical conditions. In a comprehensive neurofeedback bibliography, Hammond (2011) included neurofeedback studies targeting the treatment of asthma, brain injury, cerebral palsy, epilepsy, fibromyalgia syndrome, migraine, pain disorders, Parkinson's, stroke, tinnitus, and other medical conditions. These studies highlight the *restorative* or therapeutic applications for the conditioning of specific brain activity parameters.

As an outgrowth of biofeedback and neurofeedback methodologies and research, BCI or brain–machine interfaces have emerged as an *assistive* application of the classification and conditioning of specific brain parameters. Rather than focusing on symptom reduction or performance enhancement through the reconditioning of brain activity, BCI technology classifies brain signals to communicate or control external devices by recognizing the user's intention. While most BCI research has focused on methodological issues, the targeted therapeutic applications of BCI technology include communication, movement control, environmental control, and locomotion (Mak & Wolpaw, 2009). The targeted clinical populations for BCI technology consist of individuals with severe CNS damage including stroke and spinal cord injuries and diagnosis of amyotrophic lateral sclerosis (Birbaumer, Ramos Murguialday, Weber, & Montoya, 2009).

This chapter begins with a discussion of the origins and evolution of brain signal recordings and operant conditioning related to neurofeedback and BCI technology. Following this review, current feedback methods and technical requirements are addressed. The chapter concludes with a discussion of therapeutic applications, treatment rationale, and a review of neurofeedback and BCI-related research findings.

Historical Origins and Evolution of the Field

The historical origins of neurofeedback and BCI technology started with the discoveries of Richard Caton and Hans Berger. The first observation of electrical brain activity in live animals was reported by Richard Caton (1875), and, later, Hans Berger (1929) published his discovery of rhythmic alpha wave activity after conducting the first known EEG recordings in humans. These early experiments laid the foundation for modern electrophysiology research and over time led to the detection of spontaneous and event-related patterns of EEG activity. Spontaneous rhythms are traditionally classified into frequency bands based on the number of cycles per second of the waveform. These frequency bands are defined as delta (0.5–4 Hz), theta (4–8 Hz), alpha (8–12 Hz), sensorimotor rhythm or SMR (12–15 Hz), beta (13–30 Hz), and gamma (30–100 Hz). ERPs are activations in the brain that are precipitated by specific sensory, cognitive, or motor events. These stimulus responses are embedded in the spontaneous EEG and usually visible through the averaging of several repeated event trials. Among these ERPs, SCPs are characterized by slow wave changes or oscillations over several seconds below the 1 Hz frequency range. Discrete frequency bands, ERPs, and SCPs are among the most common signals used in neurofeedback and BCI applications.

Following roughly the same time course as EEG research, the process of classical conditioning was established by Ivan Pavlov (1927) following his investigation of stimulus–response interactions. He observed that an *unconditioned response* was not learned and occurred naturally in response to an *unconditioned stimulus*, i.e., salivating at the sight of food, while a *conditioned response* could be learned and elicited by a *conditioned stimulus* that was previously neutral until paired repeatedly with an unconditioned response, i.e., salivating upon hearing footsteps of the person delivering the food (Pavlov, 1927). The process of operant conditioning was established through the work of Edward Thorndike and B. F. Skinner. Expanding on Thorndike's *Law of Effect*, which held that behaviors followed by an aversive consequence had a tendency to decrease while behaviors followed by a pleasurable or rewarding consequence had a tendency to be repeated, Skinner (1953) developed the process of shaping behavior and learning through reinforcement or punishment. Skinner postulated that *reinforcers* are designed to increase and strengthen the probability that a desired behavior will be repeated by providing a pleasurable consequence (positive) or removing an unpleasant consequence (negative). Equally, *punishments* are designed to decrease or weaken the probability of a specific behavior occurring by providing an aversive consequence (positive) or removing a pleasurable consequence (negative).

The paths of EEG and behavioral conditioning did not converge until the 1930s, when researchers began to investigate the possibility of conditioning brainwave activity (review; see Sherlin et al., 2011). Early research focused on evaluating the therapeutic effects of restorative neurofeedback methods for epilepsy and attention-deficit/hyperactivity disorder. In most cases, these studies employed training parameters extracted from the classically defined frequency bands. Shortly thereafter, restorative and assistive feedback methods began to incorporate SCP frequency activity and classification of other ERP components for BCI development. The latest generations of feedback and BCI methods focus on the regulation or classification of BOLD signal. Specifically, real-time fMRI (rtfMRI) applications provide feedback of BOLD response changes (Weiskopf et al., 2003) and NIRS applications feedback changes in the concentrations of oxyhemoglobin and deoxyhemoglobin during the hemodynamic response (Sitaram et al., 2007). The therapeutic applications and treatment findings of EEG, SCP, NIRS, and rtfMRI-based neurofeedback methods will be discussed later in the chapter.

Basics, Methods, and Requirements

Whether it is for healthy or pathological populations, clinical or research settings, restorative or assistive feedback methods, or utilization of EEG, SCP, ERP, or BOLD signal data, there are some standard principles that guide neurofeedback training and BCI research. At the most basic level, both methods require extraction of real-time brain signal information, specific training goals or tasks, and instantaneous feedback and reward to shape behavior. Both neurofeedback and BCI classification are guided by the principle that specific mental states, cognitive processes, and disorder-related symptoms have specific neurological correlates that can be measured, classified, and visualized. This activity can either be retrained through operant conditioning or classified to operate assistive interface devices, resulting in cognitive, behavioral, or physiological improvements. Neurofeedback and BCI-specific training goals differ by diagnosis, device features, behavioral and neurological correlates, and assessment practices. For example, SCP feedback for the treatment of epilepsy may focus on increasing the differentiation between positive and negative potentials over central sites, while EEG feedback protocols may reward enhanced SMR amplitudes over central electrode sites. BCIs may activate the grasping function of a robotic orthosis following the desynchronization of SMR activity during an “intention to move” task, while others may activate letter selection features following P300 spikes during a visual discriminant task.

For neurofeedback applications, training protocols target pathological or performance-related components of the brain activity. Protocol selection may be guided by EEG, fMRI, and NIRS research or quantitative EEG (QEEG) analysis with or without database comparisons. While older feedback methods utilize cortical EEG activity of the outer layers of the brain for entrainment parameters, newer methods provide feedback of low-resolution electromagnetic tomography (LORETA) current source densities from deeper cortical levels (Congedo, Lubar, & Joffe, 2004). In any case, the brain signal information is linked to various feedback instruments and presented as a game-like task in which points or audiovisual rewards are earned for meeting all parameters. The feedback may represent frequency band waveforms, averaged frequency amplitudes, power ratios, percentages of time under a specific threshold, muscle artifacts amplitude, etc. Through the process of operant conditioning and shaping procedures, the individual learns self-regulation strategies.

BCI applications target components of the EEG, ERPs, and BOLD signal that encode and strongly correlate with the “intent” of the user. The individual is asked to execute imagery or motor tasks that produce activations in specific areas of the brain. Task-related components are then extracted and converted into BCI device commands using dynamic translation algorithms (Wolpaw & Wolpaw, 2011). The accuracy of classification and prediction for machine-learning algorithms can be optimized through the repeated acquisition of the task components. In turn, this improves the performance, accuracy, and speed of the BCI technology in response to the commands. The neurofeedback component of BCI training also helps to optimize performance by providing information that will allow the user to develop, modify, and consolidate state-specific brain activation strategies to operate the BCI technology (Min et al., 2010).

Depending on the learning strategy employed, individuals complete assessments and training blocks while seated in front of a training computer or while lying in an fMRI scanner in view of a projected image of the training screen. Training sessions may occur at a frequency of multiple sessions a day to single weekly sessions. Session lengths vary and may last 30 minutes to 1.5 hours, including preparation and clean-up. Within the individual sessions, baseline, feedback, and task conditions may be organized into training runs of cued trials and reward, blocks of continuous feedback, or alternating blocks of activation/deactivation or classification/application. In research, neurofeedback protocols typically include 20–40 training sessions with supplemental training to help the individual generalize newly acquired self-regulation skills for long-term symptom improvement. In clinical settings, the length of treatment is dependent on individual response and may include session titration and/or booster sessions. BCI applications are designed for long-term assistive use by individuals to communicate, move, and control their environment. However, the majority of studies on BCI technology have focused on proof of concept, classification algorithms, and product development. Few have assessed longer-term usability in clinical populations.

The following sections provide a discussion of the acquisition procedures for EEG and BOLD brain signals. For each signal type, a description of the signal origin, technical requirements, signal quality, and signal-processing methods will be addressed.

EEG Signal Activity

EEG activity reflects the summation of excitatory and inhibitory postsynaptic potentials in the pyramidal cells of the cerebral cortex, with additional contributions from granular and glial cell activity (for reviews, see Lopes da Silva, 1991; Speckmann & Elger, 1999). The coordinated action of glial networks (Fellin et al., 2009) and the synchronous extracellular current flow of neurons with a similar spatial orientation radial to the scalp generate large field potentials that can be recorded on the surface of the head. The recording of EEG brain activity may be an invasive or non-invasive procedure. Invasive applications are less common and rely on electrical activity recorded from electrodes surgically placed on the surface of the cortex under the skull. Non-invasive applications acquire activity from electrodes (typically, silver/silver chloride) applied to the scalp with conductive paste or electrode caps. A series of head measurements ensures that electrodes are placed in accordance with the international 10–20 system and target areas producing meaningful neural information. Preparation of the skin with mildly abrasive gels allow for the removal of oil and dead skin, enhanced signal quality and impedances, and skin resistance measures of 5–10 kΩ for each lead. Control of muscle-, ocular-, cardiac-, and respiratory-related artifacts is paramount for quality feedback and signal classification.

Monopolar, bipolar, multiple-channel, or whole-head montages may be utilized during the recordings and dictate the manner in which electrode pairs are connected to the amplifier, referenced, and positioned on the scalp. In both invasive and non-invasive procedures, the electrical brain activity is acquired, amplified, and digitized for analysis, feedback, or feature extraction. Spectral decomposition of raw EEG activity through Fourier transforms allows for the separation of the classic frequency bands (delta, theta, alpha, SMR, beta) and the calculation of activity within each band range (e.g., amplitudes, power ratios). Bandpass filtering, manipulation of time constants ($<$100 ms to 10 s), and averaging of time-locked stimulus cues allow for the assessment of specific ERPs (e.g., P300) and SCP data (see Birbaumer, Elbert, Canavan, & Rockstroh, 1990, for review). The processed signal is then linked to feedback parameters or routed into BCI algorithms.

Technological advancements and improvements to amplifier recording capabilities, electrode quality, artifact control, and signal processing have enhanced the quality of recordings. EEG is an inexpensive, portable, user/research-friendly technique with high (ms or better) temporal resolution (Min et al., 2010). However, this method of brain signal recording has limited spatial resolution (approximately 1–2 cm^3) and may be affected by inter-individual differences in the thickness, geometry, and conductive properties of the skull and brain tissue.

BOLD Signal Activity

NIRS- and rtfMRI-based neurofeedback and BCI methods rely on metabolic brain signals related to the hemodynamic response. The BOLD response is considered as an indirect measure of neural activity. Logothetis (2002) reports that increases in neuronal activity correspond with increases in BOLD response, while Shmuel, Augath, Oeltermann, and Logothetis (2006) report that the negative BOLD response is coupled with decreased neuronal activity. BOLD activity is influenced by shifts in deoxygenated hemoglobin concentrations related to changes in cerebral blood volume, cerebral blood flow, and oxygen metabolism following neural firing (Buxton, Uludağ, Dubowitz, & Liu, 2004). Technological advancements in fMRI and NIRS data acquisition and processing techniques have allowed for real-time fMRI analysis and feedback of the BOLD signal from a targeted region of interest. While the temporal resolution of BOLD changes in the fMRI and NIRS signal is low (1–2 s) to moderate ($>$100 ms) due to hemodynamic delays, the spatial resolution is superior in comparison to EEG (Min et al., 2010). The spatial resolution of fMRI is maximally 1 mm and 1 cm for NIRS.

During fMRI signal acquisition, a series of brain images are acquired, measuring the increases and decreases of paramagnetic load of blood-flow to activated poles of neurons (Sitaram, Caria, & Birbaumer, 2009). The data collection procedure begins with prepping the individual to be placed into the MRI scanner. Earplugs are provided to reduce noise discomfort due to the scanner sequence sounds, while head padding and bite guards are utilized to help prevent head and muscle movement artifacts. Functional images are exported to a host computer, freed of artifact, signal denoised, and then used for incremental statistical analysis and generation of functional maps of a region of interest. Calculated and baseline-normalized differences in BOLD activity between target and reference regions of interest can be linked to feedback instruments or routed to BCI algorithms (Sitaram et al., 2009).

NIRS imaging methods utilize light in the near-infrared range to determine cerebral oxygenation, blood flow, and metabolic status of localized regions of the brain, producing a signal that is equivalent to the BOLD signal (Sitaram et al., 2009). During NIRS acquisition, pairs of light sources and light detectors (optodes) operating at two or more discrete wavelengths are used to record changes in oxygenation. This procedure is based on the observation that the functional state of living tissue will influence the properties of light passing through the tissue. The optodes are applied to the head at a distance of 2–7 cm to allow continuous light to pass through the intermediate layers of the scalp, skull, and tissue, at a depth of approximately 1–5 cm. The attenuation of light at the detector optodes yields qualitative differences in the concentrations of oxygenated (oxyHb) and deoxygenated hemoglobin (deoxyHb) that can be linked to feedback instruments or routed to BCI algorithms.

The following sections focus heavily on the review of neurofeedback research for the treatment of drug-resistant epilepsy and migraines, as well as the clinical applications of BCI technology for individuals with amyotrophic lateral sclerosis (ALS) and severe CNS damage including stroke and spinal cord injuries. Additionally, a brief discussion of neurofeedback applications for other medical conditions including asthma, brain injury, cerebral palsy, fibromyalgia syndrome, chronic pain, Parkinson's disease, stroke, and tinnitus will be provided.

Clinical Applications of Neurofeedback

The efficacy of neurofeedback treatment methods has been investigated in childhood and psychiatric disorders. Two recent meta-analyses have reported on the efficacy of neurofeedback as a non-medication treatment alternative for attention-deficit/hyperactivity disorder. Analysis of several randomized controlled trials and pre/post studies indicated an overall medium effect size (Lofthouse, Arnold, Hersch, Hurt, & DeBeus, 2012) for the reduction of ADHD core symptoms, medium effect size for hyperactivity, and large effect sizes for inattention and impulsivity (Arns, de Ridder, Strehl, Breteler, & Coenen (2009). Additional publications have reviewed treatment effects for autism (Holtmann et al., 2011), substance abuse disorders (see Sokhadze, Cannon, & Trudeau, 2008, for review), anxiety (see Moore, 2005, for review), depression (Dias & van Deusen, 2011), and other disorders. The findings have largely been positive, leading to the investigation of these treatment approaches for a variety of general medical conditions.

Epilepsy

Epilepsy is one of the most common neurological disorders worldwide and is characterized by recurrent seizures resulting from a disturbed balance between excitation and inhibition of neurons located predominantly in the cerebral cortex and hippocampus. This chronic disorder affects people of all ages and has an annual prevalence of 7.1 per 1,000 people in the United States alone (Hirtz et al., 2007). Epilepsy results from head injuries, infections, tumors, congenital and genetic conditions, cerebrovascular disorders, and, for about 60% of individuals, an unknown cause (WHO, 2009). Seizures may be a product of activation of neurons "focused" in one or more areas of the cortex with or without loss of consciousness (partial) or activation of neurons in both hemispheres (generalized). While medication is the most common treatment for the disorder, feedback of EEG rhythms has been successful in the treatment of epilepsy.

The investigation of EEG-based feedback methods for the treatment for intractable epilepsy has a 40-year history and essentially spurred the field of neurofeedback. Epilepsy-related neurofeedback research in the United States has historically focused on the augmentation of SMR with or without simultaneous inhibition of slow frequency rhythms, whereas research in Europe has focused on the self-regulation of SCP activity. SMR training has its roots in animal research. Sterman and colleagues at UCLA were the first to discover that cats were able to learn to increase the production of 11–15 Hz activity over the somatosensory cortex (see, Sterman, 2000, for review). Serendipitously, this training resulted in a curious confound in a future study investigating the convulsive properties of toxic compounds used as rocket propellants. Non-conditioned cats in the study were found to have convulsions with exposure to the toxic compound, while SMR training appeared to increase seizure thresholds for the conditioned cats. Sterman and Friar (1972) were the first to investigate the effects of SMR training on seizure suppression in a single human case study design. Following SMR training, the individual reported the suppression of seizure activity for a 3-month period, as well as enhanced sleep and mood changes. These and future findings eventually led to the hypothesis that the entrainment of thalamocotical regulatory mechanisms through SMR training reduces neuronal excitability, blunts the impact of transient neuronal discharges, and stabilizes state characteristics, thus countering the abnormal and excessive synchronous neuronal discharges and cortical hyperexcitability observed in epileptic populations (Sterman, 2000).

Birbaumer and colleagues developed a physiological model in which SCP activity was hypothesized to reflect threshold regulation mechanisms of cortical activation and inhibition, with negative shifts reflecting increased firing probabilities of a cell assembly and positive shifts reflecting inhibited firing probabilities (see Birbaumer et al., 1990, for review). Research indicated that healthy and clinical populations were able to learn self-regulation of negative and positive SCP shifts over central electrode sites (Birbaumer, Roberts, Lutzenberger, Rockstroh, & Elbert, 1992; Holzapfel, Strehl, Kotchoubey, & Birbaumer, 1998). The application of this feedback method as a treatment for epilepsy was supported by the neurological characteristics of the disorder and the observation that negative shifts proceed and persist during ictal discharges and positive shifts develop after seizure termination (Ikeda et al., 1997). Therefore, epilepsy was conceptualized as a problem of restraining the hyperactivation of neurons accompanied by increased cortical negativity and decreased thresholds for paroxysmal activity. The learned suppression of negative SCP activity was hypothesized to attenuate epileptic discharges and reduce seizure frequency. Two multicenter studies have shown that individuals with epilepsy are able to learn self-regulation of SCP activity leading to significant reductions of seizure incidence (Rockstroh et al., 1993; Kotchoubey et al, 2001).

In a comprehensive review of the early neurofeedback studies (1972–1996), Sterman (2000) reported summarized data related to seizure reduction and EEG changes following SMR training. Tabulation of salient findings indicated that 82% of individuals reported significant seizure reduction (>30%), with 5% reporting complete control of seizure for up to 1 year. Evaluation of EEG changes during training sessions and clinical recordings indicated that 66% of participants showed significant effects. A meta-analysis of EEG feedback studies (1974–2001) targeting individuals with treatment-resistant epilepsy indicated that operant conditioning of SMR and SCP activity produced a significant ($p < 0.005$) reduction in seizure frequency (Tan et al., 2009). Inclusion criteria required the studies to be peer-reviewed publications, utilize SMR or SCP protocols, provide complete information on patient selection, and individual pre-post treatment seizure rates. The meta-analysis population was diverse, including individuals aged 6–55 years with varied seizure types. Following treatment, a mean reduction in seizure incidence was reported in all studies, and 74% of patients reported fewer weekly seizures in response to neurofeedback (Tan et al., 2009). Table 15.1 provides a summary of the treatment studies included in this meta-analysis, with emphasis on study protocol and treatment outcome variables.

In a series of recent publications, Walker and colleagues reported on the efficacy of QEEG-based neurofeedback protocols. Walker and Kozlowski (2005) developed individualized protocols that targeted power and coherence abnormalities throughout the brain. Training locations and frequency bands were not limited to the semi-standardized SMR or SCP protocols. Patterns of statistically abnormal activity were triaged and targeted in 5–10 sessions each. Review of individual case studies indicated that QEEG-based training led to seizure-free periods (with and without

Table 15.1 Summary of neurofeedback research for epilepsy

Authors	*Placement/Protocol*	*Results*
Sterman et al. (1974)	Rolandic cortex Contingent feedback ↑ SMR (12–16 Hz)	Following NF, non-epileptic participants showed increased 12–16 Hz activity at 20–25 μV over central and frontal areas. Epileptic participants failed to demonstrate enhanced SMR amplitudes, but the increased occurrence of this frequency was accompanied by a significant reduction in EEG spectral power, epileptic spike activity, and seizure incidence. The reduction of tonic-clonic and myoclonic seizures were the most marked.
Kaplan (1975)	Rolandic cortex Contingent feedback ↑ SMR (12–14 Hz) or ↑ 6–12 Hz	Following NF of 12–14 Hz, two epileptic participants demonstrated no effect on clinical EEGs, seizure incidence, or proportion of EEG spectral power in the training range. Following NF of 6–12 Hz, two of three epileptic participants experienced reductions in seizure not accompanied by medication changes or learning of 6–12 Hz activity.
Lubar et al. (1976)	Rolandic cortex Contingent feedback ↑ SMR (12–14 Hz) with ↓ 4–7 Hz	Following NF, two participants were seizure free for periods of up to 1 month. Others developed the ability to block seizures and reported a decrease in the intensity and duration of seizures. Successful participants demonstrated an increase in the amount and amplitude of SMR during training.
Kuhlman et al. (1978)	Rolandic cortex Non-contingent/ contingent ↑ SMR (9–14 Hz)	Following contingent NF, five participants reported seizure reductions and changes in EEG activity, but not when NF was non-contingent.
Sterman et al. (1978)	C3-T3 A-B-A reversal ↑ SMR (12–15 Hz) or ↑ 18–23 Hz with ↓ 6–9 Hz	Six of eight participants reported significant and sustained seizure reductions following reward for either SMR or 18–23 Hz in the absence of 6–9 Hz. Seizure rates returned to baseline when SMR reinforcement contingencies were reversed, but not when 18–23 Hz contingencies were reversed.
Cott et al. (1978)	Rolandic cortex Contingent feedback ↑ SMR (12–14 Hz) with ↓ 4–7 Hz	Following NF, five or seven participants demonstrated a significant reduction in seizure incidence and severity. Three participants showed an increase in SMR, and four showed reduced 4–7 Hz activity.

Table 15.1 (*Continued*)

Authors	*Placement/Protocol*	*Results*
Quy et al. (1979)	Rolandic cortex Non-contingent/ contingent ↑ SMR (12–16 Hz) ↑ 8–10 Hz ↓ High-voltage EEG	Following NF, all three participants experienced a significant reduction in seizure rate. Seizure rate reduction was not related to any one particular training condition, suggesting that the therapeutic mechanism might involve placebo effects, relaxation training, or a facilitation of EEG desynchronization.
Lubar et al. (1981)	Rolandic cortex A-B-A reversal ↓ 3–8 Hz/↑ SMR (12–15 Hz) or ↓ 3–8 Hz/↑ 11–19 Hz	Participants were assigned to three treatment groups based on different schedules of EEG feedback. Following NF, five of eight participants experienced a decrease in their mean monthly seizure rate as compared to baseline.
Tozzo et al. (1988)	Rolandic cortex Multiple baseline ↑ SMR	Following a single-subject, multiple-baseline design utilizing six phases (baseline one, relaxation training; baseline two, biofeedback training one; baseline three, biofeedback treatment two and follow-up), all participants were able to significantly increase percent time in SMR activity. Five of six participants demonstrated decreased seizure frequency during the treatment phase, two benefited from relaxation training, four demonstrated significant negative correlations between percent SMR and seizure rates.
Kotchoubey et al. (2001)	Rolandic cortex, Cz Contingent feedback Bidirectional SCP Respiration training Medication/ counseling	Clinical, cognitive, behavioral, personality, and placebo measures were assessed before and after treatment. Participants in the SCP and medication groups reported a significant decrease in seizure frequency, while participants in the respiration training group did not. Sociopsychological adjustment was obtained in all three groups, with maximal improvement observed in the respiration group.

Note: NF = neurofeedback, SCP = slow cortical potential, SMR = sensorimotor rhythm medication) of 3 months for nine of 10 study participants. In a follow-up study, Walker (2008) reported treatment outcomes for an additional 25 individuals, indicating that all patients became seizure-free after addressing a majority of their QEEG abnormalities. Analysis of the frequency of QEEG abnormalities revealed a variety of deviations in absolute and relative power and coherence measures, with all patients having at least one area of focal slowing and 75% presenting with theta-band hypocoherence. These studies support the use of QEEG assessments to enhance and supplement standardized protocols.

In some cases, researchers report that proprietary symptom-based profiles and checklists developed through clinical neurofeedback experience may be helpful in guiding protocol selection, especially in complex cases. In a recent multiple case study, Legarda, McMohon, Othmer, and Othmer (2011) presented treatment outcome data for three children with epilepsy spectrum disorder. In each case, the children suffered seizures in addition to comorbid learning or psychological disorders, polypharmacotherapy, and diverse QEEG findings. The information collected from the EEG Spectrum International symptom profile checklists (Othmer, 2008) proved to be more informative in guiding treatment than QEEG data. In all cases, multiple bipolar training sites were utilized to target the EEG activity from infra-slow oscillations (as low as 0.0001 to .2 Hz) up to 40 Hz activity that correlated with specific brain structures and desired behavioral state shifts (calmness, alertness, clarity). Reported treatment outcomes included a reduction of headache frequency, sleep enhancement, titration of medication, seizure and comorbid symptom reduction, and improvements on the test of variables of attention (Legarda et al., 2011).

As a whole, the body of research on the use of neurofeedback for the treatment of epilepsy is positive. The treatment rationale and efficacy of SMR- and SCP-based protocols have consistently been shown and are well established. However, as with other interventions, not all individuals respond to these protocols. Additional research should focus on conducting large-scale randomized control studies, treatment comparisons, assessing treatment response prediction, and the establishment of rationales for QEEG or checklist-based protocols.

Migraines

Akin to the rationale for the use of SCP feedback for the treatment of epilepsy, it was hypothesized that training individuals with migraines to suppress negative SCPs (i.e., to produce positive shifts) would attenuate cortical excitation, resulting in a reduction of migraine frequency and intensity. This was supported by the research of Welch and Ramadan (1995), in which disordered mitochondrial oxidative phosphorylation and decreased intracellular free magnesium in the brain and body tissue of migraine patients was hypothesized to produce instability of neuronal functions due to neuronal hyperexcitability. Migraine patients also appeared to produce increased contingent negative variation (CNV) amplitudes and reduced habituation compared to healthy controls (see Kropp, Siniatchkin, & Gerber, 2002, for review), resulting in greater general allocation of attentional and mental resources to tasks in a migraine population.

The clinical efficacy of SCP training for the treatment of childhood migraines was investigated in a population of 10 children suffering with migraines, compared to 10 healthy controls and 10 wait-listed migraine sufferers (Siniatchkin et al., 2000). Migraine sufferers demonstrated an impaired ability to regulate negative shifts during the initial two sessions, especially during the transfer trails. However, after the completion of 10 SCP feedback sessions, no significant difference in the ability to self-regulate SCP activity was observed between the children with migraines and healthy controls. Additionally, the children with migraines showed a significant reduction in CNV amplitudes and reported significant reductions in migraine or other headache frequency.

In a review of neuromodulatory approaches for treating chronic pain conditions, Jensen, Sherlin, Hakimian, and Fregni (2009) summarized several early neurofeedback studies targeting headache and migraine reduction. Alpha enhancement training (variable reward; 8–13 Hz) in the occipital lobe was reported to lead to a reduction in the frequency of headache activity, and variable findings in the reduction of headache intensity, durations, or EEG changes. Two recent studies have investigated other protocol-based or QEEG-informed frequency training. The first study utilized a combined neurofeedback (average of 30 sessions) and thermal biofeedback (average of 10 sessions) treatment (Stokes & Lappin, 2010). The neurofeedback protocol followed the EEG Spectrum International (2005) approach, targeting the reduction of frequency ranges with the highest amplitudes and rewarding the difference between amplitude activities over multiple bipolar homologous sites. The temperature training protocol involved hand warming biofeedback and passive infrared hemoencephalography (pIR HEG) biofeedback in which the individual was challenged to increase forehead temperatures at FPZ using a headband sensor. Following the combined training, Stokes and Lappin (2010) reported that 70% of the migraineurs experienced at least 50% reduction in headaches as well as improvements to focus, mood, and sleep. The major limitation of this study was that the combined treatment approach did not allow for neurofeedback-specific effects to be assessed, as both biofeedback techniques have been shown to be effective in migraine and headache reduction (Andrasik, 2010).

In a QEEG-based investigation, Walker (2011) presented outcome data from 71 individuals diagnosed with migraine without aura. Following a QEEG assessment, all individuals presented with excess beta activity (21–30 Hz) in multiple areas of the cortex. The migraineurs self-selected neurofeedback ($n = 46$) or drug therapy. The neurofeedback protocol consisted of rewarding 10 Hz activity and inhibiting beta (21–30 Hz) activity at several QEEG-based locations for five sessions each. Following treatment, the comparison of neurofeedback versus drug therapy revealed that migraine reduction was superior for the neurofeedback group (Walker, 2011). For the individuals in the neurofeedback group, 54% reported complete cessation of migraines, 39% reported a 50% reduction of migraines, 4% reported

<50% reduction of migraines, and only one individual reported no changes to migraine frequency. For the individuals in the drug therapy group, no individuals reported cessation of migraine, 8% reported a 50% reduction of migraines, 20% reported a <50% reduction of migraines, and 68% reported no change in migraine frequency.

Chronic pain

Subsequent to case studies and controlled trials suggesting that neurofeedback improved function and reduced symptoms associated with seizure severity (Tan et al., 2009), migraine, and attention (Arns et al., 2009), researchers began to investigate the utility of this method to alter the cortical processing of nociception, or the ability to sense pain (see, Jensen, Sherlin, Hakimian, & Fregni, 2009, for review). A series of studies have assessed pain reduction for individuals diagnosed with chronic pain, complex regional pain syndrome (CRPS), fibromyalgia, and spasm-related pain. Melzack and Perry (1975) were among the first to explore the use of neurofeedback, specifically alpha training, as a method for pain management. They asserted that alpha training contributed to pain relief by teaching individuals to distract themselves from pain by redirecting attention to inner feelings or a training task, promoting hypnotic suggestibility, reducing arousal and pain sensory input, and developing an individual locus of control through self-regulation training. To test this hypothesis, they recruited 24 patients with medication-resistant chronic pain and assigned them to a combined alpha training and hypnosis group ($n = 12$), or a hypnosis only ($n = 6$) and alpha only ($n = 6$) training groups. The results indicated that occipital alpha training in combination with hypnotic training that emphasized ego strengthening, progressive-relaxation techniques, and placebo effects such as distraction, suggestion, and anticipation of pain reduction led to marked reduction in severe clinical pain (Melzack & Perry, 1975). However, neurofeedback alone only produced trends in pain reductions.

Utilizing another combined procedure, Sime (2004) presented a case study in which a combination of peripheral biofeedback (muscle tension reduction and diaphragmatic breathing), stress management, and neurofeedback was applied to treat trigeminal neuralgia in a 46-year-old woman. Overall, the individual experienced a reduction in pain and bruxism, improved sleep quality, medication titrations, and was able to avoid surgery to sever the trigeminal nerve. Neurofeedback training was guided by the EEG Spectrum International (Othmer & Othmer, 2000) methodology. Protocols targeted the sensorimotor strip (including T4, C3, C4, C3-C4, and T3-T4), rewarded activity between 7.5 Hz and 10.5 Hz, and inhibited activity at 2–7 Hz and 22–30 Hz. According to the clinician, the individual experienced the greatest amount of pain reduction following training at T3-T4, with treatment effects lasting throughout a 13-month follow-up period (Sime, 2004).

In a retrospective study, Jensen, Grierson, Tracy-Smith, Bacigalupi, and Othmer (2007) presented outcome data from 18 individuals with complex regional pain syndrome type I that participated in a multimodal training program consisting of neurofeedback, medication management, physical therapy, and psychotherapy. Neurofeedback protocols were guided by the EEG Spectrum International protocol decision tree and training rationale, targeted activity at a series of bipolar training sites (P3-P4, FP1-FP2, T3-T4, FPO2-A2, Cz-Fz, F7-F8, and F3-F4). Adjustments to the frequency band reward and inhibits were made on a client-by-client basis, utilizing a signal bandwidth of 0.5–30 Hz activity. Following neurofeedback, a substantial (large effect size; $d = 1.03$) and statistically significant reduction in pain intensity at primary pain sites was reported, with 50% of participants reporting a 30% or greater reduction in pain levels (Jensen et al., 2007).

Due to the multimodal approaches utilized by Sime (2004) and Jensen et al. (2007), treatment specificity of EEG-based neurofeedback for chronic pain cannot be established and requires further research. However, the investigation of rtfMRI feedback methods utilized careful experimental control and strict design methods to determine potential treatment effects. For example, deCharms et al. (2005) investigated the efficacy of rtfMRI feedback of the rostral anterior cingulate cortex (rACC) on the pain levels of 16 healthy volunteers and 12 patients with chronic neuropathic pain compared to several control conditions. The rACC was selected as the activation signal of interest due to its involvement in pain perception and regulation. Active feedback participants were requested to use a variety of cognitive strategies (modulation of attention, stimulus quality percept, stimulus severity percept, and control percept) to increase and decrease BOLD activity in an imaginal training task. Participants in the control groups (four groups, $n = 32$) were trained and assessed using similar procedures, without valid rACC rtfMRI information provided. The healthy individuals in the active feedback group ($n = 8$) learned to control rACC activity, with control increasing monotonically over the training sessions, and corresponding with changes in their perception of pain measured through pain intensity ratings. The improvement in control over pain intensity was significantly larger in the active feedback group compared to individuals in control groups that received extended practice without feedback, extended training on focusing attention away from pain, or sham feedback (activation of a different brain region or presentation of another individual's brain activity). The individuals with chronic pain ($n = 8$) in the active feedback group reported a substantial reduction in their average baseline pain ratings, a 44–64% reduction in pain ratings after training, and decreased pain intensity. These participants also reported significantly greater (3X) pain reduction compared to individuals assigned to sham feedback (feedback of skin conductance, heart rate, and respiration activity). Finally, a significant correlation was observed between the extent to which an individual learned to control rACC activation and their decrease in pain ratings (deCharms et al., 2005).

Fibromyalgia syndrome (FMS)

FMS is a syndrome causing long-term, body-wide tenderness and pain in muscles, tendons, soft tissues, and joints, and is often associated with sleep problems, fatigue, cognitive impairment, depression, anxiety, and headaches (Fibromyalgia, 2012). The initial application of neurofeedback as a treatment from FMS was based on the research of Alanoğlu et al. (2005) and Ozgocmen et al. (2003) indicating that individuals with FMS demonstrated reduced P300 amplitudes and the findings of Egner and Gruzelier (2001) revealing that rewarding SMR activity enhanced P300 amplitudes (as cited in Kayiran, Dursun, Ermutlu, Dursun, & Karamursel, 2007). Using a case study design, Kayiran et al. (2007) investigated the efficacy of a theta (4–7 Hz) inhibit and SMR (12–15 Hz) reward protocol for symptom reduction in three women diagnosed with FMS. It was hypothesized that SMR enhancement training would have a therapeutic effect for individuals suffering with FMS by promoting activation of inhibitory processes implicated in the perceptual amplification of pain and neurosensitization. The efficacy of similar theta-SMR protocols is well documented in the treatment of attention-deficit/hyperactivity disorder (see Arns et al., 2009, for review) and was hypothesized to address the cognitive symptoms of FMS. Following neurofeedback therapy, the women reported varying levels of improvement including reductions of pain, fatigue, depression, anxiety, improvements in social and physical functioning, general and mental health, and protocol-specific changes to EEG activity (Kayiran et al., 2007).

Based on the preliminary findings of this investigation, Kayiran, Dursun, Dursun, Ermutlu, and Karamursel (2010) designed a randomized single-blind investigation comparing neurofeedback and medication for the treatment of FMS. The experimental group received the same neurofeedback protocol employed in the pilot investigation (Kayiran et al., 2007) and control participants received 10 mg of escitalopram (SSRI) per day. Following the assigned course of treatment, both groups had significant reductions to FMS core symptoms, pain, fatigue, depression, and anxiety symptoms and reported improvements of functioning (physical, emotion, and social), vitality, and general and mental health (Kayiran et al., 2010). However, the neurofeedback group displayed greater symptom improvement and experienced faster therapeutic effects compared to the control group.

Focused on addressing both somatic and cognitive symptoms of FMS, Caro and Winter (2011) assessed the efficacy of neurofeedback to a “treatment as usual” control group. All participants were assessed for somatic symptoms before and after treatment. The neurofeedback group also completed an audio and visual continuous performance test (CPT). The neurofeedback protocol rewarded the reduction of theta (4–8 Hz), reduction of beta (22–30 Hz), and the enhancement of SMR (12–15 Hz) activity. Following the treatment period, the neurofeedback group reported a significant reduction of pain, fatigue, tender point scores, and subscales of the visual CPT related to attention, commission errors, and response sensitivity and variability (Caro & Winter, 2011). Post-hoc analysis of the control group did not yield significant somatic improvements during the same treatment period.

Cerebral palsy and Parkinson's disease

Several case study and small group designs have investigated the application of EEG and rtfMRI feedback for movement disorders including cerebral palsy and Parkinson's disease. Supported by the work of Al-Sulaiman (2001) and Maruyama et al. (2002), indicating the diagnostic and predictive value of EEG activity in a pediatric population with cerebral palsy (CP), Ayers reported a 25-year history of treating patients with QEEG-based neurofeedback (as cited in Ayers, 2004). Ayers indicated that EEG activity is quite variable in this population and clinicians require extensive knowledge of the neurological reflexes and deficits of the disorder in conjunction with access to EEG, MRI, and other neuroimaging data to create successful training protocols. Most commonly, bipolar training montages were employed and focused on the reduction of excess theta activity over the motor and sensorimotor cortex for mobility training and spasticity. In the case study presented, Ayers (2004) indicated that theta reduction protocols targeting leg, arm, and speech centers produced significant and long-term improvements to academic, behavioral, and physical functioning in a 9-year-old boy with CP and tonic spasticity. Similar improvements were reported in another case study, indicating that the inhibition of theta and reward of SMR activity over the sensorimotor cortex resulted in reduced spasticity and startle response, improved arm mobility, and enhanced cognition and mood (Bachers, 2004). The feasibility and test–retest reliability of EEG-based brain-mapping procedures in children with CP was recently investigated. Lee et al. (2012) reported excellent reliability between repeated measures of reach and grasp hand movement tasks (ranging from .93 to .99, $p < .001$) and the ability of the mapping procedure to discriminate children with and without the disorder.

Thompson and Thompson (2002) employed a combined neurofeedback and biofeedback protocol for the treatment of a 47-year-old woman with a dual diagnosis of Parkinson's disease (PD) and left-sided dystonia. Training goals included the rewarded enhancement of 13–15 Hz activity over the midline (FCz-CPz), inhibits placed on dominant slowing (6–10 Hz) and high-beta (25–32 Hz) activity, and paced diaphragmatic breathing excises to increase respiratory sinus arrhythmia activity and promote relaxation. The combined training protocol was associated with a significant reduction in dystonic movements, in addition to improved concentration and the ability to control episodes of muscle freezing (Thompson & Thompson, 2002). The application of EEG neurofeedback for the treatment of PD was further extended in a randomized partial crossover sham feedback controlled study. Erickson-Davis, Anderson, Wielinski, Richter, and Parashos (2012) randomly assigned individuals with PD to an active feedback ($n = 5$; reward 8–15 Hz, inhibit 4–8 Hz and 23–34 Hz at C3-C4) or sham feedback ($n = 4$; non-contingent feedback) for 24 sessions, with the sham feedback group completing an additional 24 sessions of active feedback following the block of sham training. After the initial 24 sessions, no significant differences in symptom reduction or QEEG activity were reported between the groups; only non-significant trends were observed for decreases in dyskinesia severity for the active feedback group. After both groups completed the active feedback training, no significant QEEG differences were observed between groups. However, significant within-groups differences were reported for relative power, cross-spectral power, and coherence activity within the 25–30 Hz (decreased) and 8–12 Hz (increased) frequency ranges, indicating that EEG feedback training led to topographic changes to targeted frequency bands outside of individual training sessions (Erickson-Davis et al., 2012).

The learned self-regulation of specific brain activities in individuals with PD was further evidences in rtfMRI feedback trial. Subramanian et al. (2011) assigned five patients with PD to an active rtfMRI feedback protocol targeting enhanced activity of the supplementary motor complex during a motor imagery task and five control patients matched for PD clinical severity and medication to a non-feedback procedure. Following two rtfMRI feedback sessions, only the active feedback group demonstrated the ability to regulate activity in the targeted brain regions, accompanied by significant improvements of motor speed during a finger-tapping task and motor symptoms on the motor scale of the Unified Parkinson's Disease Rating Scale (Subramanian et al., 2011).

Tinnitus

Tinnitus, or ringing in the ears, is the perception of sound without the presences of a physical stimulus (Tinnitus, 2012). Although the condition is common and often temporary, for several individuals the ringing is constant and causes distress. The evidence supporting the efficacy of neurofeedback in normalizing deviant brain activity and reducing the frequency, intensity, and duration of pain-related conditions led researchers to investigate its utility in treating tinnitus. Early research studies develop feedback protocols on the assumption that enhancing parieto-occipital alpha activity would promote relaxation and reduce arousal thought to exacerbate tinnitus (see Dohrmann, Elbert, Schlee, & Weisz, 2007a, for review). Gosepath, Nafe, Ziegler, and Mann (2001) investigated the utility of alpha/beta training (P4 electrode placement) for the treatment of tinnitus ($n = 40$) and vertigo (control, $n = 15$). Following training, the control group was unable to regulate alpha or beta activity, while individuals in the tinnitus group were classified as alpha regulators or beta regulators. A significant reduction in tinnitus symptoms was observed in both alpha and beta regulators, with clinical improvements persisting throughout a 6-month follow-up period. Schenk, Lamm, Gündel, and Ladwig (2005) utilized training protocols that targeted alpha (8–12 Hz) enhancement or beta (16–20 Hz) inhibition in central–parietal sites (P4 or C3) within a population of 36 individuals with chronic tinnitus. Individuals that had difficulty increasing alpha activity during a relaxation task were assigned to the alpha enhancement protocol, while individuals that produced increased beta activity in relaxation recovery tasks were assigned to beta inhibition task. Following 12 sessions, the alpha group produced a significant increase in alpha activity and reported a reduction in tinnitus symptoms, while the beta group failed to decrease beta activity or tinnitus symptoms (Schenk et al., 2005).

Another group of researchers utilized neurofeedback protocols targeting alpha activity generated in sylvian regions of the brain, including the auditory cortex, which is projected to the frontal lobe (Dohrmann, Weisz, Schlee, Hartmann, & Elbert, 2007b). This activity was referred to as *tau* (8–12 Hz) activity. Dohrmann et al. (2007a) compared the efficacy of various protocols among 21 individuals with tinnitus. In all cases, training targeted activity over the fronto-central cortex (F3, F4, FC1, and FC2) and aimed at enhancing tau-to-delta (8–12 Hz/0.5–4 Hz) ratios ($n = 11$), enhancement of tau power ($n = 5$), or inhibition of delta power ($n = 5$). Overall, the individuals in each group demonstrated enhanced tau-to-delta ratios (within and between sessions) and reduction of tinnitus, regardless of protocol assignment (Dohrmann et al., 2007b). The reduction of tinnitus was stable for a period of 3–6 months. Crocetti, Forti, and Del Bo (2011) replicated the study protocol in their assessment of a group of individuals diagnosed with sensorineural tinnitus. Following neurofeedback, a significant reduction in the impact, intensity, and annoyance of the tinnitus was reported and persisted throughout the follow-up period of 3–6 months. An increasing trend in the tau-to-delta ratio was observed (Crocetti et al., 2001).

Haller, Birbaumer, and Veit (2010) investigated the application of rtfMRI feedback for symptom reduction in six individuals diagnosed with chronic tinnitus. Once localized during a baseline scan, patients were trained to reduce BOLD activation in the auditory cortex. Following the rtfMRI sessions (four training blocks in a single day), a significant reduction in auditory activation was observed, resulting in the reduction of subjective tinnitus in one-third of the study population. These studies indicate that the entrainment of BOLD signal activity in the auditory cortex or EEG projections from this area may lead to the reduction of tinnitus symptoms. Similarly, protocols that focus on arousal and anxiety reduction may promote relaxation and distraction or attention diversion to aid tinnitus sufferers in being less reactive to the percept of auditory ringing.

Traumatic brain injury and stroke

The development of neurofeedback protocols for the treatment of traumatic brain injury (TBI) and stroke-related symptoms evolved from ADHD, learning disability, epilepsy, pain research, and a groundbreaking case series presentation (Ayers, 1987). Ayers presented retrospective outcome data from 250 individuals with closed head injuries following a course of neurofeedback rewarding the increase of beta (15–18 Hz) activity during the suppression of theta (4–7 Hz) activity over the sensorimotor strip (T3-C3 or T4-C4). Following 24 sessions, individuals reported increased energy, attention, mood, and libido; reduction of headache and temper outbursts; decreased sensitivity to light and sound; dizziness; improvements to letter reversals and short-term memory; and a reduction in phasic spikes and excessive slow wave activity (Ayers, 1987). In a follow-up investigation, Ayers (1991) utilized the same protocol to treat six individuals with right-hemisphere closed head injury (placement at F8-T4). She indicated that individuals who received neurofeedback and psychotherapy reported a significant reduction in mood swings, explosive outbursts, and anxiety attacks, whereas individuals who received psychotherapy alone did not experience clinical changes (Ayers, 1991). Byers (1995) utilized a modified protocol targeting theta (4–7 Hz) inhibition with the simultaneous reward of SMR or beta (15–18 Hz) activity produced at Cz for the treatment of a woman with a mild TBI. Following 31 sessions, a general reduction of EEG activity across all frequencies and sites was observed in addition to improvements in verbal fluency, behavioral control, executive functioning, and intellectual capacity (Byers, 1995).

Keller (2001) compared the efficacy of neurofeedback ($n = 12$) and computerized attention training ($n = 9$) in the improvement of attentional processes of individuals with moderate closed head injuries. Following 10 sessions, two-thirds of the individuals assigned to the beta enhancement (reward: 13–20 Hz, Fz) group were able to increase beta amplitudes and prolong the duration of beta activity (50%). Overall, both treatment groups showed improvements on the cancellation, speed, and sustained attention tasks. However, these improvements were superior for neurofeedback training, resulting in a greater reduction in the number of errors and detected stimuli on a cancellation task, and reaction time in a sustained attention task (Keller, 2001).

Thornton (2000) assessed the efficacy of QEEG-guided protocols for the improvement of memory functioning post-injury in a five-case study presentation. The neurofeedback protocols were developed by comparing the clinical EEGs to a normative auditory "activation" database and targeted activity −1 SD below normal. For the head-injured participants, memory function improvements ranged from 68% to 181%. Walker, Norman, and Weber (2002) evaluated QEEG-guided coherence training for the remediation of mild TBI symptoms including headaches, memory and cognitive disturbances, changes in mood and sleep, etc. Training targeted the normalization of coherence scores for intrahemispheric (Fp1-F3, Fp2-F4, T3-T5, T4-T6, C4-P4, F3-O1, and F4-O2) and interhemispheric (Fp1-Fp2, F3-F4, F7-F8, C3-C4, T5-T6, P3-P4, and O1-O2) electrode placements, and led to a 72% improvement in global functioning, accompanied by reductions in headache frequency and improvement to memory loss and confusion (Walker et al., 2002).

Bounias, Laibow, Bonaly, and Stubblebine (2002) classified and tracked the improvement of 48 clinical symptoms reported by a group of 27 individuals enrolled in a neurofeedback training program for the treatment of TBI. Following symptom classification and neurofeedback treatment, rehabilitation rates were calculated for the following functional impairment sub-groups: (1) motor, 76.7%, (2) language, NA, (3) cognitive, 87%, (4) psychosocial, 77%, (5) pain-related, 80%,

(6) neuropsychiatric, 58.6%, and (7) metabolic, NA. In a subsequent analysis of the same study population, Laibow, Stubblebine, Sandground, and Bounias (2002) assessed the changes in EEG activity in relation to rehabilitation rates and functional impairment sub-groups. The findings indicated that protocol-specific changes were achieved, as decreases in theta (3–7 Hz), high beta (24–32 Hz), and EMG (70–90 Hz), as well as increases in alpha (8–12 Hz) and low beta (15–18 Hz) at Cz were observed. According to Laibow et al. (2002), TBI patients with a history of stroke demonstrated a reduction in theta and an increase in alpha activity following neurofeedback, replicating and extending the findings of several case studies investigating the role of neurofeedback in stroke rehabilitation.

Rozelle and Budzynski (1995) presented the outcome data for a 55-year-old male with a history of a left-side cerebrovascular accident, indicating he was able to learn to reduce theta (4–7 Hz) activity over the sensorimotor cortex and speech areas. Despite being unable to increase beta (15–21 Hz) activity in target regions, significant improvements in speech fluency, word finding, balance, coordination, attention, and concentration were reported, as well as moderate changes in mood and tinnitus symptoms. Putman (2002) employed a protocol developed by EEG Spectrum International, targeting SMR (12–15 Hz) enhancement with theta suppression at C4, C4-Pz, and T3-T4, and beta (15–18 Hz) enhancement with theta suppression at C3, C3-Fpz, and C3-FP1, to promote communication between cortical areas damaged following a right-hemisphere stroke in a 71-year-old woman. Although the individual participated in physical therapy and pharmacotherapy throughout neurofeedback therapy, significant improvement in gross motor control and range of motion of the left arm and leg was reported, and improvement in the speech articulation, tone, and strength was observed (Putman, 2002). Finally, Cannon, Sherlin, and Lyle (2010) reported QEEG and LORETA activity changes following a QEEG-guided treatment of a 43-year-old woman with a history of embolism of the right-hemisphere cerebral artery. Following treatment, decreased theta activity was observed in QEEG and LORETA measures and accompanied by gains in cognitive functioning, sleep quality and energy, and mood regulation.

Sitaram et al. (2012) investigated the feasibility of rtfMRI feedback as a tool for rehabilitation of upper-limb motor function in chronic subcortical stroke patients. Participants (stroke, $n = 4$; healthy, $n = 4$) were training to regulate BOLD signal activity in the ventral premotor cortex. Following the 3-day training, participants demonstrated the ability to increase BOLD signal in target brain regions, with the capability to learn self-regulation being linearly dependent on intracortical facilitation and negatively correlated with intracortical inhibition measured by transcranial magnetic stimulation prior to feedback training.

Case studies

Several case-study investigations have reported successful treatment outcomes for the treatment of chronic fatigue, physical balance, swallowing, incontinence, asthma, diabetes, essential hypertension, and cognitive enhancement following a course of neurofeedback therapy. While the study samples are limited and treatment outcomes may not be generalized, the results are promising and worthy of future research. It is important to note that the following applications have not been replicated for reliability and should be utilized with caution by advanced neurofeedback practitioners and researchers. When possible, the following paragraphs will present treatment rationales, training protocols, and treatment outcomes for exploratory applications of neurofeedback therapy.

Many of the investigations discussed in this chapter reported improvements in sleep quality and mood secondary to the targeted disorder-specific symptoms. This led clinicians to apply standardized or QEEG-based protocols for the treatment of other disorders. Employing a QEEG-based protocol focused at inhibiting left frontal theta activity, combined with self-hypnosis training, Hammond (2001) reported long-term improvement of cognitive symptoms, and fatigue, vigor, and confusion as measured with the Profile of Mood States in a 21-year-old woman with chronic fatigue syndrome.

Hammond (2005) later extended the application of a bipolar training protocol, initially reported by Ayers, targeting Brodmann areas 17 and 18 via electrode placement near O1 and O2. The reduction of theta (4–7 Hz) and reward of beta (15–18 Hz) activity over this area of the cortex resulted in improved balance, memory, and intellectual functioning in a 50-year-old man with a history of mild head injuries; aided in the improvement of balance, mobility, concentration, and incontinence in a 45-year-old woman following a brain aneurysm and neurosurgical induced stroke; improved balance in a 46-year-old woman following a series of mini strokes; and improved balance and swallowing in a 32-year-old woman with excessive delta and theta activity in the posterior regions of the brain and a history of repeated whip-lash.

Based on the hypothesis that SMR training reduces neuronal excitability and stabilizes state characteristics (Sterman, 2000), several clinicians investigated how the application of SMR (standard and modified) protocols impact disorders in which stress reactivity and hyperexcitability negatively impact symptom presentation or standard treatment. Tansey (1992) reported the long-term (1-year) efficacy of rewarding 14-Hz activity over the sensorimotor cortex for the cessation of respiratory difficulties and asthma attacks in a 6-year-old boy. Monjezi and Lyle (2007) evaluated the therapeutic effects of SMR and beta (15–18 Hz) augmentation and reduction of 2–7 Hz and 22–36 Hz activity over the sensorimotor cortex (C3, C4, or C3-C4) as an ancillary treatment for type I diabetes mellitus. Protocols were developed in accordance with the EEG Spectrum International protocol decision tree (Othmer, 2005), and led to subjective improvement to quality of life and objective improvements in glucose levels and insulin dosages of two female patients.

Protocols targeting the conditioning of specific alpha activity patterns traditionally utilized for anxiety reduction or peak performance enhancement have also been investigated to enhance self-regulation and management of other conditions. For example, Norris, Lee, Burshteyn, and Cea-Aravena (2000) reported that alpha (8–13 Hz) enhancement training at Pz led to the reduction of mean arterial blood pressure, improvements on the reaction time and reaction time variability on the test of variable attention, and improvements on the work and social life subscales of the Osterkamp and Press Self-Assessment Stress Inventory in a 49-year-old college student with essential hypertension. Angelakis et al. (2007) employed a similar protocol for cognitive enhancement of healthy elderly individuals. All training protocols utilized POz. Three elderly individuals received peak alpha frequency (PAF) training in which increased dominant frequency activity within 8–13 Hz was rewarded, two control participants received alpha 8–13 Hz amplitude training in which all bandrange activity was rewarded, and a single control participant received a sham feedback (playback of experimental participant session data). The results indicated that individuals in the active experimental and control feedback groups learned to increase alpha-related activity. The training results indicated that PAF training improved cognitive processing speed and executive functioning, but not memory, whereas alpha amplitude training improved verbal, visual, and working memory, while worsening processing speed and executive functioning in healthy elderly patients (Angelakis et al., 2007).

Summary and limitations

The body of neurofeedback research is very promising, with several applications for neurological disorders and pain conditions. Feedback methods rely on the operant conditioning of EEG signal activity and utilize standardized research protocols such as SMR and SCP training, proprietary developed protocols such as those offered by EEG Spectrum International, and individualized protocols guided by QEEG assessments and disorder pathology. Training goals are diverse and disorder specific, with most targeting the normalization of abnormal activity and regulation of neuronal excitability thresholds. A meta-analysis of epilepsy research indicates that SMR and SCP feedback produces a significant reduction in seizure frequency (Tan et al., 2009). Pain research indicates that neurofeedback leads to a reduction in the frequency of migraines and headaches (Siniatchkin et al, 2000; Stokes & Lappin, 2010; Walker, 2011), chronic pain (deCharms et al., 2005; Melzack & Perry, 1975), trigeminal neuralgia (Sime, 2004), complex regional pain syndrome – type I pain (Jensen et al., 2007), and fibromyalgia pain (Caro & Winter, 2011; Kayiran et al., 2007; Kayiran et al., 2010). Research of neurofeedback applications for movement disorders revealed improvements in motor functioning of patients with cerebral palsy (Ayers, 2004; Bachers, 2004), Parkinson's disease (Erickson-Davis et al., 2012; Subramanian et al., 2011; Thompson & Thompson, 2002), and stroke (Bounias et al., 2002; Putman, 2002; Rozelle & Budzynski, 1995). Patients with a history of traumatic brain injury showed improvements in memory (Ayers, 1987; 1991; Thornton, 2000; Walker et al., 2002), cognition (Ayers, 1987; Bounias et al., 2002; Byers, 1995; Keller, 2001; Walker et al., 2002), and mood (Ayers, 1987; Bounias et al., 2002; Byers, 1995) following neurofeedback therapy. Contingent neurofeedback protocols have been found to produce greater clinical improvements than medication (Kayiran et al., 2010), computer attention training (Keller, 2001), treatment as usual and wait-list controls conditions (Caro & Winter, 2011; Siniatchkin et al, 2000), sham feedback (Erickson-Davis et al., 2012, deCharms et al., 2005), psychotherapy (Ayers, 1991), and imagery (Subramanian et al., 2011). However, it is important to recognize the limitations of many neurofeedback studies including case study and small-N designs, lack of control or comparison groups, limited randomized control studies, heterogeneous populations, and use of multi-modal treatment approaches. These limitations need to be addressed in future studies to gain greater understanding of the mechanisms underlying neurofeedback and the specificity of this treatment method.

Additional research is needed to investigate the efficacy of rtfMRI and NIRS feedback for medical conditions. To date, rtfMRI feedback has been investigated in a variety of brain regions including motor areas, somatosensory cortex, rACC, amygdala, inferior frontal gyrus, insula, rostrolateral prefrontal cortex, parahippocampus, visual area, and auditory cortex, as well as utilized as a treatment method for chronic pain, tinnitus, depression, schizophrenia, psychopathy, and stroke (see, Weiskopf, 2012, for review). The encouraging results of rtfMRI studies not only warrant its investigation as a treatment option for other disorders, but also support the need for additional research for NIRS feedback. Currently, no publications have reported outcome data following NIRS feedback in a clinical population. Research teams at the University of Tübingen have recently started to assess the efficacy of NIRS feedback for the treatment of childhood and adult ADHD. However, the clinical application of this method is supported by a large volume of research. For example, studies have identified EEG-NIRS (see Wallois, Patil, Héberlé & Grebe, 2010, for review) and fMRI (see Chaudhary, Duncan, & Lemieux, 2011, for review) correlates of epileptic activity. Literature reporting the efficacy of blood-volume pulse biofeedback techniques (Andrasik, 2010) and pIR HEG (Stokes & Lappin, 2010), as well as research reporting hemodynamic changes and differences between individuals with and without migraines (Liboni et al., 2007; Viola, Viola, Litterio, Buongarzone, & Fiorelli, 2010), also support the investigations of NIRS feedback for migraine sufferers. The high resolution of rtfMRI and NIRS feedback may yield greater insights about the relationship between the brain and behavior and help researchers identify the processes underlying self-regulation in neurofeedback.

Clinical Applications of Brain–Computer Interfaces

The clinical application of BCI technology is a natural extension of neurofeedback research and the product of technological advancements in the rapid analysis and reward of EEG, ERP, and BOLD signal activity. Vidal (1973) identified three basic assumptions necessary to make BCI technology feasible:

> The first assumption is that mental decisions and reactions can be probed, in a dimension that both transcends and complements overt behavior, from the array of observable bioelectric signals. . . . A second assumption is that all meaningful EEG [BOLD] phenomena should be viewed as a complex structure of elementary wavelets, similar in nature to components of evoked responses, that sequentially reflect individual cortical events and create a continuous flow of neuroelectric messages. The third assumption is that operant conditioning procedures can increase the reliability and stability of these time signatures and patterns. (p. 176)

At the time, Vidal (1973) acknowledged that the BCI technology was "somewhat in the future," but these assumptions have been realized and expanded with the support of nearly 40 years of BCI research. The ability to detect, transform, and condition EEG activity has been evidenced by the research presented throughout the chapter, and demonstrated for NIRS (Sitaram et al., 2007) and rtfMRI (Weiskopf et al., 2005) activity. Although the majority of BCI research focuses on methodological issues and comparison of online mathematical algorithms, a limited number of studies have investigated BCI efficacy in clinical populations and targeting communication and motor control rehabilitation.

Communication and motor control

The restoration of communication for people who are "locked-in" has been one of the main focal points of clinical BCI research. Several patient populations may experience locked-in syndrome (LIS) or total locked-in (TLIS), including those suffering with progressive motor neuron disease (e.g., amyotrophic lateral sclerosis; ALS), Guillain-Barre' syndrome, subcortical stroke, or traumatic brain damage resulting in a vegetative state. LIS is the condition of complete paralysis with voluntary control of one or two functions (i.e. small eye tracking). In advanced states, individuals with TLIS experience the complete cessation of control over somatic–motor functions, leaving them without the ability to communicate or interact. Despite being "locked in" a body they are unable to control, ERP (Kotchoubey, 2005) and fMRI (Owen et al., 2006) studies indicate that these individuals continue to show reactivity to auditory and tactile stimulation and intact cognitive functions. In light of these findings, researchers began investigating the feasibility of using these physiological responses to drive communications devices. Similar to neurofeedback applications, communication BCIs focus primarily on EEG-based signals, specifically SCP, P300 ERP, and SMR activity (Wolpaw et al., 2002).

The restoration of motor control for people with severe CNS damage, spinal cord injuries, and stroke-related paralysis is the second major target for clinical BCI research. Paralysis and motor dysfunction represents the main cause of long-term disability and has significant social, financial, and psychological impacts on the patient, their family, and society. Similar to the neurofeedback protocols used in TBI and stroke research, BCIs for movement control most commonly target SMR and beta activity over the sensory motor strip. Research in this area may utilize active or imagined movement of the hands, arms, and legs, and/or activation of an orthosis (on or off the participant). During a motor imagery task, the BCI users are prompted to focus on the activity in a specific limb and imagine alternating activity from one hemisphere to another. This allows for one-, two-, and three-dimensional curser or movement control.

Amyotrophic lateral sclerosis

Several studies have investigated the clinical utility of BCI technology in an ALS population. Birbaumer et al. (1999) was the first to demonstrate the feasibility of SCP-BCIs for communication with two LIS patients diagnosed with ALS. In this study, a speller program presented a string of letters on the training screen. Both users were successful in learning volitional control of SCP activation and deactivation shifts to indicate a desired letter. Alphanumeric grids, binary cursers, and web browsing tools were among the most common forms of BCIs. Most of the BCI speller applications utilized P300 activity (Kübler et al., 2009; Mugler, Ruf, Halder, Bensch, & Kübler, 2010; Nijboer et al., 2008; Pires, Nunes, & Castelo-Branco, 2011; Sellers & Donchin, 2006; Sellers, Vaughan, & Wolpaw, 2010; Silvoni et al., 2009; Townsend, et al, 2010). Other applications used SMR activity (Bai, Lin, Huang, Fei, & Floeter, 2010; Kübler, Winter, Ludolph, & Hautzinger, & Birbaumer, 2005; Miner, McFarland, & Wolpaw, 1998) or NIRS activity (Naito et al, 2007). In all cases, the majority of LIS patients demonstrated the ability to learn self-regulation of the targeted brain signals. However, this was not true for TLIS patients. Most EEG-based BCIs studies have treated LIS patients that have not progressed into a TLIS state, prompting several researchers to hypothesize that BCI training may serve as a protective factor. According to Birbaumer et al. (2009), it is still unclear whether BCIs allow for voluntary control of brain responses and communications with TLIS patients. However, Ramos Murguialday et al. (2011) reported that passive limb movements and auditory stimuli continue to evoke ERP activity in TLIS patients, potentially permitting BCI communication. Sellers, Vaughan, and Wolpaw (2010) reported long-term follow-up data for an ALS patient that has been actively using a P300-speller BCI program for 2.5 years. The findings indicate that the BCI accuracy remained high and the device benefited the user by allowing him to interact, communicate, and work.

Spinal cord injury and paralysis

Several studies have investigated the clinical utility of BCI technology in injured, disabled, and paralyzed populations. In a single case study, Pfurtscheller et al.

(2000) presented data on a tetraplegic patient who was able to self-regulate central mu-rhythms to control an electrostimulation device applied to his hand muscles. By voluntarily increasing and decreasing the mu activity, the patient was able to open and close the orthosis allowing him to grasp a glass and bring it to his mouth to drink. In a series of studies with chronic stroke patients without residual hand movement, Buch et al. (2008), Broetz et al. (2010), and Ramos-Murguialday et al. (2013) demonstrated controlled outcomes, indicating that SMR-driven BCI of a hand orthosis plus physiotherapy resulted in clinically meaningful improvements in motor function and behavioral and neurophysiological assessment measures. BCI applications are more diverse for individuals suffering with paralysis and stroke and include speller programs, curser direction tools for computer and Internet software, hand and arm orthosis control, and environmental control. Most orthosis and imagery regulation tasks used EEG frequency activity such as mu-rhythm and SMR (Bai et al., 2010; Conradi, Blankertz, Tangermann, Kunzmann, & Curio, 2009; Kauhanen et al., 2007; McFarland, Sarnacki, & Wolpaw, 2010; Muller-Putz, Scherer, Pfurtscheller, & Rupp, 2005; Pfurtscheller, Guger, Muller, Krausz, & Neuper, 2000) activity, whereas the BCI-speller and other BCI tools used P300 (Hoffmann, Vesin, Ebrahimi, & Diserens, 2008; Ikegami, Takano, Saeki & Kansaku, 2011, Piccione et al., 2006; Pires, Nunes, & Castro-Branco) and spike activity (Kennedy & Bakay, 1998). In general, patients with disabilities, injury, and paralysis are capable of learning to self-regulate specific brain signals to drive communication, motor rehabilitation, and environmental control devices. The preliminary research from case studies and small *N* designs are promising and has spurred larger controlled studies; however, additional research is needed.

Neurofeedback and BCI in Behavioral Medicine

Neurofeedback therapy and BCI technology are exemplary tools within the field of behavioral medicine. As a field, behavioral medicine is concerned with the development of knowledge and techniques relevant to the understanding of health and illness and the application of this knowledge and techniques to prevention, diagnosis, treatment, and rehabilitation (Schwartz & Weiss, 1978). The research presented in this chapter addresses the development, rationale, and efficacy of these techniques for diagnosis, treatment, and rehabilitation of several medical disorders and conditions. Additionally, a large body of research explores the application of these methods for entertainment, health prevention, and performance enhancement.

In most cases, neurofeedback and BCIs are used to complement established treatments and are integrated into multimodal approaches to patient care. Neurofeedback and BCI interventions work in a bottom-up fashion to address the neurophysiological components that drive disorder-specific symptoms, whereas cognitive behavioral therapy (CBT) interventions target symptoms in a top-down fashion and assist individuals in identifying, developing, and utilizing cognitive strategies that help support their treatment goals. Combined, the methods are mutually beneficial, especially for the patient. For example, neurofeedback protocols are easily integrated into the CBT case conceptualization of pain management outlined by Keefe (1996). The three basic components of this approach are: (1) providing a treatment rationale that helps patients understand that cognitions and behaviors can affect the experience of pain and emphasizes the role of the patient in controlling their own pain, (2) coping skills training, and (3) the application and maintenance of learned coping skills (Keefe, 1996).

The first component is addressed in the following ways. Before the start of treatment, clinicians address the cognitive, behavioral, and neurobiological components of pain through psychoeducation, neuropsychological testing, and EEG/ERP assessments. EEG/ERP data may guide protocol selection and establish pre-treatment baselines. Emphasis is placed on the rationale for protocol selection and the process and role of the patient in learning self-regulation strategies. For example, a patient with fibromyalgia may be trained to inhibit theta (4–7 Hz) and enhance SMR (12–15 Hz), based on the hypothesis that SMR enhancement training promotes activation of inhibitory processes implicated in the perceptual amplification of pain and neurosensitization.

The second component is addressed in the following ways. During the neurofeedback intake, clinicians investigate the developmental course and current symptom picture of the condition, as well as the positive and negative cognitive schemas and core beliefs held by the patient. The impact of pain symptoms in the realm of work, school, and relationships are discussed, and individualized progress logs are developed to promote and track behavioral changes. During neurofeedback training sessions, clinicians help the participant identify cognitive distortions that negatively influence training performance. For example, if a participant has several successful training blocks followed by an unsuccessful training block, he or she may become frustrated or discouraged and engage in all-or-nothing thinking (“I did terrible on this training block, this treatment will never help me”) or overgeneralization (“I cannot expect to relax at my desk, if I cannot relax during a neurofeedback session”). These thoughts may trigger emotional or physical stress, which may in turn lead to pain exacerbation, additional session failures, and/or avoidance behaviors such as arriving late to training sessions, and missing or rescheduling appointments. Thus, training performance is discussed following each session in order to help the participant identify successful and unsuccessful strategies, recognize positive training parameters, dispute cognitive distortions and negative self-statements, and redirect training behaviors to avoid negative session.

The third component is addressed in the following ways. Participants are provided with “homework” tasks to help generalize neurofeedback self-regulation skills. Tasks may include training exercises using DVD simulations or wallet-sized cue cards with a picture of the training screen. Patients are encouraged to practice regulating the specific training parameters or recreating the training mental state before or during pain-evoking situations (i.e., before lectures or meetings, while sitting or lying for long periods, emotional stressors, etc.). These exercises can easily be incorporated into CBT thought log assignments.

Conclusion

This chapter provides a brief discussion of the origins and evolution of brain signal recordings and operant conditioning paradigms utilized in neurofeedback training and BCI technology. Neurofeedback is the practice of providing individuals with specific feedback and reward of brain activity in an operant conditioning paradigm to promote learning of self-regulation strategies to reduce disorder-specific symptoms and enhance overall functioning. In BCI applications, the targeted signals are utilized to drive assistive devices. Operant conditioning of EEG and BOLD signal activity has been effective in the treatment and symptom reduction of epilepsy, migraines/headaches, chronic pain, fibromyalgia, cerebral palsy, Parkinson's diseases, traumatic brain injury, stroke, and tinnitus with various neurofeedback protocols. Additionally, the classification and conditioning of these signals have been useful in the development of BCI applications permitting communication, motility, and environmental control in patients with progressive motor neuron disease or severe CNS damage, particularly chronic stroke.

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16

Electromyographic (EMG) Biofeedback in the Treatment of Pelvic Floor Disorders

Bruce Mehler and Katharine M. Larsson

The term "pelvic floor" refers to the network of muscles, ligaments, and other connective tissues in the lower abdominal area that provide support to the uterus, bladder, vagina, and rectum. Muscle weakness, poor coordination, tears, or excessive tension in pelvic floor musculature can be a source of, or associated with, a range of dysfunctions. Common disorders include urinary leakage, urinary incontinence, fecal incontinence, constipation, and pelvic organ prolapse. Conditions involving increased or decreased sensitivity associated with sexual dysfunction or chronic pain syndromes such as vulvodynia are also often categorized as pelvic floor disorders. Pelvic floor disorders (PFDs) are more common in women than in men, but should not be seen as exclusive to women as pelvic floor muscles (PFM) weakness or control issues can occur in both genders. PFDs, particularly urinary incontinence, have historically been described as being more frequent in women who have undergone vaginal childbirth due to the strain and trauma associated with delivery through the birth canal; nonetheless, PFDs are seen in many women who have not given birth and may be more broadly associated with either poor muscle tone or hypertonicity. PFDs tend to become more common with age and have been estimated to affect one in three women (Nygaard et al., 2008). According to one regional study (Olsen, Smith, Bergstrom, Colling, & Clark, 1997), almost 10% of women in the United States have surgery for urinary incontinence or pelvic organ prolapse. Another analysis estimated that over 500,000 surgical procedures are performed annually in the United States for these two conditions (Norton, 1993). A survey in Great Britain found that chronic pelvic pain was an ongoing problem for approximately one-quarter of women between the ages of 18 and 49 (Zondervan et al., 2001). These kinds of statistics make it clear that PFDs impact a significant portion of the population.

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Fortunately, underdevelopment, damage, hypertonus, and poor coordination of striate musculature are all conditions that are generally highly amenable to muscular reeducation and exercise. Not surprisingly, many individuals with PFDs have difficulty with awareness of the muscles of the pelvic floor and in isolating the muscles of interest from various other muscles groups of the abdominal region, gluteus muscles, and muscles of the upper thighs. The present chapter focuses on the role that biofeedback techniques, and surface electromyography (sEMG) in particular, can play in PFM training. Verbal guidance based on digital assessment from an examiners finger(s), manometric feedback from pressure-sensing devices, and even the use of vaginal cones can be considered as a form of biofeedback. As succinctly summarized by Haslam (2002), biofeedback not only assists in the development of PFM awareness, "but also provides interest, challenge, reward for effort, a greater feeling of control and progress monitoring" (p. 75). Many of the learning principles discussed are relevant to the treatment of PFDs, and muscle dysfunction in general, regardless of whether sEMG biofeedback instrumentation is employed.

Kegel and the Semi-Invention of Clinical Biofeedback

In the seminal paper "Progressive resistance exercise in the functional restoration of the perineal muscles," Arnold Kegel (1948) enumerated a number of principles of what we now recognize as fundamental tenets in the field of behavioral medicine and the basic clinical training concepts of biofeedback-assisted neuromuscular reeducation. Reading the original and key follow-up papers (e.g., Kegel, 1951; 1952; 1956) is a worthwhile undertaking not only for the historical significance but the clarity and relevance of the clinical recommendations. It can reasonably be argued that Kegel effectively invented clinical biofeedback 20 or so years before the term was coined and the principles reintroduced to the medical community (Perry & Talcott, 1989).

Kegel (1948) provided a detailed review of the ways in which the muscles of the pelvic floor are stretched and are likely to be injured during the process of childbirth. He highlighted the fact that the motor end-plates that provide the neural connections to individual muscle fibers are prone to be torn from their associated nerves. The degree to which injured muscle cells recover their innervation and function is in large part dependent on the extent to which the muscles are actively exercised. Kegel stressed that a lack of exercise of deinnervated striated muscle fibers leads to atrophy. On the other hand, individual nerve fibers are capable of growing and multiplying branches, and, if appropriately stimulated, may eventually supply a larger number of muscle cells than they did prior to the injury.

Commenting on surgical repair procedures, Kegel observed that such "a procedure will ordinarily lead to a restoration of the gross form of the perianal structures but will not in itself bring about a return to normal function. In some way, re-innervation of muscle cells must be accomplished and the injured muscle cells must again be educated to function" (p. 240). In his 1952 paper, he went on to assert that it is not uncommon to find that, 6 months following an otherwise well-performed vaginal repair, the tissues, in particular the perineum, will again become thin and weak. The implication again being that suitable exercise of the muscles of the pelvic floor is required to restore healthy anatomical support and functional relationships of the pelvic structures. He focused particular attention on the pubococcygeus muscle as being a central in this process.

While the 1948 paper focused on muscle weakness and coordination issues post-strain, his later papers emphasized muscle weakness and lack of awareness of the PFM function as a more general problem, noting that urinary incontinence occurred in many women who had not given birth. In many cases, a careful history often revealed issues with incontinence prior to giving birth. Kegel clearly stated that he was not the first to see the need to develop an effective approach to rebuilding (or building) appropriate muscle tone and coordination in the pelvic floor musculature, but observed that little guidance was available in the literature on how best to go about such training. He cited, as one exception, Scott and Van Wyck, who reportedly "described a procedure in which the patient contracts the gluteal muscles, at the same time drawing in the rectum as though to check the passage of feces through the lower bowel" (Kegel, 1948, p. 241). Kegel noted that many physicians instructed their patients to increase muscle tone by repeatedly "drawing-in" the perineal region. An early paper by Davies (1938) advocated giving "married" women careful instruction that included identifying relevant pelvic floor musculature by attempting to stop the flow of urine midstream. Success in stopping flow is often suggested as an indicator that the muscles that need to be trained by repetitive contraction have been identified. Davies also recommended that the muscles surrounding the vagina be intermittently contacted during intercourse as a method of strengthening underdeveloped muscles. Kegel (1951) made note of Davies' recommendations, while emphasizing that previous work did not fully appreciate the role of the puboccygeus muscle and the need for specificity of muscle training.

Kegel referred to this behavioral approach to treating urinary incontinence as "physiologic therapy" and described therapy as being divided into two phases – muscle education and resistive exercise. Both Davies and Kegal stressed the importance of "awareness of function" in the reeducation/restoration of muscle function. Davies noted that many of the women he saw did not consider the possibility that the muscles of the lower abdominal/pelvic floor region were under voluntary control and that urinary incontinence often could be traced to general physical underdevelopment of muscle tone and control as opposed to damage resulting from labor. Consequently, patients with stress incontinence who lack gross anatomical damage should be trained to develop voluntary muscle control as opposed to resorting to surgical intervention.

Kegel discussed in detail the use of digital assessment via the clinician's finger to initially monitor a patient's attempt to contract the PFMs and the use of verbal feedback to help them understand when the muscles are being correctly engaged.

He emphasized that it is critical when measuring the function of the pubococcygeus muscle to ensure that a patient is not contracting “extraneous” muscles such as the abdominal, gluteal, or introital-region muscles. The importance of discrimination training represents one of the arguments for the value of multichannel sEMG monitoring of other muscle groups, as is discussed in more detail later.

Interestingly, Kegel (1951) makes a distinction between the training in voluntary contractions that is initially provided by the clinician through digital monitoring and the “resistive exercise” phase. He states that, while voluntary contractions alone will increase muscle strength and function of the major components of the levator sling, “they have little effect upon the extensions of the pubococcgeus muscle, which interdigitate and insert into the intrinsic musculature of the walls of the proximal urethra and middle third of the vagina.” He goes on to argue that exercise of these muscle fibers must involve contractions that extend over the entire circumference of the vagina, and that this is facilitated by having an object to squeeze against (recall Davies’ recommendation for practicing contractions during intercourse). The “perineometer” device that Kegel developed serves this, and other, important functions. Kegel’s perineometer is a pneumatic apparatus consisting of a cylindrical, rubber-covered resistance chamber measuring 2 cm in diameter by 8 cm in length (Figure 16.1). A manometer (pressure gauge), calibrated from 0 to 100 mm Hg, is attached to the distal end by a rubber hose. The gauge can be used by the clinician to assess contractions, or held by the patient to observe the magnitude and characteristics of contractions. Kegel states that both “muscle education and resistive exercises are facilitated through visual control of the effort exerted.” The use of visual feedback to assist the patient in learning how to effectively contract the PFMs and to obtain reinforcement for continued practice (observing higher and more sustained pressure readings as PFM control and strength increases) clearly represents what is now called biofeedback training.

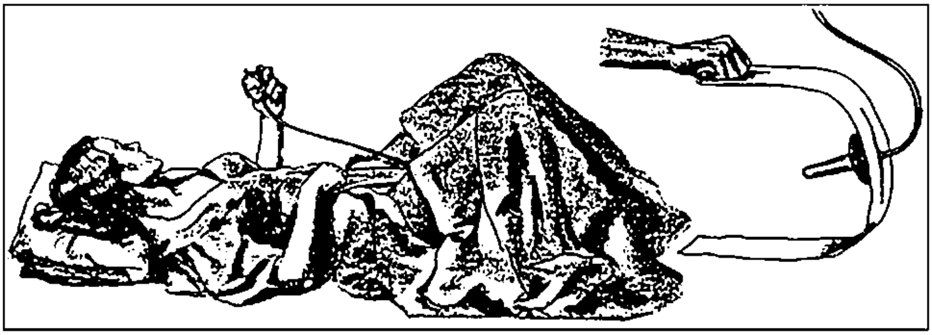

Figure 16.1 Original Kegel perineometer for aiding learning of “progressive resistance exercises of lax perineal musculature” (Kegel, 1952). The handheld pressure gauge provided objective information on the relative strength of muscle contractions.

As clinical guidance, Kegel emphasized that, following confirmation that the patient contracts the correct muscles and understands how to train with the perineometer, the patient is instructed to establish a home exercise routine with the aid of the device to do 100 contractions over a 20-minute period, 3 times a day (300 contractions, 60 minutes a day total). (As discussed later in more detail, guidance from a range of professionals often recommends working-up to a sequence of holding contractions for 10 seconds and then relaxing for 10 seconds.) Kegel also observed (1956) that a treatment approach that combined exercises with the perineometer with exercises without the device produced the most rapid and lasting results. Thus, in addition to the instrument-assisted exercises, he advised doing five contractions in bed before getting up, followed by five additional contractions upon standing, and then trying to hold the PFMs in a contracted position while walking to the bathroom. He also encouraged interrupting the urinary stream several times during each voiding. Lastly, he recommended doing the same contractions five times every half-hour throughout the day during the active training period. Kegel stated that a weekly check of the patient's progress, typically for the first month, is essential as he found that a majority of patients generally were not using the right muscles at the beginning of treatment and required careful reinstruction. He advised that the most common cause of failure is letting a patient continue to exercise week after week without determining whether the patient is actually activating the pubococcygeus. Kegel stressed that "correct" contractions are always more important than strong contractions, and that this should be made clear to patients. Complaints of fatigue or muscle aches in the back or abdomen suggest unnecessary co-contraction of extraneous muscles when exercising.

Kegel (1951) reported that, in cases of "simple" urinary incontinence (stress incontinence – leakage only with coughing, sneezing, or straining), improvement is usually seen within a few weeks, and complete relief after 6–8 weeks. More complex cases of long-standing incontinence, in particular in cases where muscle tissue was significantly damaged by surgery, treatment could extend over periods as long as a year. Kegel (1956) observed that the goal of his behavioral approach to the treatment of stress incontinence is to train the patient in the activation of the muscles associated with the control of micturition such that a reflex pattern is established and becomes self-perpetuating. He specifically recommended that training continue well beyond the disappearance of symptoms to ensure that the "conditioned reflex of control is firmly established" as it is in normal individuals.

While Kegel clearly played an important role in popularizing pelvic floor exercises that are now identified with his name ("Kegel exercises"), Perry and Talcott (1990) assert that his real contribution was his development of instrumental-based feedback as a method to assist patients in learning how to properly exercise the pelvic floor musculature. They further argue that the descriptions of "Kegel exercises" often found in the popular literature bear little resemblance to the methods he originally advocated. Mention of Kegel's perineometer largely disappeared from the literature from the late 1950s through the 1970s, and brief references to advising patients to exercise the PMFs remained.

Development of the sEMG Perineometer

John Perry presented a paper before the Biofeedback Society of New England in 1978 in which he described the development of a vaginal myograph. He began this work initially building on Greer's development of a vaginal photoelectric plethysmograph (PPG) for purposes of studying sexual arousal (Perry, 1978). Perry added sEMG recording electrodes to a vaginal PPG sensor so that both vasocongestive (blood flow) and myotonic features of the different stages of sexual arousal could be monitored. He was later to remark that he quickly found that monitoring the activity of the muscles of the pelvic floor proved to be much more interesting, and he experimented with several designs both with and without the PPG component. While Perry continued to use vaginal sEMG recordings to study both healthy sexual function and dysfunction, he increasingly became involved in using sEMG monitoring of the PFMs in a clinical biofeedback context to treat a range of PFDs, including urinary and fecal incontinence. Perry became a major advocate of the use of PFM sEMG biofeedback in the treatment of incontinence and, in 2001, was awarded the Association for Applied Psychophysiology and Biofeedback's Shelia M. Adler Award, based in part on his contributions to obtaining Medicare reimbursement for biofeedback in the treatment of urinary incontinence.

Perry saw sEMG biofeedback training as a logical extension of Kegel's original manometric technique, both because Kegel's device was no longer in production and due to what he saw as limitations in the design (Perry & Talcott, 1990). Perry's first sensor was a "tampon-like" cylinder with a 5/8th inch (1.6 cm) outside diameter with three silver rectangular electrodes set longitudinally on its surface (Perry, 1978). Later variations added a retaining bulb on the insertion end and a larger bulb on the distal end to serve as a "stop." Early versions of these sensors were handmade out of dental acrylic and were intended for use across multiple patients after chemical sterilization. Mass-produced plastic probes following this same basic configuration and using stainless steel electrodes have since been introduced that are intended for multiple-use by a single patient. Shorter and smaller-diameter sensors were also developed for rectal use or for vaginal insertion in cases where the smaller size is appropriate. Figure 16.2 shows one of the early handmade dental acrylic rectal sensors along with newer plastic vaginal and rectal sEMG sensors. Compared to the somewhat cone-shaped sensor developed by Kegel, Perry has argued that the combination of the retaining bulb and the external stop bulb make for a sensor that is easy for patients to insert on their own and that maintains a relatively consistent placement for comparing readings over time.

Just as Kegel was, Perry is a strong advocate of home practice and the use of take-home biofeedback devices for this purpose. Fairly reasonably priced, basic sEMG and manometric devices are now available that make it possible to provide instruments for take-home use on a purchase, rental, or on-loan basis. Individual professionals or clinics that are not set up to provide or support the use of units for take-home use for various reasons should not feel that they cannot provide

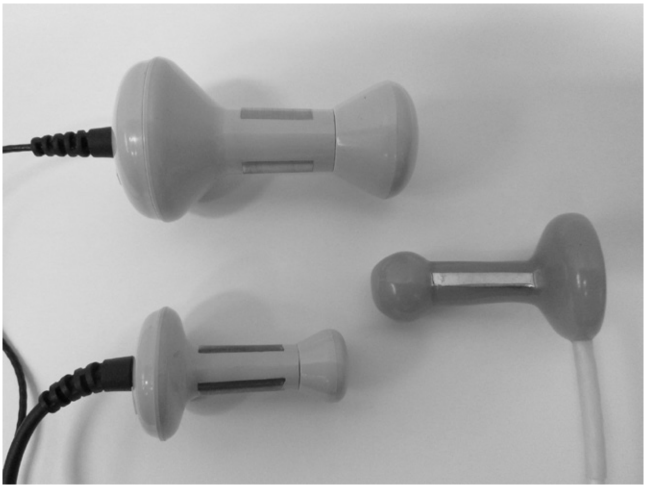

Figure 16.2 On the left are mass-produced vaginal (top) and rectal (bottom) sEMG sensors based on Perry's design and an early handmade, dental acrylic rectal sensor on the right. Three longitudinal metallic strips provide the two active recording contacts and reference (ground).

respectable PFM training as a result. Perry notes that arrangements can often be made with medical supply firms to handle all aspects of take-home device rental or purchase. It is also the case that many patients are able to learn how to exercise their PFMs correctly through in-clinic instrument-assisted instruction so that they can then practice between clinic sessions without instrumentation. Internalization of control is in fact the goal of all biofeedback training.

Perry Assessment Protocol

Kegel discusses at length the use of digital palpation and monitoring of a patient's initial attempts at contracting the PFMs, and only briefly discusses the use of the manometric perineometer for formal assessment. Perry focuses equally on the sEMG device as a source of clinical assessment and patient feedback information. This difference is likely traceable in part to Kegel's background as a gynecologist and Perry's as a psychologist; however, Perry (Perry & Talcott, 1990) argues that advances in electronic monitoring allow for more accurate methods of quantifying PFM activity than were available when using Kegel's device. He has advocated for a standardized diagnostic testing sequence for consistency of evaluation, comparison of data across clinics and research groups, and for third-party reimbursement considerations. The full protocol consists of three components: (1) a series of rapid, short contractions (“flicks”), (2) a series of alternating 10-second-on/10-second-off, work/rest cycles, and (3) an endurance test. Perry recommends that, whenever possible, the evaluation is carried out in a naturalistic environment with the individual fully clothed and seated in a comfortable chair. An inserted vaginal or rectal sEMG perineometer (sensor) is used to monitor EMG activity. Based on clinical judgment, monitoring of one or more accessory muscle sites, such as the abdominals, may be carried out at the same time to assess co-contraction and specificity of muscle activation. (This will be considered in more detail in the discussion of multi-channel sEMG systems.)

As with any device, an initial check is made to confirm that the sEMG instrumentation is providing reasonable signals and whether the patients understand what they are supposed to do by asking them to make an initial contraction of the PFMs. Instructions are typically to make as strong a contraction as they can and to hold it as long as they can (see personal communication note in *Acknowledgements*); this guidance assumes an initial assessment session where the expectation is that any sustained contraction will be relatively short. After observing the magnitude of the contraction, the scaling of the instrumentation display can be adjusted as needed.

Perry then calls for moving to the formal assessment, which begins with a 10–20-second resting baseline reading. This is followed by a series of six short contractions (commonly called “flicks”) and an additional 10–20-second post-contraction period. Note is made of the peak value of each contraction and whether the resting level for the post-period returns to pre-contraction levels, as would be expected in healthy muscles. Peak values of the flick tests are intended to assess the strength of the fast-twitch (phasic) striated muscle fibers. In a large sample of older, non-institutionalized incontinent women, Brink, Sampselle, Wells, Diokno and Gillis (1989) reported a mean value for six rapid unsustained contractions (flicks) of 5.61 microvolts (SD 3.9).

The core part of the assessment consists of a 10–20-second baseline reading followed by a series of six 10-second contraction periods, each interspaced with a 10-second relaxation/recovery period (see Figure 16.3). A 10–20-second post-period is again included. This portion of the assessment protocol mirrors the basic protocol for actual biofeedback training in which the patient engages in alternating sustained contraction and rest periods.

Modern instrumentation has greatly simplified and improved the consistency of this form of assessment. Auditory and/or visual cues can be provided to prompt patients when to contact and relax while also providing consistency of timing and automated data reduction. At one point, Perry recommended that, based on psychometric principles, automated assessment software should discard the highest and lowest interval scores and base calculations on the remaining four. None of the packages implementing his protocol that he reviewed actually do that, and he sees it as reasonable for clinicians to simply comment in reports about any outliers.

A standard measure of resting-level muscle activity (“tension”) is calculated as the mean value of the six rest periods. Perry reports that a typical resting level is

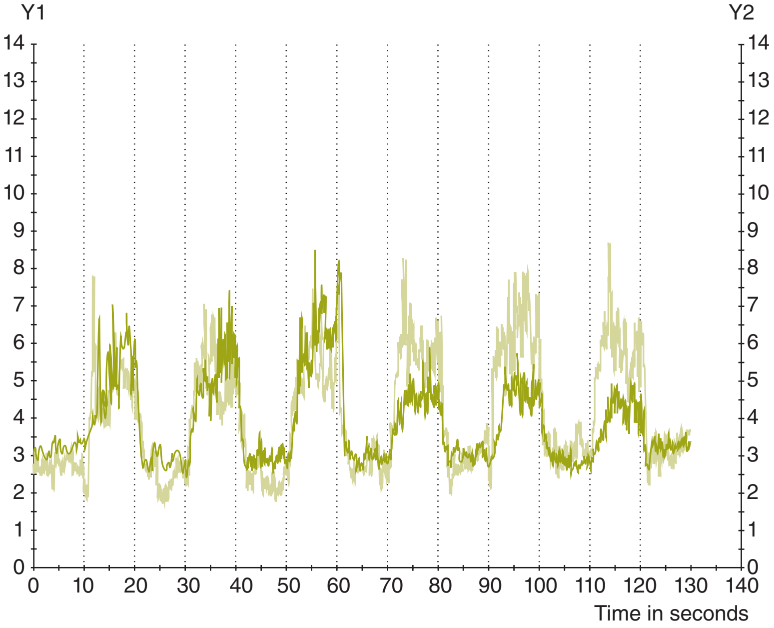

Figure 16.3 Initial sEMG discrimination training. Darker tracing is a recording from the abdominal musculature, and the lighter tracing is of activity from the pelvic floor musculature (PFM). Note the drop in co-contraction of the abdominal muscles in the fourth through sixth contractions as discrimination learning takes place.

somewhat below 2 microvolts RMS, and a good resting level is somewhat below 1 microvolt. (Note that "typical" sEMG values are influenced by the bandpass characteristics and quantification method employed in a given instrument; as discussed later, wider bandpass instruments will generally produce slightly higher readings.) If the resting values are significantly higher than the initial baseline, or if there is an increase in the resting readings across the contraction series, this may suggest poor conditioning and hyper-irritability of the muscles.

Perry recommends calculating a standard measure of contractile strength that is the mean value for the contraction periods minus the mean value for the resting periods. This contractile strength calculation is a composite measure of the ease with which the pelvic floor musculature is activated, phasic contractile strength, the ability to maintain tonic contractile activity for the 10-second period, and the ease with which muscle activity is released. Some have taken the approach of dropping the first second of the contraction period since it includes a lag interval as the patient responds to the prompt and attempts to activate the PFMs. Perry sees this as well intended, but argues that this interval actually contains useful information on how easily and rapidly the patient can engage the PFMs in a full contraction. Note that,

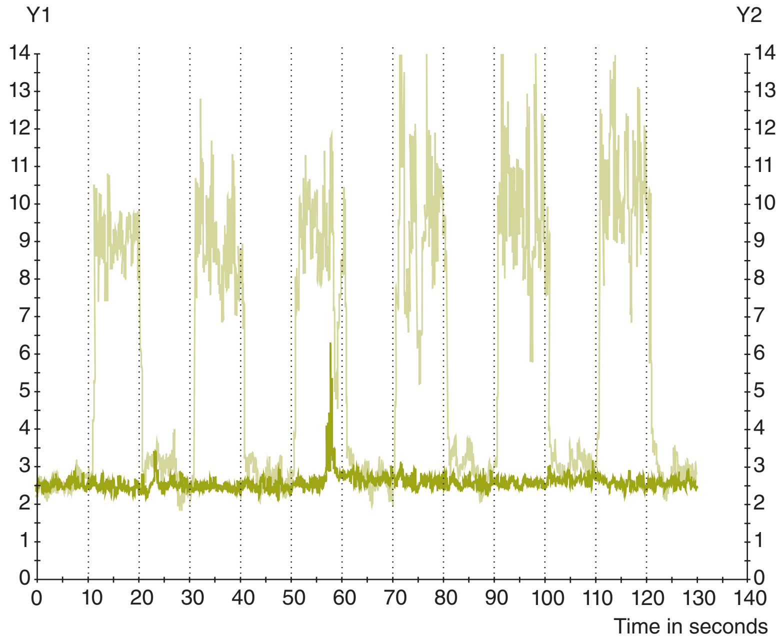

Figure 16.4 After a limited number of biofeedback trials, co-contraction of the abdominal muscles (darker tracing) has dropped out, and mean contractile strength of the PFMs has increased from approximately 6 microvolts in Figure 16.3 to approximately 10 microvolts for the final three contractions here. Note also that the resting baseline values have dropped from about 3 microvolts in Figure 16.3 to approximately 2.5 here.

in using Perry's approach to quantify contractile strength, scores for patients with elevated base levels of muscle tension will improve both with increases in contractile strength and as inappropriate "resting" tension is released. Perry reports that a typical non-patient contraction level is around 10 microvolts. A contraction level of 20 or greater is considered good in non-patients. Rectal measures are typically slightly higher than vaginal measures. Data from Brink et al.'s (1989) sample of incontinent older women showed a first contraction peak of 6.07 microvolts (SD 4.3), held for a mean of 4.83 seconds (SD 6.8) at 50% or better. Peak contractions are generally observed to decrease in strength in untrained, symptomatic individuals and the mean value for the six 10-second held contractions for this sample was only 2.79 microvolts (SD 2.5).

The final component of the full protocol is an endurance test. This is described (Perry & Talcott, 1990) as following standard practice in physical therapy in which the maximal contraction point is noted and the time in seconds that the patient is able to sustain the contraction above 50% of the maximum is determined. As opposed to the flick assessment, this is considered as an estimate of the strength of the slow-twitch (tonic) striated muscle fibers of the PFMs.

While Perry likes to show patients the difference between all three tests, he recommends that practitioners, at a minimum, collect the 10-second work–rest cycles in which the mean resting level is subtracted from the mean contraction level to calculate a "net" strength" value. Based on some of Perry's comments on the short "flick" contractions, it might be argued that they may be more of a historic and/or research interest and less useful in normal clinical training situations. The longer 10-second "hold" contractions have been found to correlate with urinary and fecal control, but the flick contraction strength does not (Perry & Talcott, 1990). Perry (1991) notes that patients should be discouraged from doing short contractions as part of their therapeutic exercises; it is presumed that they will not contribute significantly to the development of tonic slow-twitch fibers necessary for continence control.

Contraction Length and Frequency of Practice

Both Kegel and Perry emphasize the importance of frequent practice while patients are learning to be aware of the PFMs and establishing/reestablishing healthy muscle tone and control. From their perspective, making training "easier" for a patient would be a disservice. As detailed previously, Kegel (1956) specified a home exercise routine with a perineometer consisting of 100 contractions over a 20-minute period, three times a day (300 contractions, 60 minutes a day total), along with five device-independent contractions every half-hour throughout the day. (See also the description of practice contractions associated with voiding.)

Perry advocates exercises built around the same 10-second-contract/10-second-relax model used in his assessment protocol, although starting with shorter work/rest periods as needed to build-up to these intervals are acceptable; for example, starting with 3-second contractions and 6-second rest periods (Perry, 1991), and then gradually increasing the duration of each. The amount of exercise expected at the start of therapy is a trade-off involving several factors. Perry notes that if too much exercise is attempted at first, fatigue and pain from spasm may result; if too little is undertaken, little gain may be seen and the patient will become disillusioned. Two general guidelines apply. If patients are not showing improvement, use in-clinic instrumentation and observational assessment to determine whether they are doing their exercises correctly; coach as needed in modifying their behavior if they are not. If they are able to exercise correctly, then confirm whether they are actually practicing at home, and increase the exercise assignment as needed.

Active exercise should be considered to maintain gains posttreatment, and Kegel reportedly recommended 100–150 non-monitored contractions a day for life (Perry, 1991), which equates to Kegel's five contractions every half-hour during waking hours. Whether active maintenance practice at this level is actually required in otherwise physically active individuals remains an open question. Nonetheless, the principle of ongoing exercise at some level and increasing practice should symptoms return is straightforward.

In a research study, Capelini et al. (2006) conducted 12 weeks of twice-a-week in-clinic training sessions monitoring sEMG from both an abdominal placement and a vaginal sEMG sensor. Each in-clinic biofeedback session consisted of three series of 10 sustained contractions followed by a relaxation period (30 contractions). For the first 4 weeks, contraction periods were of 5 seconds duration, and the relaxation periods were 10 seconds long. For the next 4 weeks, the contraction periods were increased to 10 seconds each. During the final 4 weeks, both contraction and relaxation periods were extended to 20 seconds each. Significant gains were quantified in terms of reductions in pad weight, number of leakage episodes, daytime frequency, and in urodynamics (Valsalva leak-point pressure, cistometric capacity, and bladder volume). Gains were maintained at a 3-month follow-up.

Continuous Feedback, Motor Learning, and Digital Assessment

An important drawback of relying solely on verbal instruction in "Kegel exercises" is that some women have difficulty correctly identifying the pubococcygeal muscle and in learning to exercising it properly (Burns, Marecki, Dittmar & Bulloch, 1985). A fundamental principle of instrumental learning is the provision of feedback to signal that the desired behavior is being successfully acquired. Burgio, Robinson, and Engel (1986) conducted a carefully controlled study that compared training in PFM exercises through clinician based verbal feedback with biofeedback assisted training. In the verbal feedback group, a clinician used digital assessment via gloved fingers of one hand placed in the patient's vagina while the other hand was placed over the abdominal region to monitor the patient's abdominal muscles. The biofeedback group received visual feedback of bladder pressure, rectal pressure, and external anal sphincter activity. Both groups received the same number of contraction trials per session, were taught coping skills strategies to assist in generalization of results outside the clinic, had equal contact with the clinician, and were given similar home exercise programs. Both groups showed improvement, but the gains were markedly larger for the biofeedback group, showing an added benefit of the instrumental training over verbal instruction alone.

As noted earlier, the use of a clinician's fingers as a sensing device and the prevision of verbal feedback can be considered as a form of biofeedback. However, the use of instrumentation that can provide highly sensitive and continuous information more fully represents what is traditionally thought of as clinical biofeedback training. Burgio and colleagues suggested that the "biofeedback" condition in their study was more effective than more traditional verbal training since it was more finely graded and precise, it was continuous rather than intermittent, and it was immediate whereas feedback from the clinician tends to be delayed. As elegantly expressed by Tries (1990), the "lack of continuous and immediate feedback during acquisition of a new motor skill could be compared to someone trying to learn to play a musical instrument while hearing only one half the sounds with a 1-second delay factor" (p. 74).

While the Burgio et al. study employed pressure-sensing technologies, the same learning principles apply to sEMG monitoring. Comparing PFM training alone with PFM training with biofeedback that used sEMG, Berghmans et al. (1996) reported that both groups showed similar gains after 12 weeks of treatment. However, they emphasized that the gains were evident in the biofeedback group at 6 weeks, and that the groups were statistically distinct at that point. This would tend to indicate a learning speed advantage to the biofeedback-assisted approach. The authors concluded that adding biofeedback may have an advantage in supporting shorter treatment protocols. In modern clinical environments where treatment sessions and staff are limited, this appears to be a distinct advantage.

While digital assessment (using the examiner's fingers) to assess muscle tone and coordination plays a practical and highly useful role in the daily clinical practice of many professionals, that should not obscure the fact that there are limitations to this approach. Brink et al. (1989) compared a digital assessment in which patients were instructed to squeeze the pelvic muscles and hold several contractions following a structured protocol to sEMG assessment. The digital assessment scores were compared to EMG values obtained from a first maximal sustained contraction, mean strength of six 10-second contractions, and mean EMG values for six "flicks" (rapid unsustained contractions). This study is remarkable for the size of the sample, which consisted of 338 non-institutionalized women with urinary incontinence. Data collection was carried out using a computerized protocol and "dumbbell"-shaped vaginal probes (standard and small) of dental acrylic into which three silver contacts were embedded. (The descriptive details make it highly likely that Perry style sensors were used.) The relationships between digital assessment and EMG values were all positive, statistically significant, but functionally modest. Correlation coefficients (r values) ranged from of .53 to .60. Test–retest values for the digital assessment were also collected approximately 6 weeks apart for 228 participants; values of $r = .65$ were obtained. Again, these are statistically significant for a sample this large but are modest in their absolute value. Often, values are expected to be in at least the .7 to .8 range to be considered satisfactory for many types of assessments.

Technical Considerations in the Use of sEMG Instrumentation

Surface vs. inserted sensors – One limitation to the widespread use of sEMG-based biofeedback-assisted PFM training when it began to attract significant attention in the 1980s and 1990s was the relative expense of the early multi-user vaginal and rectal sensors. Some creative clinicians who were already familiar with using sEMG techniques for recording from a wide range of muscle groups explored the use of standard disposable-adhesive-patch-style sEMG sensors placed externally in the perianal region to detect PFM activity as opposed to using vaginally or rectally inserted sensors. While disposable-adhesive-patch-style sEMG electrodes are relatively easy to attach for monitoring abdominal, gluteal, or upper-thigh muscles, placement in the genital and rectal regions is problematic due to skin folds and the typical presence of pubic hair. In many ways, the use of external electrodes to record PFM activity is more invasive than the use of vaginal or rectal sensors. Patients can be instructed descriptively and through the use of diagrams in how to properly insert vaginal and rectal sEMG sensors themselves in the privacy of an exam room or bathroom, while the attachment of external sensors realistically requires intimate skin preparation and attachment by a trained individual. Given that relatively inexpensive single-user vaginal and rectal sEMG sensors are now available, there are a number of reasons to recommend the use of inserted as opposed to surface sensors for recording PFM activity.

Vaginal vs. rectal sensors – When using inserted sensors, sEMG training for urinal incontinence in females is typically carried using vaginal sensors, whereas training for males is, obviously, restricted to the use of rectal sensors. The closer anatomical proximity of the relevant muscle tissue of the bladder outlet and urethra and that of the vagina relative to the more distal location of the rectal area, makes an intuitive case for a preference for vaginal placement. Nonetheless, very positive results have been obtained using manometric-based anorectal training (e.g., Burgio et al., 1998), thus making it reasonable to consider the use of rectal placements for urinary incontinence applications, should vaginal insertion not be desirable for some reason. The puboccygeus muscle originates from the pubic bone and forms a sling around the urethral opening, the vagina, and the rectum. Bo (2004) states that the only known voluntary function of the PFM is a mass contraction that is generally experienced as an inward lift and squeeze around all three orifices. Perry and Talcott (1990) similarly observe that most patients are not able to differentiate regions of the PFMs and exercise them as a group.

Electrode configuration – The sensor design developed by Perry uses a conventional bipolar recording configuration consisting of two active recording contacts and a reference contact. (A reference contact is also sometimes referred to as a "common" or "ground.") A bipolar recording array is almost universally employed in sEMG monitoring as it is an integral part of a differential amplifier circuit, which provides a means of canceling electrical noise that is common between the active and the reference recording sites. In the Perry configuration, the contacts are rectangular metallic strips arrayed longitudinally along the middle portion of the probe. When oriented as recommended, the two active contacts are positioned on the left and right sides of the pelvic floor and the reference contact is located in a ventral position. The early handmade versions utilized silver contacts, and subsequent mass-produced versions of the Perry-style (Figure 16.2) and most other current vaginal and rectal EMG sensors utilize stainless steel. Perry patented the three-bar-array configuration, and it is open to question as to the extent to which some subsequent designs have been based on technical or patent considerations; for example, use of an external reference.

Prior to the widespread development of vaginal and rectal sensors specifically for sEMG recording, vaginal and rectal probes for electrical muscle stimulation were introduced. Hopkinson (1966) described an hour-glass shaped anal "plug" style device with two parallel circumferential electrodes plates spaced 1 cm apart at either end of the neck. Larger vaginal probes with circular ring style contacts were later introduced into clinical use for electrical stimulation purposes. As interest in sEMG recording of the pelvic floor musculature developed, both research and commercial developers recognized that, from a purely electrical perspective, the conductive contacts of such stimulation probes could be used for sensing myoelectrical activity as well. A number of probes are now commercially marketed for both applications. However, questions have been raised about the sensitivity of the circular ring style electrode design for recording the muscles of specific interest in PFM assessment and training.

Binnie, Kawimbe, Papachrysostomou, Clare, and Smith (1991) compared the Perry style longitudinal bar design against the ring design for recording activity of the external anal sphincter and found the latter produced contraction readings generally less than 60% of the amplitude of the longitudinal contacts. In their clinical sample of 117 patients, the pudeno-anal reflex appeared absent in 12 patients when using the ring sensor. When using the longitudinal electrode, a low-amplitude response was detected in 11 of these 12 cases. Thus, while it may be functionally practical to use the same electrode for both stimulation and recording purposes, it should not be assumed that a design that has worked adequately for stimulation purposes will necessarily perform equally well for recording sEMG; attention should be paid to the orientation issue in developing and evaluating sensor designs for PFM monitoring applications. Perry has argued that the same design advantage for longitudinally oriented sensors for recording anal sphincter activity applies to vaginal sEMG sensors as well. It is also worth noting that, as part of this work, Binnie et al. found very high correlations between sEMG recorded from the longitudinal electrodes and fine wire EMG recordings for the external anal sphincter, reporting correlation coefficients of $r = 0.99$ for resting values, 0.99 for a squeeze maneuver, and 0.91 for a strain maneuver.

Other variations in vaginal sensor design have been introduced in recent years. Auchincloss and McLean (2009) made creative use of two such sensors to study the test–retest reliability of vaginal sEMG electrodes. One of the two sensors studied included dual active sensors on both the left and right sides of the vaginal probe with independent references on the dorsal and ventral sides of the sensor (Femiscan™). This configuration allows for independent assessment of the left and right sides of the PFMs. Perhaps what is more interesting than the basic test–retest reliability data that they report is that their experimentation with different configurations of the active contact points suggests that modifying (for research purposes) the standard outputs of the six contacts of this sensor could support a systematic evaluation of the relationship between different orientations of the active contacts relative to PFMs on sensitivity of detecting PFM contractions.

Bandpass/frequency range – The electrical potential measured by sEMG is the summed activity of many muscle fibers firing in varying sequences and at different rates. Measured at the surface of the skin, this activity spans a frequency range from several cycles per second through approximately 500 Hz, with the majority of the energy often falling in the range of about 50–150 Hz depending on the muscles being measured (Basmajian & de Luca, 1989). (Needle and fine-wire EMG recording systems are configured to pick up higher-frequency components that the skin and other tissues typically filter out of the sEMG signal.) Cram (1990) estimated that close to 80% of the sEMG signal resides between 30 and 80 Hz, and the median frequency of muscle activity is now recognized to shift to slower frequencies with muscle fatigue (de Luca, 1984). Given that patients with weak PFMs are likely to show such fatigue shifts with even a few contractions and that patients with chronically tense muscles are also likely to show fatigue characteristics, the ability to accurately monitor activity in the lower frequency ranges is an important consideration. Many early sEMG systems designed for biofeedback applications used restricted frequency ranges, often attenuating signals below 100 Hz as a way of avoiding various sources of electrical (power line) and biological (EKG, EEG) artifact. Following this model, a patent Perry filed in 1981 specifies a device that records signals in the range of 100–400 Hz; however, this was before de Luca's work on frequency shifts with muscle fatigue became known in the broader literature. In the case of patients with chronically tense muscles, a device that ignores signals below 100 Hz might report very low EMG values, thus inaccurately indicating that muscles are relatively relaxed. Given advances in electronic components and circuit design, practitioners should look to properly designed instruments that record well into the low frequency range. All things being equal, lower bandwidth settings of approximately 10–35 Hz and upper bandwidth settings in the 300–500 Hz range are quite respectable. As an example, the specifications for an instrument fitting these guidelines might list a bandpass of 25–450 Hz or 30–500 Hz.

An EMG instrument may also include a "notch filter" to specifically reduce the influence of electrical artifact from standard wall power sources. Notch filters should specifically match the power characteristics of where the device is being used (i.e., either 60 or 50 Hz). Standard North American power line frequencies are 60 Hz while much of Europe uses 50 Hz.

Multi-channel capacity – It is recommended that at least a dual-channel sEMG system be used for in-clinic training, so that one channel may be employed to monitor signals from vaginal or rectal EMG sensors while the second channel is available for use with standard, disposable adhesive-surface EMG electrodes to monitor the activity of the abdominal muscles or other muscle groups that may be inappropriately recruited by the patient when attempting to contract the target muscles of the pelvic floor. Glavind, Nohr, and Walter (1996) observed that Kegel's pressure sensor had the disadvantage of detecting both intra-abdominal and intravaginal pressure at the same time and combined a vaginal sEMG sensor with a rectal catheter to detect abdominal pressure changes. A dual-channel sEMG system allows similar functional monitoring capacity integrated into a single instrument.

The capacity to monitor the abdominal muscles is particularly useful in the early stages of training to assist the patient in discriminating the difference between the contraction of the target muscle group and other muscles, such as those of the abdominal wall. As discrimination improves, the focus can shift to building up contractile strength and control of the target muscles. If both abdominal and PFM activity remains low while a patient reports actively contracting muscles, evaluate whether other muscle groups such as gluteal or upper thigh muscles are being activated. The Capelini et al. (2006) study described previously is an example of the use of a multi-channel sEMG instrument for in-clinic training. An intravaginal sEMG sensor was used to record activity of the PFMs, and adhesive surface electrodes were attached over the abdominal region to assist in discrimination of contraction of the correct muscle groups.

Some clinicians, such as Perry, feel strongly that having biofeedback units available for home practice are also quite important to maximizing success. As long as multi-channel instruments are available for more detailed in-clinic assessment and training, less expensive single-channel sEMG units can reasonably be employed for home practice between in-clinic sessions.

Other Clinical Considerations

Managing anxiety – Many patients who initially present for treatment of urinary incontinence (UI) or other PFDs are anxious about treatment. Helping ease their anxiety can be a clinical priority so that adequate learning of the skills to treat UI and PFDs can be achieved. Interventions such as peripheral biofeedback (sEMG from placements distal from the pelvic floor region such as the forearms or shoulders, thermal, or electrodermal training) or other relaxation training techniques may need to be initiated to help ease a patient's anxiety. Through mastery of some type of relaxation technique, patients can not only learn how to gain some voluntary control of their bodies, but they can also develop a greater sense of competency. Not surprisingly, treatment of UI and other PFDs can happen in behavioral medicine clinical practices with licensed behavioral health specialists who have training in the treatment of PFDs including UI, peripheral biofeedback, and other relaxation training techniques.

Sensitivity to trauma issues – While it goes without saying that practitioners need to be sensitive to the emotional state of each patient, this is particularly so in the case of presentation of excessive pelvic muscle tension, chronic pain, and sexual dysfunction. Rates of childhood physical, sexual, and emotional abuse of 27%, 25%, and 13%, respectively, have been reported for women in the general population, and rates have been reported to be as high as 64% in women presenting with chronic pelvic pain (Herbert, 2010). Herbert suggests that, in cases where a patient's emotional profile indicates that it might be appropriate to inquire about abuse, a normalizing probe can be used along the lines of "in about half of women with pain similar to yours, we have found that people treated them badly, sometimes years earlier, even in childhood" (p. 31). While the frequency of such concerns is likely to be lower in patients presenting with incontinence issues, they or other emotional sensitivities can be present and become emergent during examination and training. Practitioners who are not themselves trained, or do not have the clinical time available, to treat the emotional aspects of such cases should identify mental health professionals who can be actively involved in collaborative treatment that supports addressing emotions and memories that may emerge. Appropriately managed, spreading care across more than a single clinician and specialty can be advantageous. Jantos (2011) highlights the role for multidisciplinary input in addressing the potentially complex nature of pelvic disorders.

Supportive treatment and skilled clinician monitoring – Anecdotally, patients have reported that supportive verbal therapy while working with the biofeedback instruments in the clinic not only helps keep them motivated to learn the skills needed to treat UI and PFDs, but that the "eyes" provided by a biofeedback clinician can significantly extend the monitoring provided by an sEMG unit in the detection of inappropriate use of accessory muscles in practicing the exercises. Even when using multi-channel sEMG systems for precision monitoring, nurses, physical therapists, occupational therapists, and other healthcare professionals should not set aside their well-learned observational skills and look for problematic patterns of behavior that can be pointed out to the patient. If left undetected, excessive accessory muscle use can lead to frustration when trying to isolate and master the use of the pelvic floor muscle group to treat UI and PFDs.

Protocol management – Patients have also shared that, even though a standard 10–12-session protocol has proven helpful to treat their UI and PFDs, spacing the last two or three sessions out over time, such as allowing 4–6 weeks between appointments, helps to maintain gains made while reinforcing positive behavioral management for the treatment of their UI or PFD.

Current Research Status of Biofeedback-Assisted Behavioral Training for Urinary Incontinence

An important milestone in the formal recognition of biofeedback as an accepted clinical technique in the treatment of urinary incontinence was reached in 1992 with the publication of *Urinary Incontinence in Adults: Clinical Practice Guideline* by the US Agency for Health Care Policy and Research. This document categorized treatment into behavioral, pharmacologic, and surgical approaches, and specifically stated that “as a general rule, the least invasive and least dangerous procedure that is appropriate for the patient should be the first choice” (UIGP, 1992, p. 27). The behavioral techniques considered were bladder training, habit training, prompted voiding, and pelvic muscle exercises. The report went on to assert that behavioral techniques “are low-risk interventions that decrease the frequency of UI in most individuals when provided by knowledgeable health care professionals.” Biofeedback was recognized as a technique that can be used in conjunction with these methods. Published work specifically recognized by the panel included Baigis-Smith, Smith, Rose, and Newman (1989); Burgio, Whitehead, and Engel (1985); Burton, Pearce, Burgio et al. (1988); Middaugh, Whitehead, Burgio, and Engel (1989); and Tries (1990). Improvement rates in these studies ranged from 54% to 95%. As biofeedback emerged as a recognized clinical procedure, Perry’s approach of using vaginal and rectal sEMG sensors, Whitehead and colleagues’ work with multi-stage rectal-balloon-based pressure systems, and Kegel-style manometric vaginal sensors garnered significant research and clinical interest.

Twenty years later, government panel reports continue to support this position. The Agency for Healthcare Research and Quality report on *Nonsurgical Treatments for Urinary Incontinence in Adult Women* (Shamliyan, Wyman, & Kane, 2012) concluded that there was a high level of evidence indicating significant benefits from PFM training. Such training was found to increase continence rates and improvement compared to regular care. Notable was the study by Burgio et al. (1998), which found that behavioral treatment including biofeedback was significantly more effective than drug treatment, yielding an 81% reduction in incontinence episodes vs. 69% for drug treatment and 39% in a placebo control condition. Perceived improvement on the part of patients was also highest in the biofeedback group with “much better” ratings of 74% vs. 51% for medication, and 27% for placebo. Another particularly telling finding was that only 14% of the biofeedback group wanted to change to another treatment vs. 76% of those in the other two groups. Regarding the use of sEMG-probe-style biofeedback in PFM training, the agency report concluded that a “low level” of evidence indicated increased continence compared to usual care (e.g., only four studies met their randomized, controlled comparison criteria: Aksac et al., 2003; Burns, Pranikoff, Nochajski, Desotelle, & Harwood, 1990; Burns et al., 1993; Goode et al., 2002), but that the resulting evidence was high that the treatment resulted in improvement.

In spite of the positive findings for biofeedback-assisted pelvic floor muscle training (PFMT) as a treatment modality, consensus reviews such as those of Shamliyan et al. (2012) have concluded that, while there is good support for both PFMT and PFMT with biofeedback in the treatment of incontinence, randomized controlled studies have yet to establish a consistent gain in including biofeedback in PFMT training protocols. However, caution should be exercised in presuming that there is no advantage on the basis of such reviews. Examination of studies reporting no statistical differences between PFMT only and PFMT plus biofeedback groups often show trends in the direction of additional benefit in the biofeedback added conditions. In a study of women with stress incontinence, Aukee et al. (2004) reported no statistically significant difference between groups in rates of avoiding surgery post behavioral treatment. However, an examination of the data shows that 69% of the group that did home practice with a sEMG biofeedback device avoided surgery (11/16) vs. 53% of the group that did PFMT at home without biofeedback assistance (10/19). The relatively small sample size limited the statistical sensitivity of the study to establish the added benefit of adding biofeedback to the treatment regimen. Mørkved, Bø, and Fjørtoft (2002) assessed the impact of home practice with a pressure feedback device vs. PFMT home practice without biofeedback. They reported an objective cure rate based on leakage measurements of 58% in women using the biofeedback device and of 46% in women doing PFMT without biofeedback. In a subgroup of women with urodynamic stress incontinence but no additional urge symptoms, the reported rates for the biofeedback group was 69% vs. 50% for the group that did not include biofeedback training. The group differences are again in the direction of greater success for the biofeedback groups; however, the trends do not reach statistical significance. While Mørkved et al.'s sample size appears at first to be respectable (94 cases), they based their sample size on the position that an outcome difference of 25% or more was a reasonable criteria to establish value for including biofeedback as part of a training program. Schiotz (2003) challenged the assumptions the authors used in making their power calculations and argued that their study was underpowered as well. Aukee, Immonen, Penttinen, Laippala, and Airaksinen (2002) is another modest-sized study with 30 participants total that compared patients who received an sEMG device to use in their home practice against a PFMT-alone home practice group. Decreases in pad test values were similar in both groups, while the biofeedback group showed a trend toward better leakage index scores ($p = 0.068$). Weatherall (1999) also challenged the statistical rigor of several systematic reviews and argued that the trials considered had insufficient statistical power to detect modest but meaningful differences in the treatment protocols.

The Shamliyan et al. (2012) review also lists Glavind et al. (1996) as one of the comparison studies and states that no differences were found between the physiotherapy-only group and the physiotherapy plus biofeedback group on quality-of-life rates, yet this does not appear to be the case in reviewing the paper. In addition, the review fails to note that this study in fact showed significantly greater gains in the biofeedback group based on a standard pad weight test, and a long-term follow-up (2–3 years posttreatment) questionnaire continued to show greater benefit for the biofeedback group. In addition, 89% of the biofeedback group reported that they still did pelvic floor exercises vs. only 50% of the control group.

In contrast with the very positive findings of Glavind et al., a study in which sophisticated in-clinic training based on monitoring both vaginal sEMG and intra-abdominal pressure was carried out, another point to be considered is that most of the randomized studies comparing PFMT with and without biofeedback that report only positive trends in favor of including biofeedback have utilized simple home-trainer-style biofeedback devices. Many experienced clinicians who utilize sEMG believe strongly in the value of multi-channel training in the clinic to aid patients in learning how to correctly exercise the PFMs without inadvertently co-contracting other muscle groups. See in particular Tries' (1990) critique of the importance of multi-site muscle monitoring (p. 73). As discussed previously, Figures 16.3 and 16.4 provide illustrations of how a multi-channel display can assist a patient in learning to quickly discriminate generalized muscle contractions from contractions that are localized to the PFMs. One wonders if controlled comparison studies used more sophisticated in-clinic training along the lines of that employed by Capelini et al. (2006), so that more overt advantage for the biofeedback-assisted PFM training would be demonstrated. Personal clinical experience has demonstrated very rapid discrimination training using dual-channel displays in the early in-clinic phase of patient learning.

Conclusions

There is a substantial body of evidence demonstrating that a range of behavioral techniques aimed at increasing awareness, coordination, and strengthening of the muscles of the pelvic floor can positively impact a number of pelvic-floor-related disorders. Behavioral instruction, whether through descriptive means alone or supplemented by digital assessment and verbal feedback, has been shown to produce improvements in many patients. However, other patients have difficulty in the identification and discrimination of relevant muscles, and there is evidence that real-time biofeedback can add meaningfully to the overall gains in a treatment protocol. There is reason to suspect, based on clinical experience, as well as cited research, that modern feedback systems may speed up learning for some patients by providing finer-grained informational content, more accurate feedback, and contribute to overall interest and engagement in a training regimen. The measures supplied by the instrumentation also provide the clinician with objective data on whether a patient's in-clinic practice and home exercises are producing the desired results, or if modification in the instructional approach/treatment protocol is required. Good clinical results have been obtained with vaginal pressure sensors of the type pioneered by Kegel, as well as with more involved bladder and rectal pressure sensing systems. Multi-channel sEMG systems offer a straightforward means of training discrimination and differential activation of relevant muscle groups, employing relatively easy-to-use sensors. High-quality sEMG systems also offer advantages in behavioral medicine practices that work with patients with muscular conditions other than PFDs since surface sensors may be used work with muscle assessment and retraining literally from head to toe. Nonetheless, while both authors have an affinity for the sEMG approach, we believe the gains that may be obtained in many patients through instrument-assisted training should encourage clinicians to consider inclusion of biofeedback methodology in PFMT, regardless of the modality.

For Further Study

As mentioned at the start of this chapter, Arnold Kegel's original papers (e.g., 1948) are recommended both for historical context and the forward-thinking presentation of principles that represent cornerstones of learning theory and behavioral medicine. Kegel (1952) is particularly useful for the number and quality of the color illustrations of the PFMs. Much of John Perry's work was presented at professional society meetings and through support materials provided with the various EMG sensors that he personally produced or was later involved in developing, making current access to his work challenging. He created a website (www.incontinet.com) that, as of this writing, provides copies of many of his presentations and other useful supporting material. Interested readers can also seek out the chapter by Perry and Talcott in the edited work Cram (1990), which is presently available through online booksellers; it is particularly rich in providing clinical practice detail. Perry's US patent No. 4396019 for a "vaginal myograph method and apparatus" provides useful documentation of his work. Jeannette Tries' 1990 paper is a classic in the field, and her collaborative chapters with Eugene Eisman (Tries & Eisman, 2003a,b,c) provide extensive background material along with practical clinical recommendations covering urinary incontinence, fecal incontinence, and pelvic floor conditions involving overly tense muscular states. Readers with an interest in fecal incontinence should see the chapter on this topic by Whitehead in this present title. An extensive chapter by Jantos (2011) covers the use of sEMG in both assessment and treatment of PFDs in women, with a particular emphasis on pain syndromes. A succinct summary of manometric and sEMG biofeedback for PFM training can be found in Haslam (2002). Practitioners with an interest in vulvadynia and related conditions may wish to refer to work by Glazer and colleagues (e.g., Glazer, Rodke, Swencionis, Hertz, & Young, 1995). A good source of overall information on biofeedback is the encyclopedic work edited by Schwartz and Andrasik (2003), which includes the chapters by Tries and Eisman. Professional training courses on the behavioral treatment of PFDs are available, and a certification program in pelvic muscle dysfunction biofeedback is presently offered through the Biofeedback Certification International Alliance (see www.bcia.org).

Acknowledgments

As noted in the text, Perry's approach to assessment is documented in Perry and Talcott (1990) and various support materials supplied with his sensors (Perry, 1991). Some of the observations attributed to Perry without direct citation are from personal communications with the first author. Appreciation is extended to Alea Mehler for reviewing the manuscript.

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17

Biofeedback in Psychocardiology

Measuring and Managing Changes of Heart

Jade M. Dyer

Last week, I visited a 63-year-old Maori man in the coronary care ward of an Australian hospital to assess his psychological state following a triple bypass. While we discussed his lifestyle as a laborer in an outback mining town, I became distracted by the sound of his heart monitor. Noticing this, the patient attempted to allay my concern by explaining, "I can control the beeping by changing how I feel." This was not advice the medical staff had shared with him, but a fact he had observed himself. He went on to describe how he challenged his anxious thoughts with disputing evidence, a technique often used in cognitive behavioral therapy. This not only made him feel better, but also stopped the beeping. Unlike many patients who appear thoroughly disempowered by heart surgery and the limitations it imposes, this man was teaching himself to manipulate his heart rate at will using basic biofeedback and cognitive restructuring.

It has been recognized since ancient times that our hearts respond to our beliefs and emotions, and that in the cases of "voodoo death" or heart attack, the effects of the nervous system on cardiovascular health can be devastating (Cannon, 1942). However, regulation of the heart by the autonomic nervous system was widely believed to be beyond conscious control until the 1960s, when biofeedback was first used to manipulate heart function. It is now recognized that cardiovascular activity is amenable to self-regulation using a range of behavioral techniques, including controlled breathing, psychological intervention, and biofeedback (Taylor, 2010). There is also growing evidence that autonomic imbalance and the chronic activation of the fight-or-flight response are linked to various forms of cardiovascular risk and disease, as well as incidence of myocardial infarction (Thayer, Yamamoto, & Brosschot, 2010). Although electrophysiological measurements are routinely used to identify pathologic heart function in cardiology practice, using this information to

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manipulate autonomic and cardiovascular activity has rarely been a treatment method offered to patients. Fortunately, current biofeedback equipment has made it both easy and cost-effective to objectively measure heart function, and it is now possible for any health-conscious consumer to monitor and optimize their own heart health. In this chapter, we will explore the history and efficacy of cardiovascular biofeedback, the predictive power of heart rate variability, and potential applications for behavioral self-regulation techniques and emerging technologies.

Controlling Heart Rate and Cardiac Dysrhythmias

In the early 1960s, psychologist Donald Shearn trained six research participants to avoid electric shocks by voluntarily accelerating their heart rate. While this is thankfully not a method used today, it was one of the first empirical demonstrations that heart function could be altered by operant conditioning and was not beyond conscious control, as previously thought. Participants in the study were able to hear their heartbeats through a loudspeaker and watched a timer, which counted down to the next shock. As their timers were reset by heart rate accelerations, the experimental group learned to increase their heart rates by five beats per minute to prevent shock administration. This contrasted with results of the yoked control group, who received the same schedule of shocks regardless of their heart rate and produced progressively fewer accelerations as they became habituated to the shocks (Shearn, 1962). Findings were, however, correlated with respiratory rates, and the influence of controlled breathing on heart rate was unclear.

Almost a decade later, Weiss and Engel (1971) developed a less aversive biofeedback system for cardiac patients, involving a flashing red light to cue heart rate acceleration, a green light to cue heart rate slowing, and a yellow light to reinforce the correct response. Using these innocuous cues, the researchers trained eight patients to produce bidirectional heart rate changes in response to the yellow light. Five of the eight patients also experienced a decreased number of premature ventricular contractions during follow-up periods of up to 21 months, thus maintaining clinically significant improvements in heart rate control without further biofeedback training. Interestingly, participants in this study reported using various types of imagery while controlling their heart rates, including visualizing the movements of their heart, bouncing a ball, swinging back and forth on a swing, arguing with family members, and running through a dark street. Researchers noted these strategies were highly idiosyncratic and the emotional valencies of the images remained unexplored.

Investigations that followed have since confirmed that cardiac patients can be trained to control heart rate and avoid arrhythmias, independent of changes in muscle tension or respiration. By the mid-1970s, Pickering and Gorham (1975) had trained a 31-year-old woman to voluntarily increase and decrease her heart rate to avoid the ranges in which her arrhythmia occurred using a simple heart rate monitor. The patient reported that her symptoms were more noticeable when she was emotionally tense, but no data regarding emotional responses was collected during the experiment. Pickering and Miller (1977) later trained a 14-year-old boy and 35-year-old man to suppress their premature ventricular contractions using electrocardiogram readings and established that these changes differed from those caused by physical exercise, breath-holding, and hyperventilation. However, as each participant was given only the basic instruction to maintain a pattern of normal rhythm for as much time as he could without changing his breathing or tensing his muscles, it was again unknown if they used any particular thoughts or feelings to produce the desired heart rhythms.

As increased heart rate is universally associated with reduced lifespan (Zhang & Zhang, 2009), the ability to slow your heart rate voluntarily may be a life-saving skill, even in healthy populations. Heart rate reduction using ablation and medication have previously been shown to reduce atherosclerosis in animal models (Reil et al., 2011) and β-blocker-mediated heart rate slowing is associated with decreased mortality in cardiac patients (Feldman, Elton, Menachemi, & Wexler, 2010). Resting heart rates above 70 beats per minute are associated with significantly higher rates of heart attack and hospitalization in this group (Fox et al., 2008), indicating that a heart rate reduction below this level may be an appropriate target for biofeedback.

In the past, biofeedback equipment has been unaffordable to most and training by an experienced technician could be time consuming, if it was accessible at all. Watches with heart rate monitors are now widely available and relatively inexpensive, which has created possibilities for many patients to become aware of this important physiological marker and to practice heart rate slowing on an ongoing basis with minimal guidance. However, while it has been established that basic biofeedback can be used to achieve decreases in heart rate, most of the previous research has neglected to examine how the use of personalized emotional imagery impacts on outcomes. As such, there remains a need to explore the psychophysiological processes underlying heart rate control and to develop a treatment protocol that reliably produces optimal results, while also being flexible enough to be tailored to the abilities and needs of individual patients.

Heart Rate Variability

While an increased heart rate appears to be an indicator of ill health, increased heart rate variability is quite the opposite. Heart rate variability (HRV) is a measurement of the variation in time intervals between each heartbeat. As heart function responds dynamically to continuous changes in our internal and external environment, a raised HRV is seen as a marker of flexibility and increased ability to cope with stressors. Conversely, a low HRV reflects an imbalance of the autonomic nervous system, in which the sympathetic branch is hyperactive and parasympathetic activity is suppressed (Moravec, 2008). Although the increases in heart rate, blood pressure and blood clotting produced by the sympathetic nervous system are adaptive during times of acute stress, chronic activation of this “fight-or-flight” response places extra energy demands on the heart and eventually leads to myocardial necrosis and apoptosis. The main aim of HRV biofeedback is therefore to restore balance to the autonomic nervous system and promote parasympathetic activity, which can return the body to its normally dominant "rest-and-digest" state.

In 1987, a study of the Holter tapes of 808 heart patients showed that those with a higher HRV were five times more likely to survive the 31-month follow-up period (Kleiger, Miller, Bigger, & Moss, 1987). These striking results have been replicated in over 20 studies, with reduced HRV being consistently observed in patients with cardiac failure or history of myocardial infarction (Buccelletti et al., 2009). Lower HRV is also associated with a range of cardiovascular risk factors, including hypercholesterolemia (Christensen, Toft, Christensen, & Schmidt, 1999), high work stress (Collins & Karasek, 2010), and exposure to air pollution (Zanobetti et al., 2010). As there is a clear relationship between HRV and heart health, the assumption that interventions that reduce HRV may be protective against cardiac disease is currently under investigation and a number of studies have shown that reducing cardiovascular risk results in increased HRV.

To examine the effect of weight loss on HRV, Sjoberg and colleagues (2011) recently assisted 45 overweight and obese patients with type 2 diabetes to follow an energy-restricted diet, based on a fixed menu plan and supported by regular meetings with a dietician. After consuming only 6–7 megajoules per day for 16 weeks, the group reduced their body weight by 10% and decreased their heart rates by nine beats per minute, in addition to increasing their total HRV. Similarly, postmenopausal women following a vegetarian diet for more than 2 years have been found to have increased high-frequency HRV compared with their omnivorous counterparts, in addition to having lower cholesterol, blood pressure, and fasting blood sugar levels (Fu, Yang, Lin, & Kuo, 2006). While most patients recognize that being overweight increases cardiovascular risk, the promotion of a plant-based diet has been more controversial.

Despite decades of research evidence to suggest that a predominantly vegetarian diet can effectively prevent or reverse the progression of coronary artery disease, there is still a widely held perception among health-carers that heart patients are unable or unwilling to adhere to dietary recommendations that differ from the guidelines developed for the general population (Ornish, 2009). As a result, patients are unaware of the importance of intensive lifestyle change to their health and rely on medication and surgery instead. Though there is no denying that lifestyle change can be challenging, HRV and heart rate biofeedback may be useful to those adjusting to a plant-based diet by providing a simple method of self-monitoring, and demonstrating that their food choices are related to measurable improvements in their heart health.

Along with a healthy diet, increased physical activity is a key factor in reducing cardiovascular risk and is reliably associated with improved HRV. Increases in high-frequency HRV have been produced by hospitalized patients with as little as 5 days of progressive exercise training, following their first myocardial infarction (Santos-Hiss, 2011). Although the effects of exercise training carried out in institutional settings have been better documented (Stahle, Nordlander, & Bergfeldt, 1999; Pardo et al., 2000), home-based exercise training three times per week for 8 weeks has also been associated with increased HRV and improved functional capacity in women with coronary artery disease (Lai, Tu, Huang, & Jeng, 2011). In this context, HRV self-monitoring could again facilitate more convenient home-based regimes for those who find regular travel to hospital-based exercise programs difficult.

In contrast to the often arduous task of overhauling eating and exercise habits, one potentially heart-healthy activity that people tend to take up of their own accord is the drinking of wine. In a cross-sectional study, Janszky and colleagues (2005) examined the alcohol consumption of 102 female patients who had survived an acute myocardial infarction or heart surgery and found that wine intake was associated with increased HRV. It is important to note, however, that the consumption of beer or spirits were not related to improvements in HRV and subsequent research has indicated two glasses of red wine has the acute effect of increasing heart rate and decreasing HRV rather than improving it (Spaak et al., 2010). For this and many other reasons, it remains unadvisable to start drinking wine to promote heart health, although replacing the consumption of other alcoholic beverages with moderate wine intake could be considered harm minimization by some, particularly in otherwise healthy populations.

It is again interesting to note that the emotional correlates of changes in HRV are not usually considered by researchers. It is certainly well documented that exercise improves mood, and reductions in heart rate have been found in depressed heart patients treated with cognitive behavioral therapy (Carney et al., 2000). Mastering the application of a healthy diet plan could similarly be an empowering and positive experience for patients, as well as having the physical benefits of consuming nutritious vitamin- and mineral-rich foods. If an improved emotional state has an independent effect on heart health, this may also contribute to observed relationships between reduced cardiovascular risk and moderate alcohol consumption, which is often experienced as relaxing and socially facilitative, despite its variable physiological effects on HRV. As it is widely recognized that prolonged negative emotional states have adverse effects on autonomic and cardiovascular systems, strategies for promoting positive feelings could be useful in improving heart health and may deserve further attention in both biofeedback research and cardiology practice. In addition, as physical fitness increases HRV (Nolan et al., 2008) and reduces cardiovascular risk, exercise is likely to be a helpful adjunct to most treatments for depression and heart disease, including biofeedback interventions.

Reducing Cardiovascular Risk

Given that low HRV is a cardiovascular risk factor in itself, some researchers have sought purely to reduce HRV in cardiac patients. Del Pozo and colleagues (2004) examined the effects of HRV biofeedback on a sample of 63 patients with coronary artery disease and found that HRV did not change immediately, but increased in the treatment group 12 weeks after the end of a 6-week training program. Similarly, Nolan and colleagues (2005) found that patients with coronary heart disease who underwent HRV biofeedback training had higher HRV during and after a physical stress test, while participants receiving alternative stress management training showed no improvement. Though these studies suggested that the HRV of heart patients could be altered by biofeedback training, other physiological and clinical outcome data was not collected.

As exercise tolerance is a strong prognostic indicator of cardiac morbidity and mortality, Swanson and colleagues (2009) asked 29 heart failure patients to complete the 6-minute walk test following training with HRV biofeedback. The intervention consisted of 45-minute sessions once a week for 6 weeks, in which participants were trained in abdominal breathing and given visual feedback on a computer monitor regarding heart rate, HRV, and respiration. The experimental group members were also given written information on abdominal breathing and an HRV biofeedback software program to take home for use between sessions. Results showed that exercise tolerance was increased in members of the treatment group with high left ventricular ejection fraction, an indicator of less severe disease. Researchers therefore suggested that this type of biofeedback is more likely to be helpful in the earlier stages of heart failure. However, given that the median survival rate after the onset of heart failure symptoms is only 1.7 years, the finding that a short course of biofeedback training improved the functional capacity of a subset of these patients is promising.

In another study examining clinical outcomes, Giardino and colleagues (2004) found that biofeedback training was again associated with improvements in the 6-minute walk test in 20 patients with chronic obstructive pulmonary disease, which significantly increases the risk of developing of cardiovascular disease (Gürgün & Gürgün, 2008). In addition to making functional gains, participants had better quality of life in self-report measures and improved respiratory sinus arrhythmia, an indicator of parasympathetic nervous system activity. In this case, the intervention involved four weekly sessions of walking practice with oximetry feedback in addition to five weekly sessions of HRV biofeedback and instructions for daily home practice. While this was similar to the intervention delivered by Swanson and colleagues (2009), the inclusion of practical exercises may have enhanced results and been suited to the disease severity of patients, leading to improved psychosocial and autonomic outcomes as well as increased functional capacity.

Though HRV biofeedback is currently attracting the most research attention, other forms of biofeedback have also been used to produce meaningful clinical improvements, even in severe cases of cardiovascular disease. After one session of skin temperature biofeedback using hand warmth imagery, Moser and colleagues (1997) found that patients with heart failure had increased temperature in their hands and feet, increased cardiac output, and decreased vascular resistance and respiratory rate. It has been noted by Moravec (2008) that hypertensive patients with symptoms of high sympathetic arousal, such as a high heart rate and cool hands, tend to benefit more from biofeedback interventions. Screening for signs of sympathetic overactivity might therefore improve biofeedback outcomes for patients with other cardiovascular conditions and may warrant consideration in clinical practice.

Depression, Anxiety, and Posttraumatic Stress

Negative emotional states have universally been found to predict morbidity and mortality from heart disease (Ormel et al., 2007), and may present some of the most ideal targets for biofeedback therapies. Depressed patients tend to have higher heart rates and lower HRV (Taylor, 2010), which are both related to increased cardiovascular risk. Moreover, a prospective study by Kamphuis and colleagues (2007) found that an increase in depressive symptoms predicted cardiovascular mortality in 840 men without heart disease 10 years later, even after controlling for risk caused by physical inactivity. In a pilot study on the effects of biofeedback in patients with moderate to severe depression, Siepmann and colleagues (2008) conducted six sessions of HRV biofeedback with depressed and healthy volunteers over 2 weeks. At the end of the treatment period, depressed patients had reduced anxiety, decreased heart rate, and increased HRV, while no changes were observed in non-depressed subjects or the control group. Whether similar results would be obtained by depressed patients with cardiovascular disease remains to be seen, as does the impact of such changes on the actual incidence of heart problems. However, the treatment of depression continues to be an important factor in improving quality of life and heart health in itself, for those with or without cardiovascular disease.

Given the strong association between anxiety, fear, and sympathetic “fight-or-flight” responses, it is unsurprising that low HRV has been observed in patients with panic disorder, generalized anxiety disorder, and even non-anxious people when actively worrying (Thayer, Friedman, & Borkovec, 1996; Yeragani et al., 1995). In another pilot study, Reiner (2008) sought to test if treating autonomic arousal using a portable biofeedback device would reduce symptoms of anxiety, anger, and sleep disturbance in 24 outpatients undergoing cognitive behavioral therapy for anxiety disorders. Following a 3-week treatment period of using the devices for 20 minutes per day, participants showed improvements in all the measured domains. Furthermore, participants reported that they found the biofeedback intervention more helpful than other relaxation techniques such as meditation and yoga, and researchers noted that it was easily integrated into their clinical practice.

In their recent meta-analytic review, Edmondson and colleagues (2012) reported that clinically significant symptoms of posttraumatic stress are frequently induced by acute coronary syndromes and that they increase patient risk for subsequent cardiac events and mortality. As psychological treatments for posttraumatic stress disorder (PTSD) are not universally effective, a study by Tan and colleagues (2011) was conducted to determine if biofeedback could be a helpful adjunct to psychotherapy for veterans with PTSD. Results showed that participants with PTSD had lower HRV than control subjects at baseline and indicated that the eight sessions of HRV biofeedback had increased HRV, in addition to reducing PTSD symptoms in the experimental group. At follow-up, participants reported they were "very satisfied" with the biofeedback intervention, and 90% indicated that they preferred this type of treatment to medication.

Behavioral Treatments for Hypertension

Biofeedback has been used to treat hypertension for over 30 years and this is recommended as one of its most efficacious uses by the Association for Applied Psychophysiology and the International Society for Neuronal Regulation (Yucha & Montgomery, 2008). Although well supported by research evidence, outcomes may depend on the type of feedback used. A review of more than 100 randomized controlled trials (Linden & Mosely, 2006) found that blood pressure and electromyography (EMG) biofeedback have often failed to produce results, while thermal and electrodermal biofeedback are relatively effective treatments for hypertension. However, earlier biofeedback research was likely hampered by a lack of established treatment protocols, and even the less reliable modes of feedback have produced some positive results.

Palomba and colleagues (2011) have recently shown that blood pressure feedback and guided imagery can reduce blood pressure reactions to psychosocial stress, in addition to lowering systolic and diastolic blood pressure overall. In a similar method to that used by Weiss and Engel (1971), a group of 24 untreated hypertensive patients observed a spot on a computer monitor, which changed color and moved left or right when they modified their heart rate. After four 25-minute training sessions, patients had lower blood pressure during clinic visits and when self-monitored at home, while the control group showed no change. The experimental group also had smaller rises in pressure when asked to give an unprepared 2-minute speech on a recent unpleasant experience that would be evaluated by a group of psychologists and physicians unknown to them. Given the simplicity of the method used, the small investment of time, and the significant results that were maintained between sessions and under stressful circumstances, this could be a viable and empowering treatment for hypertensive patients.

Although blood pressure reductions were observed after the first two biofeedback sessions in this study, improvement continued during the second two sessions, which involved patients attempting to maintain their heart rate while reliving or imagining stressful situations common in everyday life. These scenes were described by a trained therapist and involved interpersonal stressors such as family arguments or work disappointments. It is difficult to discern how much influence this guided imagery exercise had on outcomes, yet the positive results do suggest that the technique is compatible with biofeedback training for hypertension. Moreover, as the imagery used by participants and their physical reactions to stressors are idiosyncratic, the researchers suggested that the use of personally relevant emotional imagery might enhance treatment effectiveness further.

While current findings are clarifying the conditions under which biofeedback could be helpful to patients with hypertension, even earlier research has indicated that blood pressure is particularly amenable to self-regulation. In 1986, Fahrion, Norris, Green, A., Green, E., and Snarr trained 77 hypertensive patients to alter the vasodilation in their hands and feet using biofeedback. Of the 55 medicated patients, 58% were able to cease taking their medication altogether, and an additional 35% were able to halve their dose due to their significant reductions in blood pressure. Similarly, 70% of the 23 unmedicated patients reduced their pressures to within normal healthy limits. Furthermore, these changes were well maintained over 33 months, with over half the patients remaining off medication.

For patients with hypertension seeking to minimize or avoid pharmacological treatments, biofeedback may be an appealing prospect. However, as an adjunct to drug therapy, Nolan and colleagues (2010) have demonstrated that biofeedback not only benefits medicated hypertensive patients, but can also be more effective than other widely recommended behavioral strategies. In their comparison of HRV biofeedback with autogenic relaxation training, only the former treatment resulted in lowered ambulatory blood pressure and increased heart rate variability during sequences of moderately challenging tasks, such as mental arithmetic. The intervention involved observing HRV readings over six 1-hour sessions and practicing daily exercises at home, which was equally time intensive as the passive relaxation procedure but with positive effects.

Traditional Self-Regulation Techniques

While the term "biofeedback" generally refers to the process of becoming aware of and learning to manipulate physiological processes using instrumentation, it has been posited that ancient Hindu practices such as *yoga* and *pranayama* involve the same processes and could therefore be considered biofeedback techniques. Though the introduction of electrophysiological measurement provides a definite point of difference, modern biofeedback interventions have certainly employed many similar methods to traditional meditation practices, such as focused attention, visualization, and abdominal breathing. As there have been more than 600 studies published examining the impact of transcendental meditation on cardiovascular disease alone (Walton, Schneider, & Nidich, 2004), reviewing the effects of relaxation strategies on heart health is beyond the scope of this chapter. However, there is clearly potential for biofeedback programs to facilitate various relaxation practices, and researchers have previously combined the two approaches in the treatment of hypertension.

In 1977, Patel and Carruthers examined the effects of biofeedback-assisted relaxation and meditation on 18 normotensive and 22 hypertensive subjects, and 18 controls. The intervention also incorporated health education and 18 smokers were included in the sample. Results of the study showed that blood pressure was reduced in all the treated groups and that smokers had decreased their number of cigarettes smoked per day. The researchers noted that the intervention was economical and acceptable to patients, in addition to being effective in the treatment of hypertension and reduction of cardiovascular risk. In a more recent investigation, Wang and colleagues (2010) ran 10 training sessions in slow abdominal breathing for 22 post-menopausal women with pre-hypertension. In the experimental group, breathing was coupled with EMG biofeedback, and all subjects completed daily home practice. Although the control group managed to produce decreases in systolic blood pressure using only abdominal breathing, participants receiving biofeedback training had significantly greater reductions in both systolic and diastolic pressures. Thus, results indicated that biofeedback can facilitate the production of a relaxation response and enhance the effect of controlled breathing on the cardiovascular system.

Conclusions

From its inception, biofeedback has been used to manipulate heart function. While this has sometimes involved multiple measures of autonomic function, in most cases one simple feedback device has been sufficient to produce significant results with less than 6 hours of training. Due to the wide range of physiological readings used and the varied applications of biofeedback in psychocardiology, standardized feedback protocols are often lacking, making research results challenging to compare. However, it has been noted by several researchers that idiosyncratic imagery and other individualized processes may contribute to the success of biofeedback treatments. The strength of biofeedback may therefore lie in its flexibility to adapt to patient characteristics and abilities, as well as to different medical and psychological conditions. Furthermore, the incorporation of biofeedback into holistic management programs has been shown not only to improve outcomes, but also to be more appealing to patients than other common forms of treatment. As biofeedback procedures are generally non-invasive, free of side effects, and can produce lasting change, this area of research is currently thriving, and potential contributions of biofeedback to heart health will no doubt continue to emerge.

Although it is now understood that the autonomic nervous system plays a role in mediating the relationship between negative emotional states and cardiovascular disease, the most neglected area of biofeedback research is currently the connection between thoughts, feelings, and autonomic change. While it is clear that the intentional generation of optimistic thoughts and positive emotional states could improve heart function, this has rarely been addressed by researchers or purposefully included in biofeedback interventions, despite being a time-honored tradition in meditative practice. As the heart has long been recognized as the emotional center of the body, it should come as no surprise to us that depression and anxiety have been linked to poorer cardiovascular health and the progression of heart disease itself. Likewise, it would not be too astounding to discover that, given the ability to objectively observe our cardiovascular function, we can learn to cultivate positive changes in our emotional and physiological responses more easily and effectively than nature ever intended. In this case, as far as our health and well-being is concerned, our hearts may indeed be able to lead us in the right direction.

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Part V

Assessment and Methodology

18

Psychometric Developments in Psychosocial Assessment in Behavioral Medicine Settings

Michael H. Antoni and Theodore Millon

Role of Psychosocial and Behavioral Factors in Health Preservation and Healthcare Delivery

Medical diseases and related conditions influence millions of American lives and consume billions of American dollars each year. Chronic medical diseases – the most expensive kind to treat – are a major health challenge as we move through the first quarter of the twenty-first century. The most prevalent among these diseases include arthritis, asthma, cancers, cerebrovascular disease/stroke, coronary heart disease (CHD), diabetes mellitus, end-stage renal disease, human immunodeficiency virus and acquired immunoeficiency syndrome (HIV/AIDS), and spinal cord injury. While not life-threatening, many other conditions reflect underlying pathology in physiological regulation of circulation (e.g., hypertension), digestion (e.g., gastrointestinal disorders), respiration (e.g., chronic obstructive pulmonary disease), energy/arousal (e.g., chronic fatigue syndrome), sensation (e.g., chronic pain), reproduction (e.g., gynecologic disorders), metabolism (e.g., thyroid disorders), and inflammation and immune function (e.g., allergies and autoimmune diseases). Together, these conditions represent the major challenges to our healthcare system as a major cohort of baby boomers reaches their golden years.

Because people often live for decades with several of these conditions, healthcare costs for "chronic disease management" reach well over US$1 trillion annually. An awareness of accelerating healthcare costs, unnecessary procedures, and significant abuse in the use of medical interventions led in the early 1990s to what was termed the *managed care revolution* (Regier, 1994). Now two decades later, the United States continues to struggle with the long-term reform of its healthcare system in

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order to increase the accessibility, efficacy, and cost efficiency of services designed to preserve health and manage disease. We focus in this chapter on identifying the characteristics of the "end user" of this system and how their traits, behaviors, and individual experiences affect both preventative health behaviors and healthcare utilization.

Behavioral medicine and clinical health psychology research gained most of its momentum in parallel with the managed care revolution. Sobel (1994) noted that a substantial proportion of healthcare costs may be affected by individual differences in psychosocial factors, such as a person's emotional state, sense of control and optimism, and their social support networks. By identifying differences in these factors, it follows that one might offer psychosocial interventions to those who are most in need in order to improve both health outcomes and costs for conditions such as acute illnesses, stress-related disorders, chronic pain, diabetes, asthma, arthritis, and surgery. This provided the impetus for developing psychometric instruments capable of screening medical care users for these and other psychosocial characteristics in order to optimize outcomes and minimize costs.

From the late 1990s to the present, several large-scale clinical trials have provided evidence that psychosocial and behavioral interventions may improve adaptation and clinical response to medical treatments in major conditions such as diabetes mellitus (DM), CHD, cancers, and HIV/AIDS (Schneiderman, Antoni, Saab, & Ironson, 2001; Schneiderman, Antoni, Penedo, & Ironson, 2010). Most gains made in these areas of clinical research and practice were initiated following observation studies which revealed that patients with similar medical diagnoses and treatments showed wide variability in the physical course and psychological sequelae of the disease. Factors such as depression, anxiety, pessimism, maladaptive coping, and social isolation seemed to predict a more negative course in diverse medical conditions. Conversely, characteristics such as optimism, sense of coherence, perceived control, and social support seemed to predict better outcomes. It is plausible that identifying differences in these psychosocial characteristics in patients at the time of screening or intake may help in deciding which individuals might benefit particularly from behavioral and psychosocial interventions.

If psychosocial interventions are effective at modulating these factors in ways that promote health and contain costs, then developing ways to identify their configuration in patients at the earliest phases of the medical utilization process could make a major contribution to the healthcare revolution. This chapter presents a case for identifying psychosocial processes for the purpose of optimizing health and healthcare delivery in medical patients. We first summarize those psychosocial factors related to how patients adapt to disease and secondary prevention efforts, as well as the role of psychosocial and behavioral factors in rehabilitation/recovery from disease and chronic disease management. We then describe some of the methods available for assessing these psychosocial characteristics of patients in specific medical environments, with a focus on some psychometric instruments that have been targeted to and normed on specific disease populations. We end with some psychometric developments in medical settings where behavioral medicine practitioners are having a growing influence.

Psychosocial factors in health maintenance

Although this chapter focuses on the role of psychosocial factors in patients with medical conditions, it is important to note that one of the first things that patients learn when they have been diagnosed with a medical condition is that they must make major changes in their health behaviors. Health psychology research has identified a number of psychosocial factors that may determine the uptake and maintenance of these health behaviors in healthy and diagnosed populations. This research has helped identify psychosocial factors associated with several aspects of health behaviors, including: (1) the reduction of negative health behaviors (risk behaviors) (e.g., substance use, smoking, sun exposure); (2) decisions to utilize diagnostic screening tests (e.g., blood lipid and blood pressure testing, skin cancer screening, mammography, Pap smears, prostate-specific antigen [PSA] testing); and (3) the practice of positive self-care behaviors (e.g., adherence to medication regimens, maintaining physical activity, or following dietary guidelines).

Evidence-based behavioral interventions directed at smoking cessation, exercise, and dietary changes can prevent significantly more deaths than do assorted medications (e.g., use of ACE inhibitors, beta-blockers, aspirin, warfarin) in patients with cardiovascular disease (Woolf, 1999). A huge amount of behavioral medicine research has identified psychosocial variables associated with the adoption and maintenance of specific health risk behaviors such as smoking, excessive exposure to ultra-violet rays, unprotected sexual behaviors, and obesity and overeating (e.g., Glanz, Lew, Song, & Cook, 1999; Rock et al., 2000). Moreover, certain psychosocial factors (e.g., depression) may interact with a genetic predisposition to engage in these risk behaviors (Lerman et al., 1998; Lerman et al., 1999). What are some of the psychosocial factors associated with health risk behaviors?

As we have noted elsewhere (Antoni, Millon, & Millon, 2008), psychosocial factors associated with engaging in risk behaviors include but are not limited to affective, cognitive, behavioral, social, and contextual factors. *Affective* or emotional factors , which are most studied in this area, involve negative affect states such as anxiety, anger, and depression. *Cognitive* factors include appraisals of self-worth, perceived susceptibility to disease initiation or progression, general outlook toward the future (e.g., optimism/pessimism), the perceived health protective effects of ceasing the risk behaviors, and their personal efficacy for making behavior changes (Turk & Meichenbaum, 1989; McCann et al., 1995). *Behavioral* factors include having the coping strategies for dealing with internal and external forces that perpetuate the practice of the behaviors. *Social factors* include interpersonal, economic, familial, and spiritual resources available for gaining the support necessary to make substantial lifestyle changes (Wallston, Alagna, DeVellis, B., & DeVellis, R. F., 1983). *Contextual* factors include prior experiences with behavior change efforts and external/environmental challenges that can influence the likelihood that the behavior will be addressed.

These factors may act as obstacles to preventative health behaviors as well as practicing positive screening behaviors, keeping follow-up medical appointments, and maintaining self-care behaviors (McCann et al., 1995; Wilson et al., 1986). As such, these factors could influence decisions by healthy individuals to pursue diagnostic screenings such as annual physical exams, Pap smears, PSA testing, occult fecal blood testing, skin cancer testing, mammography, and other medical tests that could dramatically reduce morbidity, mortality, and healthcare costs (e.g., Lerman et al., 1993). Behavioral medicine research has also focused on factors associated with adjustment to positive cancer or cancer risk test. Personality characteristics and initial reactions to these results may predict whether people make critical follow-up visits after receiving positive test results. If so, early "decision aid" interventions may be initiated with promising results and optimal cost containment (Pereira, Antoni, Simon, Efantis-Potter, & O'Sullivan, 2004; Baum & Posluszny, 1999).

Finally, these affective, cognitive, behavioral, social, and contextual factors may also contribute to what is referred to as help-seeking behavior – a symptomatic patient's delay in seeking prompt medical attention after the initial onset of physical symptoms such as suspicious skin changes, abnormal bleeding, unexplained weight loss, angina, or even heart attacks (Kolitz, Antoni, & Green, 1988; Cameron, Leventhal, & Leventhal, 1995; Neal, Tilley, & Vernon, 1986). On the other hand, a person's emotional state, cognitive appraisals, coping strategies, social resources, and life context may also cause them to "over-utilize" the healthcare system when their physical symptoms have a "functional" basis and their condition does not warrant such healthcare use (Pallak, Cummings, Dorken, & Henke, 1994).

Psychosocial factors and disease

Another major behavioral medicine research domain examines psychosocial factors that determine how patients react to their initial diagnosis of disease and their adjustment to chronic disease conditions. This area focuses on identifying patient characteristics that predict their adaptation to a new diagnosis, treatment regime, or any of the life-changing aspects of a chronic medical condition. Behavioral medicine research has also identified psychosocial factors that contribute to recovery from, relapse of, or progression of physical disease. For instance, psychosocial factors can predict a patient's initial reaction to a new diagnosis (e.g., based on HIV antibody testing), their responses to a stressful or invasive "curative" procedure (e.g., surgical mastectomy, hysterectomy, chemotherapy, radiotherapy, cardiac catheterization, or tissue transplantation), and adjustment to the burdens of a chronic disease (e.g., limitations in physical, mental, vocational, and social activities). This latter area of research is particularly relevant for predicting patient adaptation to chronic disease management (e.g., renal dialysis, insulin injections, antiviral medications, or lifestyle behavior changes).

Psychosocial factors and adjustment to disease diagnosis There is wide variability in patients' initial psychological reaction to a serious medical diagnosis. Responses often involve anxiety or depression, or may involve self-blame or anger when the condition was viewed as preventable (Taylor & Aspinwall, 1990; Antoni, 1991). These reactions can be extreme and may manifest as a post-traumatic anxiety reaction or other adjustment disorders with affective features. Some of the factors that may shape reactions to a serious diagnosis include: Premorbid psychiatric conditions, cognitive appraisals (interpretation of the meaning of the diagnosis and its ramifications, one's outlook toward the future, sense of self-efficacy, and perceived treatment efficacy), personality style and coping strategies (avoidance, active coping, denial, giving up, cognitive reframing, acceptance), perceived resources (support of friends and family, spiritual sources of support, economic means), and contextual factors (life stressors, prior experience with serious disease, pre-morbid and present functional ability).

Anxiety and depressive disorders can act as obstacles to the patient's ability to make and adapt to lifestyle changes that follow from a medical diagnosis, to engage successfully in a rehabilitation program, and ultimately return to the work force or to premorbid levels of functioning (Bremer, 1995; Taylor & Aspinwall, 1990). Anxiety reactions may vary as a function of their premorbid psychiatric history, the specific medical disease, and the nature of the treatment regimen (Christman et al., 1988; Carver et al., 1993; Taylor & Aspinwall, 1990). Other psychosocial factors (e.g., self-esteem, pessimism) may delineate which of these potential anxiety triggers is most salient for different individuals. Depressive reactions to a major medical diagnosis may impact psychological adjustment. Research suggests that up to 25% of medical inpatients suffer from severe depression (Taylor & Aspinwall, 1990). Depressed affect and related symptoms may interfere with adjustment to the lifestyle changes and treatment regimens (Lustman, Griffith, & Clouse, 1988; Antoni et al., 2006b). This research suggests that across many medical conditions, identifying psychiatric disorders or mood disturbance at the time of medical diagnosis notification may improve the ways patients adjust to illness.

Because coping strategies characterized by avoidance are associated with increased distress in people dealing with stressors, it stands to reason that the coping strategies individuals use to deal with a diagnosis may also affect their adjustment to illness (Holahan & Moos, 1986; Taylor & Aspinwall, 1990). Persons using denial as a coping strategy after a diagnosis of breast cancer (Carver et al., 1993) or HIV infection (Antoni et al., 1995) have greater levels of distress over the subsequent year. Myocardial infarction (MI) patients using denial coping had poorer adaptation to disease in the long term, including poorer adherence to lifestyle recommendations and a greater number of days of re-hospitalization (Levine et al., 1988). Conversely, coping strategies such as positive reframing and acceptance tend to predict less distress in the period after diagnosis (e.g., Carver et al., 1993; Lutgendorf et al., 1998), and over the longer-term (Taylor & Aspinwall, 1990; Young, 1992). Conversely, active coping responses to stress, a high locus of control, and greater perceived control predict better psychological adjustment in patients with different types of cancer (Burgess, Morris, & Pettingale, 1988). These studies suggest that the coping strategies and attitudes that medical patients use in dealing with the challenges surrounding the initial diagnosis of their disease can have lasting effects on their ability to emotionally adjust.

The availability of supportive resources can have positive effects on health-related processes and outcomes. Having rewarding personal relationships that provide things such as tangible aid, information, and emotional assistance (House, 1981; Schaefer, Coyne, & Lazarus, 1981) predicts better psychological adjustment to conditions such as CHD (Schneiderman et al., 2010), cancer (Siegel, Calsyn, & Cuddihee, 1987; Taylor, Lichtman & Wood,1984; Helgeson & Cohen, 1996), arthritis (Fitzpatrick, Newman, Lamb, & Shipley, 1988), end-stage renal disease (Siegel et al.,1987), and HIV/AIDS (Zuckerman & Antoni, 1995). For instance breast cancer patients perceiving greater emotional support from family and healthcare professionals evidence better emotional adjustment after the stress of diagnosis and subsequent surgery (Funch & Mettlin, 1982; Helgeson & Cohen, 1996). Religiosity and spirituality, other external resources, have also been associated with a lower risk of depression and anxiety reactions to diagnosis in medical patients (Koenig, Pargament, & Nielsen, 1998). Greater use of religion to deal with the stress of a diagnosis of HIV infection was associated with less depressed mood and anxiety in HIV-infected men (Woods, Antoni, Ironson, & Kling,1999a) and women (Woods, Antoni, Ironson, & Kling, 1999b). Religious coping also predicted better adjustment after diagnosis and surgery in early-stage breast cancer patients, though these effects varied as a function of religious orientation (Alferi, Culver, Carver, Antoni, & Arena, 1999).

Ongoing life stress is a major contextual factor that may overwhelm the patient's coping strategies, making it all the more difficult to deal with the challenges of a new diagnosis and subsequent treatment (Antoni & Emmelkamp, 1995; Antoni et al., 1991). Stressful life events can increase the risk of negative health behaviors (e.g., substance use; Morrissey & Schuckitt, 1978; Newcomb & Harlow, 1986) that can further hamper their attempts to cope with the diagnosis. A patient's perception of their overall quality of life and functional status can also contribute to their ability to adjust to a demanding medical regimen after diagnosis (Taylor & Aspinwall, 1990).

Psychosocial factors and the physical course of disease Behavioral medicine research has helped identify psychosocial factors that may contribute to an individual's resistance or vulnerability to the promotion of a subclinical pathogenic/pathophysiologic process, the onset of clinical disease, and the ultimate course of disease. These include negative affect and distress states, appraisals of self-efficacy or personal control, optimism/pessimism, coping strategies, support, religiosity and spirituality, and contextual factors such as life stress.

Some pathogenic processes that have been associated with these psychosocial factors include: coronary artery disease (Schneiderman et al., 2001; 2010); hypertension (Dimsdale et al., 1986; Krantz et al., 1987; James, Hartnett, & Kalsbeek, 1984); glucose control (Frenzel, McCaul, Glasgow, & Schafer, 1988; Brand, Johnson, & Johnson, 1986); early neoplastic changes (Antoni et al., 2006a); and immune system responses to infectious pathogens and other inflammatory conditions (Kiecolt-Glaser & Glaser, 1992; Cohen, Tyrrell, & Smith,1991; Schneiderman et al., 2010). These same psychosocial factors may also contribute to the onset of clinical endpoints such as myocardial infarction (e.g., Frasure-Smith, Lesperance, & Talajic, 1993), invasive cancer (Antoni et al., 2006a), type II diabetes mellitus (Schneiderman et al., 2010), gastrointestinal syndromes (Friedman & Booth-Kewley, 1987), rheumatoid arthritis (Anderson, Bradley, Young, McDaniel, & Wise, 1985), and AIDS (Antoni, 2003).

Longitudinal studies have revealed that many of these psychosocial factors are also associated with the physical course of many diseases listed here. For instance, depression predicts elevated incidence of myocardial infarction (MI) as well as mortality in patients with CHD (Barefoot & Schroll, 1996). Depression also predicts the progression to AIDS in HIV-infected persons (Leserman, 2008). These psychosocial factors could affect disease course by way of physiological mechanisms that involve defenses against pathogens (e.g., immune system and inflammation) or which dictate homeostatic dysregulation (e.g., endocrine system). Depression may also contribute to health outcomes via negative health behaviors (e.g., substance use) or difficulties maintaining positive health behaviors such as exercise (Blumenthal et al., 1982) and medication adherence (Carney et al., 1995).

Cognitive appraisals, coping, and social and spiritual support are related to the course of a wide variety of diseases. One cognitive appraisal variable – optimism – has been related to a lower risk of developing cervical neoplasia in high-risk cases (Goodkin, Antoni, Fox, & Sevin, 1993), and less likelihood of being re-hospitalized after coronary artery bypass graft (CABG) surgery for post-surgical wound infections, angina, and MI (Scheier et al., 1999). Several studies have related coping strategies such as active confrontation (Mulder, Antoni, Duivenvoorden, Kauffman, & Goodkin, 1995), denial (Antoni et al., 1995; Ironson et al., 1994), and realistic acceptance (Reed, Kemeny, Taylor, Wang, & Visscher, 1994) to differences in HIV disease progression.

Social support predicts faster recovery, better disease management, and reduced mortality in many diseases (House, Landis, & Umberson, 1988; Neal, Tilley, & Vernon, 1986; Marteau, Bloch, & Baum, 1987; Ell, Nishimoto, Mediansky, Mantell, & Hamovitch, 1992). Finally, religiosity and spiritual support is associated with better physical health in general (Levin, 1994; Jarvis & Northcott, 1987) and better health outcomes in specific conditions such as HIV/AIDS (Ironson & Hayward, 2008).

In sum, a set of psychosocial factors associated with health preservation, adjustment to disease, and actual disease progression include *mood and distress*, *cognitive appraisals*, *coping strategies*, *perceived resources*, and the *individual's life context*. The influence of these psychosocial factors on health preservation may be explained by changes in a person's decisions to engage in risk behaviors, seek diagnostic screening services, and seek expedient healthcare after the onset of overt symptoms. The impact of these same psychosocial factors on adjustment to disease and disease course may be mediated by changes in patients' susceptibility to stress-induced emotional difficulties, maladaptive health behaviors, and physiological regulatory processes. Thus, it could be concluded that psychosocial factors can impact the progression of many diseases through what is often termed "biobehavioral" processes.

The influence of psychosocial factors on healthcare costs

Epidemiological studies, health services research, and behavioral intervention trials suggest that integrating psychosocial assessment and behavioral intervention into healthcare delivery can increase cost savings and quality of healthcare. Epidemiologic research identifies disease co-morbidities that account for the highest utilization patterns. Health services research operationalizes costs as hospital admissions/readmissions, lengths of stay, number of outpatient visits for follow-up, and the use of expensive (e.g., surgery, chemotherapy, radiation) vs. less expensive (e.g., antibiotic and antihypertensive medications) medical procedures. Individual differences in psychosocial factors have been associated with medical utilization (short-term cost effects) and to treatment success, discharge rates, recovery times, and rehabilitation rates (longer-term cost effects).

This work has led to treatment efficacy studies that test the effects of behavioral interventions on the net "costs" of medical illnesses. One example would be a synergistic combination of pharmacologic (e.g., anti-depressant) and psychosocial intervention (e.g., supportive group therapy or individual cognitive behavioral therapy [CBT]) to complement the treatment of a primary medical condition (e.g., cancer, CHD). This combination of approaches may improve outcomes by enhancing adherence to a self-care routine/lifestyle change or promoting emotional adjustment to illness. Deciding which patients are most in need of these more intensive intervention packages can be facilitated by knowledge of a patient's psychosocial characteristics and health behavior patterns. Incorporating this information at the earliest entry point into the healthcare system could aid in containing costs and improving outcomes. What is the evidence that psychosocial characteristics of patients can predict healthcare cost outlays?

Patients with premorbid or ongoing anxiety and depression-related conditions tend to have longer postoperative hospital stays and generate greater costs for medical illness treatments (Boeke, Stronks, Vehage, & Zwaveling, 1991; Greenberg, Stiglin, Finkelstein, & Berndt, 1993; Klerman & Weissman, 1992). Among chronically ill patients, those who show poor psychological adjustment show greater utilization of medical services and generate the highest costs (Browne, Arpin, Corey, Fitch, & Gafni, 1990). Patients with significant levels of psychopathology have longer hospital stays, greater hospital charges, and use more procedures across multiple types of medical diagnosis (Levenson, Hamer, & Rossiter, 1990; Barsky, Wyshak, & Klerman, 1986; Kimmerling, Ouimette, Cronkite, & Moos, 1999; Jacobs, Kopans, & Reizes, 1995). They also may require more nursing home care, maintain fewer improvements after rehabilitation (Thompson, Sobolew-Shubin, Graham, & Janigian, 1989), and are less able to recapture their premorbid quality of life (Niemi, Laaksonen, Kotila, & Waltimo, 1988). Depressed cardiac patients may be at heightened risk for rehospitalization (Stern, Pascale, & Ackerman, 1977) after their initial MI. It is well established that a cancer patient's distress levels may affect their ability to tolerate treatment, and longer-term quality of life (Holland, 1997; Roth et al., 1998).

Since maladaptive coping strategies lead to poor emotional adjustment, resumption of health risk behaviors, disturbed patient–physician communications, and reduced adherence to the recommended treatment regime, patients using these strategies may require additional medical care with associated escalation in costs (Stone and Porter, 1995). Many other psychological factors previously associated with emotional adjustment to illness (e.g., social support, life stress) are also associated with medical utilization and healthcare costs. Among medical patients attending 43 family practices, those with lower emotional support had significantly more office visits and a greater number of total charges over a 1-year period (Broadhead, Hehlbach, DeGruy, & Kaplan, 1989). Contextual factors such as elevated life stress predicted a greater frequency of medical visits, and this association was strongest among patients with personality traits reflecting a tendency toward somaticizing (Miranda, Perez-Stable, Munoz, Hargreaves, & Henke, 1991).

Together, this work suggests that if one can identify medical patients with emotional distress, maladaptive coping styles, limited social resources, and/or elevated life stress, they could be offered psychological interventions that might be particularly cost-effective. Psychosocial interventions can reduce healthcare costs in medical patients (Levenson, 1992; Cummings & Van den Bos, 1981; Schneider, 1987; Hellman, 1990; Pallak, Cummings, Dorken, & Henke, 1994). Prior quantitative reviews revealed that medical utilization was reduced by up to 33% and hospital stays were cut by up to 1.5 days after brief psychotherapy (Mumford et al., 1984). The ability of behavioral and psychosocial interventions to reduce the costs of healthcare may be seen in studies focused on interventions designed to facilitate post-surgical recovery as well as work testing the effects of such interventions in the context of chronic disease management.

There is a long history of behavioral medicine research testing the effects of behavioral interventions in surgical patients. Among the nearly 200 studies addressing this topic between 1963 and 1989, beneficial effects for various forms of psychosocial intervention have been reported up to 84% of the time (Devine, 1992). This review estimated that length of hospital stay was reduced by 1.5 days on average with cost savings of up to $10 for each dollar invested. Interventions such as relaxation have been associated with fewer days in intensive care, fewer total days in the hospital, and fewer incidents of congestive heart failure (e.g., Aiken & Henricks, 1971). Across 13 other studies involving cardiac patients, psychosocial intervention reduced hospital stays post-MI or post-surgery by 2 full days (Mumford, Schlesinger, & Glass, 1982).

Psychosocial interventions that reduce pre-surgical stress may affect post-surgical complications by reducing stress hormone output (e.g., urinary cortisol, Doering et al., 2000), improving wound healing (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995), or accelerating immune system recovery after surgery, blood transfusions, and anesthesia (van der Pompe, Antoni & Heijnen, 1998; Lee et al., 2009). Psychosocial interventions may play a significant role in reducing long-term healthcare costs by reducing the likelihood of phenomena such as diabetic complications, recurrence of heart attacks in MI patients, and extended rehabilitation costs for spinal injury or stroke due to reinjury. Other long-term effects of psychosocial interventions are currently being explored in terms of reducing the progression rate of conditions such as HIV infection, the recurrence rate of certain cancers (e.g., breast cancer), and life-threatening and costly complications, such as kidney failure, which result from other disease processes (Antoni, 2013; Carrico & Antoni, 2008). This work may inform growing interest in the use of psychosocial assessment to guide decisions about a patient's likely response to other increasingly utilized procedures such as organ transplant, bariatric surgery, and pain-relieving surgeries.

Among patients diagnosed with chronic illnesses such as chronic obstructive pulmonary disease (COPD), diabetes, ischemic heart disease, or hypertension, mental health treatment was associated with lower costs for medical services (Schlesinger, Mumford, Glass, Patrick, & Sharfstein, 1983). Studies of patients from four major chronic illness groups – chronic pain, diabetes, asthma, and rheumatoid arthritis – have shown impressive savings from behavioral intervention or psychoeducation programs. Pain patients enrolled in one behavioral intervention decreased medical office visits by 36% up to 2 years after the program with an average savings achieved of $3.50 for every dollar invested (Caudill et al., 1991). Other behavioral intervention programs for pain patients were associated with nearly 50% reduction in hospital utilization and over $7 million in cost savings over a 4-year follow-up period (Jacobs, 1987). Reviews of studies including over 20,000 diabetic patients show that psychosocial interventions reduce hospitalization rates by up to 73% and lengths of stay by 78%, resulting in an estimated savings of over $2,000 per patient (Miller & Goldstein, 1972; Miller et al., 1981). Outpatient education programs have been shown to reduce the incidence of severe ketoacidosis by 65%, the frequency of lower extremity amputations by nearly 50%, and the number of hospital days by over 50% in diabetics (Assal et al., 1985; Davidson, 1983). In patients with asthma, those receiving psychosocial intervention showed more symptom-free days, greater physical activity improvements, and 49% fewer office visits for acute attacks over a 2-year follow-up period (Wilson et al., 1993). Finally, one health education program reduced physician visits by 43% among chronic rheumatoid arthritis patients, resulting in a saving of approximately $12 for each dollar invested over a 4-year period (Lorig et al., 1993).

Does this work suggest that every medical patient undergoing surgery or dealing with these chronic conditions should receive a psychosocial evaluation to guide decisions regarding the need for and likely benefits of psychosocial intervention? This is, of course, not practical. However, there are most likely subgroups of patients who possess certain psychosocial characteristics that make them more or less likely to benefit from behavioral or psychosocial interventions. The ability to identify these characteristics at the point of screening and intake would further increase cost savings because all patients in need of such services would be identified, while those not in need would be spared the costs or burden of unnecessary psychosocial services.

Summary

Together, the studies reviewed in this chapter support the role of specific psychosocial factors in many facets of health psychology and behavioral medicine, including health preservation/primary prevention, adjustment to medical diagnosis and treatment, the physical course of the disease, and the associated costs of healthcare. Psychiatric disturbance and persisting distress states, personality/coping style, cognitive appraisals, social and spiritual resources, and contextual factors may all contribute. With this accumulation of evidence over several decades, it is surprising that modern healthcare practice still rarely includes psychosocial assessment on a routine basis. To facilitate the use of this information in evidence-based clinical behavioral medicine practices, it is essential that the field continue to develop standardized assessment tools that are sensitive, specific, and relevant to the medical populations who are the target of these efforts. The most efficient assessment tools would be those that synthesized information representing these psychosocial factors in order to predict a wide range of medical outcomes that are relevant to the management of the patient's healthcare. In the next section, we provide some examples of psychosocial instruments that have been developed for and normed on different medical populations.

Psychometric Instruments for Assessing Medical Patients

We have provided examples of points in the healthcare system where psychosocial factors may be most relevant, including at the point of screening, diagnosis, initial treatment, or during chronic disease management. We then presented the rationale for the development and use of psychosocial assessment in medically diagnosed or at-risk populations. An emerging literature has described the development and validation of a number of psychometric instruments now in wide use in behavioral medicine research and practice. It is beyond the scope of this chapter to enumerate all of the instruments now available to measure all psychosocial factors relevant in the context of healthcare activities. Given the recurring set of psychosocial factors categorized in the prior sections we deemed it useful to focus instead on "broadband" psychosocial instruments that attempt to capture information on a range of psychosocial factors across these categories. We next highlight examples of research supporting the use of three broadband instruments, including the Minnesota Multiphasic Personality Inventory (MMPI), the Millon Behavioral Health Inventory (MBHI), and the Millon Behavioral Medicine Diagnostic (MBMD). These tools provide information on the psychosocial characteristics of medical patients for the purpose of optimizing health maintenance and healthcare activities.

The use of the MMPI with medical patients

Up to the late 1980s, investigators had gathered support for the use of psychological instruments such as the MMPI to examine the associations between psychosocial characteristics of general medical patients and the effectiveness of medical treatment and physical course of illness (Stoddard, Tsushima, & Heiby, 1988). These early efforts attempted to use the MMPI to predict emotionally mediated physical complaints (Hanvik, 1951; Imboden, Canter, and Cluff, 1961). Other work related MMPI scales representing somatization to delayed recovery in medical patients, though this work has been criticized due to a lack of replication and over-pathologizing reasonable emotional responses to medical diagnoses and treatments (Keller & Butcher, 1991). More recently, research has investigated the use of the MMPI and MMPI-2 (Butcher, Graham, Ben-Porath, Tellegen, Dahlstrom, & Kaemmer, 2001) in specific medically ill populations (Arbisi & Butcher, 2004). Most of these studies have been descriptive in nature, focused on documenting the prevalence of psychiatric characteristics that could affect the patient's adjustment to a medical condition and its treatment. This work has gone a long way to establish the need for psychosocial assessment in medical settings ranging from surgery clinics to pain treatment programs. The most recent research with the MMPI-2 has sought to relate psychosocial factors to treatment decision in pain-related conditions, pre-surgical evaluations in areas such as organ transplant and gastric bypass surgery, and to forecast CHD risk behaviors and the development of CHD (Arbisi & Butcher, 2004). We now briefly summarize this research.

MMPI and pain-related conditions Research has repeatedly demonstrated that MMPI-2 items reflecting a focus on somatic processes show elevations in patients with pain-related conditions. However, it is unclear whether the test is identifying factors that are actually predictive of or reactive to these conditions (Vendrig, 2000). The MMPI scales 1 (hypochondriasis) and 3 (hysteria) have been widely studied in the pain populations and assorted medical conditions with pain symptoms (Tellegen, Ben-Porath, McNulty et al., 2003). Elevations on these scales (13/31) may suggest that symptom expression is inflated by emotional and psychopathological features. For instance, there is evidence that cardiology patients with the 13/31 pattern who present with angina pain symptoms show less angiographic evidence of coronary artery disease (Barefoot, Beckham, Peterson, Haney, & Williams, 1992). It appears that elevations on these MMPI scales may not predict the development of pain (Hansen, Biering-Sorensen, & Schroll, 1995), and that such scale elevations are simply reactive to the pain experience rather than reflecting long-standing personality traits (Akerlind, HornQuist, & Bjurulf, 1992). Some work has used the test to identify psychiatric co-morbidity (depression) in pain patients, as it has been theorized that untreated depression may impede patients' ability to respond to chronic pain treatment (Gatchel, Polatin, & Kinney, 1995). Other psychosocial factors that the MMPI may detect in pain populations, which could impede successful treatment, include anxiety conditions and substance-abuse proclivities (Rouse, Butcher, & Miller, 1999), though predictive validity studies are limited.

Some studies show that elevations on MMPI scales 1 and 3 may predict failure to return to work (Vendrig, 1999, Gatchel, Polatin, & Mayer, 1995) and leaving work to go on disability (Bigos et al., 1991) among patients in pain treatment programs. Patients with multiple MMPI scale elevations showed poorer outcomes following a behavioral pain management program as compared to those without any scale elevations (Naliboff, McCreary, McArthur, Cohen, & Gottlieb, 1988). However, another study showed that MMPI-2 scale elevations at intake did not predict physical outcomes after an outpatient pain treatment program (Vendrig, Derksen, & de Mey, 2000; Vendrig, 1999). Finally, a study of patients receiving surgical pain interventions showed that patients with either no MMPI scale elevations or those with the "neurotic triad" pattern (elevated scales 1, 2 [depression], and 3) showed better outcomes (Riley, Robinson, & Geisser, 1999). The upshot of this work is that the MMPI scales may be useful in characterizing persons who may be more vulnerable to having difficulty managing a pain-related condition. However, it is unclear what algorithm of scores can actually be used to predict better pain treatment outcomes.

MMPI and pre-surgical evaluations Over the past 10 years, a number of studies have sought to develop an evidence base for the use of the MMPI and MMPI-2 in the context of pre-surgical evaluations before procedures such as organ transplant and, more recently, elective gastric bypass surgery. The use of psychosocial assessment in candidates for organ transplant is based on the notion that psychosocial factors such as negative mood and distress, personality, and substance use can diminish the likelihood that patients will be able to comply with post-transplant lifestyle changes and medications (Singer, Ruchinskas, Riley, Broschek, & Barth, 2001). This non-compliance could, in turn, increase the risk of mortality, morbidity, and excess healthcare utilization over the longer term (Stilley, Miller, Gayowski, & Marino, 1998). Most work with the MMPI and MMPI-2 has focused on documenting elevations in scales 1, 2, and 3 in varying transplant populations, including those awaiting lung (Ruchinskas et al., 2000), liver (Stilley, Miller, Gayowski, & Marino, 1998), or heart transplants (Trunzo, Petrucci, Carter, & Donofrio, 1999). Although these studies speculated that the existence of these scale elevations could influence recovery from and success with the transplant surgery, prospective studies to support such predictions are still needed.

Candidates under consideration for gastric bypass surgery to address morbid obesity have also been shown to have elevated MMPI-2 scores on scales 1, 2, and 3 (Maddi, Fox, Khoshaba, Harvey, Lu, Persico, 2001), which was interpreted to reflect that these individuals experience elevations in anxiety and depression. Interestingly patients showed significant decreases in these MMPI-2 scales after bypass surgery (Maddi, Fox, Khoshaba, Harvey, Lu, & Persico, 2001). Thus, MMPI-2 may be useful for documenting changes in emotional status in persons undergoing this life-changing procedure. However, it would be helpful to know whether information from a psychosocial screen, including broadband tests such as the MMPI-2 or others, can be used to *predict* which bariatric surgery patients may have more or less difficulties in maintaining their post-surgical improvements (e.g., weight loss, insulin regulation) over the longer term. For instance, it would be useful to identify pre-surgical psychosocial factors such as depression, personality and coping style, and social support that could influence the ability of patients to institute and maintain demanding post-surgical lifestyle changes (changes in the frequency, amounts, and types of food consumed). By identifying this information in surgery candidates, the behavioral medicine practitioner could recommend pre-surgical counseling or possibly other behavioral treatments in order to improve the odds of success after surgery (Millon, Antoni, Millon, Minor, & Grossman, 2007. This issue will be further addressed in a later section of this chapter.

MMPI and the course of disease A large body of work has examined whether MMPI and MMPI-2 can be used to tap a range of psychosocial characteristics (hostility, anger, Type A behavior, depression) hypothesized to be associated with the development and course of coronary artery disease (CAD) and CHD (for review, see Arbisi & Butcher, 2004). For example, research showed that MMPI Cook-Medley Hostility scores and Type A behavior scores were associated with increased risk for the development of CAD (Williams, Haney, Lee, Kong, Blumenthal, &Whalen, 1980). MMPI-2 anger scale elevations have also been shown to predict increased risk for developing CHD and angina symptoms (Kawachi, Sparrow, Spiro, Vokonas, & Weiss, 1995). Other studies went on to show that MMPI scales measuring facets of hostility, such as cynical mistrust, predicted both the development of CAD and overall mortality in multiple populations (Barefoot, Dahlstrom, & Williams, 1983; Barefoot, Dodge, Peterson, Dahlstrom, & Williams, 1989a).

Physiological processes proposed to mediate these associations included low social support and poor diet (Siegler et al., 2003, Niaura et al., 2000), poor blood pressure control (Suarez, Kuhn, Schanberg, Williams, & Zimmermann, 1998; Yan et al., 2003), and inflammatory cytokines such as interleukin-6 (Suarez, 2003). Future work should examine whether the measurement of these and other psychosocial factors prior to surgery (CABG) or other medical treatments for heart disease can predict outcomes such as reinfarction rates, disability, and mortality. Emerging work has pointed to depression and social isolation as risk factors for such negative outcomes in patients who have experienced their first myocardial infarction (Schneiderman et al., 2010).

The use of the MBHI with medical patients

One broadband instrument designed to provide comprehensive information in a synthesized manner is the Millon Behavioral Health Inventory (MBHI; Millon, Green, & Meagher, 1982). The MBHI is a 150-item self-report test that provides information on coping strategies, health-related attitudes (e.g., pessimism and hopelessness), and probable responses to major medical treatments. The MBHI has empirical support for evaluating a wide range of medical conditions including cancer (Goldstein & Antoni, 1989), pain (Gatchel et al., 1986; Wilcoxin, Zook, & Zarski, 1988), renal disease (Tracy, Green, & McCleary, 1987), headache (Gatchel et al., 1985), gastrointestinal disorders (Alberts, Lyons, & Anderson, 1988), and cardiac conditions (Kolitz et al.1988; Lantinga et al., 1988; Brandwin, Clifford, Coffman, 1989). These studies showed that the MBHI scales can predict help-seeking behaviors after the onset of heart attack symptoms, initial psychological reactions to a new life-threatening medical diagnosis, emotional adjustment to the burden of chronic disease, appointment keeping and other aspects of medical adherence, responses to rehabilitation efforts, decision-making concerning treatment choices, the progression of physical disease and related physiological changes (immune system declines), and recovery from and survival after major medical procedures such as heart transplant. Some examples of this line of work are now presented in order to exemplify how comprehensive psychosocial assessment can address a number of the phenomena highlighted in the prior sections.

The use of the MBHI in health preservation

MBHI and help seeking in response to life-threatening symptoms The MBHI has been used to examine how personality/coping style relates to behavioral and cognitive responses immediately after the onset of acute coronary symptoms in patients experiencing their first MI (Kolitz et al.,1988). Why might this be relevant? Although life-saving interventions such as angioplasty and clot-busting agents capable of removing arterial blockage accompanying MI may be successful in as many as 75% of cases (Topol et al., 1987), they are generally most effective during the first few hours after the onset of acute MI symptoms. Understanding the psychosocial factors (e.g., personality/ coping style) that are associated with a patient's decisions to seek immediate services in those initial moments and hours after symptom onset vs. delaying help-seeking may have implications for reducing the severity of the MI and its associated costs.

In one study, patients diagnosed with MI completed the MBHI after they had been transferred from the acute coronary care unit to the cardiac ward. Based on high-point codes among the test's personality/coping-style scales, three personality types were designated as follows: Angry–Moody, Dependent–Conforming, and Confident–Outgoing. Kolitz and colleagues (1988) found that those in the Angry–Moody group tended to attribute the cause of their MI to external stress, while members of the Dependent–Conforming and Confident–Outgoing groups believed their heart attacks were due to their poor lifestyle habits. The Angry–Moody group also reported the longest delay in seeking medical attention after the onset of their MI symptoms – 81% took > 4 hours and 65% took longer than 14 hours to seek help. In contrast, 91% of the Confident–Outgoing group and 75% of the Dependent–Conforming group sought medical attention in the first 1–4 hours. Interestingly, the Angry–Moody group also showed significantly higher depression scores, higher recent stress, and greater pessimism, hopelessness, and somatic anxiety than did patients in the other two groups, suggesting that these subjects were having the most difficulty adjusting emotionally to their MI during their hospital convalescence. A second study by this group largely replicated these findings in first-time MI patients drawn from two different hospitals (Kolitz et al., 1988). These findings suggest that personality/coping style, cognitive appraisals (pessimism and hopelessness, as well as attributions for the cause of MI symptoms), and social support resources may play a role in patients' decisions to seek help after the onset of life-threatening symptoms. Knowing the existence of these psychosocial factors in an at-risk population of patients (e.g., those with a history of CHD or diabetes mellitus) may be helpful in devising preventative counseling.

MBHI and the promotion of subclinical disease in high-risk populations One facet of behavioral medicine research seeks to identify samples of people who possess risk factors for the development of a disease and then evaluate the incremental variance in disease manifestation predicted from individual differences in psychosocial and contextual factors. This diathesis paradigm might involve identifying persons who are at risk for the development of coronary heart disease due to genetic (family history) and pathophysiological (e.g., hypertension, hypercholesterolemia) factors and then examining whether behavioral (e.g., tobacco smoking and other lifestyle behaviors) factors in combination with, the patient's psychiatric status (e.g., depressive disorder), personality coping style (e.g., hard-driving, time-urgent, hostile), psychosocial factors (e.g., low self-esteem, pessimism, social alienation, and lack of resources), and contextual status (e.g., high-stress job) predict the development of overt coronary disease.

Work with the MBHI has applied a similar model in persons at risk for the development of cervical cancer. Using the example of cervical neoplasia – a pre-clinical form of cervical cancer – at least four studies have related MBHI personality coping styles and other psychosocial factors to the subclinical promotion of cervical neoplasia. In one study, women with the highest MBHI Premorbid Pessimism, Future Despair, Social Alienation, and Somatic Anxiety scores showed the strongest association between negative life event stress and level of cervical neoplasia on subsequent Pap smears and colposcopic exams (Goodkin, Antoni, & Blaney, 1986). A second study found that women with higher scores on MBHI Premorbid Pessimism, Future Despair, and Somatic Anxiety scales displayed the greatest level of subsequent biopsy-determined cervical neoplasia (Antoni & Goodkin, 1988). It is plausible that these psychosocial factors relate to the promotion of cervical neoplasia via immune system changes that are associated with stressors and psychosocial factors on the one hand and the surveillance of Human Papilloma Virus (HPV)-induced cervical neoplastic changes on the other (Jensen, Lehman, Antoni, & Pereira, 2007; Goodkin, Antoni, Fox, & Sevin, 1993).

A mechanistic study examined the association between MBHI personality/coping style, pessimism, and contextual life stress factors and immune system functioning (natural killer cell cytotoxicity, NKCC) in women at risk for the development of cervical carcinoma due to the presence of multiple risk factors (HPV infection, HIV infection; Byrnes et al., 1998). After controlling for relevant behavioral (smoking) and biological (HPV subtype) covariates, higher MBHI pessimism scores, in combination with a greater number of recently experienced negative life events, were associated with lower NKCC. Greater negative life stress predicted elevated risk of developing cervical neoplasia (Pereira et al., 2003) 1 year later. These findings collectively suggest that psychosocial factors, such as those measured on the MBHI, may identify personality/coping style, appraisals, resources, and contextual factors characteristics that predict the development of neoplastic disease, opportunistic infections, and underlying immune surveillance mechanisms that control the growth of the primary pathogenic process in high-risk populations.

MBHI and adjustment to disease diagnosis In one study, healthy, symptom-free gay men completed the MBHI and provided a blood draw to evaluate their immune system approximately 5 weeks before they were tested for and notified of their HIV antibody status. MBHI personality coping style scores were then correlated with post-diagnosis notification indices of immune system status within the men who informed that they were HIV seropositive. Since the men were unaware of their disease status at the time of psychological testing, the likelihood that test responses were reactions to the news of diagnosis was minimized. As in the case of the cervical neoplasia study, an emotionally non-expressive coping style was associated with greater impairments in indices of immune system functioning relevant to viral infection surveillance (e.g., NKCC). Men with greater impairments in anti-viral immunity at this early, asymptomatic stage of the infection may be at greater risk for a faster progression to full-blown AIDS; thus, identifying those with specific psychosocial characteristics may have value for secondary prevention.

Another study tested the utility of the MBHI for identifying associations between personality/coping style and the ways in which HIV-infected people, already manifesting clinical symptoms, adapt to this chronic disease (Starr et al., 1996). Specifically, elevations of the Inhibited, Forceful, and Sensitive coping style scales were associated with higher BDI depression scores, a lower sense of self-efficacy, less perceived social support, and more frequent use of denial as a coping strategy for dealing with their infection. On the other hand, higher scores on the MBHI Sociable and Confident coping style scales were associated with lower BDI depression scores, greater self-efficacy, and less frequent use of denial. These psychosocial characteristics may also relate to difficulties in maintaining lifestyle behavior changes demanded by an HIV diagnosis. Higher scores on MBHI Forceful and Sensitive coping styles were associated with a greater number of sex partners in the past month and a higher frequency of unprotected sexual episodes (Starr et al., 1996). Thus, HIV-infected individuals with MBHI coping styles characterized by avoidance and/or interpersonal ambivalence, may be less able to adjust emotionally to this life-threatening disease and may be less able or willing to make the lifestyle changes that are required to maintain their health. This work suggests that the MBHI may be useful in identifying HIV-infected persons who could benefit from psychosocial interventions designed to change some of these psychosocial factors.

MBHI and pain treatment outcomes A few studies have used the MBHI to predict patient's success with interventions designed to help them manage pain-related conditions. One study found that a composite score based on several MBHI scales (Chronic Tension, Recent Stress, Inhibited style, Respectful style, Pain Treatment Responsivity, Life-Threat Reactivity, and Premorbid Pessimism) predicted changes in time sitting, time standing, number of stairs climbed, time on a treadmill, treadmill speed, and hand-grip strength among male and female pain patients completing a 20-day outpatient pain rehabilitation program (Wilcoxin, Zook, & Zarski, 1988). These eight MBHI scales, in combination with demographic information on age, gender, marital status, and educational level, correctly classified 96% of patient outcomes.

MBHI and renal dialysis treatment One study used the MBHI to relate 42 dialysis patients' psychosocial characteristics at the time of their intake to the Kidney Unit at a large hospital to their adjustment to treatment (Weisberg & Page, 1988). Higher MBHI Recent Stress and Premorbid Pessimism scores were associated with patients' reports of greater difficulty in accepting help from their partners and with lower satisfaction with their chosen dialysis modality (Weisberg & Page, 1988). Patients scoring higher on the MBHI Respectful coping style were less satisfied with the treatment modality chosen, showed poorer sexual adjustment, and felt less in control of treatment procedures. Higher scores on the Forceful coping style scale were associated with greater difficulty in asking partners for help, while patients scoring higher on the Sociable style were less likely to view themselves as sick and reported greater satisfaction with their treatment. This work demonstrates the usefulness of the MBHI in predicting adjustment to the demands of chronic disease management. Identifying psychosocial characteristics of kidney disease patients might help identify obstacles to successfully implementing medical treatment.

MBHI and heart transplant outcomes The value of conducting psychosocial screens prior to organ transplant has been well established over the past two decades (Arbisi & Butcher, 2004; Dew et al., 2008; McCallum & Masterton, 2006). Most of the research in this field has involved patients undergoing liver and kidney transplants. A smaller body of work has focused on the utility of conducting a psychosocial screen in the context of heart transplant. Although some element of psychological screening is a routine part of screening heart transplant candidates, the intake often involves conducting a clinical interview to arrive at a formal psychiatric diagnosis that can be used as an exclusion criterion. These assessments often do not focus on coping strategies and potential compliance problems that might actually determine the likelihood of a successful transplant. It is arguable that, once people develop severe heart disease, they may have difficulty coping with ongoing stressors, and that this can compromise medication adherence, ability to make lifestyle changes, and could possibly undermine the effectiveness of heart transplants (Schweitzer et al., 1990). Some assessment strategies do focus on these other psychosocial dimensions (e.g., Twillman et al., 1993), but require rather long, time-consuming clinical interviews and considerable experience with the population (Harper et al., 1998b).

One study examined the value of using the MBHI at the time of screening candidates for heart transplant in order to predict post-transplant indices of health behavior, as well as morbidity and mortality rates. This study recruited 90 patients with severe cardiac disease who completed the MBHI during pre-transplant screening evaluations, and were also interviewed about their coping strategies, support resources, and medical compliance history. Post-transplant follow-up of 61 living and 29 deceased patients focused on measures of survival time, post-surgical medical care, rejection and infection episodes, and nurse ratings of medication compliance and interpersonal health behaviors. The most frequent causes of death over the follow-up period were graft failure, fungal or bacterial infections, and organ rejection. A composite MBHI risk factor made up of 17 of the 20 MBHI scales was a significant predictor of survival (Harper et al., 1998a). The high- and low-risk composite groups also differed in transplant-related costs, with the high-risk MBHI group requiring more than twice the care than the low-risk group. Specific MBHI scales predicted specific post-transplant outcomes. Future Despair was significantly associated with both heightened infection rates and rejection rates. Greater scores on the Premorbid Pessimism scale predicted poorer nurse-rated medication compliance, and the greater scores on the Sensitive coping style predicted greater nurse-rated dependency indicators. In sum, the MBHI administered at the pre-transplant screening assessment successfully predicted post-transplant outcomes including survival, infection and rejection rates, and medical costs, as well as health behaviors such as nurse-rated medication compliance and dependency behaviors (Harper et al., 1998a). The MBHI was also superior in predicting post-transplant outcomes as compared to interview-based judgments. Thus, conducting a broadband psychosocial assessment at the time of screening for heart transplant can be used to identify patients at risk for problematic outcomes (Harper et al., 1998a,b).

Summary Research demonstrated that the MBHI might be a useful broadband psychometric instrument to employ in a range of medical settings. Despite the impressive results generated by studies using the MBHI to assess psychosocial characteristics in different patient populations, there were several important psychosocial characteristics that this instrument does not provide information on. These include information on: (a) psychiatric indicators that may influence the patient's adjustment to their medical condition; (b) personality coping styles reflecting revisions to the Diagnostic and Statistical Manual-4 (Millon & Davis, 1996); (c) other psychological factors related to cognitive appraisals (e.g., self-esteem, general efficacy), faith-related resources (e.g., spiritual) and contextual factors (e.g., functional abilities); (d) specific lifestyle behaviors (e.g., substance abuse, tobacco smoking, eating patterns, physical inactivity); (e) the patient's communication style (tendencies toward disclosure, social desirability, devaluation); and (f) characteristics reflecting likely patient adherence, medication abuses, over-utilization of medical services, preferences for receiving medical information, and emotional responses to stressful medical procedures. This information can be useful in informing healthcare management decision-making concerning the need for additional psychosocial treatment to augment the success of medical interventions.

These issues provided the impetus for the development of a new instrument, the Millon Behavioral Medicine Diagnostic (MBMD, Millon, Antoni, Millon, Meagher, & Grossman, 2001), which was designed to address all of these issues. The goal in developing the MBMD was to provide an instrument that would expand upon the scope of the MBHI by providing a comprehensive set of information on those psychosocial characteristics of medical patients that contemporary behavioral medicine research has identified as potentially influencing several domains of health maintenance and healthcare delivery. As was outlined previously, five such domains can be identified, including: (a) Psychiatric Indicators; (b) Coping Style; (c) Stress Moderators; (d) Treatment Prognostics; and (e) Negative Health Habits.

Psychometric development of the MBMD

The MBMD was designed to provide information on those psychosocial characteristics of medical patients that contemporary behavioral medicine research has identified as potentially influencing several domains of health maintenance and healthcare delivery. An initial validation sample for the MBMD included over 700 patients recruited from comprehensive cancer centers, organ transplant centers, behavioral medicine research centers, diabetes research institutes, and general medical hospitals and clinics (Millon et al., 2001). A series of studies was conducted to establish the internal consistency and test–retest reliability of study scales. Next, the concurrent validity of these scales was assessed through correlations between the MBMD scales and at least two sets of objective behavioral indicators: (1) well-established objective indicators of psychiatric features (anxiety and depression), coping strategies, stress moderators; and (2) staff ratings of treatment-related behaviors.

MBMD Psychiatric Indicators showed strong positive correlations with indicators of depression, anxiety, and emotional lability. Personality/coping styles were associated with corresponding coping strategies as measured on COPE (Carver, Scheier, & Weintraub,1989). Stress Moderator scales measuring illness apprehension, future pessimism, pain sensitivity, social isolation, and spiritual absence were associated in the expected direction with indicators of anxiety (State-Trait Anxiety Scale [STAI]; Spielberger, 1983), optimism/pessimism (Life Orientation Test [LOT]; Scheier & Carver, 1985), pain (Brief Symptom Inventory [BSI]; Derogatis, 1993), social support (Social Provisions Scale [SPS]; Cutrona & Russell, 1987), and religiosity/spirituality (Systems of Belief [SOB]; Holland et al., 1999).

MBMD Treatment Prognostic scales were tested for associations with clinical staff ratings of patients in healthcare environments representing some of the major patient populations targeted in the validation studies for the instrument, patients with cancers, coronary heart disease, or diabetes mellitus. These MBMD scales included: Interventional Fragility, Medication Abuse, Information Discomfort, Utilization Excess, Problematic Compliance, and a summative score, Adjustment Difficulties, reflecting predictions about overall management risks. Patients were rated by clinicians (e.g., nurses, psychologists, social case workers) who were familiar with patients in a variety of settings (diabetes research institutes, comprehensive cancer center, organ transplant units); they completed a Staff Rating Scale (SRS), tapping 11 major domains covered in the MBMD. Results indicated that each of the MBMD Treatment Prognostic scales was significantly correlated with the corresponding staff rating for that domain (Millon et al., 2001). There was also evidence of discriminant validity, given that the highest MBMD-SRS correlations were for those tapping the same domain. The summative index, Adjustment Difficulties, as expected, was associated with a number of staff-rated dimensions that would be expected to present management risks. The strongest correlations here were with compliance issues, pain experiences, symptom fabrication, medical complications, utilization problems and expenditure excesses.

The next set of analyses compared mean MBMD scores across patients drawn from different major disease groups: cancer, diabetes, HIV/AIDS, and CHD. Here, patients with HIV/AIDS had the highest scores for Guardedness and for the Introversive, Inhibited, Non-conforming, Forceful, Respectful, and Oppositional coping styles. These group differences were most evident within women, and women also revealed higher scores than men on nearly all scales. It should be noted, however, that these differences might have been related to factors other than gender since women within certain disease groups (e.g., HIV) were of a lower socio-economic level than their male counterparts. Nevertheless, these gender differences justified the use of separate score transformations for men and women, each representing a separate normative group.

Psychological distress states have been related to the rate of disease progression among HIV-positive individuals (Ironson & Hayward, 2008; Leserman, 2008;

Leserman, 2003; Sloan, Collado-Hidalgo & Cole, 2007; Ternoshok, Wald, Synowski, & Garzino-Demo, 2008). Several constructs have shown to be influential in terms of the health and treatment adherence for HIV+ persons, including depression, pessimism, low social support, and maladaptive coping styles (Leserman, 2008). Because the measures used in this research are highly variable, it is challenging for clinicians to incorporate such measures into screening batteries. One study examined the association of summary scales of the MBMD with markers of HIV disease status (CD4 and CD8 cell counts, viral load) among an ethnically diverse sample of 147 HIV-positive men and women who had recently initiated Highly Active Antiretroviral Therapy (HAART) (Burbridge et al., 2011). After controlling for age and months since HIV diagnosis, higher scores on the overall MBMD Psych Referral Summary Scale (reflecting elevated distress, negative mood, limited psychosocial resources for managing stress, negative treatment prognostic indicators, and a need for mental health treatment) were related to greater HIV viral load, suggesting poorer control of the disease. Subgroup analyses revealed that Psych Referral scores were related to greater HIV viral load only for the men who have sex with men (MSM) subgroup. These results suggest that the MBMD may also be useful in identifying individual differences in response to treatment and eventual disease outcome. These individuals could then be referred for mental health services in a timely fashion.

Other studies associated MBMD scales with well-established indices of mood disturbance, coping strategies, and other stress moderators such as optimism/pessimism, social support and spirituality in a group of HIV-infected men and women (Meagher, 2004). The first set of analyses related MBMD coping style scales with personality measures and indicators of disease-specific coping strategies. Specifically, at the time of the MBMD administration, men and women completed the NEO-PI (Costa & McCrae, 1992) and the COPE (Carver et al., 1989). The NEO-PI measured general personality traits, while the COPE measured specific coping strategies used to deal with HIV-related symptoms and stressors. Results indicated strong positive correlations between the MBMD Inhibited, Dejected, Oppositional, and Denigrated styles with NEO-Neuroticism. In contrast, MBMD Sociable and Confident coping styles were both associated strongly with NEO-Extraversion. Regarding HIV-specific coping strategies, MBMD Inhibited, Dejected, and Denigrated styles were associated with COPE scales measuring the use of alcohol and drugs, denial and behavioral disengagement (giving up), and with less use of more adaptive strategies such as acceptance and positive reframing for dealing with HIV infection. This work provides further concurrent validity for the MBMD coping style scales in a clinical population.

After demonstrating the reliability and concurrent validity of the scales composing the MBMD, a set of predictive validity studies was conducted in a variety of clinical settings. These included a series of studies using the MBMD to predict different indicators of adherence in patients with CHD (Cruess et al., 2009), heart failure (Farrell, Shen, Mallon, Penedo, & Antoni, 2011), diabetes mellitus (Kleinman, 2000), and HIV/AIDS (Cruess, Minor, Antoni, & Millon, 2007); studies using the MBMD to predict health-related quality of life in men being treated for prostate cancer (Cruess et al., 2013); and studies using the MBMD to predict outcomes in patients undergoing procedures such as stem cell transplant (Pereira et al., 2010) and liver transplant (Harper, Wagner, & Chacko, 2010). Examples of this research are now presented.

Using the MBMD to predict medication adherence in different populations

A series of studies has examined the association of a number of specific MBMD scales with indicators of adherence in several chronic diseases including HIV/AIDS, CHD, Heart Failure, and Diabetes Mellitus. This work generally supports the utility of the test for identifying characteristics that may predict difficulties with medication adherence and lifestyle/self-care regimens in a range of clinical populations.

MBMD and medication adherence in patients on an anti-coagulant regimen Warfarin is a commonly prescribed anti-coagulant medication that must be maintained within a narrow therapeutic range to optimize its effectiveness in preventing stroke in high-risk groups (Hirsh, Guyatt, Albers, & Schünemann, 2004; Samsa et al., 2000). We know that under-anticoagulation on warfarin can lead to increased risk of stroke, while over-anticoagulation may also lead to adverse events (Hylek, Skates, Sheehan, & Singer, 1996; Gitter, Jaeger, Petterson, Gersh, & Silverstein, 1995; Fihn et al., 1996). A prospective cohort study followed 156 adults who were at least 21 years of age and had commenced a warfarin regimen. The study examined the ability of five MBMD Treatment Prognostics scales, as well as three additional MBMD scales (Depression, Future Pessimism, and Social Isolation), to predict adherence to a daily warfarin regimen assessed using electronic medication event monitoring system (MEMS) caps over a median of approximately 4.5 months (Cruess et al., 2009). The MEMS cap is fitted to their pill bottle, and capturing the date and time of every instance that patients open their medication container or pill bottle. The study defined non-adherence as either failure to activate an MEMS cap in a 24-hour period or activating an MEMS cap more than once in a 24-hour period. According to these criteria, warfarin non-adherence was evident in 22% of the total patient days of observation. Four of the five MBMD Treatment Prognostic scales (Medication Abuse, Interventional Fragility, Information Discomfort, Utilization Excess) and greater social isolation predicted poorer warfarin adherence. Using the MBMD at the initiation of treatment for high-risk populations might aid in the development of behavioral interventions to enhance warfarin adherence and perhaps reduce adverse medical events.

MBMD and adherence in patients with heart failure Heart failure (HF) is a chronic, debilitating condition currently affecting over 5 million adults in the United States, and its prevalence should increase dramatically as the baby boomer population ages

(American Heart Association [AHA], 2005). Poor outcomes among individuals with HF are most likely due to medication non-adherence and failure to adhere to dietary restrictions (low-sodium diet) (Opasich et al., 2001; De Geest et al., 2003). Hauptman (2008) estimated that over half of hospitalizations for HF are preventable via improved adherence. Importantly, 44–82% of individuals are readmitted to a hospital within 3–12 months after an initial discharge for decompensated HF (Krumholz et al., 1997).

The medication and self-care regimen for HF is quite arduous and entails taking five or more HF-specific medicines everyday and adhering to a low-sodium diet (Hunt et al., 2002; Hunt et al., 2005). Among HF patients, poorer medication and dietary adherence is related to greater depression (van der Wal et al., 2006; Wray, Waters, Radley-Smith, & Sensky, 2006), hostility (Kawachi, Sparrow, Spiro, Vokonas, & Weiss, 1995), and low social support (Wu, Moser, Chung, & Lennie, 2008). Conversely, HF medication adherence is positively associated with a belief that medicines are beneficial (van der Wal et al., 2006) and with belief in one's self-efficacy to overcome a barrier that might inhibit obtaining medicines (George & Shalansky, 2006). Together, this work suggests that cognitive, affective, and social factors may predict adherence to HF medications and that psychosocial assessment may be helpful at clinical intake. Until recently, no prior studies have assessed the association between broadband personality measures and medication adherence in HF populations.

One study (Farrell et al., 2011) examined whether well-established measures of depression, social support, and hostility, in combination with the MBMD, predicted adherence to an HF medication regimen in 105 men and women diagnosed with HF. Participants included adults recruited from outpatient clinics at private and county hospitals in the Southeastern United States. Patients completed the Center for Epidemiologic Survey – Depression scale (CES-D, Radloff, 1977), the Hostility scale (Greenglass & Julkunen, 1991), the MBMD (Millon et al., 2001), and the Medication Adherence Scale (MAS, Morisky, Green, & Levine, 1986). Multiple regression analysis indicated that the MBMD Medication Abuse scores accounted for 10.7% of the variance in MAS adherence scores after controlling for depression and hostility scores and other potential confounders (Farrell et al., 2011). Secondary analyses revealed that the Medication Abuse item, concerning being embarrassed to frankly admit problems, was significantly correlated with MAS items related to forgetting to take medications and ceasing taking the medication due to feeling better. This suggests that addressing one's comfort level related to disclosing both medical and other personal problems, normalizing one's illness state, and offering emotional support related to suffering from an illness may be important aspects of an adherence intervention.

MBMD and antiretroviral medication adherence in persons with HIV Highly active antiretroviral therapy (HAART) is effective in controlling the progression of HIV infection but requires strict adherence to achieve success (Bangsberg, Hecht, Charlebois, Chesney, & Moss, 2000). Missing as few as 1–2 days of medications predicts increases in viral load and treatment failure (Holzemer, Henry, Portillo, & Miramontes, 1999). HIV viral suppression to non-detectable levels is only reached in 40–50% of patients (Lucas, Chaisson, & Moore, 1999), suggesting that individual difference factors may be associated with medication adherence. Much behavioral medicine research has been directed at identifying patient factors that may predict optimal medication adherence in HIV-positive persons.

Behavioral research conducted over the past two decades has identified individual difference factors underlying poorer medication adherence in other chronic life-threatening conditions such as CHD (Hershberger, Robertson, & Markert, 1999), and in patients undergoing renal dialysis (Christensen & Smith, 1995) and heart transplant (Chacko, Harper, Kunik, & Young, 1996). Psychosocial factors related to poorer HAART adherence include depressive disorders (Gordillo, del Amo, Soriano, & Gonzalez-Lahoz, 1999; Sternhall & Corr, 2002; Weaver et al., 2005), maladaptive coping styles (Weaver et al., 2005) and low perceived social support (Altice, Mostashari, & Friedland, 2001; Gonzalez, Penedo, Antoni et al., 2004). Despite this evidence, there is no consensus on specific psychosocial instruments that can be used at the initial stage of HAART regimens to identify individuals who may have more adherence difficulties.

One study examined the association of MBMD scales and HAART adherence among 117 HIV-positive men and women on a recently initiated HAART regimen (Cruess et al., 2007). HAART adherence as assessed through patient interview (Medication Adherence Training Instrument [MATI]; McPherson-Baker, Jones, Duran, Klimas, & Schneiderman, 2005) was monitored at a baseline assessment and at 3-month follow-up, at a point after which participants had received medication adherence training from a Doctor of Pharmacy. At study entry, 70% were categorized as non-adherent ($<$95% adherent) and 30% as adherent ($\geq$95% adherent) to their HIV medication according to the MATI. Similar results were observed at 3-month follow-up. As hypothesized, the Medication Abuse scale of the MBMD was uniquely associated with overall adherence at baseline assessment and also predicted poorer adherence at 3-month follow-up. Additional MBMD scales (e.g., Depression and Emotional Lability) were also related to overall adherence as well as specific adherence behaviors such as missed doses, following specific instructions, and overmedicating. However, the Medication Abuse scale emerged as the most consistent predictor of adherence in the study. These results suggest that the MBMD might be used to predict adherence to HAART medication in a sample of HIV-positive men and women, and may subsequently be used to identify those in need of additional counseling. Behavioral medicine interventions combining education with motivational and behavioral strategies have been shown to improve medication adherence in HIV-infected persons (Starace, Massa, Amico, & Fisher, 2006). Overall, the MBMD may be a good screening tool to identify patients who require targeted interventions such as these to improve adherence to HAART medication.

MBMD and glucose control in patients with diabetes mellitus Control of blood glucose levels is a key goal in patients with diabetes mellitus (DM), since poor glucose control may contribute to hastened disease complications such as CHD, renal failure, and life-threatening infections (Davidson, 1991). In one study, patients with DM who were attending regular check-ups at a large diabetes research institute were administered the MBMD and provided blood for tests to determine glycosylated hemoglobin (HBAC1) levels as an indicator of chronic control of blood glucose levels. Elevated HBAC1 levels are indicative of poorer glucose control over the prior 3-month period (Lustman, Frank, & McGill, 1991). Among the 78 patients in this study, higher HBAC1 levels were associated with higher MBMD scores for Cognitive Impairment, Interventional Fragility, Problematic Compliance, and Medication Abuse (Kleinman, 2000). These findings suggest that the MBMD may be useful in identifying DM patients who are in greatest need of additional education and counseling to better their illness.

Using the MBMD to predict the course of treatment

In addition to identifying psychosocial factors that predict optimal medication adherence and lifestyle modification after disease diagnosis, some work has also examined whether MBMD is useful in predicting health-related quality of life as patients move through treatment for conditions such as cancer, as well as in patients who are undergoing organ transplant or stem cell transplant procedures.

MBMD and patients receiving treatment for cancer Many factors can impact mental and physical health outcomes among cancer patients who are receiving treatment (e.g., Carver & Antoni, 2004; Antoni, 2003). Men diagnosed with and treated for prostate cancer face many challenges due to the side effects of treatment (Krupski & Litwin, 2007). These include urinary, bowel, and erectile dysfunction, fatigue, and impaired physical functioning, all of which can greatly compromise health-related quality of life (HrQoL; Potosky et al., 2007). While not all men treated for prostate cancer report extended periods of compromised HrQoL, this may be the case in a substantial subgroup of cases and may persist for years after treatment. Some individual difference factors (depression and anxiety) have been shown to predict HrQoL over time in persons with cancer, and specifically in men with prostate cancer (Nelson, Choi, Mulhali, & Roth, 2007). However, less is known about the predictive role of longer-standing personality styles, stress-moderating variables, and other psychosocial characteristics in predicting HrQoL in men being treated for prostate cancer (Siegel et al., 2007).

One study examined the utility of the MBMD as a screening tool to identify psychosocial traits that prospectively predict HrQoL status among men treated for localized prostate cancer (Cruess et al., 2013). The MBMD was administered to 66 men treated by either radical prostatectomy or radiation therapy. Standard measures of general and prostate-cancer-specific HRQoL were then assessed at a

12-month follow-up. Higher scores on both summary MBMD Management Guides (Adjustment Difficulties and Psych Referral) and higher scores on personality styles characterized by avoidance, dependency, depression, passive aggressiveness, and self-denigration predicted lower HrQoL at follow-up. Additionally, higher scores on the MBMD Depression, Tension–Anxiety, and Future Pessimism scales predicted lower HrQoL. Finally, higher scores on the MBMD Intervention Fragility and Utilization Excess scales also predicted poorer mental and physical health functioning over time. These results point to the utility of using a broadband instrument such as the MBMD to help screen for potential impairments in mental and physical health functioning in men initiating treatment for prostate cancer.

MBMD and patients undergoing transplant procedures Another very challenging type of medical treatment involves the transplantation of solid organs or cells, often done as a life-saving procedure in persons suffering from chronic medical diseases. Meta-analytic reviews have indicated that pre-transplant psychosocial evaluations have shown to be essential in ensuring successful outcomes across a wide range of procedures and populations (Dew et al., 2008; McCallum & Masterton, 2006). As noted previously, one broadband instrument, the MBHI, was shown to predict outcomes in heart transplant recipients (Chacko, Harper, Kunik, & Young, 1996; Harper, Chacko, Kotik-Harper, Young, & Gotto, 1998a, b). Two studies have used the MBMD to predict various outcomes in patients undergoing transplant procedures.

In one study, the focus was on identifying psychosocial factors associated with a failure to adhere to pre-transplant behavioral changes in alcohol and substance use in liver transplant candidates (Harper et al., 2010). Because liver transplant is often indicated in patients with conditions resulting from long periods of substance abuse (e.g., liver cirrhosis), and because persisting alcohol and substance use prior to surgery can lead to negative outcomes, it is valuable to screen patients in order to identify those who are having difficulties making pre-transplant lifestyle changes (Kotlyar, Burke, Campbell, & Weinrieb, 2008; Ehlers, Rodrigue, Widows, Reed, & Nelson, 2004). This study sought to identify characteristics of 112 patients selected for liver transplant compared to those who had not demonstrated 6 months of alcohol, drug, or tobacco abstinence at the time of candidacy assessment. In this sample, about half failed to achieve abstinence from substance use. MBMD scores were compared between the compliant and non-compliant subgroups. Results revealed that non-compliant patients showed significantly less respect for authority, less concern about their illness, and less spiritual involvement. Greater depression was related to persistent smoking. Prior drug use was associated with greater scores on the Cognitive Difficulties scale, and personality traits reflecting emotional constriction (Inhibited style scale) and a tendency to feel dejection (Dejected style scale), and greater MBMD Medication Abuse scores. This study provides evidence that broadband tests such as the MBMD may help identify psychosocial characteristics of transplant candidates that should be addressed to reduce their risk of continued substance abuse before and after liver transplant, behaviors that could affect the success of this expensive procedure.

Another study tested whether the MBMD predicted medical outcomes after another type of transplant – hematopoietic stem cell transplant (HSCT; Pereira et al., 2010). HSCT is commonly used to treat patients with hematologic malignancies, such as acute myeloid leukemia (AML), as well as those with extreme forms of anemia. Because the 1-year survival rate of HSCT recipients approaches 50% (Karanes et al., 2008), there has been growing interest in identifying psychosocial factors that predict optimal HSCT outcomes (Hoodin & Weber, 2003; Andrykowski, Brady, & Henslee-Downey, 1994). Generally, this work has found that recipients with less depressive symptoms, better coping skills, and greater sources of support show longer survival after HSCT. One study used the MBMD to examine the relationship between psychosocial characteristics and 1-year survival in allogeneic HSCT recipients (Pereira et al., 2010). Fifty-eight adults undergoing evaluation for allogeneic HSCT completed the MBMD. Analyses focused on the Spiritual Absence, Depression, and Problematic Compliance scales. After covarying for disease type and relevant biobehavioral factors, Cox regression analysis indicated that individuals with elevations on the Spiritual Absence and Problematic Compliance scales were significantly more likely to die 1-year post-HSCT, relative to those without elevations on these scales, with Hazard ratios approaching 3.0. These results suggest that having less supportive resources and evidencing difficulties with post-surgical behavioral compliance may be independently associated with poorer survival following HSCT. Using psychosocial assessments at the time of screening for HSCT could identify candidates who could benefit from additional support and behavioral counseling prior to transplant.

Psychometric developments in psychosocial assessment of medical patients

Bariatric surgery consultation One area where psychosocial assessment has played an increasing role in clinical medicine is in the context of pre-surgical evaluations for bariatric surgery patients. There is a growing obesity epidemic in the United States (Wadden Brownell, & Foster, 2002), with 25% of the population considered overweight, 10% severely overweight or obese, and about 2% "morbidly" obese. In addition, obesity stands to be the leading cause of death in coming years (Flum et al., 2005). Among the chronically obese, morbidly obese, and even among normal-weight individuals with type 2 diabetes, bariatric surgery is often viewed as a procedure of last resort. This form of surgery, involving some type of gastric bypass or banding procedure, was employed in just over 13,000 cases in 1998, but was projected to rise to well over 200,000 cases by 2010 (Bauchowitz et al., 2005; Santry, Gillen, & Lauderdale, 2005; Korenkov & Sauerland, 2007). Patients may have weight loss of about 60% after gastric bypass surgery and 40% after vertical banded gastroplasty (Buchwald et al., 2004; Sjostrom et al., 2007; Marcus, Kalarchian, & Courcoulas, 2009). However, 20–33% of these patients will regain their weight at 2 years post-surgery (Hsu et al., 1998; Delin & Watts, 1997; Benotti & Forse, 1995). In the Swedish Obese Subjects Study, a major proportion of subjects had significant weight gain over a 10-year period (Karlsson, Taft, Ryden, Sjostrom, & Sullivan, 2007).

The success of bariatric surgery depends on many factors such as age, gender, co-morbidities, and surgical volume at the institution where the procedures are conducted (Flum et al., 2005). However, psychosocial factors that predict post-operative behaviors are important as well. Maintaining surgical outcomes over the longer term depends in part on the patient's ability to make major lifestyle behavior changes after surgery (Bauchowitz et al., 2005). These lifestyle changes involve following strict nutritional and exercise guidelines (Powers, Perez, Boyd, & Rosemurgy, 1999). The link between post-operative behaviors and bariatric surgery outcomes prompted the National Heart Lung and Blood Institute to recommend psychosocial assessment and counseling before and after surgery (NHLBI, 2000), and guidelines from working groups have followed from this consensus meeting (LeMont, Moorhead, Parish, Reto, & Ritz, 2004). Despite this, there remains a lack of consensus as to which psychosocial factors are actually predictive of post-surgical clinical outcomes or mental health (Herpertz et al., 2003; Marcus, Kalarchian, & Courcoulas, 2009).

One study found that nearly two-thirds of candidates for bariatric surgery had a lifetime history of at least one Axis I disorder (Kalarchian et al., 2007). Patients with a history of binge eating are at elevated risk for poor outcomes (Green, Dymek-Valentine, Pyduk, LeGrange, & Alverdy, 2004). Other factors may include a lack of social or familial support, disturbances in body image, psychiatric difficulties, and maladaptive and coping or personality styles. These psychosocial factors are believed to increase the risk of poor outcomes via increased likelihood of post-operative problems with medical compliance, stress tolerance, impulsive acting-out, and over-utilization of health services (Antoni, 2005).

Based on these hypothesized processes, a large normative study was conducted with the MBMD on over 700 patients treated for bariatric surgery (Millon et al., 2006). Results showed nearly identical psychometric characteristics (internal consistency and test–retest reliability) for MBMD scales as those obtained in studies with the general medical patient validation samples (Millon et al., 2001). This work also generated new raw score scale conversion algorithms and several additional scales designed to address issues unique to this patient population. These newly developed scales are designed to provide specific guidelines for pre-surgical behavioral interventions, and predictions for post-surgical patient behaviors, self-perceptions, and the need for post-surgical interventions to facilitate longer-term maintenance of treatment gains. Future research in bariatric surgery would benefit from testing the utility of the MBMD in prospective designs to predict initial psychological responses to bariatric surgery, the incidence of success and complications following surgery, ability to make lifestyle changes after surgery, and the need for additional clinical services and costs over extended periods of time.

Pain management Pain is a highly prevalent and costly health issue in the United States. Low back pain is extremely common among adults, with a 6-month prevalence up to 73% (Don & Carragee, 2008), and is perhaps one of the most common reasons for seeking pain treatment. Although the vast majority of back pain episodes abate with time, rest, and perhaps pain medication, a small percentage of episodes persist for months or years, resulting in disability and high medical utilization. Surgery may be the only option for these patients. Back surgery may be successful in up to 75% of cases (Block, Ohnmeiss, Guyer, Rashbaum, & Hochschuler, 2001). Surgical implantation of a spinal cord stimulator (SCS) to alleviate pain in the lower back and other areas (Doleys, 2006) is often considered when spine surgery is unsuccessful (Chou et al., 2009). SCS success rates may range from 50% to 75% (Doleys, 2006). Surgically implanted drug delivery systems also provide another more invasive pain treatment approach.

Because spine surgery and surgical implantation of pain control devices have increased significantly over the past decade (Deyo, Mirza, Turner, & Martin, 2009), and because they may only be successful in a portion of the cases, it is important to consider the psychosocial factors that may predict optimal treatment outcomes. Research has identified a number of psychosocial factors that may predict the relatively high failure rates of invasive pain treatment procedures (e.g., Block, Gatchel, Deardorff, & Guyer 2003; Bruns & Disorbio, 2009; Doleys, 2006; Williams, Gehrman, Ashmore, & Keefe, 2003). These include anxiety and depression, maladaptive coping styles, substance abuse and poor medical compliance, and contextual factors such as social isolation and involvement in litigation (Bruns & Disorbio, 2009). Thus, an effective psychosocial evaluation can contribute to decisions about a patient's suitability for surgery and how to prepare a patient in order to increase the likelihood of a successful outcome (Block, Gatchel, Deardorff, & Guyer, 2003; Bruns & Disorbio, 2009; Don & Carragee, 2008).

Despite this range of surgical interventions, some patients who fail to achieve pain relief often go on to become "chronic pain" patients. For these individuals, a downward spiral of disability, despair, high healthcare utilization, and overall poor quality of life results in immense costs to the healthcare system (Bruns & Disorbio, 2009). The individual's unique constellation of genetics and prior experiences affects how nerve stimulation or nocioception is experienced, which in turns produces a behavioral response. Accordingly, a biopsychosocial model has guided research and clinical interventions developed to treat chronic pain (Gatchel, Peng, Peters, Fuchs, & Turk, 2007). Because psychosocial factors are so central to understanding chronic pain, conducting a comprehensive psychosocial assessment of chronic pain patients plays an essential role in developing effective treatment (Millon, Antoni, Millon, Minor, & Grossman, 2010).

The MBMD measures a variety of psychosocial factors that are central to the experience of and response to pain. However, because pain patients may comprise a unique medical population, a series of specific studies were conducted with the MBMD in order to make the test more relevant for use with different pain populations. These included the recruitment of a new normative sample of pain patients, the development of pain population norms, and the creation of separate clinical reports for pre-surgical (acute) and non-surgical (chronic pain) evaluations (Millon et al., 2010). The MBMD chronic pain norms were based on a sample of 1,200 chronic pain patients drawn from seven user sites across diverse geographical regions of the United States, representing a variety of settings in which pain patients are commonly evaluated. All patients in the sample completed the MBMD as part of the regular psychosocial evaluation conducted at the site between the years 2006 and 2009. The sample consisted of 54% females and 46% males. The majority of patients were in their 40s or 50s, mostly white, and mostly high school educated. The patients in the norm sample were further differentiated according to whether they were being evaluated for a surgical treatment – either spine surgery or surgical implantation of a spinal cord stimulator or intrathecal infusion pump – or a non-surgical treatment such as a multidisciplinary treatment program or non-surgical medical treatment. Approximately 37% received presurgical evaluations, and approximately 63% had non-surgical evaluations.

Psychometric analyses of the MBMD in this sample found it to have adequate internal and test–retest reliability. Concurrent validity evidence consisted of correlations, gathered in three different samples, between MBMD scale scores and scores on concurrently administered valid and objective self-report measures that are commonly used with pain patients. In a subsample of 596 patients in the normative sample, the MBMD scale scores showed excellent concurrent validity with MMPI-2 clinical and content scale scores, and with the newly developed MMPI-2 Restructured Form including the Restructured Clinical (RC) and Specific Problems (SP) scales (MMPI-2-RF; Ben-Porath & Tellegen, 2008; Tellegen & Ben-Porath, 2008). In a subsample of 177 patients from the normative sample, the MBMD scales showed excellent concurrent validity with the Symptom Checklist-90 (SCL-90, Derogatis, 1994), the Distress and Risk Assessment Method (DRAM; Main, Wood, Hollis, Spanswick, & Waddell, 1992), and the Coping Strategies Questionnaire-Revised (CSQ-R; Riley, Robinson, & Geisser, 1999; Robinson et al., 1997). In a final subsample of 132–160 patients, the MBMD showed strong concurrent validity with the Dallas Pain Questionnaire (DPQ; Lawlis, Cuencas, Selby, & McCoy, 1989), the Brief Battery for Health Improvement 2 (BBHI 2; Disorbio & Bruns, 2002), and the Pain Outcomes Profile (POP; American Academy of Pain Management, 2003) as part of their evaluation for suitability for treatment and to help guide treatment.

Predictive validity evidence is derived from a study in which MBMD scores obtained at intake to a multidisciplinary pain treatment program were shown to predict treatment outcome (Lattie, Antoni, Millon, Kamp, & Walker, in press). Multidisciplinary pain treatment programs, which may offer physical activity, relaxation, individual- and group-based cognitive behavioral therapy, and other techniques in a residential setting, have proven efficacy and cost-effectiveness

(Chou et al., 2009; Gatchel & Okifuji, 2006). Although some studies have found that psychosocial characteristics may predict success in multidisciplinary treatment (e.g., Vendrig, Derksen, & de Mey, 1999; Hopwood, Creech, Clark, Meagher, & Morey, 2008; Kroenke et al., 2012), there exists no consensus on psychometric predictors of treatment outcome (van der Hulst, Vollenbroek-Hutten, Groothuis-Oudshoorn, & Hermens, 2008; van der Hulst, Vollenbroek-Hutten, & IJzerman, 2005). In a predictive validity study, 93 patients completed the MBMD and ratings of current pain and average pain, prior to beginning an 8-week multidisciplinary pain management program (Lattie et al., in press). Ratings of current and average pain on the POP (American Academy of Pain Management, 2003) were completed upon program completion. Participants were classified as "successful" or "unsuccessful" program completers based on established criteria for clinically significant reductions using the POP current and average pain scores. Using these criteria, 47% of patients showed successful pain reductions after this program. Successful cases had lower scores on MBMD depression scores, and on coping style scales measuring introversive, inhibited, dejected, and denigrated tendencies. Additionally, lower pretreatment depression scores and lower scores on each of these coping style scales predicted lower magnitude of pain ratings at discharge even after controlling for educational level and pre-treatment pain ratings.

One study provided validity evidence for the MBMD in the context of patients undergoing pain-related surgery. Block and colleagues (Block et al., 2003) proposed an algorithm for combining information obtained during the presurgical evaluation of spine surgery candidates into a prediction about the patient's likelihood of experiencing a successful surgery outcome. Block's system has had a strong influence on the rationale and format for presurgical psychosocial evaluations (Bruns & Disorbio, 2009) for spine surgery, as well as surgical device implantation (e.g., Devlin, Ranavaya, Clements, Scott, & Boukhemis, 2003). Schocket (2005) linked the MBMD directly to the Block prognostic system in 60 patients undergoing psychosocial evaluation for implantable devices. Patients were first classified into the Block prognostic categories using information that did not include the MBMD, and then patients assigned to the different Block categories were contrasted on their MBMD profiles. Specifically, mean scores on the MBMD Clinical Scales were contrasted between four Block prognostic groups: (1) *Good Prognosis*: No psychological treatment recommended, (2) *Good Prognosis*: Postoperative psychological treatment recommended, (3) *Fair Prognosis*: Preoperative compliance and motivation measures recommended, and (4) *Poor Prognosis* for Invasive Procedures. For 20 of the 29 MBMD scales, there was a significant linear pattern for the mean scores to become less favorable from Group 1 to Group 2 to Group 3 to Group 4. The strongest differences between groups were (in order) for the Dejected style, Depression, Inhibited style, Utilization Excess, Denigrated style, Oppositional style, Psych Referral, and Social Isolation scales.

These studies provide evidence that the MBMD may be a useful tool to delineate patients who are likely to make significant treatment gains in different pain treatment settings, ranging from multi-week multidisciplinary pain treatment programs to surgical implantation of pain management devices. This work has led to the development of customized interpretive reports for pain patients based upon their MBMD results. The MBMD Pain Patient Reports are interpretive reports designed to provide information relevant to the psychosocial evaluation of pain patients in one of two general settings – a pre-surgical evaluation or a non-surgical evaluation (for detailed description, see Millon et al., 2010). The utility of these specialized reports is currently under study.

Summary and Conclusions

This chapter reviews the empirical evidence supporting the position that comprehensive psychosocial assessment can contribute significantly in reducing morbidity and mortality as well as healthcare costs in different medical populations. We provide samples of psychometric instruments that have been developed to tap assorted psychosocial factors that may be associated with physical and mental health outcomes in a variety of healthcare settings. A major part of this review concerned a summary of the use of "broadband" instruments (MMPI, MBHI, MBMD) that are capable of providing multilevel information on psychosocial factors using tests that have been normed on large samples of medical populations. The research using these instruments provides compelling evidence that a patient's psychiatric status, coping style, psychosocial resources, and attitudes toward health and medical treatments can be important in predicting a variety of health-promoting behaviors and outcomes.

The identification of this array of psychosocial factors has evolved to the point where psychometric instruments can reliably identify and integrate: information on psychiatric indicators that may influence adjustment to their medical condition, cognitive appraisals, resources, contextual factors, specific lifestyle behaviors, communication stylistics, and information for predicting patient adherence to required lifestyle changes and medication abuse. This information will undoubtedly be useful in informing healthcare management and decision-making in the coming years. The continued value of psychosocial evaluations in the medical arena can only be ensured by conducting research demonstrating the ability of psychometric tests to predict quality of life and actual medical outcomes in real-life treatment settings. Future research should employ prospective designs to test the ability of these instruments to predict patient psychological responses to major medical interventions, the success rates and medical complications following medical procedures, the costs of different medical treatments and follow-up care, the likelihood of medication abuse, and the ability of patients to maintain long-term self-care. Continued empirical evidence collected in relevant clinical settings may make the use of psychosocial evaluations routine in forecasting utilization and expenditures in large healthcare systems.

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19

Motivational Interviewing

Moira Sim, Eric Khong, and Gary Hulse

Things do not change, we change.

Henry David Thoreau, Walden (1854)

Introduction

Patients expect their healthcare practitioners to provide preventative care, including information and advice about healthy behaviors to improve or maintain their health (Wensing et al., 1998; RACGP, 2006; Harris, 2008). Inherent in this professional role is the necessity to provide clear advice and to be prepared to discuss the reasons for recommendations.

However, while many patients accept and follow advice from their practitioners, others question the advice or feel unable to motivate themselves to implement the behavioral change effectively. Optimal health outcomes are clearly not achieved if the patient does not use the prescribed medications or treatment, or continues with behavior that increases the risk of or exacerbates the condition.

Improved disease knowledge and advances in treatment in the twenty-first century have resulted in increased life expectancy and a change in the pattern of disease. Healthcare provision today is more about managing chronic conditions such as diabetes, cardiovascular disease, and obesity, than the treatment of acute illnesses such as infection and injury (see Table 19.1). While pharmacological treatments may assist to achieve health improvements, in the long term, the patient's lifestyle choices and health behaviors are key to effectively managing many chronic conditions. For this reason, practitioners need skills that can be used to enhance

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Table 19.1 The morbidity and mortality associated with unhealthy behaviors in the United States.

Smoking	An estimated 45.3 million people, or 19.3% of all adults (aged 18 years or older), smoke cigarettes (CDC*, 2011a). Cigarette smoking is the leading cause of preventable death (CDC*, 2002), accounting for approximately 443,000 deaths, or one of every five deaths, each year (CDC*, 2008; US Department of Health, 2004).
Alcohol	Approximately 79,000 deaths are attributable to excessive alcohol use each year (CDC*, 2010). This makes excessive alcohol use the third leading lifestyle-related cause of death (Mokdad, Marks, Stroup, & Gerberding, 2004).
Sexually transmitted diseases	The CDC* estimates that there are 19 million new sexually transmitted infections every year (CDC*, 2011b). STDs cost the US healthcare system $17 billion every year – and cost individuals even more in immediate and life-long health consequences (CDC*, 2011).
Obesity	During the past 20 years, there has been a dramatic increase in obesity. More than one-third of adults are obese (US Department of Health, 2012). Obesity-related conditions include heart disease, stroke, type 2 diabetes, and certain types of cancer, some of the leading causes of death.

* Centers for Disease Control and Prevention

patient motivation. Such skills can be used to maintain behavioral changes that reduce the impact or risk of morbidity and facilitate medication or medical treatment compliance, attendance at subsequent follow-up sessions, or attendance at another service in the case of referral.

There are an increasing number of studies to support the effectiveness of brief interventions in busy clinical settings. Brief interventions are short opportunistic interventions to promote behavior change during a clinical consultation. For example, in primary care, a patient may present with dyspepsia, which offers a quick opportunity to link behavioral change advice or education about alcohol and diet to their original concern (Kaner et al., 2007; Christian et al., 2008). However, a brief intervention is not always sufficient to alter behavior (Kaner et al., 2007; Bien et al., 1993). When positive outcomes are not apparent, the practitioner's sense of ineffectualness in altering behavior can be associated with frustration, a lack of confidence, and negative attitudes toward attempting to change health behaviors (Wens et al., 2005; Vogt et al., 2005). Health practitioners may be puzzled and discouraged by their patient's apparent lack of motivation to change their lifestyle or to follow the advice provided. In this situation, the therapeutic relationship is at risk. How do you work with your patients to help them to successfully change their behaviors?

This chapter is about one method of behavior change counseling called *motivational interviewing* (MI), which can be readily incorporated into the range of usual interactions between the health practitioner and patient. Typical consultations are often limited in time or include many complexities that reduce the amount of time that can be allocated to each specific aspect. MI is an approach that can help practitioners use these brief windows of opportunity more effectively for their patients to achieve lasting behavioral change. We hope this chapter provides the reader with a foundation for the topic, and inspires further enquiry.

Motivation, Ambivalence, and Resistance to Change

If a health practitioner wants to facilitate behavior change in a patient, understanding the factors that may motivate them toward change, their ambivalence, and their perceptions of their ability to change is a good place to start.

Various theories and models of behavior change propose that motivation is affected by internal and external factors (DiClemente, 1999). One such model, the Stages of Change model is discussed in Chapter 4 and describes the stages associated with varying degrees of readiness to change (Prochaska & DiClemente, 1982) (refer to Chapter 4 by Janice M. Prochaska and James O. Prochaska). Another psychological theory, the Self-Determination Theory (SDT), conceptualizes motivation as a continuum (Ryan & Deci, 2000; Vansteenkiste and Sheldon, 2006) (see Figure 19.1). Therefore, people can move along the continuum and range from having no interest to being very interested in change, and the health practitioner can influence the movement along that continuum.

Part of the inertia to change is a person's ambivalence. Ambivalence is a normal aspect of human nature and is a natural phase in the process of change (Miller & Rollnick, 2002). For example, a person who is dependent on a drug can have a "love–hate relationship" with it – that is, intensely positive feelings toward the drug and, at the same time, an intense dislike of the associated problems and the control that the drug has over him or her. Change and resistance to change are seen as two sides of the same coin (Miller & Rollnick, 2002).

When ambivalence is experienced, there can be a fine line between the movement toward change and resistance to change. This means that raising the issue and giving brief advice can have both positive and negative consequences. When someone believes that they are being pushed to change when they are ambivalent, the unintended consequence is that they may move to defend their position and become more resistant to change. Lundahl and Burke (2009) demonstrate this using three mathematical formulae:

1. Knowledge = change
   In a simplistic way, one could assume that knowing something is enough to trigger change. In some cases, supplying information is all it takes – for example, knowing that smoking increases the risk of heart disease or cancer. However,

sometimes the knowledge of the negative impact of the behavior alone is not sufficient to trigger change, and for this reason this formula is insufficient to represent what occurs.

2. Knowledge × motivation = change
   This formula acknowledges that knowledge is sometimes not enough. If motivation is at zero, then no amount of knowledge will trigger change. Motivation is an essential ingredient. However, sometimes, despite a desire to change, there is ambivalence and forces against change, which this formula does not capture.
3. Knowledge × motivation/resistance = change
   Ambivalence encapsulates both the forces for (motivation to change) and against change (resistance to change). Approaches that build resistance are likely to work against change and therefore more likely to fail to change behavior. Note that, in these three formulae, knowledge is still required. The question is how to build the knowledge and the motivation without increasing the resistance.

A person's internal motivation to change can be strengthened by three factors: autonomy, relatedness, and competency (Vansteenkiste and Sheldon, 2006). Autonomy is a person's perception of the self as the determining agent of change. A person who owns the reason for making changes is more likely to be successful. Relatedness can take a number of forms and has to do with how the individual connects with the world around them. The trust and relationship with the health practitioner and the importance of behavioral changes to significant others are examples of relatedness. Competence revolves around the feeling of confidence that they can succeed in changing.

Even if a person believes it is important to change, they need to believe that change is possible before they take action. The protection motivation theory was originally developed to explain the effect of fear on health attitudes and behaviors (Rogers, 1975). According to this theory, the response to the health threat depends upon threat appraisal and coping appraisal (Floyd et al., 2000). This is illustrated in Figure 19.1.

Let us take the example of a young person who drinks too much and drives too fast. He might be unconcerned when confronted with advice that a car accident could cause his death, as he considers that if he were dead he would not be around to care. The prospect of being paralyzed for life might be a severe threat, but his perceived vulnerability might be low since, in his view, all his friends drive fast and none have become paralyzed. This might lead to a low threat appraisal and therefore no action. If on the other hand, his best friend is paralyzed following a car accident, the threat appraisal may be high and can result in emotional arousal and a search for options. His action will depend on whether he believes that changing his behavior will remove the threat and whether he can successfully change his behavior. If he believes he cannot change his behavior, then the only way of reducing the emotional arousal is to deny the threat.

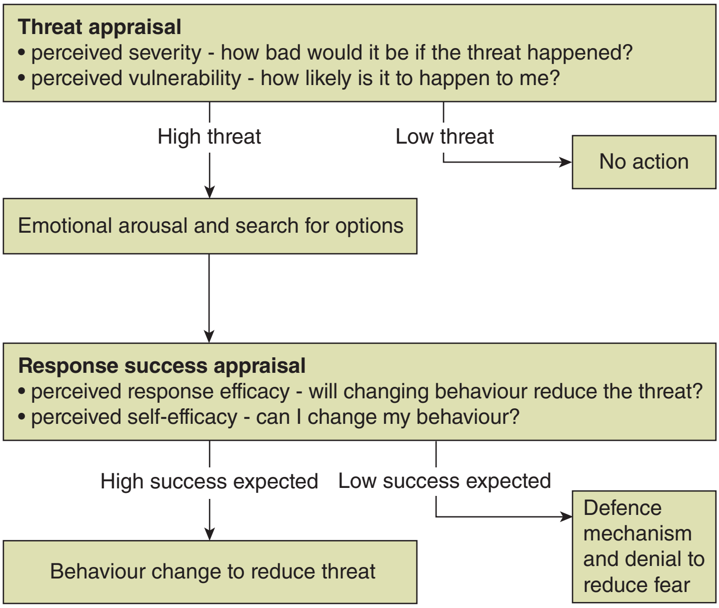

Figure 19.1 Protection motivation theory (adapted from Floyd et al., 2000).

How do you talk with your patients to help them to successfully change their behaviors? Understanding the factors that motivate them toward change, their ambivalence, and their perceptions of their ability to change is a good place to start. For example, a common situation that might be encountered is an elderly lifelong smoker who is unconcerned that his continuing tobacco consumption increases his risk of cardiovascular and respiratory disease and premature death. In this instance, internal motivation may come from relatedness to his grandchildren and his concern about their health through passive smoking.

What Is Motivational Interviewing?

Motivational interviewing is a person-centered directive method that enhances intrinsic motivation to change by exploring and resolving ambivalence, and the patient's perceptions about their ability to achieve change (Miller & Rollnick, 1991). The goal of MI is to increase intrinsic motivation rather than to impose it externally.

MI can be divided into two phases: building motivation and strengthening commitment (Miller & Rollnick, 1991). The second part, strengthening commitment, includes some of the practical aspects that health practitioners are usually comfortable with discussing – exactly what, when, and how action is to be taken and reviewed. The first part, building motivation, involves working with ambivalence to build momentum for change. To accomplish this, the practitioner uses a skillful empathetic approach, open questions, and selective responses to elicit "change talk" from the patient, that is, statements that argue for change (Miller & Rollnick, 2002).

The statements express:

- Desire to change – e.g., "I want to change";
- Ability to change – e.g., "I can change";
- Reasons for change – e.g., "I should change because . . ."
- Need to change – e.g., "I must change"; and
- Commitment to change – e.g., "I'm going to change"

These five categories of motivational speech (DARN-C) have been demonstrated to predict behavior change (Amrhein et al., 2003). The first four kinds of statements (desire, ability, reasons and need) move people toward change. The final type, a commitment statement, is the most predictive of change.

In the following sections, we will explore ways in which the practitioner can work with the patient to achieve change. The skill in MI lies in the ability to listen for cues to ask open-ended questions that evoke these "change talk" statements from the patient and to reinforce the intrinsic motivation for change through statements that support these.

MI is not a technique for persuading or even manipulating people into doing what they do not want to do. MI is based on honoring autonomy and can only evoke intrinsic motivation from a person. MI is not a "technique" or a simple process that follows a recipe. It is a complex skill, improved with practice and feedback over time. MI is not a panacea and does not address all conditions. However, when MI is helpful, it can combine with other therapies to improve clinical outcomes (Miller & Rollnick, 2009).

The spirit of MI

MI is a style for eliciting the patient's motivations to change behavior. The "spirit" of MI is collaborative (a partnership between the patient and the health professional), evocative (evoking from the patient's own values, goals, insights, motivation, and resources for change), and honoring patient autonomy (acceptance that the patient makes his/her own choices) (Rollnick et al., 2008). It is particularly useful for those who are reluctant to change or ambivalent about changing behavior (Heather et al., 1996).

Collaborative Because of the asymmetry in the power dynamic between a health practitioner and the patient, it is very easy to have a one-way dialogue. The practitioner can end up managing the conversation, and the patient becomes the passive listener. MI's approach is for a more balanced collaborative conversation and joint decision-making. If the patient is ambivalent or resistant to behavioral change, significant health benefit is unlikely until the patient accepts the need for change and takes responsibility for this.

Evocative Health practitioners have a vast array of clinical skills that can easily be applied to the patient's concerns. However, these are not going to make patients change their health behavior if they are not motivated to do so. In MI, evoking the patient's intrinsic goals, values, and aspirations, and linking that with health behavior change can trigger their motivation to change.

Honoring patient autonomy Health practitioners can become quite invested in their patient's well-being, which can cause feelings of disappointment when patients do not change their behavior. MI requires the practitioner to have a degree of detachment from outcomes, and acceptance that people have a right to make choices about their lives. A caring attitude and empathy are still important, but so is acknowledging a patient's autonomy.

Miller and Rollnick emphasized that the spirit of MI takes primacy over the specific techniques for implementing it (Miller & Rollnick, 2009). A practitioner's interpersonal skills directly increase collaboration and the likelihood of favorable outcomes (Moyers et al., 2005). Without the spirit, the intervention is not MI (Miller & Rollnick, 1995).

The guiding style of MI

The shift into MI occurs when one moves from a directive style into a guiding style. The practitioner engages patients in collaboration, affirms their strengths and aspirations, elicits their motivation for change, encourages hope, and promotes autonomy in decision-making. The move from directing to guiding is particularly useful for patients who are ambivalent about their health behaviors and for whom repeated advice may increase resistance and defense of their position.

In MI, we are interested in the patient's motivations for their health behavior. Motivations for change are individual since what matters to each of us is different, and identifying the reasons that matter to the individual is more likely to result in behavior change than imposed external reasons for change. MI explores the patient's own reasons for their behavior and reasons for changing or not changing. One way to increase intrinsic motivation is to "generate a gap," so that people perceive a discrepancy between where they are and where they want to be (Miller, 1995). Asking patients where they would like to be can demonstrate this discrepancy, but patients may unwittingly find themselves focusing on possible impediments to change, and therefore automatically lower their expectations of where they would like to be. One technique to overcome this is to ask patients to assume practitioners have a "magic wand," and with one wave they can achieve their behavior change. This approach also allows the practitioner to raise the issue of patient-perceived impediments to achieving behavioral change. In MI, it is important not to focus on impediments and instead to use this to evoke ideas on possible ways of overcoming these blocks. The development of discrepancy can move an individual from an earlier to a more advanced stage of change, as described in Chapter 4 (Prochaska & DiClemente, 1982).

In achieving behavior change, the most important answers to why and how lie within the patient, and the task is to listen in a way that will draw this out so that it can be heard by both the patient and the practitioner. Understanding what the important issues are gives us a greater capacity to help. Good listening is not just about asking questions and giving room for answers, it is about making a conscious effort to build rapport, trust, and understanding with the patient. It is also about drawing out opportunities to highlight "change talk," statements from the patient that can strengthen the motivation for change.

Patients know better than anyone else the impediments to changing their own behavior, but may sometimes lack confidence in their ability to change. Asking questions about previous successful behavior change and highlighting the individual's strengths can build confidence. This process is empowering as it demonstrates that the patient has successfully been able to change before. MI allows patients to explore and understand how they can achieve healthy behavior within the context of their own lives. A skilled practitioner encourages patients to vocalize why and how they intend to change during the consultation, knowing that the act of speaking in support of change is a behavior that both reinforces the patient's own expertise in their own actions and influences the patient's attitudes, making behavior change more likely.

The core skills in the guiding approach of MI are asking, listening, and informing (Rollnick et al., 2010). Tools used in the process of active listening include open-ended questions, affirmations, reflective listening, and summaries (see Table 19.2).

Asking open-ended questions Through open-ended questions, the patient is encouraged to express what, why, and how they might make changes. Questions that can draw out the desire, reason, need, and ability to change include: "Tell me how you feel about (the behavior)," "You say you know you should stop, why is that?," "What's the most important reason for you to consider changing (the behavior)?," "What's your greatest concern about (the behavior)?," and "You know what works best for you. If you wanted to succeed how would you go about (changing the behavior)?." These questions can be applied to many different behaviors.

Listening and reflecting Through listening to and reflecting on the patient's own words, the practitioner can demonstrate understanding and express empathy. In summarizing and reflecting back, the patient can be invited to articulate the next step, which may prompt some internal reflection and may lead to a commitment for action.

Table 19.2 Skills used in the guiding style of MI.

Core guiding skills	*Examples*
Ask open-ended questions that avoid brief "yes" or "no" responses and encourage the patient to do most of the talking. These questions establish rapport, gather information, and increase shared understanding. They can also evoke "change talk," statements in which the patient declares what, why, and how change should occur.	How do you feel about your drinking? I understand that you've been concerned about your smoking, please tell me more about this? There are many different ways to reduce your risk of heart disease, such as stopping smoking, cutting down alcohol use, eating more healthily, and exercising more. Which ones would like to talk about? Why do you think smoking would be the easiest to work on first? If you wanted to succeed, how would you go about quitting smoking?
Listening and reflecting, which involves rephrasing the answers the patient provides to reflect understanding. On a basic level, it can be just repeating what the patient has said back. More skillful reflections will include comments about the patient's response. The aim of reflective listening is to not only reflect what the patient has said, but also sometimes what the patient might be thinking but has not yet said.	It sounds to me that you don't want to drink as often as you do. Right now you don't feel like you could deal with cutting down your alcohol use. However, you know that contributes to your tiredness, and it's not good for you, so you know at some point you'll need to do it. Where does that leave you? You've been very worried about having a heart attack, especially as you're heading toward the age of 50 when your father had a massive heart attack. However, life has been stressful, and you've found yourself stuck in a daily routine with no time to think about exercise. It's pretty uncomfortable for you to think about that approaching 50th birthday. What would you like to do? It looks like you've had some health problems caused by heroin use, and your family is really worried. You've been starting to consider going to the local clinic and getting some help.
Informing and asking permission to provide information to assist the patient with their choices	We've been discussing the some of the issues around alcohol use for you. Do you mind if I add an issue we haven't talked about that I'm concerned about? As you know, your mother has had breast cancer. It's become clear that drinking alcohol increases the risk of breast cancer. I'm wondering if you know about or have thought about this? You've tried stopping smoking lots of times, and each time you've gone back to it. Would you like me to talk about some of the new medications that might be helpful?

Source: Rollnick et al., 2010.

Informing While respecting the patients' autonomy to make their own decisions, health practitioners have expertise and knowledge that can be shared to help the patients. This is a legitimate part of guiding, which differentiates MI from a non-directive counseling style where the counselor does not seek to influence the behavior. It is the role of health practitioners to help patients improve their health and therefore provide advice with permission. For examples, see Tables 19.2 and 19.3.

MI with GRACE

Another useful acronym, which is easy to remember and which provides some strategies for use during the consultation, is GRACE (Kraybill, 2003).

G – *G*enerate a gap – As previously noted, motivation for change happens when people perceive a discrepancy between where they are and where they want to be (Miller, 1995). The practitioner asks questions to explore values and goals and the view of the current situation, in order to reflect back the divergence between what is desired and what is the current situation. For example, a person may value being healthy or being supportive to the family, but finds the current drug use to be inconsistent with these values. Gently raising awareness of this inconsistency can move the person toward change.

R – *R*oll with resistance – If the individual perceives a threat (e.g., forceful instructions from the practitioner, such as "You really should give up smoking today"), a natural defensiveness can ensue, which raises resistance. If this situation is handled poorly, the end results are protective coping strategies that reduce the discomfort but do not alter behavior. Rather than fighting resistance, the practitioner in MI "rolls with" the momentum, viewing ambivalence as normal and exploring it openly. Momentum can be used to the consultation's advantage with a goal of shifting perceptions in the process (Miller, 1995) – for example, "Oh no, you're not going to have a go about my smoking again!" can be met with "Has someone been giving you a hard time over it? Why's that? What are they worried about? What do you think of that?" These questions can evoke consideration of and reasons toward change from the individual.

A – *A*void arguing – It should be the individual and not the practitioner who voices the reasons for change (Miller & Rollnick, 1991). The goal in MI is to encourage patients to hear themselves say why they want to change. If the practitioner is perceived as challenging the patient's position and not listening, then the patient will work harder to try to convince the practitioner of the reasons for not changing. These arguments are consolidated in the patient's mind, and resistance to change is increased. Avoid the "yes, but . . ." arguments where you argue for and the individual argues against change. Instead try "It sounds like you don't want to go there. What would you like to do?" or "It sounds like my ideas aren't working. Do you have any ideas?" It is better to move on than to argue.

Table 19.3 An example of a MI consultation which embodies the three guiding skills.

Person	*Conversation*	*Guiding skill*
Practitioner	Hello Jane, thanks for coming back for a check up. It looks like you've gotten over your pneumonia.	
Patient	I feel great now. I took all my antibiotics and even stopped smoking temporarily.	
Practitioner	Yes, that's good news. Is it OK if we talk about your smoking?	Asking
Patient	OK. What do you want to know?	
Practitioner	Well, as you know it's part of my job to help you look after your health. What do you already know about smoking?	Asking
Patient	Well, everyone knows that smoking is bad for you. I've tried a few times to stop. It's not easy.	
Practitioner	So you are aware that smoking can be harmful but haven't found it easy to stop.	Listening
Patient	Well, yes, there's so much information out there about smoking. You can get lung cancer and emphysema.	
Practitioner	Yes, those are pretty scary things to have.	Listening
Patient	It's not that I don't want to stop, but it's not easy. When I go to the club with friends, I end up having a cigarette with a drink. I guess old habits are hard to give up.	
Practitioner	It sounds like you want to stop smoking. I guess it's hard not to smoke when your friends smoke too. Tell me about where else you smoke.	Listening Asking
Patient	I never smoke when I'm around my kids. James has bad asthma, and I know it's just not healthy for him.	
Practitioner	So, when you have a good reason, you can be strong and not smoke.	Listening
Patient	Yes, that's right.	
Practitioner	You're well aware of the harms of smoking, and you've been able to reduce the impact on your family. Did you know that smoking might have made you more susceptible to pneumonia?	Listening Informing
Patient	I sort of suspected that. I really don't want to go through being as sick as I have been again.	
Practitioner	Yes, you were almost hospitalized. Would you like to talk about ways you can quit smoking?	Informing Asking

C – Can do – Even if a person is convinced of a need to change they will not move toward change without self-efficacy (the belief that they can succeed) (Bandura, 1982). Without self-efficacy, this discrepancy is likely to result in defensive coping mechanisms (e.g., rationalization, denial, procrastination) in order to reduce discomfort instead of achieving behavior change (Miller, 1995). The practitioner takes opportunities to affirm strengths and encourage hope and confidence.

E – *E*xpress empathy – This is about listening and communicating acceptance, understanding ambivalence and communicating respect for the individual's decisions (Miller, 1995). Tools used in the process of active listening include open-ended questions, affirmations, reflective listening, and the use of summaries. See Table 19.4 for examples of these.

Putting it together – eliciting "change talk" in a clinical consultation

The following dialogue is an example of raising the topic, eliciting change talk, and ending with an action question.

The patient starts by defending his choices and offering reasons for not changing. The practitioner does not engage in a debate on this, instead keeping the conversation focused on behavior change. The practitioner acknowledges the patient's reluctance to change but does not agree with it. Using a combination of open-ended questions, reflective listening, and the spirit of MI, commitment statements are elicited at the end of the session (see Table 19.4).

Figure 19.2 is a diagrammatic representation of the dialogue that occurs typically in most MI consultations.

There are many other acronyms and tools that have been developed to facilitate the use of MI. The number of tools reflects how MI has flourished across the globe. Each practitioner can choose from a wide variety. We have not listed them all as the list would be extensive and there is an overlap between them. However, one deserves a mention as it is so commonly associated with brief MI interventions. FRAMES (Feedback, Responsibility, Advice, Menu, Empathy, and Self-Efficacy) are six elements proposed by Miller and Sanchez (1993). More information can be found at http://www.motivationalinterview.org.

Finishing the consultation on good terms

You have almost come to the end of the consultation, and you want to end on good terms. This is important, as patients remember both the good and not-so good-encounters. The path you take when you reach the fork in the road depends on the patient's response to a key question such as "Where does this leave you now?" (Miller & Rollnick, 2002). There are broadly two types of responses (Dunn & Rollnick, 2003).

Responses that indicate moving into discussing action:

- I'm determined to make a change now (strong commitment).
- Well, I don't know. I'm not sure about that but I'll think about that (less commitment, but open to discussion).

Table 19.4 Putting it together: The spirit of MI, GRACE, the three guiding skills and change talk.

Person	*Conversation*	*Component*
Practitioner	Hi Mike, I've been sent a hospital report about you. I see you've had some surgery recently.	
Patient	Yeah, well, I was in a car accident and broke my arm.	
Practitioner	I'm glad it wasn't more serious.	Express empathy
Patient	Me too!	
Practitioner	What happened?	Asking
Patient	It wasn't my fault. Another car just pulled out in front of me.	
Practitioner	The report also says that you were drinking.	Informing Generate a gap
Patient	Well, yes, I just had a few beers.	
Practitioner	So, the alcohol didn't have anything to do with the accident?	Asking Avoid arguing
Patient	No way, it was the other guy! I don't have a drinking problem Doc.	
Practitioner	Well, the doctors at the hospital found out that alcohol has caused some problems to your liver.	Generate a gap
Patient	Yeah, they told me about that. But I don't know how that can be. I don't drink that much.	
Practitioner	What do you think was going on with the blood tests?	Asking Avoid arguing
Patient	OK, I admit I might drink a bit more than the average person some days. But my friends are all the same.	
Practitioner	You're pretty confident that you don't have a problem with alcohol.	Listen Roll with resistance
Patient	That's right. I've never blacked out.	
Practitioner	So, the way you see it, as long as you never blacked out from drinking, it means that alcohol's not causing any problems.	Listen Avoid arguing
Patient	Well, not exactly. I mean I guess I drink a bit but it's not that bad. I've got my drinking under control . . . most of the time.	
Practitioner	What about the rest of the time?	Asking
Patient	I guess sometimes I know I've done some stupid things when I've had too many.	
Practitioner	Can we talk about that?	Honoring autonomy
Patient	No, I'm fine. I'm just like anyone else.	
Practitioner	That may be so, but I'm worried all the same with what's happened to you. The car accident, the broken arm, and the liver.	Generate a gap Informing
Patient	Just bad luck, I guess.	

Table 19.4 (*Continued*)

Person	*Conversation*	*Component*
Practitioner	Are you sure?	Asking Generate a gap
Patient	I didn't mean to drink that much at the club that night, but you know . . . when you're with your friends and having a good time . . .	
Practitioner	Yeah, it's easy to lose count of the number of drinks.	Express empathy Listening
Patient	Yeah.	
Practitioner	Let me ask you this. How important is it for you to be healthy? Say, on a scale of 1 to 10, with 10 being very important.	Asking Generate a gap
Patient	Definitely a 10.	
Practitioner	That's at the top of the scale. Why so high?	Asking
Patient	Well, I want to be healthy, so I can see my daughter graduate college.	Reason to change
Practitioner	How old is she now?	Listening
Patient	She'll be 5 next week. Here's a photo.	Reason to change
Practitioner	She's gorgeous. She's worth being healthy for. Mike, do you mind if I tell you something about what's happened?	Express empathy Honoring autonomy
Patient	Sure.	
Practitioner	Since your liver tests are abnormal, you're lucky enough to be getting a warning sign now. Even if you didn't cause the accident, maybe if you hadn't been drinking you might have been able to react quicker and get out of the way.	Informing Generate a gap
Patient	You're right. I've been thinking that too.	Reason to change
Practitioner	So, where does this all leave you now? What will you do?	Honoring autonomy
Patient	I guess I don't have to drink that much. It's just an excuse to be stupid when I'm out with the guys. It's not like I drink every day. It would save a few dollars too.	Ability to change
Practitioner	Sounds to me that cutting back might help your finances.	Generate a gap
Patient	Definitely. Times are tough at the moment, and every cent counts.	Reason to change
Practitioner	If you wanted to succeed how would you go about making this change?	"Can do" attitude
Patient	I just need to do it, just say I'm not going to drink. I can. I just needed a reason to do it.	Ability to change
Practitioner	And now you have it. How would you feel about coming back to follow up on your liver health?	Honoring autonomy

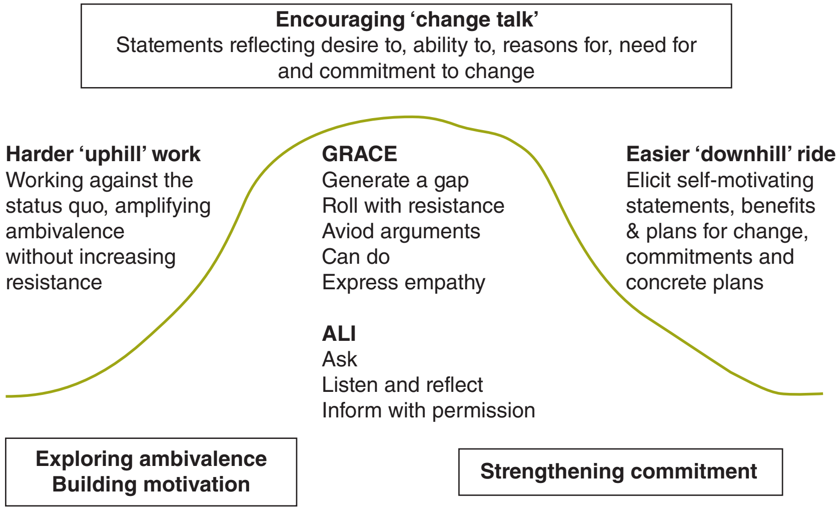

Figure 19.2 Climbing the change mountain (adapted from Justice System Assessment and Training; n.d., last modified 2006).

Responses that indicate that the patient is not ready:

- Thanks for your concern, but no, that's not for me.
- It's just not a problem at the moment.

So that you can both feel good about the consultation, it is good to reach an agreement. This is called *closing on good terms* (Dunn & Rollnick, 2003). Possible outcomes might include:

- Agreeing to monitor the behavior
- Agreeing to think about it
- Agreeing to review the behavior at a future time
- Agreeing that the patient does not want to change at present

Although the last point may make the consultation feel futile, it sometimes is the endpoint on that day. There may be future opportunities to continue the conversation. It is important that the patient be involved in the decision-making process, whether that leads to change or not. There is a considerable body of evidence which shows that patient-centered or relationship-centered consultations can make a difference to health, ranging from better adherence to prescriptions to better control of chronic illnesses (Cooper et al., 2011; Sibille et al., 2010; Stewart et al., 2000). Studies have also shown better patient satisfaction and less malpractice litigation (Forster et al., 2002; Levinson et al., 1997). In some situations, the practitioner will have to agree that the patient does not want to change, in order to create a strong partnership for future encounters.

The Evidence for MI

MI has been applied to many aspects of behavior change, ranging from lifestyle and drug use to self-destructive behaviors involving the law. These include alcohol and drug dependence, smoking cessation, weight loss, physical activity, the treatment of asthma and diabetes, adherence to treatment and follow-up, and criminal activity (Miller & Rose, 2009; Lundahl & Burke, 2009; Rubak et al., 2005).

A systematic review and meta-analysis of randomized controlled trials using MI as the intervention found that an effect was demonstrated in 74% of the trials (Rubak et al., 2005). The number of encounters and length of follow-up were more important than the length of each encounter, with 64% of studies in the meta-analysis using brief encounters of 15 minutes being effective. Both psychologists and physicians obtained an effect in 80% of the studies (Rubak et al., 2005).

The efficacy of MI has varied among trials, among clinical issues to which it has been applied, among populations, and among practitioners (Miller & Rose, 2009). There have been clinical trials where MI has had a positive effect in helping diabetic patients improve their glycemic control (Chen, Creedy, Lin, & Wollin, 2012; Channon et al., 2007); reduce alcohol, smoking, and other drug use (McCambridge & Strang, 2004; Hettema & Hendricks, 2010; Colby et al., 2012); and improve diet and exercise (Martins & McNeil, 2009). MI has been found to be less effective in the domains of smoking cessation and HIV risk behaviors (Burke et al., 2003). Other meta-analyses found that relying solely on group-delivered MI appears to be less effective than one-on-one MI (Lundahl & Burke, 2009). In a trial comparing family physicians who were randomized to MI training or not, family physicians who were trained in MI evaluated it to be more effective and no more time-consuming than “traditional advice giving” (Rubak et al., 2006).

There is a growing evidence base for MI, with more than 200 randomized clinical trials to date (Miller & Rollnick, 2012). There are theories as to why MI may not be effective in certain scenarios – for example, therapist style and practice (Vansteenkiste and Sheldon, 2006; Miller & Rose, 2009). Therefore, we suggest that practitioners make informed decisions about the value and applicability of MI in their clinical work, and not view MI as a “magic bullet” or cure-all to change patient’s behaviors.

Health practitioners are usually confident in helping people who have made a decision and commitment to change. MI fills the gap in providing strategies to build motivation and strengthen commitment in those who are not yet considering change or who are uncertain about change.

Brief Motivational Interviewing

One of the common concerns expressed by health practitioners is the time taken to implement behavior change counseling. While MI was originally developed and researched in psychological therapy settings, where more time was available for patient encounters, briefer forms of MI have evolved. Rollnick et al. (1992)

Table 19.5 A menu developed to facilitate brief motivational interviewing.

1	Opening strategy: lifestyle, stresses, and substance use	• Ask about current lifestyle and stresses • Ask "Where does (the behavior) fit in?"
2	Opening strategy: health and substance use	• Ask about health • Ask "Where does (the behavior) affect your health?"
3	A typical day	• Ask about a typical day from beginning to end, "What happened? How did (the behavior) fit in?" • Acknowledge any problems raised and come back to it later
4	The good and less good things	• Ask "What are some of the good things about (the behavior)?" (To build rapport and understand) • Ask "What are the less good things about (the behavior)?"
5	Providing information	• Ask permission, "I wonder, would you be interested in knowing more about. . .?" • Ask "I wonder, what do you make of this? How does this tie in with. . .?"
6	The future and the present	• Ask "How would you like things to be different in the future?" • If future aspirations are identified, ask, "What's stopping you from doing these things now?" and, if appropriate, "How does (the behavior) affect you at the moment?"
7	Exploring concerns	• If a concern about the behavior has been identified, summarize it, and ask about other concerns until all concerns have been identified. • Summarize the benefits of and concerns about the behavior to highlight the ambivalence.
8	Decision-making	• If some desire to make a change has been expressed (usually after exploring concerns), ask "Where does that leave you now?"

Source: Rollnick et al., 1992.

developed a brief form of MI in a medical setting that took 5–15 minutes to complete within a consultation. It makes use of the ongoing relationship with the practitioner or the health service, where at a future consultation further discussion can occur. It moves between a directive and non-directive style using a menu of strategies, as outlined in Table 19.5.

Any one or two items can be selected from the menu for use within a consultation, and the selection will depend on the perceived readiness to change and the ease of introducing the topic. The items at the top of the menu can be used with almost any patient, while the ones toward the bottom will work better as patients are moving toward a greater readiness to change. For example when unsure about how someone might feel about the topic or if you have reason to think that this person may not be keen to change, items 1 or 2 on the menu might be appropriate to start the conversation. When someone has already identified, at this or a previous consultation, that they wish to change their behavior, items 7 or 8 may be more helpful to start discussing the next phase for action. Note that the strategies in this menu can be used at different points in time, at separate consultations. Any point on the menu is used to begin the discussion for that day, and reflective listening and summaries are used to work with the patient to reach an agreement at that consultation to either take action or to respect the decision not to change at that point and to pick up that conversation at another time.

Components of the menu described in the preceding text can be used in brief intervention approaches in the general healthcare setting (see Table 19.6). While

Table 19.6 Brief intervention examples using tobacco smoking.

Questions	*Rationale*
Brief: Can be used in a 5-minute discussion	
"What do you like about (your smoking or other behavior)?"	This question is unexpected as most would be expecting a long discourse about the harms of smoking. It gives an opportunity to listen and to build rapport. It also gives very valuable information that helps to understand the context of the behavior, and it may be important to consider how to replace this function if the behavior were to stop.
"What don't you like about it?"	This question is critical, as it draws out the internal motivation for change.
If appropriate, you can add your own concerns	If you believe that adding your own concerns about the behavior might help tip the balance toward change and not increase resistance, this can be done.
Summarize "So you like . . . but you don't like . . ., so where does that leave you?"	It is up to the patient to decide what needs to be done.
Summarize, agree on a plan	Aim to get commitment to a plan that might range from action to change, an agreement to return to discuss further, or an agreement for the issue to be raised again later.
Brief: The following questions can be used within a 1–2-minute discussion if the topic has already been raised and a willingness to discuss it has been signaled.	
"On a scale of 1–10, where 10 is a lot, how much do you want to (make the change)?"	The patient will usually pick a number that is higher than 2. Regardless of the answer, you can usually ask the next question. If the answer is 2 you can ask, "Why so high, why is it not 1?"
"Why so high?"	The patient then tells you why (s)he wants to change, i.e., argues for change
"So what do you want to do about it?"	The patient then states how to move toward change. Again, aim to get a commitment to a plan that might range from action to change, an agreement to return to discuss further, or an agreement for the issue to be raised again later.

these are not examples of MI, they show how MI can influence the conversations that take place in day-to-day interactions in general medicine, chronic disease management, dental care, and many other areas of health. The attitude of collaboration, respect and listening, the questions used in MI that evoke the patient's own call for change, and the gentle direction toward change while respecting the patient's autonomy have much to contribute to improving our effectiveness and communication.

Conclusion

In this chapter, we have provided an overview of motivational interviewing. As Miller and Rollnick (2009) admit, MI is widely used in so many fields that new therapeutic adaptations and understandings have come into existence. While MI practice across the globe is now diverse, the consistent core elements of MI are about establishing a suitable climate for change by promoting the patient's control over the decision-making process. MI is more about listening than telling, evoking rather than directing, and communicates that "You have what you need, and together we will find it" (Hettema et al., 2005).

This chapter has provided you some background in MI but cannot develop proficiency. To do this, we encourage you to find more information at http://www.motivationalinterview.org, attend courses, and actively seek out colleagues who practice MI to develop your skills.

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20

Ecological Momentary Assessment in Behavioral Medicine

Research and Practice

Megan L. Robbins and Thomas Kubiak

Introduction

The goal of behavioral medicine is to promote "the study of the interactions of behavior with biology and the environment, and the application of that knowledge to improve the health and well-being of individuals, families, communities and populations" (Society of Behavioral Medicine, 2010). To study such complex interactions, an equally sophisticated research approach is warranted. Exclusively studying participants' behavior, biology, and well-being in a laboratory or via participants' retrospective reports excludes a central component of behavioral medicine: the real-life context of the environment. To thoroughly study how psychosocial processes influence and are influenced by health, researchers should consider using Ecological Momentary Assessment as part of their program of research (EMA; Smyth & Stone, 2003; Stone & Shiffman, 1994; Stone, Shiffman, Atienza, & Nebeling, 2007).

EMA is a framework for assessing momentary self-reports in situ, typically implemented as *electronic diaries* on a handheld computer or smartphone (Kubiak & Krog, 2012), with the goal to obtain ecologically valid, real-life data. As such, it enables researchers to study these processes in context, optimizing the chance that interventions based on this knowledge will be effective when employed in people's daily lives. Overlooking this step can jeopardize the translation of research into practice. For example, in cancer coping literature, studies consistently find that the quality of social relationships matters greatly to adjustment and physical health, but social support interventions based on this knowledge are relatively less effective (Coyne, Stefanek, & Palmer, 2007; Helgeson & Cohen, 1996). Therefore, using a

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more naturalistic approach is necessary to "determine the kind of naturally-occurring support and support intervention that should influence these mechanisms" (p. 144; Helgeson & Cohen, 1996). EMA can help bridge such gaps between research and the design of effective interventions in behavioral medicine.

The implementation of EMA usually entails a signal-contingent protocol, an event-contingent protocol, or a combination of both (see Conner & Lehman, 2012). *Signal-contingent sampling schemes* are among the most frequently used: Participants are "beeped" at several (random) times a day to complete an electronic diary record. While signal-contingent sampling is most suitable to obtain representative daily life self-reports on psychological variables, such as symptoms or well-being, it is less suitable to capture less frequent events, such as whether a participant is actively engaging in certain health behaviors. For obtaining the latter kind of data, *event-contingent sampling* is used. For this type of sampling, participants are instructed to complete diary entries themselves whenever the event of interest occurs (Moskowitz & Sadikaj, 2012). For example, participants can complete diary entries whenever they engage in binge eating (Stein & Corte, 2003) or smoke a cigarette (Moghaddam & Ferguson, 2007). Modern software platforms for EMA also allow protocols that go beyond self-report only. For instance, cognitive tests can be included (Kubiak & Krog, 2012). Online analysis of the records entered into the diary offer new possibilities for sophisticated adaptive sampling schemes where question and sampling patterns change depending on what patients entered on previous occasions (see Siewert et al., 2011, for an example).

A brief history of EMA in behavioral medicine

The concept of studying participants in their natural context is not novel, but is still underutilized (Conner, Tennen, Fleeson, & Feldman Barrett, 2009). Some of the very first studies collected participants' reports of their momentary experiences, such as symptoms and behaviors (Favill & Rennick, 1924), mood (Flügel, 1925), and laughter (Kambouropoulou, 1926) over the course of several days or weeks. These methods developed through various disciplines, and therefore under different labels, such as experience sampling, daily diary assessment, and other, domain-specific approaches. Experience sampling was originally developed to capture representative momentary experiences by random signal-contingent sampling throughout participants' days or weeks (Hektner, Schmidt, & Csikszentmihalyi, 2007). Daily diaries, on the other hand, tend to require participants to report their experiences once per day, typically at the end of each day over the study period (Bolger, Davis, & Rafaeli, 2003; Conner et al., 2009).

In a similar vein, the Rochester Interaction Record (RIR) was developed as a domain-specific assessment tool to answer basic questions surrounding the small, mundane social interactions that comprise most of daily life (Reis & Wheeler, 1991; Wheeler & Nezlek, 1977). The RIR originally required participants to complete information about the quality of every social interaction that day lasting 10 minutes or longer (Reis, Nezlek, & Wheeler, 1980; Wheeler & Nezlek, 1977). This was first done as a daily diary method, in which participants responded at the end of each day, but now is more commonly used in real time, as an event-based sampling method where participants complete the measures as soon as possible after an event of interest (e.g., ostracism; Nezlek, Wesselmann, Wheeler, & Williams, 2012).

EMA and Other Methods of Ambulatory Assessment in Behavioral Medicine

Momentary reports are not the only type of methods that can be employed to understand how human experience, states, and behavior unfold and interact in their natural context. The overarching notion of *Ambulatory Assessment* developed from a psychophysiological and behavioral perspective, encompassing not only momentary self-reports but also methods that monitor cardiovascular activity during strenuous work, environmental triggers of psychological symptoms, or behavioral disorders manifested in daily life that do not require participants' reports (Fahrenberg, 1996). Combining EMA with other methods of Ambulatory Assessment, such as physiology and/or behavior, raises interesting and important possibilities for the study of behavioral medicine (Kubiak & Stone, 2012). Analyzing such rich data sets that combine different levels of interest (experience, physiology, behavior, context) offer the opportunity to disentangle (causal) relationships across levels. This is of particular importance when studying disorders relevant to behavioral medicine, as they usually manifest themselves on different levels. With the capabilities of today's technology for real-time analysis of physiological signals and EMA data, adaptive EMA schemes (also labeled *adaptive monitoring*, cf. Siewert, Kubiak, Jonas, & Weber, 2011, or interactive monitoring, cf. Ebner-Priemer, Koudela, Mutz, & Kanning, 2012) have become feasible where, for example, the physiological signal triggers EMA beeps, making it easy to capture episodes of interest. Table 20.1 summarizes key features of EMA and other methods of Ambulatory Assessment that can be combined with momentary self-reports to answer specific research questions.

Physiological monitoring. The first attempts at ambulatory physiological monitoring yielded electrocardiogram (ECG) devices that were substantially large in size and weight (Fuller & Gordon, 1948; Holter & Gengerelli, 1949). Since this essentially prohibited the study of physiology in *normal* daily life, they were soon replaced by more practical, lightweight methods (Holter, 1961; Wilhelm, Perrez, & Pawlik, 2012). Though some were obtrusive, these first studies laid the foundation for researchers to understand behavioral medicine in context. For example, endocrinological studies in daily life typically use salivettes, which are a fairly easy-to-use

Table 20.1 Ecological momentary assessment and other approaches of ambulatory assessment.

	Domain			
	Subjective experience	*Physiological processes*	*Social behavior*	*Physical activity*
Examples of target variables	Momentary affect, satisfaction with social interactions; pain	Heart rate, tidal respiratory volume, salivary cortisol levels	Number and quality of social interactions	Exercise frequency and intensity, sleep quality
Methodological approach	EMA	Ambulatory monitoring	Naturalistic observation	Activity monitoring
Examples of technical solutions	(Electronic) diary, Rochester Interaction Record	Multimodal physiological monitoring systems portable ECG; salivettes	The EAR; Passive Telemetric Monitoring	Pedometer; Actiwatch
Burden for participant	Intrusiveness, interruption of daily life	Interruption of daily life, burden of the size of device	Intrusion of privacy	Minimal, depending on the size of device
Burden for researcher	Instructing and training participants	Instructing and training participants; financial cost	Coding and transcribing sound data (EAR)	Financial cost
Reference	Stone et al. (2007)	Ebner-Priemer & Kubiak (2007)	Mehl et al. (2012); Goodwin et al. (2008)	Ebner-Priemer & Bussmann (2012)

method for participants to provide saliva samples throughout their day, in order to assess hormones such as cortisol (Schlotz, 2012). Combined with EMA, these methods yield data about how physiology changes within and in response to people's natural environments, providing critical information about real health risk factors in daily life. Furthermore, physiological signals, such as an increase in heart rate or an increase in physical activity, may also serve as a trigger to prompt patients completing a momentary self-report (Ebner-Priemer et al., 2012; Myrtek & Foerster, 2001). Disadvantages to this type of method include the cost of assays and of more elaborate monitoring devices. Further, methods that require participants to interrupt their daily life (e.g., to provide a saliva sample) can be burdensome for participants. Though these costs should be seriously considered when deciding whether and how to employ physiological EMA methods in one's own research, the benefits of the knowledge gained by using them often outweigh them (e.g., Bhattacharyya et al., 2008).

Monitoring of social behavior and context. Researchers often want to know about the objective aspects of social environments or automatic behaviors that participants cannot report. Behavioral observation was first used among researchers who did not trust self-reports or the constraints of in-lab observation to accurately capture behavior (Mehl, Gosling, & Pennebaker, 2006; Stone et al., 2007). Barker and Wright (1951) employed a research team to record everything a 7-year-old boy did for one 14-hour day, simply to study his behavior in its natural context. Similarly, one study had a female researcher live with three breastfeeding women for 2 days every month for 1 year to record their food weight and milk secretion, as well as take notes on their home activities and emotional reactions (Hunscher, Vincent, & Macy, 1930; Wilhelm et al., 2012). Naturalistic observation, in conjunction with EMA, can be used to measure the discrepancy between objective aspects of social environments, such as actual support received, and participants' perceptions of support received, which can yield meaningful information relevant to coping outcomes (Bolger, Zuckerman, & Kessler, 2000). This method allows researchers to study social environments without being filtered through participants' perceptions. It is also optimized for the assessment of automatic behaviors such as language use. Observation is necessary because participants can only report what they notice and remember, which necessarily excludes automatic behaviors that can be coping-relevant (e.g., swearing; Robbins et al., 2011; sighing; Robbins, Mehl, Holleran, & Kasle, 2011). The electronically activated recorder (EAR) is one naturalistic observation method that records snippets of ambient sounds as people carry out their normal, daily life (Mehl et al., 2001; Mehl & Robbins, 2012). As an unobtrusive device that clips to participants' waistline, the EAR captures an acoustic sample of uninterrupted social life. The EAR, however, is not without its limitations. Though there is essentially no practical burden for participants (i.e., no measures to complete and the device is lightweight), it does create a potential psychological burden for them (Mehl, Robbins, & große Deters, 2012). Because it records snippets of ambient sounds in daily life, privacy is a central concern. For this reason, all EAR participants have the chance to review and delete any sound files they do not want researchers to hear, before any research personnel listens to them. This ensures that participants only provide the information they would like to share with study personnel. For researchers, on the other hand, most of the burden of naturalistic observation methods lies in processing many hours of data. However, this burden does not greatly differ from the coding and/or transcribing that is required for in-lab observation data processing (e.g., Heyman, 2004).

Activity monitoring. Activity monitoring in natural settings can assess health behaviors such as exercise frequency and sleep quality, yielding important information about their association with quality of life, health risks, and clinical endpoints including mortality. Assessing these behaviors via EMA methods is critical to accurate measurement. Across several studies, discrepancies between self-reported and activity-monitored movement range from 44% to 138% (Bussmann & Ebner-Priemer, 2012). These discrepancies are consistently found across age groups. Both parent-reported activity of children and seniors' reports of the amount of walking fail to show an association with objective assessments of physical activity. Examples of activity monitoring include pedometers, which count the number of steps taken, and wrist actigraphy (e.g., Actiwatch, Philips Healthcare, Eindhoven, Netherlands), which also provide data about movement, but include its intensity. For example, actigraphy has been able to distinguish the motor activity patterns of depressed versus non-depressed participants, where depressed participants engaged in lower motor activity levels during the day, but higher activity levels while sleeping, compared to non-depressed participants (Volkers et al., 2003). In addition to yielding clinically relevant, accurate data, activity monitoring places little to no burden on participants. Most devices are very small and lightweight, allowing participants to carry out their normal, daily lives during monitoring periods. The burden to researchers, however, can be substantial financial cost, depending on the method used (e.g., pedometers are fairly inexpensive, but wrist actigraphy can at times be more costly).

Advantages and Disadvantages of the EMA Approach

To achieve the goal of behavioral medicine, and to improve health and well-being by applying knowledge of psychosocial influences on health, these processes must be studied within the same context to which they will later be applied: people's normal, daily life. There are several methodological and conceptual advantages to using EMA in behavioral medicine. The basic methodological rationale for EMA is threefold, according to Stone and colleagues (2007): (1) to avoid memory problems and bias associated with retrospective self-reports, (2) to achieve ecological validity, and (3) to enable the study of dynamic processes over time, within persons. Conceptually, EMA allows researchers to include discovery-oriented, in addition to theory-driven, studies in their program of research (Lewin, 1951; Reis, 2012).

A large body of evidence supports the idea that "memory is reconstructive and recall is heuristic" (Stone et al., 2007, p. 6). Problems with memory can introduce systematic, rather than random, bias in data because people use estimation strategies and lay theories about "what must have been" to report the frequency and intensity of their states and behavior (Schwarz, 2007; 2012). Use of lay theories is supported by research finding that predicted and remembered feelings are strongly related, but that both types of reports differ from assessments done in real time. For example, patients are prone to reporting that their past condition was worse than their present condition, regardless of whether or not they have improved (e.g., chronic pain; Linton & Melin, 1982). This means that using retrospective patient reports of intervention efficacy can artificially inflate results, seriously altering conclusions that the behavioral medicine community may make about such interventions.

Another common source of bias is the excessive influence of recent and salient events on current reports (Stone et al., 2007). For example, Cohen and colleagues (1988) found that induced mood affects participants' reports of negative life events and levels of social support. This finding challenges conclusions from past retrospective self-report studies of the effects of social support on stress. In studies exclusively employing retrospective self-report methods, shared method variance may account for the majority of the relationship between predictors and outcomes. Collecting momentary reports or observations of phenomena in real time drastically reduces, and, in some cases, eliminates, this concern, bypassing the biases associated with using retrospective self-reports.

In-lab observational or experimental methods also eliminate problems with memory and bias, but do share some of the same ecological validity challenges as retrospective self-reports. Ecological validity is the extent to which a study represents the conditions under which a phenomenon occurs in the "real world." Brunswik (1956) advocated "representativeness" in sampling both participants *and* contexts for studies' results to be maximally generalizable. Indeed, a substantial body of evidence has revealed that what happens in a controlled, laboratory setting may not occur over the course of normal, daily life. For example, "white coat hypertension," where patients' blood pressure is higher in a doctor's office compared to ambulatory assessments in their natural setting (Pickering et al., 1988), is a well-known phenomenon. Similarly, Smyth and Stone (2003) explain that there is "surprisingly weak" concordance between in-lab and naturalistic studies of endocrine reactivity (p. 39). They point out that studies of plasma and urine catecholamine responses and cortisol responses to stressors in the laboratory do not mirror those found in EMA studies of stressors in real life. Conner and Barrett (2012) further explicate this point by discussing evidence that physiological processes (e.g., acute autonomic, hormonal, or immune responses) are more closely linked with people's experiences, rather than traits, which underlies the stronger association between bodily processes and EMA measures of psychosocial processes, compared to findings from retrospective reports. Clearly, context can influence important health markers, and therefore ecological validity should be given serious consideration in behavioral medicine research.

EMA facilitates measurement of experiences and states to allow examination of how these processes unfold over time in a natural setting (Stone et al., 2007). For instance, studies of the relationship between psychosocial processes and health often acknowledge that these factors likely influence each other in a dynamic process (e.g., the biopsychosocial model; Engel, 1980), but only EMA designs allow the empirical study of processes that occur in such close temporal proximity to one another. One study underscoring this assertion found that daily measures of affect, but not aggregate measures of depression, predicted heart rate variability among people with coronary artery disease (Bhattacharyya, Whitehead, Rakhit, & Steptoe, 2008). Another striking example was demonstrated in two studies of cardiovascular patients who underwent ambulatory ECG monitoring in their daily lives. The first study found that ischemic episodes in daily life, including those that were asymptomatic, predicted earlier death for patients (Gottlieb et al., 1988). The second study instructed participants to rate their emotions approximately three times per hour for 2 days, in addition to the ambulatory ECG monitoring, and revealed that negative emotions such as tension, sadness, and frustration predicted increased risk for ischemia during the subsequent hour (Gullette et al., 1997), revealing that cardiovascular patients who experience more frequent negative emotion may be at higher risk for earlier death. Together, these findings highlight the significant impact that daily life studies can make in researchers' and clinicians' understanding of biopsychosocial processes.

In addition to the various methodological reasons for employing EMA in studies of behavioral medicine, Reis (2012) discusses a long-standing conceptual rationale. Methodological pluralism (Campbell & Fiske, 1959) allows discovery-oriented and theory-driven studies to coexist in a program of research, while maximizing internal and external validity. Lewin (1951), the father of modern social psychology, also advocated field studies in order to ground psychological theories in their real-world implications. While EMA is optimized for capturing mundane events that comprise the majority of daily life and helping researchers uncover associations between behaviors, states, and environments, controlled laboratory research tests the causal direction of these associations. Because context can influence behavior, experiences, and states, it needs to be both studied with EMA *and* controlled for in laboratory studies. In other words, understanding a phenomenon in the "real world," with all its contextual components, is equally as important as isolating those components in a laboratory setting (Reis, 2012).

As one complementary part of a program of methodologically pluralistic research, EMA is not without its own difficulties. First, not all studies require EMA. Rare and important events (e.g., a wedding) and regular and frequent events (e.g., showering and other routine hygiene behaviors) within participants' awareness do not require momentary assessments (Schwarz, 2007). Likewise, if you are interested in studying people's perceptions of a general aspect of their lives (e.g., global relationship satisfaction), rather than their in-the-moment assessment of it (e.g., daily happiness in a relationship), then a retrospective report is warranted (Reis, 2012).

Second, EMA studies often place more burdens on participants. Studies using EMA methods require participants to carry a device for assessment. While most methods are designed to be as small and unobtrusive as possible, this may still result in a higher refusal rate and/or more missing data and attrition within the study. In turn, EMA studies may yield a less representative sample than traditional in-lab or survey studies, in which participants are required to complete measures on fewer occasions than in EMA studies (Barta, Tennen, & Litt, 2012).

EMA also generally requires participants to periodically interrupt their day to complete measures. Though the repeated assessment involved in ESM is an advantage to using this method, it can also be a challenge because it imposes more burden on participants. It can be inconvenient or disruptive to stop one's current activity to complete a questionnaire. For example, if ESM is employed at time-based intervals, the signal to complete the measure may interrupt a nap, a test, or an emotional conversation. Instructing participants to complete these measures does not greatly differ from instructing them to complete single-assessment, retrospective questionnaires, but because many ESM studies employ handheld computerized devices, participants will have to be familiarized with them (Hektner et al., 2007). This will be increasingly less of a problem, however, as technology becomes a more common part of people's lives.

Momentary self-report methods also share a few of the problems associated with retrospective self-reports. Problems with recall and social desirability are greatly reduced when assessed in-the-moment, but can still occur. Further, reactivity is a problem in which the assessment itself influences behavior or states (Gunthert & Wenze, 2012; Kazdin, 1974). Some of these problems can be remedied using momentary observational (e.g., the EAR; Mehl, Pennebaker, Crow, Dabbs, & Price, 2001) or physiological assessments (e.g., ambulatory monitoring of heart rate) in conjunction with EMA, but certainly no single method eliminates all potential challenges.

Finally, EMA yields "rich," complex data, especially if one employs sophisticated sampling schemes or opts for multimodal monitoring and combines EMA with other Ambulatory Assessment approaches such as physiological monitoring. However, in the past decades, data analytical approaches have evolved that are apt to tackle the complications with analyzing EMA statistically. These include, among others, multilevel analyses and mixed models (Nezlek, 2012), evolving standards for momentary self-report psychometrics (Shrout & Lane, 2012), or analytical rationales building on time series that may prove to be particularly useful for single-case analyses in a clinical context (Rosmalen et al., 2012).

In summary, EMA methods introduce solutions to long-standing problems with laboratory and retrospective self-report methods, in many cases, allowing more accurate assessments of health-relevant constructs. However, no single method is flawless, and therefore the most optimal use of EMA methods may be to include it in a program of methodologically pluralistic research.

EMA in Behavioral Medical Practice

Essentially, EMA is related to diary approaches, which have been a cornerstone in behavioral medical treatment from the very beginning (Ferguson & Taylor, 1980). Diary approaches have been important tools in the treatment of many relevant somatic diseases, such as pain, asthma (National Heart, Lung and Blood Institute, 2012; see chapter 35), or diabetes mellitus (American Diabetes Association, 2012; see Chapter 36): Patients record self-care-related behavior, symptoms, and situations to optimize their disease self-management. Moreover, diaries are an important source of information for healthcare professionals to assist the patient and to offer tailored advice. Besides common medical conditions, diary techniques are often used in stress management interventions (Linden, 2004) or cognitive behavioral approaches in general (Beck, 2001).

Electronic diaries and sophisticated sampling schemes offer new opportunities for practice applications that go beyond what can be achieved with conventional paper–pencil diaries. This holds for both clinical applications in one-to-one therapeutic settings and for evaluation research, where EMA now is the gold standard to assess patient-reported outcomes. In the remaining part of this chapter, we want to highlight two selected applications of EMA in behavioral medicine and outline some important recent developments.

EMA as a tool in outcome research. Patient-reported outcomes (e.g., self-reported health behavior, symptoms, well-being, health-related quality of life) play an increasingly important role in the evaluation of treatments, and ultimately in health economics and health policy with regard to decisions about reimbursement. This also pertains to outcome research related to behavioral medical interventions. Recent shifts in policies of government agencies reflect the necessity to assess patient-reported outcomes in a momentary fashion: For example, the US Food and Drug Administration (FDA) argues that patient-reported outcomes based on retrospective self-reports are likely to be of limited validity and recommends “the [patient-reported outcome] instrument use appropriate methods and techniques for enhancing the validity and reliability of retrospectively reported data (e.g., ask patients to respond based on their worst (or best) experience over the recall period or make use of a diary for data collection)” (FDA, 2009, p. 13). The FDA’s position statement specifically points toward memory biases that may hamper the validity of retrospective self-reports. At the time of this writing, outcome research still needs to adopt this policy and implement EMA-style patient-reported outcomes, particularly in behavioral medical intervention research as compared to drug evaluation trials. Exceptions, however, do exist. For example, Hermanns et al. (2007) used a symptom diary as a primary outcome for a behavioral medical intervention design to improve the perception of low blood glucose levels in people with diabetes. To take full advantage of EMA in outcome research, further issues have to be resolved pertaining to standards of EMA patient-reported outcome measures. For instance, Stone, Broderick, Schneider, and Schwartz (2012) examined momentary measures in the domain of pain with the aim of how to best use momentarily assessed pain ratings as an outcome measure. They conclude that mean pain ratings based on momentary report may not be the most suitable outcome measure for treatments as other ways of aggregating momentary reports better reflect the patients' perceived change in symptomatology.

EMA as an intervention tool. Until now, EMA has primarily been used as an assessment tool. Exact "time stamping" of records, that is, each momentary self-report is recorded together with an objective time stamp, and the option to collect data in a signal-contingent fashion are among the key advantages that EMA has compared to conventional paper–pencil diaries. Its potential benefits as a tool for intervention in behavioral medicine have yet to be explored. Self-monitoring and diary approaches are a cornerstone in the treatment of various medical conditions, not only for diagnostics but also as a component of treatment in itself. Diary techniques are highly reactive (Barta et al., 2012). While this can be considered a nuisance from a research perspective, taking a therapeutic angle, reactivity may offer benefits such as an increased focus on symptoms or improved symptom awareness in patients, in addition to potential positive effects on the patients' motivation to actively engage in self-management (cf. Kanfer & Arnold,).

EMA offers new opportunities to enhance existing diary techniques, for example, by means of online analysis of data and the implementation of feedback features. To give two examples for this augmented EMA, we want to draw on two studies – one in diabetes research, and one in the domain of emotion regulation. Online analysis of data and feedback of results may be used to improve the accuracy of symptom perception. Perceiving fluctuations in blood glucose and especially recognizing low blood glucose levels (hypoglycemia) in time is essential for people with type 1 diabetes (Cryer, 2002). EMA has been used to study symptom perceptions of low blood glucose levels in diabetes early on (e.g., Clarke et al., 1995). Going beyond the assessment-only approach, Kubiak, Hermanns, Kulzer, and Haak (unpublished data) used an enhanced electronic diary to improve the recognition of hypoglycemia in people with type 1 diabetes mellitus with impaired awareness of hypoglycemia (Graveling & Frier, 2010). Patients were "beeped" several times a day in a signal-contingent fashion for 2 weeks to complete momentary symptom reports and a simple choice reaction task implemented within the diary. Upon completing the task, they were prompted to estimate their performance and received immediate feedback on their actual performance. The underlying rationale was to help the patient notice subtle decrements in cognitive performance, which are common early signs of falling blood glucose levels. Figure 20.1 shows the trajectories of the perception of low blood glucose levels over the course of the 2-week study compared with the results from controls who also used an electronic diary without the cognitive task and feedback. The EMA intervention was associated with more accurate cognitive performance estimations (not shown) and with an improvement in the recognition of hypoglycemic events.

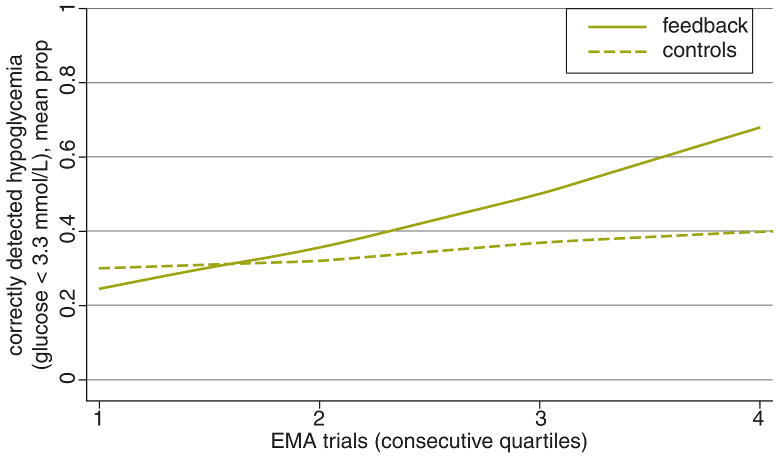

Figure 20.1 Example of an intervention building on EMA: $N = 59$ type 1 diabetes patients received cognitive performance feedback on a reaction choice task implemented within an electronic diary to improve the recognition of low blood glucose levels. Figure shows the detection of low blood glucose levels over time in this feedback group vs. controls who used EMA without feedback ($N = 69$).

A second example of EMA enhanced with an intervention component applies EMA to modify emotion regulation: Huffziger, Ebner-Priemer, Koudela, Reinhard, and Kuehner (2012) tested whether EMA can be used to induce distinct modes of emotion regulation in healthy participants focusing on functional and dysfunctional ways of ruminative thinking (cf. Watkins, 2008). They successfully instructed participants with messages displayed on the diary's screen to adopt a distanced (non-self-immersed), reflective perspective when (re)thinking about past events. This perspective is generally considered to be a more functional form of rumination as compared to rumination characterized by a high emotional involvement and self-immersion (cf. Kross, Ayduk, & Mischel, 2005). This approach may prove to be a promising tool for the prevention of depression or the modification of dysfunctional emotion regulation in other (somatic) disorders.

In a recent review, Heron and Smyth (2010) coined the term of *ecological momentary interventions* for treatment options building on EMA. They summarized several studies that document the feasibility and benefits of such an approach in fields as different as weight management, eating behaviors, or smoking cessation. With ever-improving platforms for electronic diaries, such as Internet-enabled smartphones (Kubiak & Krog, 2012), further novel options unfold by adding server-based applications or remote individual counseling and feedback in a telemedicine-like approach. First findings in this line of research are promising. For instance, Sorbi et al. (2007) successfully used mobile counseling in people with migraines where the patients completed EMA-style electronic diaries that were linked to server-based individual feedback.

Conclusions

In this chapter, we gave a brief overview on applications of EMA in behavioral medicine. EMA has evolved to become the gold standard for the assessment of in situ self-reports. This holds for self-reported symptoms or psychological variables, as well as self-reported behaviors. Recent technological developments, such as EMA implemented on smartphones, make the method much more accessible for researchers and clinicians. Combined with other sources of data, such as in situ physiological monitoring or behavioral observation via audio recordings, EMA will offer new opportunities linking self-reported experience to context. Finally, ecological momentary interventions are a promising development for clinical behavioral medicine, with its full potential and challenges yet to be fully explored.

Suggested Further Readings

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21

The Interrelationship Between Behavior Analysis and Behavioral Medicine

Nicole M. Davis and R. W. Maguire

Introduction

Behavioral medicine may be defined as the application of behavior analytic techniques to treat medical issues and influence physical symptoms that are derived from medical conditions. Behavior analysis is a science that seeks to determine functional relations between observable and measureable behavior and observable and measureable environmental events. If such a functional relation exists, then the systematic manipulation of environmental variables (i.e., antecedent, postcedent, and contextual stimuli) should result in systematic and replicable changes in the behavior of interest. Thus, the intersection of behavioral medicine and behavior analysis is manipulation of behavior–environmental relations to improve a patient's medical condition.

Since 1938, when Skinner published *The Behavior of Organisms*, the science of behavior analysis has repeatedly and conclusively demonstrated the systematic covariance between environmental events and behavior, both in the laboratory and applied settings. Although the practice of behavior analysis has a greater history in areas such as the education and rehabilitation of persons with developmental disabilities, research in a variety of diverse areas, including health behavior, has increased significantly in the past decade. Such behavior analytic contributions have included studies on eating disorders (e.g., Cameron, Maguire, & McCormick, 2011), exercise (e.g., Dittrich, 2011), smoking cessation (e.g., Dallery, Meredith, & Glenn, 2008), and addiction (e.g., Dixon, Jacobs, & Sanders, 2006). This chapter will present a brief overview of the science, describe its relevance in the area of behavioral medicine, and provide additional resources for further examination.

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Overview of Behavior Analysis

Applied behavior analysis (ABA) is the application of the principles of behavior, identified and documented in the laboratory, on behavior change that positively impacts the life of the participant (i.e., produces socially significant outcomes). To produce such outcomes, the interrelationship between environmental variables and behavior is assessed, measured, and manipulated to produce systematic changes in that behavior. The following four-term contingency explains the basics of this interrelationship

Contextual stimulus
Antecedent stimulus–behavior–consequence

If one applies this model to cigarette smoking, the following analysis emerges:

Assume the antecedent stimulus to be an actual cigarette in close proximity to the participant. Such a stimulus may reliably evoke smoking behavior (i.e., in the presence of a cigarette, smoking is evoked; in its absence, it is not), especially if the participant has not smoked a cigarette in some time. So, the passage of time since the last cigarette was smoked is a contextual variable that affects the probability of smoking behavior (e.g., if one just smoked a cigarette minutes ago, then the probability of smoking is less than if one has not smoked a cigarette for hours). Smoking behavior may be followed by a variety of reinforcing consequences (e.g., physiological pleasure, social pleasure, etc.) that increases the future probability of smoking behavior, in the presence of both the antecedent and contextual stimuli. This complete contingency can be seen in the following representation:

Contextual Stimulus: Time since last cigarette
S^D: Cigarette–R: Smoking–S^{R+}: Consequence: (accelerating effect) or punishment (decelerating effect)

Such four-term contingencies can also come under the contextual control of additional variables. For example, suppose our participant is a teenager who has a cigarette in his shirt pocket and has not smoked for hours. The cigarette should evoke smoking behavior that would then be reinforced, especially given an extended period of time between cigarettes. However, suppose he is in the presence of his parents who do not know of and do not approve of his smoking. Now, the four-term contingency comes under the control of another contextual variable (i.e., the presence/absence of parents), and a five-term contingency analysis is required. Human behavior is often under the control of multiple contextual variables simultaneously (Smyth, Barnes-Holmes, & Barnes-Holmes, 2008), which makes the analysis and treatment of human behaviors, difficult and complex, especially in the arena of medical intervention.

The use of applied behavior analytic protocols to behavioral medicine require the analysis, measurement, and manipulation of each term within the relevant contingencies to determine how they affect the behavior of interest. Thus, a thorough understanding of consequential, antecedent, and contextual stimuli is required in the analysis of health behavior.

Consequences

Consequences come in two basic types: those that accelerate behavior (i.e., reinforcers) and those that decrease behavior (i.e., punishers). Reinforcers and punishers can have their effects on responding via the addition and removal of stimuli following behavior. If behavior is reliably followed by reinforcing or punishing stimuli, then their future probability will either be accelerated or decelerated, respectively. To illustrate, when a compulsive gambler places a large amount of money on a bet and wins a larger amount of money, he/she may be more likely to make large bets in the future. In that case, the behavior has been reinforced. If the same gambler plays a new game and loses such a large amount of money that he/she does not return to that game, the behavior has been punished. It is important to note that if the person loses the money and continuously plays the game, the loss has not punished the behavior sufficiently.

Antecedents

If a reinforcer or punisher reliably follows an antecedent–behavior chain, those antecedent environmental events that reliably precede behaviors can come to evoke (i.e., control) that behavior, even in the absence of the reinforcing or punishing stimulus. For example, certain locations or people can come to evoke addictive behavior (e.g., substance abuse) because they consistently preceded the behavior-reinforcing consequence chain. When this occurs, a three-term contingency has developed, consisting of an evocative antecedent stimulus, and an evoked behavior followed by a behavior-altering consequence.

Contextual variables

As previously noted, contextual stimuli exert control over other *n*-term contingencies and impact the probability of behavior. The most common types of contextual control are satiation and deprivation. Behavior tends to happen more frequently when the individual is in a state of deprivation from some reinforcing stimulus and less frequently when the individual is in a state of satiation. Such processes, which temporarily alter the potency of a reinforcer or punisher and therefore alter behaviors that have been followed by them, are frequently referred to as *motivating* *operations* (MO) (Laraway, Snycerski, Michael, & Poling, 2003). For instance, if someone who is dieting has been deprived of food for an extended period of time, food that has made him or her feel satisfied in the past will serve as a stronger reinforcer, and behaviors that have resulted in those foods will be more likely to occur.

Unfortunately, some forms of contextual control may be difficult to measure and manipulate. This is especially true in cases that involve escape and avoidance-maintained anxiety, as some medical procedures may generate. Escaping or avoiding a medical procedure may serve as a reinforcing consequence because that behavior not only terminates the procedure itself but also the associated anxiety. Even just talking about the procedure may generate anxiety (e.g., experiential avoidance; Hayes, Wilson, Gifford, Follette, & Strosahl, 1996). If this is indeed the case, then some forms of contextual control may lie "within the skin" of the individual (Skinner, 1993), and be inaccessible to clinicians. Under these conditions, one must rely on the self-report of participants, a potentially unreliable data source under certain conditions (Midanik, 1989). In recent years, efforts have been made to apply behavioral protocols to variables that may be inaccessible, or not publically observable. As technology advances, measurement of such internal events may become more public. This may be especially true if internal events correlate with some physiological behavior that can be measured (e.g., heart rate, respiration, etc.). The important point is that, regardless of where they exist (i.e., within a person's internal or external environment), stimuli can come to affect the behavior of an individual. Only through analysis of such events can behavior analysts address behaviors that may affect the health of a patient.

Behavior Analytic Protocols in Behavioral Medicine

Given the broad scope of behavioral medicine, a comprehensive text on a behavior analytic approach exceeds the confines of this chapter. Thus, the remainder of this chapter will be devoted to reviewing seminal behavior analytic behavioral medicine literature. The intention is that, through discussion of past studies, the interrelationship between behavioral medicine and behavior analysis will become not only apparent, but also promote future investigations.

As previously indicated in this text, there are three reasons why a patient typically seeks the help of a behavioral health professional: (1) he/she is engaging in behaviors that will be harmful to his/her overall health or a given medical condition, (2) his/her behavior is negatively affecting the way he/she is feeling, and (3) he/she is seeking neutrally mediated treatment of some sort. Behavior analysts practicing in the field of behavioral medicine have addressed health behaviors related to the first two reasons. To this point, behavior analysis has not focused on neutrally mediated control. In addition to attending to behaviors directly affecting the health of patients, some behavior analytic studies have addressed preventative medicine, training self-care behavior, and enhancing the effects of other types of approaches to patient treatment. Regardless of the complexity of the behaviors targeted for change or the patient population, behavior analytic protocols have made use of the most accurate measurement systems available in order to analyze and manipulate the *n*-term contingencies affecting patient behavior.

Adherence

Perhaps the most efficacious application of behavior analysis to behavioral medicine may be adherence to medication regimes and medical protocols. Osterberg and Blaschke (2005) reported on the environmental variables impacting an individual's compliance with medication. Although they did not use the terms *contextual*, *antecedent*, and *reinforcing stimuli*, they did discuss controlling these variables to improve patient compliance. For example, contextual variables included high medication costs, the complexity of the dosing schedule, and personal psychological issues; antecedent variables included reminder and signaling systems (e.g., via cell phones); and reinforcing stimuli were variables such as physician feedback, tokens, and even monetary rewards. The behavior, adherence, was measured objectively via direct observation and blood levels, and subjectively via self-report and questionnaires. These authors noted the effectiveness of behavioral procedures on patient adherence but also cautioned that these interventions were often labor-intensive and costly.

Reiss and Bailey (1982) evaluated the effectiveness of five methods on parent's adherence to their children's follow-up dental visits. In addition to a control group, 125 families were randomly assigned to groups that utilized both antecedent- and consequence-based strategies to increase "kept" appointments. The experimenters found that multiple contacts prior to the appointment (i.e., an antecedent-based technique) and two strategies that employed a monetary consequence yielded significantly more kept visits than only giving the contact information for additional visits. Similarly, Rice and Lutzker (1984) examined the effectiveness of four treatments for compliance with appointments in a family practice medical setting. The researchers found a reduced appointment rate to be the most effective treatment to increase patients' adherence with appointments. They also found that less expensive methods (e.g., appointment cards) were ineffective antecedent-based strategies to change such patient behavior.

The most interfering barrier to patient compliance with medication may be the indirect system of measurement (e.g., patient report) that is typically used. Patients can distort, misremember, and actively conceal their non-compliance (Osterberg & Blaschke, 2005). Timers and watches, which are intended to serve as an antecedent stimulus for getting medication, have been used for over four decades. However, Azrin and Powell (1969) found that patients were more likely to adhere to their medication regime when the device also utilized the principle of reinforcement in addition to the antecedent signal. Like a watch or timer, the apparatus emitted a tone when medication was to be taken. In order to turn off the unpleasant sound, the patient turned a knob that released the pill(s) into his or her hand. The authors suggested that termination of the sound served as reinforcement for turning the knob and holding the pill evoked pill taking, not unlike the chime in car that is terminated only upon the passenger wearing the seat belt.

Chronic conditions

Behavior analysts have also studied effective methods to teach patients to manage their own health conditions. Renne and Creer (1976) developed an effective package to teach children with asthma to use an intermittent positive-pressure breathing device. The package consisted of both scripted lesson (antecedent) and reinforcement (consequences) for engagement in each of the three necessary responses. Direct measurement reported increases in the desired target behaviors and direct health benefits (e.g., increased relief of symptoms). The package was also replicated with the patients' nurses.

Similarly, McComas, Lalli, and Benavides (1999) examined the effects of behavior analytic training methods to teach independent health-management behavior. The researchers employed a chaining procedure and prompting with use of a doll to train two girls to perform a three-step intermittent self-catheterization behavior chain. Results indicated that accuracy and latency to self-catheterization improved across multiple environments for each patient.

Shapiro (2008) examined symptom and non-symptom identification of hypoglycemia for children with diabetes and their parents. He used overt behavioral symptomology (behavior) as physical correlates of internal states (hypoglycemia) that should also serve as antecedent stimuli to evoke appropriate health management. Using behavioral interventions, participants were taught to accurately identify internal states (antecedent conditions) that correlated with symptoms of hypoglycemia (behavior) and then react with appropriate medical intervention (consequence). Shapiro demonstrated an elegant manipulation of antecedent and consequence stimuli that resulted in an improvement in patients' medical conditions.

Issues of public health have also been a focus of behavior analytic research. Montesinos, Frisch, Greene, and Hamilton (1990) compared three methods to target the partner notification of persons diagnosed with sexually transmitted diseases. The researchers measured partner notification through calculating the percentage of partners who sought treatment. The control group received traditional counseling and encouragement to contact sexual partners. Infected patients in both experimental groups engaged in the same counseling as the control group and were given access to cards that could be given to partners as notification. Such occasion cards may serve as an antecedent stimulus, evoking some delivery behavior, but may also change the form of the notification itself. It is possible that patients may be more likely to send a card anonymously than engaging in some identifying behavior (e.g., a phone call). Additionally, clinic fees for patients in group two and their partner(s) were waived, contingent on the partner seeking treatment (management of a contextual variable). If the partner(s) of patients in group three did not seek treatment after 1 week, medical personnel made a follow-up phone call. Though the analysis of how the follow-up phone call affected behavior may be less clear (i.e., did the notification behavior change, or did seeking medical attention of the partner change?), the greatest percentage of partners of patients in group three sought treatment.

Likewise, Taub and colleagues (1994) suggested a behavioral approach to increase the use of impaired limbs of patients following strokes. The authors reported preliminary data suggesting that restricting use of the unimpaired limb along with initially reinforcing little use of the affected limb, and gradually increasing the degree of use needed for reinforcement, was a more effective treatment than restriction alone. In a similar study, Boyle and Greer (1983) examined the effects of contingent preferred music on the discrete movement of patients in comas. Results differed between patients; however, responding followed by music did increase significantly for one patient. Demonstrations of the effects of reinforcement on such behaviors that have seemed to be restricted by physiological variables provide grounds to further examine the contingencies surrounding similar behavior.

Eating, physical activity, and weight loss

Healthy eating behavior and increased physical activity have been discussed when addressing many different patient profiles (e.g., those with vascular headaches; Fitterling, Martin, Gramling, Cole, & Milan, 1988). Additionally, both diet and exercise have been suggested as behaviors that can prevent disease (Malnick & Kobler, 2006) and are pertinent components to a healthy lifestyle. Many behavior analytic studies have examined approaches to measuring, assessing, and changing eating and exercise behaviors. Participants in such studies have included obese children and adults, those with eating disorders, and populations targeted for prevention.

Though weight and body mass index are commonly tracked and analyzed, they are not accurate measures of eating or physical activity (Hustyi, Normand, & Larson, 2011). Likewise, patient self-report may be used when direct measures are not available, but do not provide reliable data. In a study with college students, Wysocki, Hall, Iwata, and Riordan (1979) made reinforcement contingent on not only the participant's own exercise, but also on observation of other participants' behavior. Although direct observation would yield the most accurate results, it is hardly feasible to observe an individual for their entire day. Thus, behavior analytic studies have made use of technology to provide more reliable measurement systems. Such systems have included use of pedometers (Normand, 2008) and equipment for measuring physiological changes during exercise (Dittrich, 2011).

Additionally, patient self-report has been utilized to assess potential variables that evoke and maintain binge eating (Johnson, Schlundt, Barclay, & Engler, 1993). Such studies have suggested private variables such as negative emotion to evoke bingeing. In order to develop successful interventions, determination of overt events that occasion behavior can provide guidelines for appropriate interventions. Cameron and colleagues (2011) conducted extensive assessment of context and antecedents of binge eating for a 24-year-old patient. Through descriptive assessment, the authors determined when bingeing was most likely to occur daily; most preferred tastes, textures, and temperatures of food; and what types of food created a feeling of satiation.

Successful interventions in this arena have typically included manipulation of all three variables in the four-term contingency (i.e., contextual, antecedent, consequence). Many packages have included self-monitoring, contingency contracting, some sort of goal setting, specific antecedent control, and contingent reinforcement. An early study investigated the effects of contingency contracting and deposit reinforcement on the exercising of college students (Wysocki et al., 1979). The authors contracted with students to deposit personal items that could be bought back with points earned through exercise. In addition, the participants set goals, or criterion, for the amount of exercise that would result in points. The package resulted in significantly more exercise for seven out of eight participants. Similarly, VanWormer (2004) studied the effects of self-monitoring by using a pedometer on the walking behavior of overweight adults. Though paired with a brief web-based counseling, self-monitoring of steps taken was itself shown to have an effect. All participants engaged in more walking a day, with two almost doubling the number of steps taken.

Manipulation of antecedent variables has also been evaluated in behavior analytic research of eating behavior. Based on the results of the aforementioned preference assessments, Cameron and colleagues (2011) assessed replacing foods that were shown to evoke bingeing with more nutritious and less calorically dense counterparts, in addition to extensive self-monitoring of weight, nutrition, and bingeing, The authors decelerated binge eating, increased the time between bingeing episodes, and increased exercise up to 7.5 hours per week during treatment.

Behavior analytic approaches to increasing physical activity have included similar methods. De Luca and Holborn (1992) examined the effects of reinforcement and systematically changing the criteria for reinforcement for the bicycle riding of obese and non-obese boys (the rate of pedaling behavior was gradually increased). Under the most successful reinforcement condition, two of the three obese boys engaged in rate of pedaling similar to their non-obese counterparts.

Dittrich (2011) employed a treatment package designed to increase the exercise behavior of participants in a 10-step behavioral weight loss program. The package included some previously discussed methods, including self-monitoring (VanWormer, 2004) and response shaping (De Luca & Holborn, 1992). In addition, the intervention included correspondence training via social networks. Correspondence training involved each participant posting their exercise goal daily to a private group on Twitter, engaging in the exercise, and posting the actual activity that he or she did. Results indicated a change in both direct measures of physical activity (e.g., frequency of exercise) and measures associated with exercise (e.g., strength and endurance).

Addiction

Addictive behavior has been addressed in behavior analytic literature since the late 1960s (i.e., Elliot & Tighe, 1968), and typically addresses the *n*-term contingency. Since the antecedent and reinforcing stimuli to addictive behavior is usually the addictive stimulus itself (e.g., cigarette, alcohol, slot machine), most methods for behavior change involve manipulation of these variables to minimize their influence.

Clear definitions of behaviors, systems of measurement, and parameters targeted for change become pertinent when studying effects of environmental variables on addictive behavior. Further, the behavior of interest may actually be multiple behaviors, forming a response class. For example, smoking is frequently measured as the number of cigarettes smoked in a specific time period, data routinely acquired via patient self-report. More recently, researchers have used carbon monoxide testing, and video-taped or web-cast the testing for reliability (e.g.. Dallery, Meredith, & Glenn, 2008). Other research has targeted modification of cigarette smoking behavior including not only decreasing/ceasing smoking behavior (e.g., Dallery et al., 2008) but also changing the discrete behaviors engaged in a smoking episode (e.g., decrease the rate of puffs, duration of puffs, and duration of whole cigarettes smoked; Frederiksen, Miller, & Peterson, 1977; Frederiksen & Simon, 1978).

A number of researchers have examined the effect of different consequence systems on the consuming behavior of participants with drug addictions. For example, monetary-based contingency management systems have been reported to affect addictive drug behaviors (Dallery & Raiff, 2012). Engaging in drug-related behavior results in immediate reinforcement (e.g., feelings of inebriation), while abstaining from drug use results in no immediate contingent consequences. In actuality, the aversive consequences are typically so far in the future (e.g., avoidance of disease or arrest) as to have no effect on the immediate behavior. Dense schedules of money, or some other reinforcer, provide more immediate and potent reinforcement of abstaining behavior.

McCaul, Stitzer, Bigelow, and Liebson (1984) examined the effects of such contingency management systems with patients in a methadone clinic. The researchers compared relapse behavior of one group, whose opiate-free urine tests resulted in a monetary reinforcer and positive tests resulted in a labor-intensive methadone treatment punishment protocol (i.e., experimental group), to a group with no such consequences (i.e., control). Patients in the experimental group yielded significantly more opiate-free urine tests than those with no contingent consequence. Similarly, Dallery, Shroff, Patak, and Lerass (2008) examined the effects of a web-based reinforcement system on not only smoking abstinence, but also adherence to the measurement system. Monetary reinforcement was initially delivered for providing the CO-sample, regardless of the rating. Fixed amounts of money were then delivered for rating under a set CO criterion, and faded. Although large monetary amounts were initially delivered frequently, positive results were maintained multiple days with only US$5 per day serving as the reinforcer.

In addition to direct monetary-based consequences, more cost-effective methods to consequate abstinence from drugs have been explored in the applied behavior analytic literature. Petry et al. (2005) investigated the possible reinforcing value of chance to win prizes on drug use. The authors found that cocaine and methamphetamine users in the experimental group, earning more chances to win prizes the longer they abstained, remained in treatment significantly longer and attended more counseling sessions, than those without the contingency. In another attempt to find cost-effective consequence-based methods for smoking cessation, Dallery, Meredith, and Glenn (2008) compared smoking abstinence between two groups of heavy smokers. The first group earned vouchers (i.e., to be traded in for money) for not smoking, while the experimental group deposited money prior to the study, and periods of non-smoking were followed by recoupment of their own money. Though there was no significant difference between the two groups, members of each group substantially decreased smoking behavior. As cost is a frequent complaint of reinforcement-based systems, the authors suggested that deposit systems might be a more cost-effective alternative.

An earlier study examined the use of a behavioral treatment package to decrease the caffeine drinking of three adults (Foxx & Rubinoff, 1979). In addition to a deposit monetary reinforcement system, similar to that of Dallery and colleagues (2008), the researchers employed a self-monitoring method. Immediately following caffeine intake, participants recorded the beverage name, the amount of caffeine in it, and cumulated the caffeine for the day. The participants also charted their caffeine intake on a graph, with a criterion line displaying the maximum amount of caffeine intake, in order to recoup the deposited money. Such self-monitoring techniques can be used not only to measure behavior, but also to impact the actual occurrence of behavior because of the effects of self-monitoring.

Contextual variations have also been compared to such reinforcement-based systems. For instance, Glenn and Dallery (2007) compared a similar consequence-based intervention to the use of nicotine replacement products. The theory underlying such products is that cigarettes would be less valuable in the presence of another yet different nicotine source and therefore smoking would decrease. However, the authors found that patients engaged in significantly less smoking behavior when periods of non-smoking were followed by vouchers for reinforcement than during conditions of patch wearing without contingent delivery of reinforcement. In contrast, researchers have found some consequence-based systems to be effective only with the addition of some contextual variable. For example, McCaul, Stitzer, Bigelow, and Liebson (1984) examined the effectiveness of the previously mentioned contingency management system combined with the contextual variable of methadone and then with the use of placebos in later weeks of treatment. Results indicated that the difference between experimental and control groups was not significant during the placebo phase, which suggested some level of contextual control. Analysis of the results from both studies may present an excellent example of the strength of the entire contingency, rather than control exerted from individual variables.

Other studies have demonstrated clear contextual control of multiple types of addictive behavior. To note, Dixon and colleagues (2006) examined the value of gambling behavior in different locations. The authors found that many pathological gamblers would prefer smaller amounts of money immediately than larger amounts of money further in the future, when they were surrounded by stimuli related to gambling (e.g., bars, horse racing on televisions in area). However, this did not recur in areas not previously associated with gambling (e.g., a coffee shop).

Researchers have also examined the role of contextual variables on alcohol consumption. For example, an early study looked at the effect that the drinking behavior of peer confederates had on the alcohol consumption of participants with alcoholism (Caudill & Lipscomb, 1980). In addition to the modeling of peers, the experimenters manipulated the contextual variable of location. The first experiment took place in a mock wine tasting, while the second occurred in a bar. During each experiment, the alcohol consumption of the participants was recorded during varying intervals of "heavy" or "light" drinking by the confederates. Results indicated that two of the participants' drinking positively co-varied with the consumption of the confederate (i.e., drinking less during a modeled light drinking interval and more during a heavy drinking interval) in both experimental conditions. The third participant co-varied in the bar setting, but did not during the wine-tasting scenario. This demonstrated the powerful effect that context could have on behavior. The wine (i.e., antecedent) was accessible to the same extent and the consequential effects (e.g., feelings of inebriation) were reached; however, drinking behavior changed with the drinking behavior of another person.

The complexity of the contingencies acting on health behaviors leaves room for substantial analysis of controlling variables. In practice, use of more accurate measurement systems such as change in heart rate and carbon monoxide testing may allow for not only more accurate data collection, but also interventions that focus on the healthful behavior, themselves, analysis of patient behavior response chains may become more precise as well. Continued investigation of cost-effective consequence-based treatments and effective manipulations of context may lead to very effective interventions for addiction, obesity, eating disorders, and other behaviorally addressed conditions.

The Future of Behavior Analysis in Behavioral Medicine

The majority of behavior analytic studies in behavioral medicine identified, assessed, and manipulated one or more variables in the four-term contingency. These interventions also attempted to improve the measurement of behavior by not defaulting to patient self-report. The results of these studies indicated that, if the relevant variables are specifically manipulated and a reliable measurement system is employed, then patient behavior can be positively impacted. Although this brief overview of behavior analysis and some of the contributions to behavioral medicine may seem simplistic, it has been presented in a way that clearly demonstrates the interrelationship between the two. Behaviors as complex as those that have some effect on patient health require much deeper analysis.

With more thorough analysis of overt and covert events that may affect patient behavior, new models of patient care may be developed, To give one example, in a recent book (2009), Heyman argued that addiction was voluntary choice behavior, under the control of contexts and consequences. Simply put, the choice is between an immediate reward (e.g., drug/alcohol *now*) versus the longer-term outcomes (e.g., health and financial stability) and avoidance of negative outcomes (e.g., illness, dependency). There is a tipping point, after consecutive days and weeks of abstinence, where refraining from drug use becomes the more potent and immediate reward. This model of immediate versus long-term behavioral intervention may be applied to the treatment of other behavioral medicine issues, especially adherence to medical protocols and appointments.

The overarching question becomes, if such effective models are being designed, why is there not a stronger behavior analytic presence in the behavioral medicine community? A number of factors have been proposed. First, many researchers have lamented that, although behavioral interventions may prove effective, they are time and labor intensive and costly. Add to this list the fact that these interventions often require esoteric and technical knowledge, and one can immediately see how the field would default to more general approaches, such as patient education and counseling.

Treatments are only effective if they are employed and employed correctly. If the professionals coming in contact with patients on a daily basis are not familiar with or do not acknowledge the usefulness of behavior analysis in medicine, then the use of behavior analytic protocols in medicine will be minimal.

Collaboration between the behavior analytic and medical communities is a necessary component to increase the use of effective behavior analytic treatments. Allen, Barone, and Kuhn (1993) provided some recommendations for behavior analysts to collaborate with pediatric medical professionals. Although the article was directed toward a behavior analytic audience, some of the suggestions may be bi-directional. First of all, medicine and behavior analysis are two fields with very specific vocabularies. In order to collaborate successfully, it is important that both parties communicate using common vocabulary. Since the technicality of both languages is geared toward precision, learning each other's technical jargon may be helpful. Reading and publishing in multi-disciplinary journals may be a step toward such collaboration. Ultimately, accurate communication between the behavioral medical community and the behavior analytic community will further the relationship.

Perhaps the solution is for medical facilities to hire behavior analysts to begin to practice their craft within medical settings. This would certainly address the concerns of cost-effective and technical expertise. This is what the special education field has done over the past few years, and the result has been an increase in effective services for students with disabilities as well as familiarization of general education staff with behavior analytic protocols (Cooper, 2001). Perhaps a similar approach would work for the field of behavioral medicine. In lieu of, or possibly in attempt to move toward, such a model, a number of steps need to be taken to identify and promote the most effective prevention and intervention plans for patients. This chapter has been an attempt to break down the science of behavior into simple explanations, in order to demonstrate its relevance in relation to behavioral medicine. In addition to exposing some of the effective practices demonstrated in the literature, it was meant to raise interest in such techniques. Hopefully, such steps will promote collaboration between the two communities and head toward a joint approach to changing patient health behavior.

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22

Psychological Treatment of Irritable Bowel Syndrome

Sarah E. Quinton and Laurie Keefer

Psychosocial research in gastroenterology is primarily focused on functional bowel disorders, the most common and costly of which is irritable bowel syndrome (IBS) (Spiegel, 2009; Hungin et al., 2005; Saito et al., 2002). Advances in functional neuroimaging and neuroimmunology have shifted the etiological paradigm of IBS from a psychosomatic framework to a biopsychosocial framework; this was set into motion by Drossman in 1998 (Drossman, 1998), and widely adopted by the field after the publication of the 2006 ROME Report, a diagnostic and classification system for the functional bowel disorders (Drossman, 2006). The biopsychosocial approach to IBS, centered on the complexities of the brain–gut connection, lends itself well to the use of psychological treatment for IBS.

The purpose of this chapter is to (1) provide a rationale for the use of psychological therapies in IBS based on what is now known about the pathophysiology of IBS, and (2) describe the structure, focus, and efficacy of the primary psychological interventions used to treat IBS.

Diagnosis and Burden of IBS

IBS affects approximately 10–20% of the population (Hungin et al., 2005; Saito et al., 2002) and is second only to the common cold as a cause for missed days of work (Spiegel, 2009). It is a disorder that impacts the gastrointestinal tract and is often characterized by abdominal discomfort and/or pain with accompanying diarrhea or constipation (or a combination of both) in addition to other symptoms (Remes-Troche et al., 2009). Bloating is a particular concern, with 76% of IBS patients

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Table 22.1 ROME III diagnostic criteria for IBS*

Recurrent abdominal pain or discomfort** at least 3 days/month in the last 3 months associated with *two or more* of the following:

1. Pain/discomfort improves with defecation
2. Onset of pain/discomfort associated with a change in frequency of stool
3. Onset of pain/discomfort associated with a change in form (appearance) of stool

* Criterion fulfilled for the last 3 months, with symptom onset at least 6 months prior to diagnosis

** Discomfort means an uncomfortable sensation not described as pain

In pathophysiology research and clinical trials, a pain/discomfort frequency of at least 2 days a week during screening evaluation is recommended for subject eligibility.

experiencing this symptom despite it not being included in formal diagnostic criteria (Ringel et al., 2008). Prior to the biopsychosocial approach to IBS, the diagnosis was one of exclusion, assigned only after patients had undergone a barrage of often intrusive and uncomfortable diagnostic procedures that failed to show any abnormalities or biological markers. While the American College of Gastroenterology uses the clinical criteria of abdominal pain or discomfort that occurs in association with altered bowel habits over a period of at least 3 months (Remes-Troche et al., 2009, p. S2), IBS is most often diagnosed using the ROME III criteria established in 2006 (Longstreth, 2006).

In the absence of alarm features such as bleeding, weight loss, and/or an onset after the age of 50, an individual must experience abdominal pain/discomfort that is either associated with a change in frequency and the form and/or appearance of stool and/or relieved by defecation for at least 3 months, with a symptom onset of at least 6 months prior (Longstreth et al., 2006). Classification is further broken down into predominant bowel patterns, which include constipation-predominant (IBS-C); diarrhea-predominant (IBS-D); or mixed/alternating-type (IBS-M) patterns. IBS sometimes occurs after an infection, leading to a diagnosis of post-infectious IBS (IBS-PI), a useful model for understanding the biological and psychological bases of IBS. IBS symptoms are often unpredictable, and patients may fluctuate between these subtypes throughout the course of their lifetime. Research into the prevalence of each IBS subtype has been somewhat inconclusive, although Guilera and others (2005) have credibly estimated the prevalence of IBS-D at 30.9%, IBS-C at 57–66%, and alternating type of IBS as 63%. The onset of IBS most commonly occurs prior to the age of 50, but can occur at any age. Worldwide prevalence rates remain similar across ethnic and cultural groups (Sperber, 2009) ranging from 10% to 30% of the population, although rates in South America are reported as high as 46% (Quigley et al., 2006).

Women are almost two to three times more likely to be diagnosed with IBS than men (Payne, 2004), with approximately 60% of IBS patients being female (Longstreth et al., 2006; Toner and Akman, 2000). Some studies of female IBS patients show fluctuating symptom severity with the menstrual cycle, indicating that potential hormonal differences may play a role (Heitkemper & Jarrett, 2008; Altman et al., 2006; Houghton et al., 2009). However, women are also four to five times more likely to seek medical care for their IBS symptoms than men (Payne, 2004), indicating that healthcare-seeking behavior and gender socialization may account for higher prevalence rates than true biological gender differences (Drossman et al., 2002). For example, in Pakistan, 56% of IBS patients are male, versus 44% female (Jafri, Yakoob, Jafri, Islam, & Ali, 2007). Further, prevalence of IBS diagnosis among men in the United States is on the rise, particularly among returning veterans (Tuteja et al., 2008). Given that research has indicated that sexual trauma, and trauma in general, is a risk factor for IBS (with as much as 33% of IBS patients reporting abuse histories), this increase in prevalence can be understood (Drossman, 2011).

For those with IBS, healthcare utilization is very high, in part due to a lack of effective medical treatments, and is similar to that of patients with heart disease and diabetes (Shih et al., 2002). IBS patients have higher costs for prescription medications, physician visits and outpatient visits, which Martin and colleagues (2003) found was comparable to costs incurred by asthma patients. It is estimated that, in the United States alone, IBS accounts for approximately $20–$30 billion in annual medical spending, with $1.7–$10 billion in direct costs, and $20 billion in indirect costs (Hulisz, 2004). Levy and others (2001) found a 49% increase in medical costs associated with a diagnosis of IBS, and a 2007 study (Nyrop et al., 2007) found that, on average, patients annually incurred a direct cost of $5,049 and over $400 in out-of-pocket expenses. Given the growing patient population, the costs of IBS are on the rise, and are only expected to increase (Spiegel, 2009).

Not only does IBS have a huge economic impact, but quality of life among IBS patients is also greatly impacted. IBS patients report poor health-related quality of life especially as it pertains to diet restrictions, sleep, mood, and daily activities (Longstreth et al., 2005; Groll et al., 2002; Patrick et al., 1998). Abdominal pain, bloating, and bowel difficulties are the symptoms most commonly associated with reduced quality of life, and Drossman and colleagues (2009) found that IBS patients are not only significantly troubled by these symptoms, but willing to give up 15.1 years of their lives if a treatment could completely eradicate them.

Considering the growing patient population, ever-rising healthcare costs associated with IBS, and the negative impact that IBS has on work productivity and quality of life, treatment of this illness is a complex and important issue. Standard treatment options have been largely ineffective (Schmulson et al., 2009, Camilleri and Mayer 2009), and many patients not only report a high level of dissatisfaction with their current treatment but have misperceptions about what IBS is, believing that it may even lead to other conditions such as malnutrition, colitis, and cancer (Halpert et al., 2006). By some estimates, as much as 50% of IBS patients turn to alternative medicine after unsatisfactory experiences with more traditional treatment (Shen and Nahas, 2009). In a 2006 survey of IBS patients, Halpert et al. found that IBS patients were most interested in treatment that involved information regarding dietary management (60%), medications (58%), coping strategies (56%), as well as information on the causes of IBS, and psychological factors related to IBS (55%).

Management of IBS

Many patients with IBS focus on dietary management of their symptoms, despite the fact that there are no empirically supported dietary guidelines for IBS. While research is limited, some have suggested that 40–60% of IBS patients experience some form of food intolerance (Atkinson et al., 2004), although true food allergies are uncommon (Dainese et al., 1999). Dairy, wheat, and fructose have been found to contribute to IBS symptoms in many patients (Choi et al., 2008; King et al., 1998), and it is not uncommon for patients to modify their diets to exclude or reduce some or all of these products. Research indicates that only a subset of IBS patients with lactose and fructose intolerances have benefited from dietary modifications (Ducrotté, 2007). Studies suggest that 12–67% of patients have found some benefit from an exclusion diet, but these studies often lack randomized control groups and generalizability. Probiotics have also been found to be beneficial for symptom management, particularly *Bifidobacteria infantis* 35624 (Brenner, 2009), but further studies are needed to fully understand the potential benefits.

In addition to diet, the majority of IBS patients have, at some point in their illness, used medications to manage individual symptoms. Those with constipation predominant IBS (IBS-C) are most often prescribed stimulant laxatives (Brenner, 2012), but data is weaker for the osmotic laxatives (Zurad & Johanson, 2011). Tegaserod, a 5-HT4 agonist (Ford, 2009a) and a chloride channel activator, lubiprostone have demonstrated modest efficacy in IBS-C (D. A. Drossman et al., 2009). Linaclotide (Linzess), a peptide agonist, was recently approved for use in patients with moderate to severe IBS-C. In the first round of Phase III clinical trials, 800 patients received either linaclotide or a placebo; in those patients taking linaclotide, 50% reported reduced symptoms of pain and 34% reported reduced constipation (Johnston et al., 2009). Anti-spasmodic agents such as hyoscyamine are common for those with diarrhea-prominent IBS (IBS-D), and newer medications with fewer side effects are now available. In addition to laxatives and anti-spasmodic medications, antidepressants and serotonin agonists are commonly prescribed. In a meta-analysis of RCTs to determine efficacy of all available 5-HT agents in IBS, Ford and colleagues (2009b) found results that have been mixed at best, with some studies showing that low doses of tricyclic antidepressants are more effective than SSRIs. More recently, a non-absorbable antibiotic, rifaximin, which was previously used for traveler's diarrhea, is showing promise in treating IBS, particularly in cases where patients have small intestine bacterial overgrowth and in which bloating is a primary feature (Pimentel et al., 2011).

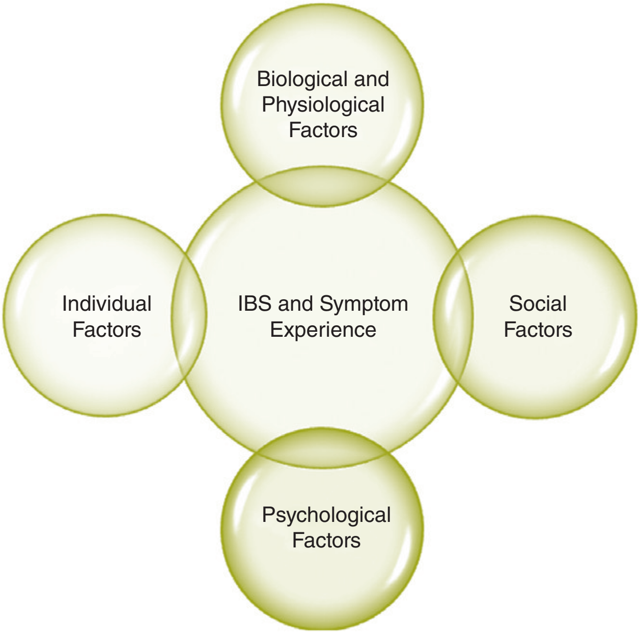

Figure 22.1 The biopsychosocial model of IBS.

IBS is a complex, multifactorial disease, and research has shown that biological, psychological, and social factors all play a role in the illness. Patient dissatisfaction with treatment, rising medical and workplace costs, adverse medication side effects, and patients' own expressed interests in learning about psychological factors and better coping are all driving forces behind new and innovative treatment models. Viewing IBS in the context of a biopsychosocial framework offers the most comprehensive approach toward understanding the treatment needs of patients.

Pathophysiology of IBS

Biology and genetics

While no single cause has been implicated in the onset and maintenance of IBS, there are numerous physiological factors and multiple biological systems that are involved in the disease. IBS is most often described as a functional disease, as the GI tract may be functioning abnormally but no physical abnormalities of an anatomical nature are present and nothing abnormal appears on blood tests. Despite this, the nervous and limbic systems have all been shown to play a central role in IBS, and a biological basis for IBS is further evidenced by the increased prevalence of medical comorbidities, documentation of an altered gut microbiome, particularly in post-infectious IBS (Jeffery, Quigley, Ohman, Simren, & O'Toole, 2012; Spiller & Lam, 2012); and more recent research into the contribution of genetics, increased mast cells, altered immunity, and serotonin dysregulation (Spiller & Lam, 2012).

A central theory of IBS is that the bi-directional interaction between the brain and the gut, mediated by the central and enteric nervous system, is disrupted (Koloski et al., 2012). When the brain and the gut are communicating in an uninterrupted and coordinated way, the gastrointestinal system functions normally; however, when there are interruptions or disturbances in the communication between the brain and the gut, gastrointestinal problems are likely to occur (Koloski et al., 2012; Blankstein et al., 2010). As the brain and gut attempt to compensate for the dysregulation, normal stimuli becomes amplified, which in turn leads to increased or exaggerated stress and pain responses, a process known as *visceral hypersensitivity.* Murray and others (2004), in a brain imaging study comparing healthy controls with those with gastrointestinal disease, found that IBS patients had a heightened visceral sensitivity to a variety of extraintestinal and gastrointestinal stimuli than did the healthy controls.

Increased visceral sensitivity has also been associated with increased reactivity of the muscle in the GI tract, which is indicative of abnormal functioning in the autonomic and enteric nervous systems (van der Veek et al., 2008). Further, Blankstein and colleagues (2010) conducted brain imaging studies to study abnormalities found in the brains of IBS patients and concluded that IBS patients have increased hypothalamic grey matter that is likely related to the association of IBS and stress. They also identified possible pre-existing supraspinal abnormalities that may make some individuals more vulnerable to IBS.

The *limbic system*, which influences the functioning of the autonomic nervous system and the endocrine system, also plays an important role in IBS, particularly *the anterior cingulate cortex* (ACC), which determines how pain is emotionally experienced. Activation in the ACC is often elevated in IBS patients, indicating that IBS patients may experience heightened sensitivity and responsiveness to undesirable stimuli such as pain or stress (Mayer et al., 2009). Similar increased activation in the ACC is seen in other chronic pain disorders. Another hormone, corticotropic releasing hormone (CRH), which impacts motility, stress levels, and pain sensitivity, has also been found at elevated levels in IBS patients (Fukudo, 2007), indicating increased activity at the level of the *hypothalamic–pituitary adrenal (HPA)* axis.

IBS patients are also at risk for increased prevalence of comorbid medical conditions such as fibromyalgia (FM), chronic fatigue syndrome (CFS), chronic migraines, sleep disorders, and/or gynecological or urinary disorders, all of which have been shown to decrease quality of life and reduce health outcomes (Riedl et al., 2008). Those IBS patients experiencing a comorbid condition are more likely to report a lower quality of life in addition to increased healthcare costs and utilization than other gastrointestinal patients (Johansson et al., 2010).

Whitehead and others (2002), in a study of comorbid disorders involving nearly 100,000 IBS patients, found that nearly half (49%) were also diagnosed as having fibromyalgia, and over half (52%) were diagnosed with chronic fatigue syndrome, while 94% of respondents reported a psychiatric comorbidity such as anxiety or depression. Chronic migraine patients have also reported increased gastrointestinal symptoms, with approximately half being diagnosed with IBS (Cole et al., 2006). Tietjen and colleagues (2007) found a statistically significant link between IBS, migraines, and endometriosis. Chronic fatigue syndrome, fibromyalgia, chronic migraines, bloating, and endometriosis are all conditions that predominantly impact women, and some researchers have proposed that estrogen may play a larger role in the HPA than previously thought (Warnock and Clayton, 2003). Although there are many similarities in terms of symptoms between some of these conditions, it is largely unclear if there is an underlying physiological connection between them. Fibromyalgia, for example, is often attributed to somatic hypersensitivity, whereas IBS is attributed to visceral sensitivities (Chang et al., 2000; Labus et al., 2009). For additional reading on the brain–gut axis, see Gershon (1999).

Psychological factors

While the biological and physiological factors of IBS are clear, including medical comorbidities, research has indicated that psychological factors play an increasingly large role in our understanding of the etiology and maintenance of IBS. While some studies suggest that upward of 94% of IBS patients have a psychiatric comorbidity (Whitehead et al., 2002), the majority of studies indicate that 60% of IBS patients typically experience either anxiety or depression at some point during their illness. Increased psychological distress and reported decreased interpersonal support have been shown to exacerbate symptoms of IBS, although psychosocial factors have been shown to exacerbate symptoms in illnesses other than IBS as well (Jones et al., 2006; Pinto et al., 2000).

Anxiety is the most common disorder, present in at least 58% of patients (Gros et al., 2009; Whitehead et al., 2002), with IBS patients being five times more likely to be diagnosed with generalized anxiety disorder (GAD) than healthy controls (Lee et al., 2009). Most research indicates that an anxiety disorder likely preceded the onset of IBS itself but that IBS symptoms exacerbate the anxiety (Sykes et al., 2003; Lee et al., 2009). A majority of IBS patients report being worried about their symptoms, including worry that their symptoms are indicative of a more severe medical issue such as cancer. Even more troublesome, the worries often relate to how their symptoms will have a negative impact on other responsibilities such as work and personal relationships (Crane and Martin, 2002). Worry and the inability to manage uncertainty are also higher among IBS patients (Keefer et al., 2005), even for those patients without a diagnosis of generalized anxiety disorder (Lee et al., 2009).

Depression is also fairly common among IBS patients and has been reported in 10–34% of patients. Unlike generalized anxiety disorder, however, depression is more likely to occur after the onset of IBS rather than having been present prior to its onset (Canavan et al., 2009; Ballenger et al., 2001), with only 7% of IBS cases having been diagnosed with dysthymia (Lydiard et al., 1993). Somatization has also been reported among IBS patients, ranging anywhere from 15% to 48% (Lydiard et al., 1993). It should be noted, however, that this may not be an accurate reflection of true prevalence as many IBS patients have high rates of healthcare utilization prior to receiving an IBS diagnosis (Miller et al., 2001).

Mood is an important factor in terms of quality of life and health outcomes. Patients diagnosed as IBS-D who have co-occurring panic disorder (41%) report the lowest levels of quality of life, although women with IBS-A report higher distress and lower quality of life than women diagnosed with IBS-D and IBS-C (Tillisch et al., 2005). Miller and others (2004) found that, because of the bowel problems, 38% of IBS patients had seriously considered suicide, a finding that was related to a reported sense of hopelessness regarding effective treatment for their condition. In a study examining the relationship between dysfunctional attitudes and the unpleasantness of pain (pain affect), Lackner and colleagues (2005) found a correlation between pain catastrophizing and greater disability and psychological distress. Further, a propensity toward negative thinking, concerns regarding harsh judgment from others, and self-critical beliefs all contributed to greater levels of disability and pain. Stress, too, can lead to lower quality of life, and, like mood, has been shown to have a noticeable impact on IBS symptoms

Psychological Treatment for IBS

Currently, while there is a wide range of medical treatment options for IBS, many of these have been found to be largely ineffective, particularly for the full range of symptom experience (Schmulson et al., 2009; Camilleri and Mayer, 2009). IBS patients also report dissatisfaction with many of their current treatment options. Medical interventions have often focused on one aspect of IBS, such as the symptoms of diarrhea or constipation. In 2010, based on a series of meta-analyses, the American College of Gastroenterologists issued guidelines suggesting that current medical therapies for IBS were largely ineffective for the full range of symptoms, indicating the need for treatment that targets global symptom relief (Schmulson et al., 2009; Camilleri & Mayer, 2009).

Psychological therapies for IBS, especially considering the general ineffectiveness of medical and dietary approaches, is of increasing relevance, and a growing body of research indicates that multiple classes of psychotherapy may be effective in managing IBS and reducing symptoms. The rise of psychological interventions for IBS was likely motivated by a number of factors, including patient's perceived stigma and the trivialization of their illness by healthcare providers, in addition to the educational needs of patients that have not traditionally been met by standard care

(Halpert et al., 2007). The prevalence of psychiatric comorbidities in IBS (as found in many chronic medical conditions) and the large role psychosocial factors play in the disease are indicative of the need for psychological therapies, and the relevance of these aspects are further supported by research that has indicated the efficacy of psychotropic medications (Clouse, 2003; Clouse, 1994) and variety of psychological therapies.

While there are any number of psychological interventions for medical and psychiatric illness, randomized controlled trials that have demonstrated efficacy in the treatment of IBS are limited to three broad classes of psychotherapy: brief psychodynamic therapy, gut-directed hypnotherapy, and cognitive behavioral therapy (CBT). A meta-analysis of psychotherapy and IBS research indicates that the psychological interventions are modestly effective when compared to wait list control conditions (Lackner et al., 2004), and further studies have indicated that psychological interventions in combination with medical therapies are superior to stand-alone medical treatments for IBS (Heymann-Mönnikes et al., 2000).

Brief psychodynamic therapy

Psychodynamic therapies often focus on the underlying psychological processes and early experiences that contribute to an individual's current state. Short-term therapies retain much of this focus but were developed out of a need to make therapy briefer and more effective than traditional psychoanalytic or psychodynamic treatment, in addition to making treatment more affordable. Brief psychodynamic therapies have three factors that distinguish them from more traditional long-term therapies – duration is predetermined and time is rigidly maintained, the therapeutic process is accelerated through a range of therapist techniques, and treatment centers around a well-defined and rigorously maintained focus. (Osimo, 1991, p. 207).

For patients with IBS, *psychodynamic* therapy is directed toward helping them to identify their feelings regarding their symptoms and disease, developing insight into how their experiences contribute, and exploring the impact that the disease has on interpersonal relationships. Randomized controlled trials support brief psychodynamic therapy as not only beneficial in treating IBS (Guthrie et al., 1993; Svedlund et al., 1983), but its effectiveness is equivalent to the use of paroxetine in reducing symptoms of IBS (Creed et al., 2003). In addition, this class of psychotherapeutic intervention has been found to be particularly helpful for those patients experiencing interpersonal difficulties (Hyphantus, Guthrie, Tomenson, & Creed, 2009) and patients with history of sexual abuse (Creed et al., 2005).

Gut-directed hypnotherapy

One of the more accepted definitions of hypnosis is that it is a treatment characterized by a state of attentive, receptive concentration containing three concurrent features of varying degrees: dissociation, absorption, and suggestibility (Hammond, 1998, p 1). It has been used as a treatment for many gastrointestinal disorders, and gut-directed hypnotherapy is one of the first empirically supported treatments for IBS (Whorwell, Prior, & Faragher, 1984; Whorwell, Prior, & Colgan, 1987; Miller and Whorwell, 2009; Galovski and Blanchard, 2002), with response rates above 85% (SB). Gut-directed hypnotherapy uses very specific post-hypnotic suggestions to target bowel symptoms and has been of particular benefit in refractory cases (Whorwell et al., 1984, 1987; Palsson 2006).

Two specific models of gut-directed hypnotherapy have shown efficacy in the treatment of IBS, the Manchester Model (Whorwell, 2006), and the North Carolina protocol (Palsson, 2006). In a study examining gut-directed hypnotherapy in refractory IBS, Whorwell and others (1984) noted significant reductions in bloating, abdominal pain, and dysfunction bowel habits when compared to control groups consisting of medication placebo and supportive therapy. A later study, utilizing a larger sample size, noted consistent improvements in symptoms for refractory IBS patients, with 95% reporting minimal to no symptoms (Whorwell et al., 1987) after treatment.

While the underlying mechanism of gut-directed hypnotherapy remains unknown, many case studies in addition to independent randomized controlled trials support the efficacy of hypnosis (Palsson et al., 2002; Gonsalkorale et al., 2003; Lea et al., 2003; Palsson, Turner et al., 2006; Palsson and Whitehead, 2002). Hypnosis has facilitated the reduction of somatization, depression, and rectal sensitivity while promoting cognitive change. Not only has the treatment modality been especially beneficial to the most treatment-impervious forms of IBS, but changes in symptoms have been shown to be long lasting (Gonsalkorale et al., 2003).

Cognitive behavioral therapy (CBT)

Of all the psychological treatments to date, CBT, for the treatment of IBS, has shown the most promise, and is the most well supported of the treatments discussed (Lackner et al., 2010; Lackner et al., 2008; Blanchard et al., 2007; Drossman et al., 2003). In fact, early CBT programs when compared to standard medical therapies of the time (dietary advice, supplementation of fiber, and the use of antispasmodics) were shown to be as effective in treating IBS, if not superior (Corney et al., 1991; Shaw et al., 1991). While it is likely that the trend in healthcare settings for evidence-based and time-limited treatments have influenced the popularity of CBT, this approach is especially well suited for the treatment of IBS for a number of reasons. Understanding IBS from a biopsychosocial framework highlights the importance of addressing multiple aspects of the disease experience that can be suitably addressed in CBT.

CBT uses a systematic and goal-oriented approach that addresses dysfunctional or problematic behaviors, emotions, and thoughts; a major premise of CBT theory is that changing maladaptive thinking will lead to change in behavior and affect. When IBS was viewed as a predominantly psychosomatic illness, the first-generation CBT trials emphasized the psychological distress experienced by patients (Blanchard et al., 1987; Green and Blanchard, 1994; Payne and Blanchard, 1995) – most notably, anxiety, avoidance behaviors, and unproductive self-talk. The most commonly shared features of these early trials were the use of problem-solving training, assertiveness training, relaxation therapy, and the use of cognitive restructuring. Newer-generation CBT trials, while featuring many of these same elements, do so while also emphasizing symptom-based outcomes, self-management, and techniques that utilize minimal contact. This current trend is likely influenced by the need for more accessible treatments that are less expensive and time-intensive, as well as research which has indicated that most patients treated from a CBT approach respond within the first 4 weeks (Lackner et al., 2010).

CBT treatment protocols (both first-generation and later) are perhaps particularly effective in the treatment of IBS because they address prominent characteristics and skills deficits found in IBS patients. Cognitively, IBS patients tend to engage in two common thinking errors: negative prediction (the tendency to overestimate the likelihood of something negative occurring) and catastrophizing (where the outcome of a negative event or potential negative event is blown out of proportion, and one's perception of the ability to cope is reduced or nonexistent).

IBS patients, unlike those with other chronic GI conditions, are far more likely to overestimate the potential of symptoms occurring and then to perceive the consequences of their symptoms as being much worse than they actually are (Lackner and Quigley, 2005). In addition to common thinking errors, treatment can also address maladaptive core beliefs held by many IBS patients. The three most common core beliefs among IBS patients are perfectionism, a need for approval, and feelings of over-responsibility, any of which will cause a patient to experience stress over their symptoms.

IBS patients have also been found to be fairly rigid in terms of problem-solving, approaching all problems in a similar manner regardless of whether or not a situation is controllable or uncontrollable. IBS patients are unique in that they do not lack problem-solving skills; rather, they have superior skills if a problem is solvable (Cheng et al., 2003). However, when confronted with uncontrollable situations or when having to adapt to the unpredictable nature of their illness, this skill is less adaptive. CBT focuses on flexible problem-solving skills to increase their ability to adapt to and manage those situations and aspects of their illness that are outside of their control. CBT is also beneficial in focusing the IBS patient on those aspects of their experience that can be modified. First-generation trials often focus on relaxation techniques to such great benefit that it is often an integral part of current treatment. By modifying arousal through relaxation techniques such as meditation, progressive muscle relaxation, and biofeedback, IBS patients reduce the physiological impact of stress.

Case Study

Mary is a 35-year-old, married, Caucasian female diagnosed with IBS-D in her late twenties. She presents complaining of pain, increased urgency, bloating, and multiple bowel movements during the day that are loose and watery. She relates that, because of the urgency and her fear of having an accident, she has begun to experience increased anxiety and symptoms of panic when she leaves the house, leading her to often cancel appointments or commitments and isolate herself. In particular Mary relates that this has severely impacted her social life, which once included weekly dinner with a close group of friends. Mary relates she *would die of embarrassment* if she had an accident while out, and that she doesn't want to disappoint or worry her friends if she has to get up to use the restroom in the middle of a meal. Despite Mary's concerns, she reports never having had an accident, and that her friends have long known about her IBS diagnosis.

Working from a CBT stand point, a therapist could help Mary use evidenced-based logic to recalculate the risk of her having an accident while out of the house: *I have never had an accident before, so the chance I will have one is slim; I have never been unable to find a bathroom before, and will likely locate one quickly and easily.* Further, Mary appears to be maximizing the potential consequences of a situation (dying of embarrassment) while underestimating her ability to cope. A key feature of CBT is decatastrophizing, the goal of which is to remind patients that, while IBS can be embarrassing to them, they have the ability to cope with their experience using a variety of means. Decatastrophizing includes asking the patient to problem-solve around those aspects that they can control (bringing an extra change of clothing, finding the location of the bathroom) and to recognize their capability to cope with that which is outside of their control (Is the situation time limited? Can they manage their feelings for that time period?).

Two excellent resources for self-management for IBS are Barney et al. (2010) and Lackner (2007).

Group treatment

Two forms of group treatment for IBS, patient education groups and CBT group therapy, have been shown to be beneficial for patients. Group treatment is not only less expensive than many individual therapeutic formats but it may offer certain benefits not found in other treatments (Colwell et al., 1998; Hungin, 2006; Saito et al., 2004). Over half of IBS patients report feelings of stigmatization, and IBS has many characteristics that make it susceptible to stigma, including limited treatment options, unpredictability and uncontrollability of symptoms, and the lack of a clear etiology. Patients report experiencing stigma not only from friends, family, and coworkers, but from their medical providers as well (Jones et al., 2009; Taft, Keefer, Artz, Bratten, & Jones, 2011). Group treatment, by its very nature, can help reduce the sense of isolation and stigma, which in turn may reduce the stress related to experiencing symptoms. IBS patients have also expressed frustration over the lack of information regarding their illness (Halpert et al., 2007, 2008, 2010), and nurse-led patient education groups appear to fill this need. CBT group therapy, while uncommon, has also shown efficacy in the treatment of IBS. One RCT indicated that group therapy was associated with reduction in abdominal pain, increased use of adaptive coping, and reduced behavioral avoidance. Further, these changes were found to be long lasting (van Dulmen et al., 1996).

The use of CBT for IBS has been found to be highly beneficial when used in more traditional individual or group treatment. Current technology, however, has allowed for the expansion of treatment delivery options to now include teletherapy, video therapy, and Internet-based CBT. Jarrett and others (2009), in a study of self-management and IBS, found that therapy conducted over the telephone could be as effective as in-person treatment. Further, the use of new technologies offers distinct advantages in terms of reaching individuals who would otherwise be unable to access care.

Conclusion and Future Directions

In this chapter, we have demonstrated ways in which research into functional bowel disorders, and most notably IBS, has broadened our understanding not only of the pathophysiology of the illness but in the manner in which we treat it. Once viewed as a psychosomatic illness, IBS is now better understood when viewed within a biopsychosocial framework. Advances in research have led to newer, more effective medications to treat symptoms, a more complete understanding of the brain–gut connection and other contributing biological factors, and more effective, focused psychological treatments. Psychological treatments, particularly cognitive behavior therapy, have a significant place in the future of IBS care, and therefore the health psychologist should be equipped to deal with these patients.

Future directions

Research has also indicated the need for further study of IBS from multiple avenues. First, because IBS lacks a reliable biomarker, the endpoints used in clinical trials are widely varied and symptom-driven. Recent efforts to standardize patient-reported outcomes in IBS trials are underway, but much work is still needed. Identification of reliable biomarkers for IBS could streamline management and serve as a universal endpoint for research trials as well. Secondly, there have been no comparative effectiveness studies to date of either psychological therapies (e.g., CBT v. hypnotherapy) or medical therapies (Linaclotide v. lubiprostone), or their combination (CBT v. amitryptaline). This poses a significant problem in terms of matching patients to the best treatment for their specific circumstance. In part because of the lack of comparative effectiveness studies and in part due to other scientific limitations, there is a limited understanding of the *mechanisms* through which effective therapies work. A more complete understanding of such mechanisms, either through neuroimaging before and after therapy or through dismantling studies on effective psychotherapies, could lead to more tailored treatments and an improved understanding of the pathophysiology of IBS.

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Part I

Health Disorders and Specialties

23

Psychoneuroimmunology of Interpersonal Relationships

Both the Presence/Absence of Social Ties and Relationship Quality Matter

Lisa M. Jaremka, Heather M. Derry, and Janice K. Kiecolt-Glaser

Being socially connected has health benefits. For example, married people had lower premature all-cause mortality rates, higher 5-year cancer survival rates, and fewer chronic health conditions than their non-married counterparts (Johnson, Backlund, Sorlie, & Loveless, 2000; Schoenborn, 2004; Sprehn, Chambers, Saykin, Konski, & Johnstone, 2009). In addition, people with more diverse social ties had lower premature all-cause mortality rates and a better prognosis following a myocardial infarction or stroke than people who were less socially integrated (Colantonio, Kasl, Ostfeld, & Berkman, 1993; Holt-Lunstad, Smith, & Layton, 2010; Ruberman, Weinblatt, Goldberg, & Chaudhary, 1984). On the other hand, distressing interpersonal relationships enhance risk for a variety of health problems such as coronary heart disease, delayed wound healing, metabolic syndrome, and premature all-cause mortality (Holt-Lunstad et al., 2010; Kiecolt-Glaser et al., 2005; Orth-Gomér et al., 2000; Whisman, 2010). Importantly, the links between close relationships and health remain after controlling for important sociodemographic and health-relevant risk factors.

Growing evidence suggests that immune function may be one potential pathway linking close relationships and health (Robles & Kiecolt-Glaser, 2003); proper immune function is essential to health (Glaser & Kiecolt-Glaser, 2005). Indeed, inflammation and other forms of immune dysregulation increase risk for premature all-cause mortality and a variety of diseases including cardiovascular disease, cancer, and metabolic syndrome (Ershler & Keller, 2000; Hansson, 2005; Hotamisligil, 2006; Nabipour, Vahdat, Jafari, Pazoki, & Sanjdideh, 2006; Parkin, 2006). Studies addressing inflammation, herpesvirus latency, vaccine responses, and wound healing can provide windows into how close interpersonal relationships impact immune function.

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In this chapter, we suggest that the mere presence of close relationships confers immunological benefits. Next, we investigate the quality of these relationships and argue that distressing relationships dysregulate immune function, whereas supportive relationships may be immunoprotective. We also discuss the immunological consequences of relationship loss, and conclude by suggesting areas for future research. Throughout this review, we focus on the empirical adult human literature addressing close relationships and immune function.

Presence/Absence of Relationships

Marriage, many adults' most intimate and close relationship, appears to benefit immune function. For example, married older adults had more vigorous antibody responses to an influenza virus vaccine than their non-married counterparts (Phillips et al., 2006), reflecting an adaptive vaccine-related immune response (Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996). Several inflammatory protein markers (e.g., fibrinogen) were lower in married men compared with non-married men (Engström, Hedblad, Rosvall, Janzon, & Lindgärde, 2006). Furthermore, men with lower levels of these inflammatory protein markers had a lower risk of coronary events and stroke over an 18-year period (Engström et al., 2006). Chronic systemic inflammation increases risk for premature all-cause mortality and age-related diseases such as cardiovascular disease, type II diabetes, metabolic syndrome, neurodegenerative disorders, and frailty (Ershler & Keller, 2000; Hansson, 2005; Harris et al., 1999; Hotamisligil, 2006), suggesting one mechanism underlying the health benefits of marriage.

The immunological benefits evident in the marital literature also extend to other relationships. For instance, social integration, the number and/or diversity of a person's social ties, appears to be immunoprotective. Among a nationally representative sample of adults, more socially integrated individuals had lower levels of systemic C-reactive protein (CRP), an inflammatory marker linked to cardiovascular disease, than less socially integrated individuals (Ford, Loucks, & Berkman, 2006). Consistent with this data, additional studies demonstrated that people who were more socially integrated had lower systemic inflammation, as indexed by CRP and interleukin-6 (IL-6), than those who were less socially integrated (Heffner, Waring, Roberts, Eaton, & Gramling, 2011; Koenig et al., 1997; Lutgendorf, Russell, Ullrich, Harris, & Wallace, 2004; Shankar, McMunn, Banks, & Steptoe, 2011). In addition, compared to more socially isolated people, those who were more socially integrated had larger antibody responses to an influenza virus vaccine (Pressman et al., 2005). One intriguing study demonstrated that nasal inoculation with a rhinovirus (the common cold virus) produced clinically verified common colds less frequently among people with more diverse social ties than those with less diverse social ties (Cohen, Doyle, Skoner, Rabin, & Gwaltney, 1997). Accordingly, being married or having numerous social ties is linked to lower systemic inflammation, more adaptive vaccine responses, and less susceptibility to the common cold.

Some studies suggest that the immune-relevant effects of being married and socially integrated may be stronger for men than for women. In a population-based study, married men exhibited significantly lower levels of systemic CRP compared to unmarried men, married women, and unmarried women (Sbarra, 2009). Compared to their less socially integrated counterparts, more socially integrated men had lower systemic CRP and IL-6; inflammation and social integration were unrelated among women (Loucks, Berkman, Gruenewald, & Seeman, 2006; Loucks et al., 2006). Thus, multiple studies show that the immune benefits of being in or out of a relationship are most evident among men.

Quality of Relationships

The negative side of relationship quality

While the presence of a spouse generally benefits immune function, a marriage wrought with conflict and discontent can take a toll. For example, people in poorer-quality relationships are more stressed and depressed than those in better quality relationships; both stress and depression dysregulate immune function (Jaremka, Lindgren, & Kiecolt-Glaser, 2013). Indeed, compared to more happily married people, people in distressed relationships had smaller antibody responses to an influenza virus vaccine (Phillips et al., 2006). Furthermore, individuals in more distressed marriages had higher Epstein-Barr virus (EBV) antibody titers than those in less distressed marriages (Kiecolt-Glaser et al., 1987, 1988). Because herpesviruses, including EBV and cytomegalovirus (CMV), are better able to reactivate and replicate when the cellular immune system is compromised, higher antibody titers to a latent herpesvirus reflect poorer cellular immune system control over viral latency (Glaser & Jones, 1994).

Observational studies of marital conflict discussions provide a unique window into the effects of marital distress on immune function; behavioral coding systems assess actual relationship behaviors, and thus do not rely on self-reported marital quality. A provocative study using this paradigm demonstrated that wound healing, an immunologically-mediated event, was slower after a marital disagreement than a socially supportive discussion (Kiecolt-Glaser et al., 2005). In addition, production of inflammatory cytokines at the wound site was lower following the conflict than the support discussion. In contrast to systemic inflammation, which is linked to a variety of age-related diseases (Hansson, 2005; Hotamisligil, 2006; Nabipour et al., 2006; Parkin, 2006), local inflammation at the wound site is adaptive and critical to effective wound healing. These results show that marital conflict produces clinically meaningful stress-induced immune dysregulation, as evidenced by differences in wound repair.

Negative and hostile behaviors during a conflict discussion, such as blaming or interrupting the partner, appear to be particularly detrimental. A conflict discussion led to slower wound healing among couples displaying more hostile behaviors compared to those with fewer hostile behaviors (Kiecolt-Glaser et al., 2005). Furthermore, whereas hostile couples had higher systemic inflammation following a conflict discussion compared to a social support discussion, low-hostile couples had similar levels of inflammation across both discussions (Kiecolt-Glaser et al., 2005). Indeed, repeated hostile interactions may cause long-lasting immunological alterations and poor health over time.

Although older couples displayed fewer negative behaviors during marital discussions than younger couples, older adults' negative relationship behaviors were still linked to poorer immune function (Kiecolt-Glaser et al., 1997). These results suggest that the immune system does not habituate to negative social interactions over time. Because aging enhances immune dysregulation, negative marital interactions may be particularly detrimental among older adults (Fagundes, Gillie, Derry, Bennett, & Kiecolt-Glaser, 2012).

Divorce, a clear hallmark of distress in a marriage, also has negative immunological consequences. Recently separated/divorced women had higher EBV antibody titers compared to sociodemographically matched married women (Kiecolt-Glaser et al., 1987). Interestingly, EBV antibody titers were highest for women whose spouses initiated the separation (Kiecolt-Glaser et al., 1988).

Lonely people feel socially isolated from those around them and are at increased risk for depression (Cacioppo, Hawkley, & Thisted, 2010). Indeed, loneliness is an interpersonally distressing state that dysregulates immune function (Jaremka, Lindgren, et al., 2013). Lonelier people had higher EBV, CMV, and human herpesvirus 6 (HHV-6) antibody titers than less lonely people (Dixon et al., 2006; Glaser, Kiecolt-Glaser, Speicher, & Holliday, 1985; Jaremka, Fagundes, Glaser, et al., 2013). Lonelier people had smaller antibody responses to an influenza virus vaccine than those who were less lonely (Pressman et al., 2005). In addition, compared with people who were more socially connected, lonelier individuals exhibited upregulation of proinflammatory genes and downregulation of anti-inflammatory genes (Cole et al., 2007). Recent data also demonstrated that loneliness exacerbates stress-related immune dysregulation. Among healthy adults and post-treatment breast cancer survivors, systemic inflammation was higher after an acute laboratory stressor among those experiencing greater loneliness compared with those who were less lonely (Hackett, Hamer, Endrighi, Brydon, & Steptoe, 2012; Jaremka, Fagundes, Peng, et al., 2013).

The immunological consequences of distressing relationships may be particularly strong for women compared with men (Kiecolt-Glaser & Newton, 2001). For example, marital stress was associated with heightened systemic inflammation in young women but not young men (Whisman & Sbarra, 2012). A marital conflict discussion led to greater negative affect and immune dysregulation among women compared with men (Kiecolt-Glaser et al., 1993; Mayne, O'leary, McCrady, Contrada, & Labouvie, 1997). Negative affect can dysregulate immune function (Jaremka, Lindgren, et al., 2013), and women may be more emotionally affected by marital conflict than men (Kiecolt-Glaser et al., 1993; Mayne et al., 1997). Taken together, these results could help explain elevated immune dysregulation among women in distressing relationships.

In sum, distressing relationships clearly dysregulate immune function, and initial evidence suggests that these effects may be most prominent for women. One interesting question is whether the immunological consequences of distressing relationships are driven by negative features of the relationship, a lack of positive features, or a combination of the two. Research about the positive side of relationship quality begins to address this question.

The positive side of relationship quality

Initial evidence suggests that supportive marriages confer immunological benefits (Kiecolt-Glaser & Newton, 2001), potentially because they buffer against stress and depression (Cohen & Wills, 1985). For example, couples who displayed more cognitive engagement during a marital conflict discussion had lower systemic IL-6 responses than those displaying less cognitive engagement (Graham et al., 2009). People with rheumatoid arthritis, an inflammatory disease, had less disease activity in response to stressful life events if they were in better-quality marriages than if their marriages were more distressed (Zautra et al., 1998). In addition, rheumatoid arthritis patients reporting better marital quality at study entry had lower systemic inflammation 6 months later, suggesting that positive relationships can benefit immune function over time (Kasle, Wilhelm, McKnight, Sheikh, & Zautra, 2010).

Other supportive relationships may also confer immunological benefits. Although a full review of the social support literature is outside the scope of this chapter, we highlight select findings about immune function and perceived social support, the perception that close others are available for support in times of need (for a recent review, see Uchino, Vaughn, Carlisle, & Birmingham, 2012). The majority of perceived social support research suggests that people who feel more supported have better immune function than those who feel less supported. For example, people reporting more supportive relationships had lower systemic inflammation, as indexed by IL-6 and IL-8, than those with less supportive relationships (Friedman, 2011; Friedman et al., 2005; Marsland, Sathanoori, Muldoon, & Manuck, 2007). People with more social support had larger antibody responses to pneumococcal pneumonia, hepatitis B, and influenza virus vaccines than those with less social support (Gallagher, Phillips, Ferraro, Drayson, & Carroll, 2008a, 2008b; Glaser et al., 1992; Phillips, Burns, Carroll, Ring, & Drayson, 2005). In addition, people who felt more supported had lower EBV and HHV-6 antibody titers than those with less social support (Dixon et al., 2006; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991). Interestingly, one study suggested that the relationship between social support and herpesvirus antibody titers may be strongest for higher-socioeconomic-status (SES) people. Among higher-SES women, those with more support from friends had lower EBV antibody titers; no effect was found for lower-SES women (Fagundes, Bennett, et al., 2012).

Relationship Loss

The death of a spouse, family member, or friend is a profoundly stressful experience that often causes intense distress (Bodnar & Kiecolt-Glaser, 1994; Zisook et al., 1994). In this way, loss is a unique type of relationship stress. Thus, it is not surprising that the death of a loved one dysregulates immune function. For instance, people who experienced the death of a spouse in the past year had smaller antibody responses to an influenza virus vaccine than those who were currently married (Phillips et al., 2006). Bereaved spouses also exhibited heightened levels of systemic inflammation, as measured by IL-6 and interleukin-1 receptor antagonist (IL-1ra), compared to non-bereaved controls (Schultze-Florey et al., 2012). Husbands' immune responses to three different mitogens decreased substantially following their wives' deaths (Schleifer, Keller, Camerino, Thornton, & Stein, 1983). Mitogen responses may provide an analog to understanding white blood cells' ability to replicate or proliferate when challenged. Accordingly, husbands' immune responses reflected decrements in cellular immunity from pre-to-post bereavement.

Providing care for a loved one with Alzheimer's disease or a related dementia is a stressful experience. Indeed, some caregivers describe their loved ones' loss of mental function as a process of living bereavement (Schulz et al., 2003). In addition, caregivers report more loneliness, stress, and depression than non-caregivers (Kiecolt-Glaser et al., 2003, 1991). Consequently, dementia caregiving enhances risk for immune dysregulation. For instance, Alzheimer's disease caregivers had higher levels of systemic inflammation than non-caregivers (Damjanovic et al., 2007; Lutgendorf et al., 1999; von Känel et al., 2006). In addition, spousal and offspring dementia caregivers had higher herpes simplex virus type 1 (HSV-1) and EBV antibody titers than non-caregivers (Glaser & Kiecolt-Glaser, 1997; Kiecolt-Glaser et al., 1987). Compared to non-caregivers, spousal dementia caregivers had smaller antibody responses to an influenza virus vaccine and diminished antibody responses over time to a pneumococcal pneumonia vaccine (Glaser, Kiecolt-Glaser, Malarkey, & Sheridan, 1998; Glaser, Sheridan, Malarkey, MacCallum, & Kiecolt-Glaser, 2000; Kiecolt-Glaser et al., 1996). In addition, one provocative study demonstrated that a punch biopsy wound took longer to heal among spousal and offspring dementia caregivers compared with non-caregivers (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995).

The immunological consequences of caregiving are also evident among people caring for a loved one with other chronic medical conditions. For instance, primary caregivers for a family member with brain cancer had higher systemic CRP and upregulated pro-inflammatory transcription factors compared with non-caregivers (Miller et al., 2008). In addition, parents caring for a child with a developmental disability had smaller antibody responses to a pneumococcal polysaccharide vaccine than non-caregivers (Gallagher, Phillips, Drayson, & Carroll, 2009).

Longitudinal data provide additional evidence that the chronic stress of caregiving dysregulates immune function over time. Compared to non-caregivers, spousal dementia caregivers had larger EBV antibody titer increases over time (Kiecolt-Glaser et al., 1991). Primary caregivers for a family member with cancer had larger systemic CRP increases over time than non-caregivers (Rohleder, Marin, Ma, & Miller, 2009). Spousal dementia caregivers' average rate of increase in systemic IL-6 over 6 years was about four times as large as that of non-caregivers (Kiecolt-Glaser et al., 2003). Interestingly, IL-6 increases did not differ between current caregivers and former caregivers, even several years after the death of the dementia patient. However, perceived stress also did not differ between current and former caregivers, suggesting that psychological recovery from relationship loss may be critical to immune system recovery over time.

Future Directions

Distressing relationships negatively affect immune function (Jaremka, Lindgren, et al., 2013). However, some people may be more resilient in the face of stress than others. Indeed, psychological resources (e.g., self-esteem) may buffer against the negative effects of relationship distress. For example, in response to being told that a potential dating partner left the study early, higher-self-esteem participants explained the other person's behavior with more benign (e.g., the other participant was sick) than malevolent (e.g., the other participant did not like me) attributions (Ford & Collins, 2010). This study suggests that, compared to their lower-self-esteem counterparts, people with higher self-esteem may interpret ambiguous interpersonal situations as less threatening. Exploring whether these self-esteem differences translate into altered stress-related immune function is an interesting research direction.

The presence/absence of relationships versus the quality of those relationships appears to affect men and women differently. Compared to women, men reap more immunological benefits from being married. On the other hand, women are more sensitive to marital quality and thus experience more immune dysregulation when marriages take a negative turn (Kiecolt-Glaser & Newton, 2001). These findings may help explain gender-based health differences; men's health benefits more from being married, whereas women's health is more closely tied to marital quality (House, Robbins, & Metzner, 1982; Kiecolt-Glaser & Newton, 2001). It remains unclear whether these gender differences extend to non-marital relationships; the loneliness and social support literatures largely do not report gender differences, either because they do not exist or because they were not studied. In either case, a full exploration of gender differences is necessary in order to understand the immunological consequences of close relationships.

Preliminary evidence suggests that social interactions via social media websites (e.g., Facebook) can be both positive and negative. For example, frequent Facebook users experienced more supportive interactions than non-frequent users (Ellison, Steinfield, & Lampe, 2007; Muise, Christofides, & Desmarais, 2009), but they also experienced more jealousy (Muise et al., 2009). One interesting question is understanding whether the affective consequences of social-media-based relationships have immunological consequences.

Relationships may affect immune function differently in older versus younger adults. Both social integration and relationship quality likely evolve with age. Social networks of older adults contain fewer peripheral relationships than those of younger adults, and older adults view emotionally close relationships as more important than novel friendships (Fung, Carstensen, & Lang, 2001). Thus, older and younger adults appear to view relationships differently, which may have immune consequences. Longitudinal studies may be useful in answering whether age-related relationship changes alter immune function.

Conclusion

In sum, being married and having diverse social ties confer immunological benefits. On the other hand, distressing relationships have negative immunological consequences. Furthermore, immune dysregulation is evident among people experiencing relationship loss, either through the death of a spouse or providing care for a loved one with a deteriorating medical condition. Because immune function is essential to health, these studies may provide mechanistic insight into the ways that relationships affect health.

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24

Chronic Fatigue Syndrome

Rehabilitative Treatments and Mechanisms of Change

Trudie Chalder

Introduction, Definitions, and Prevalence

Fatigue is a very common complaint but is typically transient, self-limiting, or explained by other circumstances. Chronic fatigue syndrome (CFS) is characterized by persistent or relapsing unexplained fatigue of new or definite onset lasting for at least 6 months. It is not a new condition and corresponds very clearly to an illness called *neurasthenia*, commonly seen in Europe around the turn of the twentieth century. The terms "myalgic encephalomyelitis" (ME) and "post-viral fatigue syndrome" have also been used to describe CFS, but are misleading and unsatisfactory: ME implies the occurrence of a distinct pathological process, whereas post-viral fatigue syndrome wrongly suggests that all cases are preceded by a viral illness.

Operational criteria developed for research purposes by the US Centers for Disease Control and Prevention (CDC) (Fukuda et al., 1994) and from Oxford (Sharpe et al., 1991) are now widely used to define CFS. The American criteria require at least 6 months of persistent fatigue causing substantial functional impairment and at least four somatic symptoms (from a list of eight) occurring with the fatigue in a 6-month period. The presence of medical disorders that explain prolonged fatigue excludes a patient from a diagnosis of CFS, as do a number of psychiatric diagnoses. Although the British definition is similar, it differs by requiring both physical and mental fatigue, but no physical symptoms. By including a requirement for several physical symptoms, the American definition reflects the belief that an infective or immune process may underlie the syndrome.

The prevalence of CFS has been reported as 0.1–2.6% in community- and primary-care-based studies, depending on the criteria used (Wessely, Chalder,

The Handbook of Behavioral Medicine, First Edition. Edited by David I. Mostofsky.

Hirsch, Wallace, & Wright, 1997). Women are at higher risk than men (Relative risk 1.3–1.7) (Wessely, 1995).

Diagnosis

There are no diagnostic signs or symptoms of CFS. The clinical evaluation of chronically fatigued patients is aimed at excluding underlying medical or psychiatric causes of fatigue. In individuals with fatigue of more than 6 months duration, a thorough history, physical examination, routine laboratory tests (full blood count, ESR, renal, liver and thyroid function, and urinary protein and glucose), and mental state examination are sufficient to reach a diagnosis of CFS in most cases. Where abnormalities are revealed on physical or laboratory investigation, further investigations can be helpful (serological tests for Epstein-Barr, CMV, Q fever, toxoplasmosis and HIV, chest x-ray, rheumatoid factor, and antinuclear factor), but should otherwise be limited to avoid the risk of iatrogenic harm. Specialist referral should be limited to situations where there is an increased probability of an alternative diagnosis.

The relationship between CFS and psychiatric illness is more complex. Fatigue is a common symptom in mental illness, and where an individual's fatigue is fully explained by a specific psychiatric disorder, a diagnosis of CFS should not be made. However, psychiatric co-morbidity (particularly with depressive, somatoform, and anxiety disorders) is also common, and when present should be diagnosed and treated in addition to the symptoms of CFS. This does not mean that psychiatric disorders are the cause of CFS, and indeed a substantial minority of patients do not fulfill criteria for any psychiatric diagnosis (Wessely, Hotopf, & Sharpe, 1998).

Predisposing, Precipitating, and Perpetuating Factors

In relation to etiology, a number of different biological, social, and psychological factors are thought to work together to predispose an individual to CFS and to precipitate and perpetuate the illness (Afari & Buchwald, 2003).

Several studies have investigated childhood experiences in relation to a diagnosis of CFS in later life. Fisher and Chalder (2003) used a retrospective case-control design to compare early illness experience (up to the age of 16 years) between 30 adults with CFS and 30 patients attending a fracture clinic. No differences were found between the two groups on any self-reported childhood illness category, but they found increased levels of childhood maternal over-protection in those with CFS, compared with the ill controls.

In the only prospective study, higher emotional instability and self-reported stress in the pre-morbid period were associated with higher risk for CFS-like illness, 25 years later (Kato, Sullivan, Evengard, & Pedersen, 2006). In two retrospective population-based studies of adult CFS patients and non-fatigued control participants, CFS patients reported significantly higher levels of childhood trauma compared with controls (Heim et al., 2006, 2009). Both studies used a self-report childhood trauma questionnaire with moderate to severe cut-off scores. The Heim and others (2009) study also showed that adults with CFS who had experienced childhood trauma had flattened cortisol-awakening response profiles compared with healthy participants. In this study, adults with CFS who had not experienced emotional maltreatment during childhood exhibited normal cortisol profiles. The authors suggest that childhood trauma might cause long-term impairment in terms of the individual's ability to successfully adapt to stress, for example, via disturbances to the HPA axis, thereby conveying a risk to developing CFS.

There have been three longitudinal studies investigating the relationships between activity levels in childhood and the onset of CFS in adults. In the first, lower levels of exercise in childhood were associated with a greater risk of CFS in later life (Viner & Hotopf, 2004). Conversely, a second study, which defined high levels of exercise as "engaging in sporting activities weekly" in childhood through to adulthood (13–43 years) found that high levels of exercise were associated with an increased future risk of CFS in adulthood (Harvey, Wadsworth, Wessely, & Hotopf, 2008a). A third study did not replicate either of these studies, finding no prospective association with either little exercise or lots of exercise in childhood and CFS in adulthood (Goodwin, White, Hotopf, Stansfield, & Clark, 2011).

Many patients link the onset of their symptoms to infection and, while it is unlikely that serious viral illness perpetuates fatigue in CFS, serious infections such as mononucleosis, hepatitis, meningitis. and Q-fever are known to trigger onset in some individuals (Cleare & Wessely, 1996). Other risk factors for developing CFS include previous psychological illness (Harvey, Wadsworth, Wessely, & Hotopf, 2008b), and severe life events or difficulties in the months before onset (Hatcher & House, 2003).

A wide range of factors may act to perpetuate chronic fatigue. Coping responses to acute fatigue are important determinants of prolonged fatigue: extreme physical activity after an acute illness may allow insufficient time for recovery, whereas prolonged bed rest may cause exacerbate symptoms. Illness beliefs and the attribution of symptoms to a physical cause, with minimization of psychological or personal contributions, are also important and have been related to increased symptoms and worse outcomes in CFS (see Chalder & Hill, 2012, for review). Similarly, catastrophic beliefs that exercise will be damaging or worsen symptoms leads to the avoidance of physical and mental activities and greater disability (Petrie, Moss-Morris, & Weinman, 1995). Disrupted sleep patterns resulting from excessive daytime rest may contribute to fatigue, muscle pain, and poor concentration.

The response and attitudes of others are also important in determining the course of fatigue. Overly concerned carers may reinforce patients' maladaptive beliefs and coping strategies by inadvertently encouraging disability. Skeptical or stigmatizing reactions from relatives, health professionals, or work colleagues can cause frustration and leave the patient feeling isolated and unsupported (Deale & Wessely, 2001;

Van Houdenhove, Neerinckx, Onghena, Vingerhoets, Lysens, A., Lysens, R., & Vertommen, 2002).

Cognitive Behavioral Model and Treatment of CFS

Early cognitive behavioral models focused on the perpetuation of symptoms and disability associated with CFS (Wessely, David, Butler, & Chalder, 1989; Chalder, Butler, & Wessely, 1996). The essence of cognitive behavioral therapy (CBT) is to help patients to change behavioral and cognitive factors, focusing specifically on changing avoidance behavior, unhealthy sleep patterns, and unhelpful beliefs in order to improve levels of fatigue and disability. The focus is largely on the here and now, and the model applies whether the outcome is fatigue or psychiatric disorder or both. While treatment trials, recently reviewed in a meta-analysis (Castell, Kazantzis, & Moss-Morris, 2010), have provided some validity for the model, a developmental perspective is probably needed to understand more fully why people get into the predicament they find themselves in.

In 1995, Surawy and colleagues (Surawy, Hackmann, Hawton, & Sharpe, 1995) described a cognitive model of understanding CFS. They suggested that a patient's interpretation of somatic symptoms such as fatigue as being physical as opposed to psychological was vital for the development and continuation of the disorder. The model advocated that these physical illness attributions may have evolved as a consequence of childhood experiences in which the expression of negative emotion would have been met with unsympathetic or hostile responses. The model proposed that a somatic attribution (attributing symptoms to a physical cause) makes the patients' symptoms and illnesses easier to understand. The diagnosis of CFS, in a sense, can be seen as a protective mechanism that the individual has employed in order to preserve identity and self-esteem. Over time, the individuals' focus on the symptom of fatigue leads them to try and control it. The downside to this is that the individual then purportedly gets into a vicious circle in which the desire to control symptoms leads to avoidance in general. Although avoidant coping strategies may help in the short term, the long-term consequences are potentially extremely unhelpful. The side effects of behavioral avoidance or inactivity are well understood, whether related to disease processes or not.

Cognitive Behavior Therapy and Graded Exercise Therapy

The evidence suggests that the most effective treatments for CFS are CBT and graded exercise therapy (GET). The CBT model attempts to incorporate the heterogeneous nature of the condition and stresses the role of perpetuating factors. The treatment for CFS therefore involves planned activity and rest, graded increases in activity, a sleep routine, and cognitive restructuring of unhelpful beliefs and assumptions.

GET is a treatment that involves establishing a baseline of consistent activity and regular sleep–wake cycle, and then mutual negotiation of an incremental increase in the duration of time spent being physically active (most commonly walking), followed by an incremental increase in the intensity of exercise, aiming at half an hour of physical exercise five times a week. It is based on a model of deconditioning and avoidance of activity, both of which predict and maintain fatigue and disability (Fulcher & White, 2000). Systematic reviews have confirmed that patients with CFS are less physically active and are more deconditioned than healthy controls (e.g., Nijs et al., 2011).

Process of CBT

Assessment

The assessment should include not only a detailed description of symptoms but also, more importantly, a detailed behavioral analysis of what the individual is able to do in relation to work, home, private, and social aspects of their lives. The quality and quantity of sleep should be enquired about. A detailed account of activity, rest, and sleep patterns should be obtained by asking the patient to keep a diary for 2 weeks. This will be used as a guide for setting the initial behavioral goals and can be used throughout treatment to monitor progress. Specific fears about the consequences of activity and exercise should be elicited, as should more general ideas about the nature of the illness. Circumstances surrounding the onset should be discussed, as this information may be useful when giving the patient a rationale for treatment, and lifestyle factors may need to be addressed during treatment. It is also extremely helpful to elicit compassionately the patient's family and personal history. Previous trauma in childhood is associated with CFS in adulthood, and making links between trauma and fatigue may be helpful during the process of therapy. The presence of depression and/or anxiety should be assessed, and, if severe, such disorders may require treatment in their own right, either before CBT or concurrently.

Engagement

Engaging the patient and their significant other in treatment and forming a therapeutic alliance is a continual process. During the assessment, the individual who may be sensitive to being disbelieved may be looking out for evidence that the therapist thinks the problem is "all in the mind." During the early stage of treatment, it is helpful for the therapist to be explicit in conveying belief in the real and physical nature of the symptoms. Careful attention should be paid to the language that is used. The term "psychological" is probably best avoided, first because it is a broad term that means different things to different people, but also because it may set the scene for unnecessary disagreement between the patient and the therapist. The patient's symptoms are real, and it helps to state and restate this. Rather than debating whether the problem is physical or psychological, a mind/body split which is unhelpful in any illness, it is far more useful to direct the discussion toward how the problem can best be managed, taking into account the physiological, behavioral, and cognitive factors.

Rationale for treatment

Once a thorough assessment has been carried out, the therapist should share with the patient an initial formulation of the problem. While openly acknowledging that this is to some extent hypothetical, it should help the process of engagement and will form part of the rationale for treatment, a pre-requisite to any intervention. It stands to reason that having an understanding of how and why treatment works will aid compliance.

The rationale will obviously vary depending on the individual's circumstances, but essentially the patient should be told that the emphasis in treatment in the early phases will be on perpetuating factors. Initially, diary keeping of activity and sleep patterns will highlight areas of inconsistency. These are used to set goals with a view to establishing a consistent level of activity everyday regardless of symptoms. The amount of activity is then gradually increased and rest decreased as the patient becomes more confident. It can be helpful to point out that rest is useful in an acute illness but is rarely restorative in the longer term. A sleep routine should also be established as quickly as possible.

The rationale may be discussed several times throughout treatment. It can be useful to ask the patients to describe how they think the approach works in order to check out whether the potential benefits of treatment have been clearly understood, and to discuss any concerns. Before commencing treatment, it is important that the patients and their family are clear about what it entails. The aims of treatment should be explicitly negotiated and agreed with the patients. These aims are best defined in terms of specific and realistic achievements or behavioral goals that are worked toward gradually, and depend on the individual needs.

Structure

Patients are usually seen fortnightly for up to 15 sessions of face-to-face treatment. Follow-ups are carried out at 3–6 months and then 1 year to monitor progress and tackle any residual problems. Written material and self-help books are offered (Chalder, 1995; Burgess & Chalder, 2005) to supplement verbal interactions. Questionnaires are given to assess fatigue and disability before and after treatment and at follow-up. At the beginning of treatment, long-term targets are negotiated with the patient to ensure therapist, patients, and significant others are working toward similar goals. At every subsequent session, short-term goals are agreed upon.

Patients keep records of their activity and rest throughout treatment so that progress can be monitored and problems discussed.

Problems are anticipated and problem-solving strategies are used to elicit effective coping. Discussion during sessions often revolves around exploring issues that may be preventing the patient from making changes. A variety of techniques are used to facilitate change. Socratic questions are used to explore specific concerns or difficulties. The therapist may need to slow down the expectation of success. Less pressure to succeed often results in quicker success, on the part of therapist and patient.

Activity scheduling

Goals usually include a mixture of social- and leisure-related activities, as well as activities related to responsibilities. Short walks or tasks carried out in even chunks throughout the day are ideal and are interspersed with rests. The emphasis is on consistency and breaking the association between experiencing symptoms and stopping activity. The goals (for someone less disabled), for example, walking for 10 minutes three times daily, are gradually built up as tolerance to symptoms increase, until the longer-term targets are reached. Fatigue levels do not decrease very much initially, but between discharge and follow-up, marked reductions in fatigue would be expected. Tasks such as reading, which require concentration, can be included, but mental functioning does seem to improve in synchrony with physical functioning.

Establishing a sleep routine

Early on in treatment, patients are asked to keep a diary of bedtime, sleep time, wake-up time, and get-up time. The total number of hours spent asleep is calculated, and a variety of strategies can then be used to improve both quality and quantity of sleep. A routine of going to bed and getting up at a pre-planned time, while simultaneously cutting out daytime catnaps, helps improve both hypersomnia and insomnia. Change in sleep routine can be done slowly, depending on the severity of the problem. For those who sleep too much, the amount of time they spend asleep can be reduced gradually. A detailed description of how to manage sleep problems is provided by Morin and Espie (1994). It can be difficult for people with CFS to establish a sleep routine, particularly when they are not at work or college. Some flexibility should be built into the negotiated program.

Modifying negative and unhelpful thinking

The initial aim of this component is to prevent unhelpful thoughts from blocking progressive increases in activity. Information about the nature of CFS and the process of rehabilitation should be shared with the individual throughout treatment, as many patients will have been given incorrect or misleading information about their illness. Explanations regarding the physiological effects of inactivity can help patients understand the rationale for activity scheduling, while demonstrating the effect of attention on symptoms can also help patients use enjoyable activities as a form of distraction.

Information to assist self-help given at various stages of treatment can be helpful. In reality, unhelpful beliefs about the harmful effects of exercise will diminish as the patient becomes more active and confident. However, some will need more structured cognitive therapy using traditional methods. Specific negative thoughts such as “My muscles will be damaged by exercising too much” should be recorded in a diary. Patients should be encouraged to elicit alternative, less catastrophic interpretations of events. These too should be recorded in a diary and discussed during consultations. In some patient’s core beliefs such as “I am incompetent” and dysfunctional assumptions such as “I must do everything perfectly to be acceptable to myself and /or others” may be discussed.

Treating co-morbidity

Some patients with severe depression may benefit from anti-depressants. Others will find their mood improves with activity scheduling and cognitive re-structuring. For those with an anxiety disorder, discussion about the physiological aspects of anxiety can be helpful. Many patients are unaware of the physiological aspects of anxiety and the associated physical symptoms. Giving information about the nature of autonomic arousal often helps explain the patients’ experience of intrusive, frightening somatic sensations.

Tackling psychosocial problems and trauma

Related social or psychological difficulties will often emerge during treatment. It is important that these are tackled in a problem-solving way, otherwise they may prevent further progress. However, the focus needs to be on rehabilitation. Being distracted from the main task at hand may lead to treatment failure. Improvements in one particular area of a patient’s life will usually generalize to other areas. However, should the patient reveal early life trauma, the therapist should try to facilitate emotional processing in an evidence-based way. Compassion may not be what the patient is used to and he or she may experience some difficulty in revealing past trauma.

Employment

There is no black-and-white rule about how to negotiate employment. From a therapeutic perspective, several factors need to be considered: the patient’s level of fear; the degree of disability; the age of the patient, plans for the future, and the employer's view when relevant and degree of support. The long-term goal may involve a return to work, but some patients may be negotiating medical retirement. Others may be on state benefits, which will make recovery more difficult. Clearly, the longer a person is away from work, the less confident the person will become, making a return even more daunting.

Facilitating Change

Resistance to change is maintained by dissonance reduction. It can be recognized by the way in which patients respond to situations or information that challenge or contradict their beliefs. A reluctance to accept an interpretation or advice is often a consequence of efforts to maintain a consistent interpersonal stance. Change has to occur slowly in order to maintain an adaptive and socially acceptable level of historical continuity. In the first instance, the therapist should support the patient's point of view, thus accepting and working with their attributions of cause and control. Therapeutic change can then occur slowly without arousing too much dissonance (Kirmayer, 1990).

Contrary to popular belief, it is not necessary to challenge individual beliefs about the etiology of the illness directly. Rather, specific cognitions about the danger of activity and exercise can be examined and, if appropriate, addressed. Joining and accommodating to the individuals beliefs is far more advantageous to the process of change.

Telephone Treatment

Many patients are unable to travel to specialist units for treatment. In addition, there is a shortage of specialists who are suitably qualified to deliver CBT. To overcome these problems, a telephone treatment package of CBT, consisting of 13 telephone and two face-to-face sessions, was developed. In an initial pilot study, nine patients with a diagnosis of CFS who were unable to attend regular outpatient appointments were offered telephone treatment after an initial face-to-face assessment. Patients were given a self-help manual and were phoned fortnightly for up to half an hour to discuss progress, problem-solve any difficulties, review diaries sent by post to the therapist, and discuss plans for the coming fortnight. Patients also attended a face-to-face discharge appointment. Eight patients completed treatment; improvement was seen on all measures at discharge, and fatigue had improved by 75%. At 6-month follow-up, levels of functioning had continued to improve. This pilot study demonstrated that telephone CBT resulted in a reduction in fatigue and improvement in disability (Burgess & Chalder, 2001). The advantage of a telephone-based approach is that it is less time consuming for the therapist, therefore allowing more patients to be treated. The advantages for the patients are that it is less time consuming and less disruptive to their life.

Given the promising results of the pilot study, the next obvious step was to compare telephone CBT with face-to-face CBT. Significant improvements in the primary outcomes of physical functioning and fatigue occurred and were maintained to 1-year follow-up after discharge from treatment. Improvements in social adjustment and global outcome were also noted, and patient satisfaction was similar in both groups. Despite these encouraging results, the dropout rate was relatively high, and therapists should be aware of this potential problem (Burgess, Andiappan, & Chalder, 2011).

Treatment Evidence

A systematic review showed that CBT administered in specialist centers by skilled therapists led to improved physical functioning and quality of life compared with relaxation therapy or standard medical care (Price, Mitchell, Tidy, & Hunot, 2008). Randomized controlled trials (RCTs) evaluating graded exercise therapy (GET) have found that it improves measures of fatigue and physical functioning compared with flexibility training and relaxation training or general advice (Reid, Chalder, Cleare, Hotopf, & Wessely, 2004). More recently, a meta-regression examining CBT and GET of adults with CFS showed a dose effect, with those who received more sessions showing better outcomes (Castell, Kazantzis, & Moss-Morris, 2011).

The recently published PACE trial found that CBT and GET were more effective in reducing both fatigue and physical disability than adaptive pacing therapy (APT), when each was added to specialist medical care (SMC), and more effective than SMC alone (White, et al., 2011). Recovery was defined operationally using multiple criteria. The proportions of participants in each group (CBT; GET; APT & SMC) meeting each individual criterion for recovery were compared. In addition two composite criteria, defined as (a) recovery in the context of the trial, and (b) clinical recovery from the current episode of the illness, however defined, both at 52 weeks after randomization were compared. The percentages (number/total) meeting trial criteria for recovery were 22% after CBT and after GET, 8% after APT, and 7% after SMC. Similar proportions met criteria for clinical recovery. The odds ratio (OR, 95% CI) for trial recovery after CBT was 3.36 (1.64, 6.88) and for GET 3.38 (1.65, 6.93), when compared to APT. This confirmed that recovery from CFS is possible, and that CBT and GET are the therapies most likely to lead to recovery (White, Goldsmith, Johnson, Chalder, & Sharpe, 2013).

There is insufficient evidence to suggest that antidepressants, corticosteroids, or other pharmacological agents are beneficial in the treatment of CFS, and no reliable evidence that dietary supplements, evening primrose oil, or intra-muscular magnesium are helpful (Reid et al., 2004). Prolonged rest cannot be recommended as a treatment for CFS, and may actually perpetuate or increase fatigue in people recovering from a viral illness. A literature review of treatments for CFS reported both limited benefits and substantial adverse effects with immunoglobulin therapy

(Rimes & Chalder, 2005). There is insufficient evidence for the use of interferon as an effective treatment for CFS.

Mediators of Change

There have been several studies that have attempted to examine mediators of change in relation to treatment outcome in CFS. Identifying mechanisms of change may elucidate ways in which treatment can be developed, tailored, or optimized to suit the needs of different individuals (Laurenceau, Hayes, & Feldman, 2007). It may also provide information about the clinical utility of the model on which treatment is based.

Patients receiving GET who reported overall improvement were no more physically fit than those not improving, but did perceive less effort with exercise, and those who improved their physical function had a smaller heart rate response to sub-maximal exercise (i.e., they were fitter) (Fulcher & White, 2000). Another trial of GET found a reduction in symptom focusing and an increased ability to exert oneself as assessed by maximal heart-rate-mediated change in mental and physical fatigue (Moss-Morris, Wash, Tobin, & Baldi, 2005).

In the context of CBT, a reduction in fearful cognitions was associated with better outcomes in an early trial comparing CBT with relaxation (Deale, Chalder, & Wessely, 1998). Several years later, a Dutch group found that a decrease in focusing on fatigue mediated the effect of CBT on fatigue and impairment in a trial of CBT compared to two control conditions (Wiborg, Knoop, Prins, & Bleijenberg, 2011). In summary, change in symptom focusing mediated treatment outcome in two trials, one of CBT and one of GET.

Interestingly, in the context of a trial of CBT, compared with counseling for chronic fatigue (not CFS) in primary care, a good fatigue outcome was associated with the patient acknowledging, expressing, and accepting distress (Godfrey, Chalder, Ridsdale Seed, & Ogden, 2007).

Acceptance

Research on patients with chronic pain has suggested that attempting to control pain that is uncontrollable (lack of acceptance) is associated with distress and frustration (Aldrich, Eccleston, & Crombez, 2000) and reduced physical functioning (McCracken, Carson, Eccleston, & Keefe, 2004). Lack of acceptance has also been shown to be inversely related to the ability to undergo positive, personal change for better health and well-being (Afrell, Biguet, & Rudebeck, 2007). Conversely, increased acceptance – giving up attempts to control pain – has been associated with less psychological distress and better well-being and adjustment (McCracken, 1998).

Despite the wealth of research into acceptance and chronic pain, the concept of acceptance in relation to chronic fatigue is discussed much less. One study that does consider the relationship between acceptance and CFS symptoms found that higher levels of acceptance were associated with greater psychological well-being and less distress in patients with CFS (Van Damme, Crombez, Van Houdenhove, Mariman, & Michielsen, 2006). In another study, lack of acceptance was the key factor associated with impaired physical functioning and work and social adjustment cross-sectionally. After a course of CBT, patients showed significantly increased acceptance, as well as reduced concern over mistakes (negative perfectionism), less fatigue and impairment of physical functioning, and improved work and social adjustment. (Brooks, Rimes, & Chalder, 2011).

This study showed that acceptance increased after CBT, despite not being directly incorporated into the cognitive behavioral model of CFS. It may be useful therefore to address acceptance directly during a course of CBT, as this may lead to improved physical and social functioning and less fatigue. While "willingness" is incorporated into CBT, acceptance is often not directly addressed, with CBT focusing more on graded increases in activity, sleep management, and addressing unhelpful cognitions concerning symptoms, coping strategies, and perfectionism. CBT could focus on acceptance of the symptom of fatigue using attentional strategies to facilitate this. It must be stressed, however, that acceptance of disability is not being advocated here. Indeed, the research demonstrates that disability can improve with rehabilitative therapies.

Perfectionism

Unhelpful aspects of perfectionism have been linked to CFS. Several studies (White, & Schweitzer, 2000; Deary & Chalder, 2010; Kempke et al., 2011) have found a link between CFS and the negative aspects of perfectionism (doubts about actions, concern over mistakes). More specifically, "self-critical" perfectionism has been shown to be related to increased stress sensitivity and depression in CFS patients (Luyten et al., 2011). Patients report positive change in certain aspects of perfectionism after CBT (Brooks et al., 2011). However, it is possible that enduring perfectionist traits may hinder improvement and / or put people at risk for future episodes of CFS or depression.

Prognosis

CFS is not associated with an increased mortality rate and rarely constitutes a missed medical diagnosis when an attempt has been made to exclude organic illness prior to making the diagnosis. A systematic review of studies describing the prognosis of CFS identified 14 studies that used operational criteria to define cohorts of patients with CFS (Cairns & Hotopf, 2005). Full recovery from untreated CFS is rare, and an improvement in symptoms is a more commonly reported outcome than full recovery. The median full recovery rate was 5% (range 0–31%), and the median proportion of patients who improved during follow-up was 39.5% (range 38–64%). Less fatigue severity at baseline, a sense of control over symptoms, and not attributing illness to a physical cause were all associated with a good outcome. Psychiatric disorder was associated with poorer outcomes. The review looked at the course of CFS without systematic intervention, but, as we have seen, there is now increasing evidence for the effectiveness of cognitive behavioral and graded exercise therapies. More recently, evidence suggests that recovery from CFS is possible, and that CBT and GET are the therapies most likely to lead to recovery (White, Goldsmith, Johnson, Chalder, & Sharpe, 2012).

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25

Pediatric Rheumatologic Disease

Laura Chiel and Robert Sundel

Introduction

Pediatric rheumatologic disorders tend to be systemic in scope. They may affect a wide variety of organ systems, and the combination of objective and subjective manifestations varies greatly from patient to patient. One girl with arthritis, for example, might have mild stiffness in the morning but no pain, yet her joints may be gradually eroded by aggressive and locally invasive synovitis. In contrast, another child may complain of severe and diffuse pain despite normal physical examination, laboratory testing, and imaging studies. This variety of expressions makes diagnosing and managing such conditions particularly challenging.

Not coincidentally, these same characteristics of rheumatologic disorders necessitate the use of complex lists of signs and symptoms as diagnostic and outcome markers. In juvenile idiopathic arthritis, for example, no single manifestation adequately encapsulates the multiple ways in which arthritis may affect a child. Instead, six domains are used to measure disease activity (Giannini et al., 1997):

1. Physician global assessment of disease activity
2. Parent/patient assessment of overall well-being
3. Functional ability
4. Number of joints with active arthritis
5. Number of joints with limited range of motion
6. Serologic marker of systemic inflammation (e.g., erythrocyte sedimentation rate)

The Handbook of Behavioral Medicine, First Edition. Edited by David I. Mostofsky.

Adding to the challenge, these domains include objective (e.g., laboratory tests), subjective (e.g., patient and physician global assessment), and ill-defined amalgamations of both subjective and objective data (e.g. joint motion and functional measures). Not only actual joint inflammation but also pain, damage, motivation, mood, and physiologic state affect these determinations. It is not surprising, therefore, that behavioral medicine has an important role to play in pediatric rheumatology. Perhaps less intuitively obvious, however, is the fact that such an approach impacts both the objective as well as subjective components of rheumatologic disorders. Systemic inflammation and the amount of joint swelling, as well as complaints of pain and stiffness, may be triggered, exacerbated, mitigated, or relieved by emotional factors and behavioral interventions. This chapter will provide an overview and illustrations of the role of behavioral therapy in the most common pediatric rheumatologic disease, juvenile idiopathic arthritis (JIA).

Environmental Factors and Rheumatologic Disease

Interactions between the immune system and environmental factors are addressed more fully elsewhere in this volume, but a brief overview of this topic in pediatric rheumatologic disorders will provide a framework for discussing therapeutic approaches to these conditions. Further, while psychoneuroimmunologic cross-talk in children parallels that in adults, age-related variations in conditions such as arthritis and systemic lupus erythematosus provide perspective on the unique aspects of these conditions in the pediatric population.

Up until the end of the nineteenth century, no medications apart from narcotics were available to treat inflammatory or autoimmune diseases. For the next 40 years, only aspirin was added to the armamentarium. Unfortunately, these analgesics had no effect on disease progression, disability, or mortality, so it is not surprising that much of the focus of the research community was centered on the negative effects of arthritis on mood, cognition, and life experiences (Jones, 1909). This led to studies analyzing the possibility that stress contributes to the onset of arthritis, and ultimately to the description of a specific “arthritis personality” characterized by a tendency to turn aggression inward rather than expressing it outwardly (Mueller & Lefkovits, 1956).

Although epidemiologic data supported a stress–disease interaction, difficulty characterizing and quantifying both the independent and the dependent variables led to a search for more objective measures. Several studies correlated the onset of autoimmunity in adults with stress-related increases in lymphocyte reactivity and pro-inflammatory cytokines (Segerstrom & Miller, 2004). Among other things, this offered a potential explanation for the fact that up to 80% of cases of autoimmune diseases occur in females, whose immune response is more robust due to both genetic and hormonal factors (Oertelt-Prigione, 2012). Exposure to environmental stressors in childhood, including abuse, domestic violence, and parental substance misuse, was shown to have long-lasting effects on immune function, and even to increase the risk of developing autoimmunity in adulthood (Danese et al., 2009; Dube et al., 2009). Most recently, variations in telomere length and epigenetic modifications related to stress and life events suggest that emotionally laden occurrences from gestation onward may have lifelong effects on susceptibility to autoimmunity (Kiecolt-Glaser et al., 2011).

Evaluation of these correlations and their mechanisms has progressed slowly in children. This is due both to the late development of pediatric rheumatology as a specialty, and the relative rarity of autoimmune conditions in children. Nonetheless, the lack of co-morbid pathology in children holds the promise of allowing purer and more precise analysis of genetic, epigenetic, and environmental factors in the development of arthritis, lupus, and related conditions. Indeed, studies of stress as a provoking and modulating factor in juvenile arthritis suggest an even more potent effect in children than in adults (Herrmann, Scholmerich, & Straub, 2000). The interaction is likely bidirectional, as some studies suggest that chronic diseases, including rheumatic conditions, may be associated with an increased prevalence of psychiatric disorders and mental impairment. Even parents of children with arthritis seem to demonstrate an increased rate of depression (Timko, Stovel, & Moos, 1992). Yet, while JIA appears to be associated with numerous familial and social problems, psychosocial outcomes are likely related more to family pathology than to disease severity (Aasland, 1997). This provides yet another realm in which behavioral interventions hold great promise: there is, after all, little doubt that the supportive family environment necessary for an optimal psychosocial outcome is more amenable to behavioral interventions than to anti-inflammatory medications.

Arthritis and Pain

Musculoskeletal pain is the most common reason that pediatricians refer children to a pediatric rheumatologist, despite the fact that pain is an unreliable marker of rheumatologic conditions in children (McGhee, Burks, Sheckels, & Jarvis, 2002). Juvenile fibromyalgia syndrome (JFS) is unique in being defined by a history of chronic pain in conjunction with associated symptoms including fatigue, depression, tender points, and the absence of abnormal laboratory values (Anthony & Schanberg, 2001). On the contrary, other inflammatory conditions cared for by pediatric rheumatologists, including JIA, systemic lupus erythematosus (SLE), juvenile dermatomyositis (JDM), vasculitis, and scleroderma do not include pain among the diagnostic criteria. Thus, as an example, a diagnosis of JDM is made based on the presence of a characteristic rash, weakness, and evidence of muscle inflammation; the presence or absence of pain is not considered.

In fact, when pain does affect children with rheumatologic diseases, it may have a variable relationship to the underlying disorder. On the one hand, although pain is not used to diagnose JIA, some studies suggest that pain is in fact present in many children with the disease. One group of researchers found that 86% of 293 children with arthritis reported pain during a clinic visit (Sherry, Bohnsack, Salmonson, Wallace, & Mellins, 1990). Others have found that 60% of children with arthritis experienced joint pain at disease onset, with 40% continuing to experience pain after 5 years (Lovell & Walco, 1989). Researchers have analyzed JIA patients' daily diaries to show that children reported having pain an average of 73% of days over a 2-month period; 76% reported pain on more than 60% of days (Schanberg, Anthony, Gil, & Maurin, 2003). The fact that this opinion so openly contradicts the contrary view that musculoskeletal pain is a rare initial complaint for children with JIA illustrates the limitations of knowledge regarding pain in children with arthritis (McGhee et al., 2002).

One way to reconcile these differences is to recognize the fact that pain may be a direct result of the joint inflammation characteristic of arthritis, or alternatively it may represent a secondary hypersensitivity state not inherently related to synovitis. Patients' sensitivity to noxious stimuli vary greatly, with some demonstrating pain strikingly out of proportion to the clinical manifestations of their JIA; up to 10% of children with JIA meet criteria for fibromyalgia, the archetype of pain hypersensitivity syndromes (Schikler, 2000). Some children with JIA have differences in their pain-coping abilities and stress and anxiety levels, causing them to experience more pain than their caregivers would expect based on objective findings. Research suggests that children who engage in pain catastrophizing, devoting increased attention to their pain and ruminating over it, had higher pain intensity ratings, as well as pain in a greater number of locations in their bodies (Schanberg, Lefebvre, Keefe, Fredrich, & Gil, 1997). Clearly, more systematic methods of pain evaluation coupled with the development of methods to reliably quantify subjective complaints will be necessary in order to fully illuminate the role that pain plays in JIA and measure its importance in diagnosis and treatment.

Although the frequency and severity of pain in JIA remains controversial, a unified theory recognizing an integral relationship between inflamed joints and increased sensitivity to noxious stimuli is broadly accepted. This model includes biological, behavioral, and cognitive factors as described by a group in North Carolina (Anthony & Schanberg, 2005). Figure 25.1, taken from this paper, illustrates the combination of factors that contribute to the child's pain experience; together, these can amplify or dampen perceived sensations. This global model has proven useful in juvenile fibromyalgia, where the presence of pain is universally recognized. It is beginning to be actively incorporated into the care of children with JIA as well.

Cognitive behavioral factors, including mood, stress, and pain-coping skills, are altered in patients with JIA. A recent study found that, although JIA patients reported symptoms on most days, they also reported positive mood on more than 90% of days (Schanberg, Gil, Anthony, Yow, & Rochon, 2005). While worsened mood was predictive of an increased report of symptoms, this study was unable to establish whether stiffness, pain, and fatigue determined children's moods,

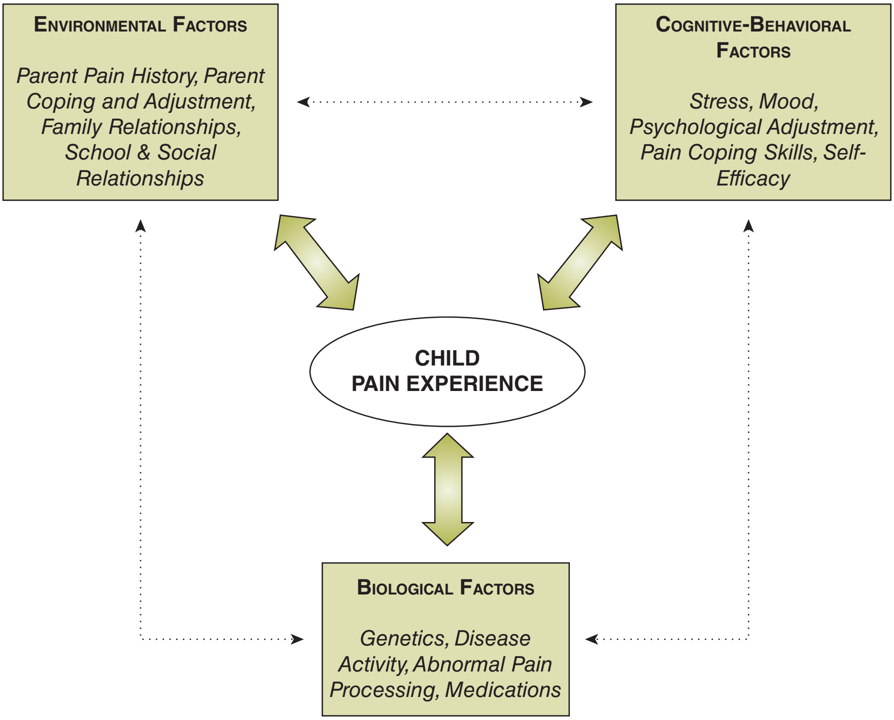

Figure 25.1 Biopsychosocial model of pain. From K. K. Anthony and L. E. Schanberg (2005). "Pediatric pain syndromes and management of pain in children and adolescents with rheumatic disease." *Pediatric Clinics of North America 52*(2): 611–639, vii.

or were exacerbated by them. In fact, the interplay is bidirectional, and the authors were able to show a correlation between state of mind and severity of symptoms. In addition to being related to reports of symptoms, stress and mood also correlated with the extent to which children with arthritis participated in activities. Daily mood, stiffness, pain, and fatigue predicted children's likelihood of refraining from social activities, while mood and stiffness were predictive of decreased school attendance. Interestingly, however, children were even more likely to limit participation in social activities than school activities. Although this may stem from the greater perceived importance of school compared to social events, it also has significant therapeutic implications, given that a reduction in social activities may contribute to feelings of loneliness and diminished quality of life. In fact, there is evidence to suggest that children with arthritis are at increased risk of developing a sense of isolation and struggling with peer relationships (Schanberg et al., 2005). Since social isolation at a young age may be difficult to repair later on, the need for a broad biopsychosocial approach to patients' symptoms, anxiety, and stress levels is clear.

Therapeutic Approaches to Pain in Juvenile Arthritis

The use of cognitive-behavioral interventions has been crucial to favorably altering psychological and social factors that contribute to pain in children with arthritis. Regardless of whether pain is integral to joint inflammation or superimposed upon it, treatment of pain through so-called "complementary" interventions is crucial to the well-being of children with JIA. Eyckmans and colleagues (2011) identified five main themes of well-being that should be considered and incorporated into a multidisciplinary approach to pain: (1) physical impact, (2) medication, (3) relationships with family, (4) friends, and (5) perceptions of the future (Figure 25.2).

Several of these domains, particularly the physical impact of arthritis and the medications used to treat it, are self-evident, and they generally fall within the purview of medical therapy. Other factors, however, less clearly respond to the episodic, sick-visit model of traditional medical care. For example, a tendency toward greater social isolation among children with chronic diseases has a

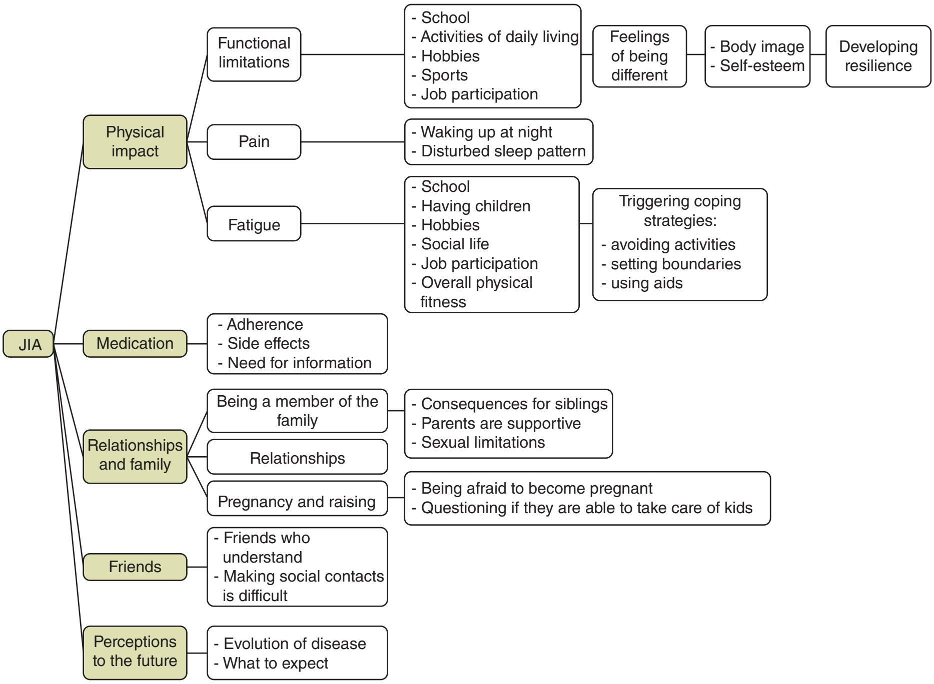

Figure 25.2 Patients' perceptions of physical and emotional effects of JIA. From L. Eyckmans, D. Hilderson et al. (2011). "What does it mean to grow up with juvenile idiopathic arthritis? A qualitative study on the perspectives of patients." *Clinical Rheumatology 30*(4): 459–465.

negative impact on well-being that will not be ameliorated by improved morning stiffness. While one study showed that stiffness, pain, and fatigue account for withdrawal from daily activities, other studies have emphasized that factors only slowly responsive to medical therapy (such as joint deformities and damage, osteoporosis, and growth abnormalities) may be even more responsible for the tendency of children with JIA to isolate themselves (Anthony & Schanberg, 2005). Yet other researchers found no clear association between the degree of physical disease and psychological function (Baildam, Holt, Conway, & Morton, 1995). Furthermore, although high pain levels may keep children out of school, one study found that Norwegian women with JIA had higher education levels than Norway's general population. The authors suggested that this might be due to recognition of the importance of entering a career demanding cognitive rather than physical exertion. It could also reflect responder bias, as patients with higher education could be more willing to answer the study questionnaires (Ostile, Johansson, Aasland, Flato, & Moller, 2010).

School attendance also may impact a child's activity level, participation in physical education classes, and opportunity to play sports with peers. Patients with JIA "are often less physically active than their peers as a result of disease symptoms, and have decreased aerobic capacity and endurance, decreased exercise time, and decreased peak workload as compared with healthy controls" (Anthony & Schanberg, 2005). In light of evidence that physical conditioning may beneficially impact inflammation, pain, and self-image, inactivity may be yet another subtle headwind challenging the overall well-being of children with JIA (Walsh et al., 2011).

Whether or not issues relating to mood and anxiety are responsible for decreases in school attendance and social participation, treatments that directly address these factors are valuable. For example, massage therapy, a treatment intended to address patients' pain, has the added bonus of lessening anxiety and stress; at least one study has shown it to be an effective therapy for patients with JIA. Thus, Field and coworkers randomized patients to receive a daily 15-minute massage by one of their parents for 30 days, or to participate in a 15-minute relaxation exercise with a parent every day for a month (Field et al., 1997). The researchers observed less anxiety among patients in the massage group as well as lower salivary levels of cortisol, a pro-inflammatory hormone that correlates with the stress response. Furthermore, the patients in the massage group reported less pain after the study period.

The study's sample size was small, and more research on the utility of massage versus other relaxation techniques is necessary. The authors do hypothesize, however, that relaxation therapy might have been less effective than massage therapy in this study, as the children were too young to actively and fully engage in the relaxation exercises. They suggest that there may be benefits to a better-designed relaxation regimen. Importantly, parents administering the massages in the massage group also experienced a reduction in stress levels. As parental attitudes can significantly impact a child's experience of disease, parents' involvement in pain therapy may be beneficial to both the parent and the patient (Logan et al., 2012). This potentially synergistic role of parent participation is important to remember when designing therapies for JIA.

Coping strategies incorporate training patients to move away from thoughts about their pain such as "It is awful and I feel that it overwhelms me" or "I worry about it all the time" in order to reduce pain levels (Schanberg et al., 1997). Other approaches have found that positive self-statements and behavioral distraction lead to reduced pain in patients with JIA, and have confirmed that patients who displayed catastrophizing had reduced tolerance and threshold to pain as well as greater intensity of pain (Thastum, Zachariae, & Herlin, 2001). Although Thastum and coworkers demonstrated a correlation between distraction coping strategies and lower reported pain, the authors acknowledge the difficulty of identifying cause and effect: Patients with less pain simply might be better able to employ distraction coping strategies, rather than distraction strategies leading to less pain. The authors explain, "High pain patients could be so overwhelmed by their pain that they are unable to use distraction strategies." A better understanding of individual variations in the efficacy of various coping strategies, and whether these strategies are feasible for patients with JIA regardless of initial pain level, will be crucial in developing better therapies for the patients.

The biopsychosocial model of pain proposed by Anthony and colleagues (2005) includes self-efficacy as an additional cognitive behavioral factor (Figure 25.1). As with many of the data concerning the interactions of disease and behavior in JIA, research regarding the status of self-esteem in patients with JIA is mixed. While one study found better self-concept in children with JIA, and even reduced anxiety, others have found that patients with JIA "viewed their appearance and popularity less favorably than their siblings" (Baildam et al., 1995).

Cognitive behavioral therapy (CBT) has been found effective in helping children cope with chronic diseases in general, but the utility of this therapeutic regimen in JIA appears to hold particular promise. At least two studies have demonstrated reduced self-report of pain in JIA patients following cognitive behavioral therapy, both immediately following treatment and 6-months later (Anthony & Schanberg, 2005). In a 1992 study in *Pediatrics*, children with JIA were trained in a three-part regimen: (1) *progressive muscle relaxation*, which involved tensing and relaxing major muscle groups; (2) *meditative breathing*, involving medium inhalation through the nose, followed by slow exhalation through the mouth, while saying "relax" silently to oneself; and (3) *guided imagery*, where children imagine themselves in pleasant pain-free scenes of their choosing as a way of escaping pain. The authors of this study found statistically and clinically significant benefit, both in the short term and long term, and recommended adding CBT to traditional pharmacological treatments (Walco, Varni, & Illowite, 1992). In general, research on the use of CBT in JIA is limited by many of the same shortcomings as are other studies of non-pharmacologic interventions, including small sample sizes, limited scope of age-appropriate interventions, and lack of functional outcome measures. Nonetheless, greater ability to take advantage of the therapeutic potential of CBT in patients with JIA would likely be very fruitful and should be pursued.

In addition to addressing cognitive behavioral factors implicated in the genesis of pain, environmental factors offer a potential therapeutic target as well. Parent pain history, parent coping and adjustment, and aspects of well-being such as family, school, and social relationships also play a role in the pain experience of a child with JIA. Behavioral interventions may be of use in modifying those environmental factors negatively impacting a patient with JIA.

Parental pain history, exemplified by family history of chronic pain conditions, parental pain that disrupts activities, and high parental pain intensity all affect a child's pain. Such factors are associated with both a child's self-report of pain and likelihood of engaging in pain catastrophization, and with the doctor's evaluation of disease status (Anthony & Schanberg, 2005). Thus, a child is more likely to use approach and distraction if these are modeled by parents, and more likely to use pain-catastrophizing if that is the parents' default response to pain (Thastum et al., 2001). Importantly, parents have been shown to rate their child's health-related quality of life lower than the patient would him or herself. Researchers suggest that this might be related to the fact that children are better able to adapt to their disease (Sawyer et al., 2005). Alternatively, pain perception may be affected by genetic and learned factors, with pain intensity and tolerance in both low- and high-pain JIA patients correlating with parents' pain experiences (Thastum et al., 2001).

As noted in the preceding text, the interaction between disease and mood is bi-directional. Similarly, interventions affecting the child's disease can positively or negatively impact a parent's psychological state. Barlow and Ellard (2004) reported that parents who attended a residential workshop "had fewer episodes of disease-related stress and improved psychological well-being. Almost half of the parents felt that they were communicating more effectively with their adolescent child, and felt more assertive in accessing resources such as home tuition." Interestingly, just as paying attention to patients' risk of social isolation is important, enabling parents to meet others like themselves was similarly of benefit. Interventions that focus on the health and knowledge of parents of children with JIA thus might be expected to translate into improved health outcomes.

Another example of an effective intervention targeting parents was a program that linked mothers of JIA patients between the ages of 2 and 11 with mothers of young adults who had had JIA for some time. "The intervention aimed to enhance informational support (dealing with teachers), affirmational support (e.g., giving praise), and emotional support (e.g., feelings). Compared with the control group, the mentoring group showed improvements in maternal mental health and social support" (Barlow & Ellard, 2004). Further research on interventions that target parents will be edifying and will have practical implications for therapeutic management.

Yet a further level of complexity regarding the potential of cognitive behavioral interventions for children with juvenile arthritis lies in the area of family dynamics. Interactions within families of children with a variety of chronic illnesses, including JIA, have been shown to differ from those in families without such a child. Enmeshment, overprotectiveness, rigidity, and lack of conflict resolution are generally viewed as a problematic pattern that is often witnessed in families of children with chronic diseases. Nonetheless, they may provide benefits in certain circumstances. To a degree, there is a negative correlation between cohesion and pain intensity, implying that "a close family environment may be beneficial rather than stressful" (Thompson, Varni, & Hanson, 1987). On the other hand, different researchers have found that just as maternal anxiety is associated with higher pain ratings in JIA patients, so, too, is family harmony. Perhaps one reason for this surprising finding is that cohesive families may be more accepting and encouraging of a child's display of pain reporting and behavior. In fact, "families with less harmonious environments, due either to less organization and cohesion or higher conflict, may have less capability for responding to reported pain" (Ross et al., 1993). This, in turn, might make it less likely for children to engage in pain-driven behaviors.

Finally, parents, particularly those who use complementary medicine for themselves, sometimes attempt to treat their children with non-traditional therapies. A recent study showed that, in general, complementary medicine was not used as a substitute for traditional medicine, but in addition to it (Feldman et al., 2004). These therapies include the use of copper bracelets, patent medicines, vitamin and mineral supplements, and dietary alterations. These approaches are, at best, unproven, and some may be detrimental. Research suggests, for example, that dietary changes may be dangerous as children with JIA are often underweight, and depriving them of further nutrition is ill-advised (Southwood, Malleson, Roberts-Thompson, & Mahy, 1990). Nonetheless, the full spectrum of medical, emotional, and familial effects of complementary therapies on children with arthritis is only poorly understood. It represents yet another area ripe for investigation.

Conclusions

Juvenile arthritis is a multidimensional inflammatory disease of the joints accompanied variably by pain, psychological stress, and familial disruption. These factors, in turn, influence and are influenced by the child's mood, motivation, support structures, and physiologic state. Complex interactions between these factors cannot be addressed by traditional therapeutic interventions alone. Rather, pharmacologic and non-pharmacologic therapies must be seamlessly integrated if the underlying joint inflammation and secondary biopsychosocial variables are to be optimally benefitted. While the need for greater understanding of the underlying neurobiological mechanisms of arthritis is taken for granted, the importance of integrating behavioral medicine into current clinical practice is no less essential for the treatment of childhood rheumatologic diseases to continue to improve.

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26

Non-pharmacologic Approaches to Stress-induced Infertility

Ameigh V. Worley and Sarah L. Berga

Introduction

Scholars typically view infertility as a medical condition with psychological consequences and fail to recognize a subset of infertility that is a psychological condition with medical consequences. Much evidence has accumulated regarding the contribution of psychological factors to infertility in women. Stress-induced physiological changes are predictive of decreased probability of achieving pregnancy. Through years of research, the gradual unraveling of the complexities of psychoneuroendocrinology has led to mounting evidence pointing to an endocrine disequilibrium in response to stress, and describes a hierarchy of biological mediators (catecholamines, adrenal steroids, endorphins, prolactin, thyroid hormone, serotonin, dopamine, melatonin, ghrelin) involved in the resultant reproductive failure. This chapter aims to critically assess the evidence of stress linked to human infertility.

The Basics of Neuroendocrinology

The hypothalamus

The primary role of the hypothalamus is homeostasis, or adaptation and maintenance of physiological stability in a setting of dynamic perturbations. It does so via equilibrium adjustments and neuronal regulation mechanisms based on pathophysiological afferent impulses. Through an intricate network of neuronal synapses, transmission is sent along "axes" from the hypothalamus to the pituitary and further

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down the peripheral cascade to the target tissue (Figure 26.1). These axes include the well-known hypothalamic–pituitary–adrenal axis (HPA), hypothalamic–pituitary–ovarian axis (HPO), and hypothalamic–pituitary–thyroid axis (HPT). Neuromodulation is not restricted solely to these pathways, but rather there is a complex interplay in which a myriad of hormones, neurotransmitters, and neuropeptides all interconnect, leading to either excitation or inhibition. The main hypothalamic regulatory peptides, or "releasing hormones," released from the hypothalamus include gonadotropin-releasing hormone (GnRH), growth-hormone-releasing hormone (GHRH), corticotrophin-releasing hormone (CRH), and thyrotropin-releasing hormone (TRH). These act upon the pituitary to further propagate response.

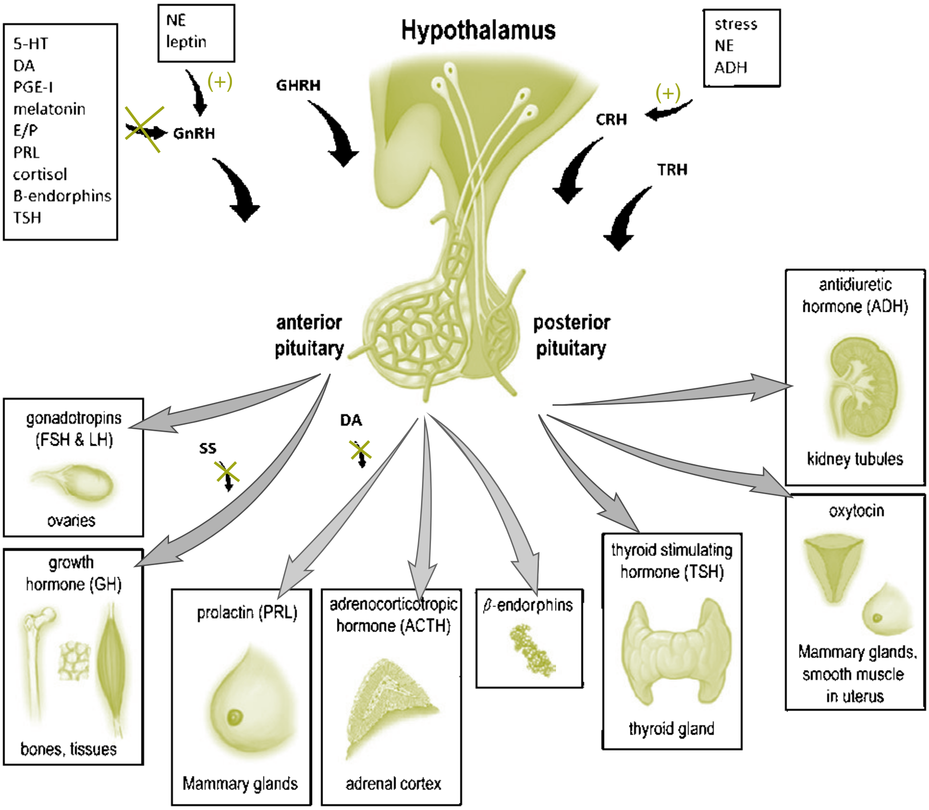

Figure 26.1 Diagram of the multiple hypothalamic–pituitary–gland axes and the complex interplay of hormonal neuroregulation. Neuromodulator hormones include: serotonin (5-HT), dopamine (DA), prostaglandin inhibitors (PGE-I), estrogen/progesterone (E/P), prolactin (PRL), thyroid stimulating hormone (TSH), norepinephrine (NE), gonadotropin-releasing hormone (GnRH), growth-hormone-releasing hormone (GHRH), corticotrophin-releasing hormone (CRH), thyrotropin-releasing hormone (TRH), follicle-stimulating hormone (FSH), luteinizing hormone (LH), and somatostatin (SS).

The pituitary

The pituitary gland is a protrusion off the base of the hypothalamus. It sits within a protective bony enclosure called the sella turcica and is functionally connected to the hypothalamus by the median eminence via the infundibulum. Segregated into two main lobes, the anterior portion (adenohypophysis) arises from an invagination of the oral ectoderm and forms Rathke's pouch, while the posterior portion (neurohypophysis) originates from neuroectoderm.

Hypothalamic hormones are released by the parvocellular neurosecretory cells and are secreted to the anterior pituitary by way of a special capillary system called the hypothalamic–hypophysial portal system. These hormones then signal the anterior pituitary to secrete follicle-stimulating hormone (FSH), luteinizing hormone (LH), growth hormone (GH), prolactin (PRL), adrenocorticotropin hormone (ACTH), β-endorphins, and thyroid-stimulating hormone (TSH). In contrast, the posterior pituitary receives its signals via axons that project directly from the magnocellular neurosecretory cells of the hypothalamus, through the infundibulum, terminating in the posterior pituitary, thereby causing release of antidiuretic hormone (ADH, also known as vasopressin) and oxytocin.

The glands

Two of the most complex glands in the human body include the adrenals and the female gonads.

The adrenal gland is composed of an outer cortex and an inner medulla. The cortex has three separate portions: the glomerulosa (responsible for aldosterone secretion), the fasciculata (responsible for cortisol secretion), and the reticularis (responsible for androgen secretion). The adrenal medulla releases the catecholamines norepinephrine (NE, also known as noradrenaline) and epinephrine (also known as adrenaline) when signaled by the sympathetic portion of the ANS in response to stressful stimuli. This response is commonly known as the "fight-or-flight" mechanism.

The main pathway of the HPA axis involves secretion of CRH from the hypothalamus, which principally results in secretion of ACTH from the pituitary, and subsequent glucocorticoid release from the adrenal cortex. CRH has additional sites of action, including: (1) stimulation of the posterior pituitary's release of vasopressin and oxytocin, (2) stimulation of the adrenal medulla's noradrenergic activity via sympathetic nervous system activation, and (3) secretion of β-endorphins from the anterior pituitary.

Regulation of the gonads begins with GnRH, which is secreted from a cluster of neurons called the arcuate nuclei, located within the median eminence of the hypothalamus. The secretory pattern of GnRH is pulsatile in nature. GnRH reaches the pituitary, where it stimulates gonadotropin secretion (FSH/LH). The accumulation of gonadotropins to a maximum level, through a series of events, leads to ovulation, along with the secretion of estradiol (E2) and progesterone (P). GnRH is subject to feedback regulation by ovarian estradiol and progesterone, as well as numerous other hormones and neuropeptides (Figure 26.1).

Activation of prostaglandin E2 (PGE) synthesis is an essential step in the sequence of events leading to GnRH release from the median eminence (Ojeda & Negro-Vilar, 1984). Thus, PGE inhibitors such as NSAIDs block GnRH release and can subsequently abolish the mid-cycle LH surge. Opioids/β-endorphins (under the effect of CRH) exert an inhibitory effect on GnRH release. This has been confirmed with studies in which naloxone, an opioid blocker, increased LH levels (Khoury, Reame, Kelch, & Marshal, 1987). Interestingly however, GnRH is unaffected by exogenous opioids (Ropert, Quigley, & Yen, 1981). Dopamine inhibits GnRH release (Ropert, Quigley, & Yen, 1984) while metoclopramide, a dopamine receptor blocker, accelerates it (Berga et al., 1991). TSH, serotonin (5-HT), melatonin, cortisol, and PRL (inhibited by DA), all inhibit GnRH release, while leptin and NE facilitate it.

The menstrual cycle

The menstrual cycle, under the control of the neuroendocrine system, is commonly divided into three phases: the follicular, mid-cycle, and luteal phases (Figure 26.2).

During the follicular phase, follicles in the ovary begin developing under the influence of FSH. As they mature, they secrete increasing amounts of E2, which serves to initiate the formation of a new layer of endometrium in the uterus. (As such, the follicular phase is also commonly referred to as the uterine proliferative phase.) Eventually, one follicle becomes dominant, and the rising E2 from that follicle suppresses FSH and, in turn, the other follicles atrophy. The dominant follicle that reaches maturity is called a Graafian follicle, and it contains the ovum. Throughout this process, E2 suppresses production of LH from the anterior pituitary via negative feedback at the E_α-receptor. When the egg reaches maturity, the rate of rise of E2 reverses this effect and E2 actually *stimulates* the production of a large amount of LH via the E_β-receptor. This is known as the LH surge (Hu et al., 2008). Approximately 24–36 hours after LH surges, the dominant follicle releases the ovum.

After ovulation, the remains of the dominant follicle in the ovary become a corpus luteum. This body has a primary function of producing large amounts of P to prepare the endometrium for potential implantation by the blastocyst if fertilization occurs. (It also has the side effect of raising basal body temperature, which has become a commonly used tool for women to track ovulation and identify times of peak fertility.) If implantation does not occur, the corpus luteum involutes, and sharp drops in E2/P cause the uterus to shed its lining and results in menstruation. (As such, the luteal phase is also commonly referred to as the uterine secretory phase.) The loss of the corpus luteum can be prevented by fertilization of the egg, whereby the resulting embryo produces human chorionic gonadotropin (hCG), which preserves its presence.

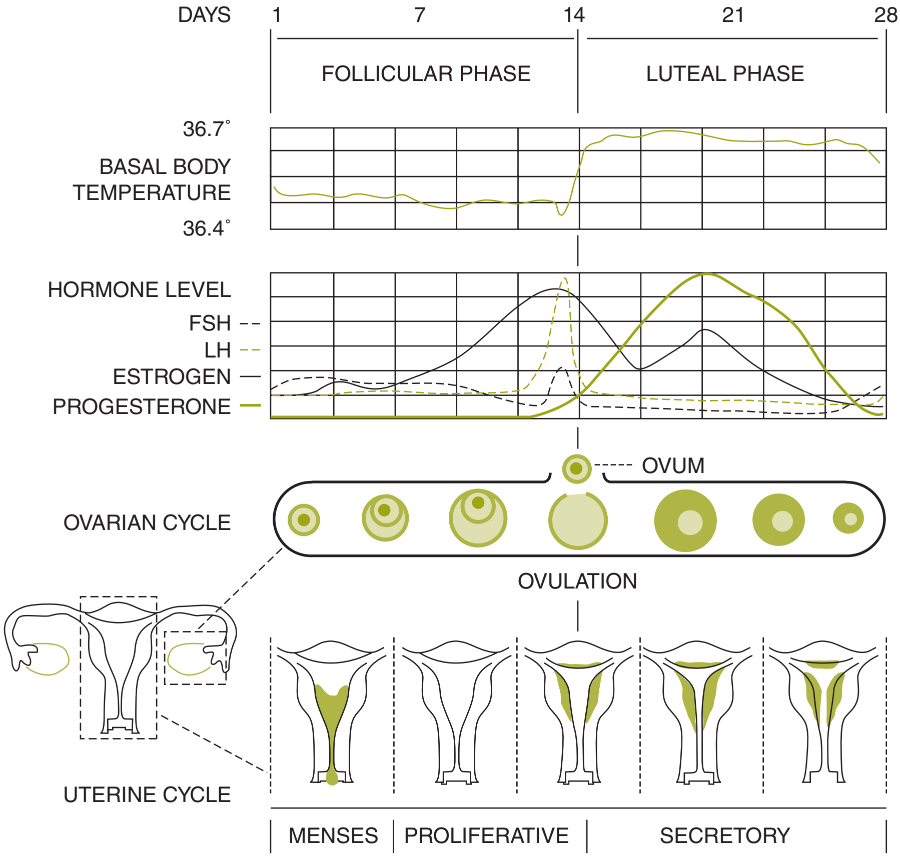

Figure 26.2 The female menstrual cycle. (Permissions granted to copy and distribute from http://en.wikipedia.org/wiki/File:MenstrualCycle2_en.svg under the GNU Free Documentation License, http://www.gnu.org/copyleft/fdl.html. Date accessed: February 1, 2013).

Menstrual cycle abnormalities

The typical menstrual cycle has an interval of 28 days, with a standard deviation of ±7 days. Cycles with intervals lesser than 21 days are referred to as "polymenorrhea," and cycles exceeding 35 days are called "oligomenorrhea." "Amenorrhea" refers to an absence of menses for greater than 3–6 months during reproductive years, disregarding pregnancy.

The absence of ovulation is called "anovulation." Menstrual flow can occur without ovulation preceding it. This is referred to as an anovulatory cycle. With anovulation, E2 levels rise as usual in the early phase of the cycle but never cause an LH surge. Without an LH surge, ovulation fails to occur; in the absence of ovulation, a corpus luteum never forms and P is not produced. The result is an endometrium that moves into a hyperproliferative state, which ultimately outgrows its E2 supply. This leads to irregular, excessive menstrual flow due to sloughing of the disorganized, thickened endometrium, which has lost its structure and integrity at different global aspects at different times as a result of spiral arteries failing to undergo physiological senescence.

Blood flow volume in a normal cycle averages 35 cc per week. Flows exceeding 80 cc is called "menorrhagia." Intermenstrual blood flow is known as "metrorrhagia." And heavy, irregular menstruation is "menometrorrhagia."

Causes of Infertility

Infertility is defined as 12 months of focused attempts to conceive without success for women aged 34 or younger, or after 6 months for women aged 35 and above (Chandra, Marinez, Mosher, Abma, & Jones, 2005). Recent epidemiologic studies report that 12% of couples suffer from infertility (WHO, 2003). In developed nations, infertility has reached epidemic levels and is primarily attributed to delayed childbearing, as more women are pursuing higher education and entering the workforce (Heffner, 2004). Infertility is definitely age dependent, affecting approximately 11% of women aged 15–29, 17% of women aged 30–34, 23% of women aged 35–39, and 27% of women aged 40–44 (Chandra et al., 2005). Thirty percent of cases are attributable to factors that affect males, 30% are due to female factors, 30% are caused by a combination of problems in both partners, and approximately 10% of infertility cases are unexplained or idiopathic.

Male factor infertility is always related to altered semen quality. The etiology can be secondary to hypothalamic–pituitary dysfunction, chromosomal abnormalities such as Klinefelter's syndrome (47, XXY) or Y chromosome microdeletions, obstructive processes such as a history of prior vasectomy or congenital bilateral absence of the vas deferens (associated with cystic fibrosis), a testicular mass or varicocele, or iatrogenic introduction of chemotherapy or radiation therapy.

Among the causes contributing to female infertility are endocrine factors and anatomic/mechanical factors. Anatomic factors that interfere with female infertility can occur at any level of the pelvic reproductive organs (Table 26.1). Cervicovaginal causes include imperforate hymen, transvaginal septum, and cervical stenosis. Uterine malformations such as congenital Müllarian anomalies, fibroids, polyps, chronic endometritis, synchiae, and Asherman's syndrome may also play a role in infertility. Tubal factors comprise occlusions or hydrosalpinges, usually related to a history of pelvic inflammatory disease, endometriosis, or prior abdominal surgery. Ovarian factors consist of gonadal dysgenesis (46, XX, which indicates a congenitally low initial follicle count), Turner's syndrome (45, XO, which is associated with increased follicle atresia), autoimmune destruction, a history of chemotherapeutic or radiation exposure, or surgical damage. Peritoneal factors include pelvic adhesive disease from prior pelvic inflammatory disease, pelvic surgery, a history of ruptured appendix, endometriosis, or chronic inflammation from inflammatory bowel disease.

Table 26.1 Anatomic causes of female infertility.

Cervicovaginal Factors
- Imperforate hymen
- Transvaginal septum
- Cervical stenosis

Uterine Factors
- Müllerian anomalies
- Fibroids
- Polyps
- Chronic endometrisis
- Synchiae
- Asherman's syndrome

Tubal Factors
- Occlusions
- Hydrosalpinges

Ovarian Factors
- Gonadal dysgenesis
- Turner's syndrome
- Autoimmune disease
- Oophoritis
- Radiation/chemotherapy/surgery

Peritoneal Factors
- Pelvic adhesive disease
- Inflammatory bowel disease

Endocrine etiologies of infertility are usually categorized by physiological hormonal status (Table 26.2).

Hyperandrogenic states include: (1) polycystic ovary syndrome (PCOS), characterized by elevated LH secretion, excessive production of male hormones, hyperinsulinemia, and hirsutism; (2) congenital adrenal hyperplasia (CAH), associated with excessive androgen production due to enzymatic deficiencies and subsequent shunting of chemicals involving the cholesterol metabolic pathways; (3) Cushing's syndrome, which involves inappropriate production of ACTH and subsequent elevated cortisol levels; and (4) androgen-secreting tumors such as Sertoli-Leydig. Each of these disorders manifests with feedback inhibition on GnRH release and subsequent amenorrhea/anovulation.

Hypergondatropic hypogonadism refers to a state of elevated hypothalamic GnRH production (and pituitary FSH/LH release) in response to diminished ovarian hormone levels. This is most commonly encountered in situations of ovarian failure such as menopause or idiopathic premature ovarian failure.

Hypogonadotropic hypogonadism denotes a physiological condition in which ovarian hormone levels are low as a result of diminished or absent GnRH or FSH/LH secretion. In other words, the derangement lies in the hypothalamus or pituitary

Table 26.2 Endocrine causes of female infertility.

Hyperandrogenic Causes
- Polycystic ovarian syndrome
- Congenital adrenal hyperplasia
- Cushing's syndrome
- Androgen-secreting tumors (Sertioli-Leydig)

Hypergonadotropic Hypogonadism
- Menopause
- Premature ovarian failure

Hypogonadotropic Hypogonadism
- Hypothalamic failure
- Kallman's syndrome
- Stress
- Pituitary dysfunction
- Empty sella syndrome
- Sheehan's syndrome
- Simmond's syndrome
- Pituitary stalk lesions
- Pituitary adenoma
- Hypothyroidism

gland and manifests as ovarian dysfunction. This is in direct contrast to *hyper*gonadatropic hypogonadism in which the decrement begins in the ovaries and results in appropriate hypothalamic–pituitary response in an attempt to increase ovarian hormone levels, which are unable to respond due to existent ovarian failure.

The causes of hypogonadotropic hypogonadism are numerous and can occur at either the level of the hypothalamus or the pituitary. Congenital absence of GnRH release from the hypothalamus occurs as a result of Kallman's syndrome – a rare disorder characterized by congenital absence of GnRH synthesis and anosmia secondary to failure of embryologic neuronal migration due to a mutation on the short arm of the X chromosome. GnRH suppression can also be due to stress-induced activation of the HPA axis, which results in elevated cortisol levels that feedback inhibit GnRH. Stress can be physiological (nutritional restriction as seen in anorexia nervosa, extreme energy expenditure associated with excessive exercise, states of chronic disease) or psychological (extreme emotionality, social instability).

At the level of the pituitary, hypogonadotropic states can occur as a result of complete pituitary failure or interference with normal secretion (Figure 26.3). Complete failure (no hormonal secretion) may occur from empty sella syndrome (a condition in which no pituitary hormones are secreted due to a congenital defect of the sella diaphragm, leading to herniation of arachnoid into the pituitary gland and displacement of any normal tissue), Sheehan's syndrome (panhypopituitarism as a result of a pituitary infarct that occurred in pregnancy or immediately postpartum), or Simmond's syndrome (panhypopituitarism resulting from a pituitary

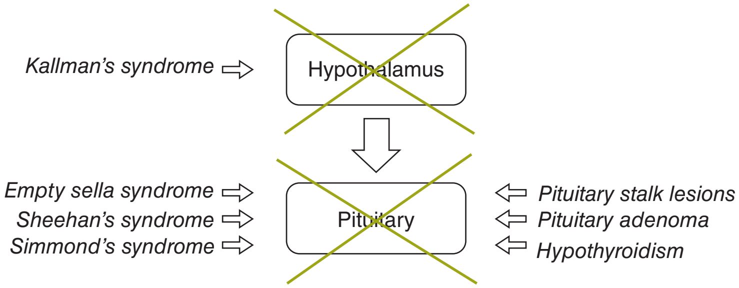

Figure 26.3 Organic causes of reduced GnRH release from the hypothalamus or reduced FSH/LH secretion from the anterior pituitary.

infarct *not* associated with pregnancy). On the other hand, there are situations in which pituitary hormone secretion is possible, but signaling is inhibited. The most common causes of such occurrences include pituitary stalk lesions such as craniopharingiomas (which interfere with the signaling pathways), adenomas (most commonly prolactinomas, which cause negative feedback to GnRH), or hypothyroidism (which leads to elevated PRL and subsequent GnRH inhibition).

Functional Hypothalamic Amenorrhea

Pathogenesis

Stress-related amenorrhea has been referred to by many names, including "hypogonadotropic hypogonadism," "hypothalamic hypogonadism," "stress-induced anovulation," and "functional hypothalamic amenorrhea." For purposes of this chapter, we will use the term *functional hypothalamic amenorrhea*, or FHA.

The pathogenesis of FHA is quite complex but, in totality, is simplistically due to suppression of GnRH pulsations. GnRH neurons are endogenously pulsatile. They are active during fetal life (Rasmussen, Liu, Wold, & Yen, 1986), and then inhibited until the onset of puberty (Terasawa, 1995). Kisspeptin, a G-protein-coupled ligand for the GPR54 receptor first identified in 1999, has an important role in initiating secretion of GnRH at puberty via direct stimulation of neurons in the arcuate nucleus (Messager et al., 2005) (Figure 26.4). This is evident by findings that spontaneous mutations or targeted deletions of GPR54 in humans cause hypothalamic amenorrhea and infertility (Smith, Clifton, & Steiner, 2006).

Appropriate GnRH drive is required for ovulation. Inappropriate input lowers pituitary secretion of FSH/LH below the threshold needed to sustain full ovarian function and results in a spectrum of menstrual cycle compromise. For folliculogenesis to result in ovulation, GnRH must remain above critical thresholds for approximately 12–14 days. Intermittent gonadotropin insufficiency can lead to

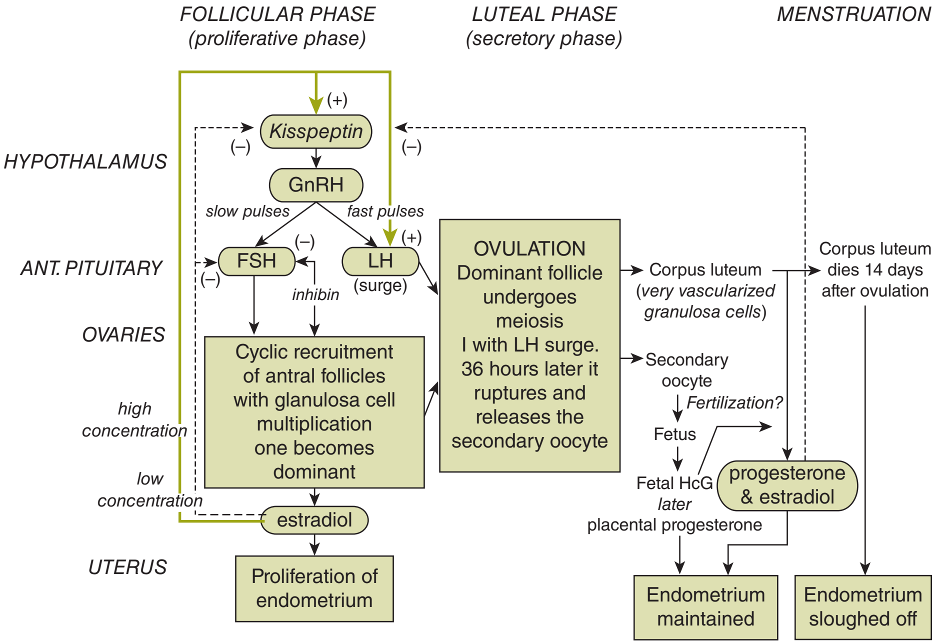

Figure 26.4 Regulation of GnRH activation at puberty by Kisspeptin, and diagram of the subsequent menstrual cycle cascade. (Permissions granted to copy and distribute from Wikipedia under the Creative Commons Attribution-Share Alike 3.0 Unported License, http://creativecommons.org/licenses/by-sa/3.0/deed.en. Date accessed: February 1, 2013).

early follicular demise, whereas a reduction in drive leads to luteal insufficiency (Figure 26.5).

In a series of experiments on oophorectomized monkeys, endogenous GnRH administered hourly led to a mid-cycle LH surge (Knobil, 1980). However, when the pulse frequency was increased to one pulse every 20 minutes or decreased to one pulse every 3 hours, gonadotropin secretion was inhibited and no LH surge or ovulation occurred. This was confirmed by a human study which demonstrated that women with FHA had altered GnRH pulse frequency (Crowley, Filicori, Spratt, & Santoro, 1985). Ergo, control of tightly parametered GnRH section is critical for the maintenance of ovulation.

Reduced GnRH drive rarely has an organic cause such as Kallman's syndrome or pituitary dysfunction, as described in the preceding text (Figure 26.3). Typically, the cause is "functional" – a consequence of physical/psychosocial stress rather than an identifiable organic cause. Advances in neurobiology and behavioral sciences have provided a sound basis for understanding the effect of psychological conflict on the coordinated function of the HPO axis. FHA was most eloquently described as "a form of gonadal compromise in which psychophysiological and behavioral responses

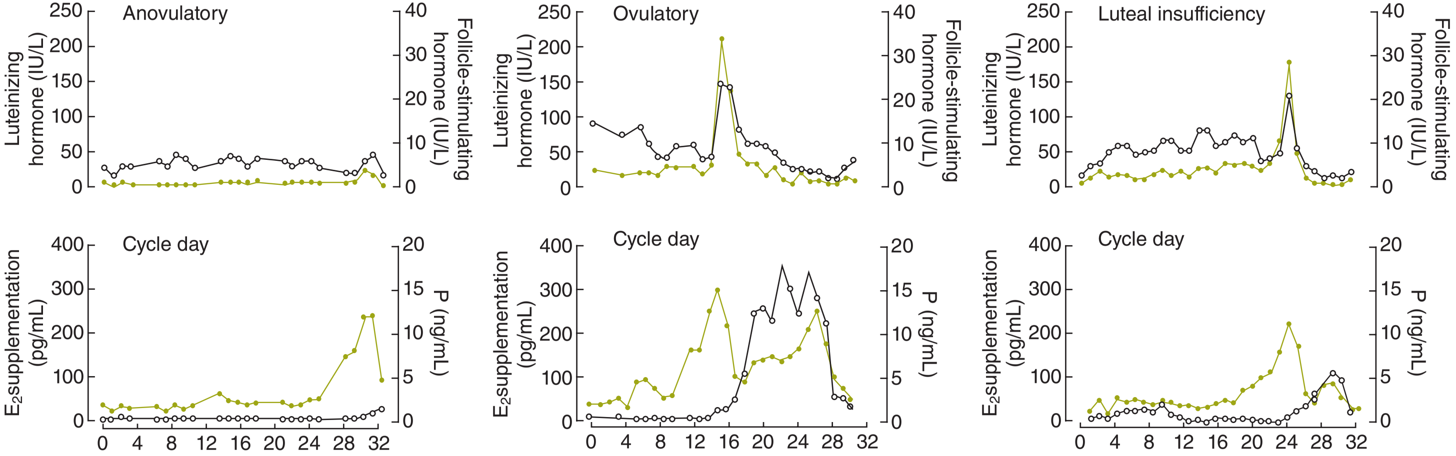

Figure 26.5 Examples of the effects of different GnRH drives on the menstrual cycle. When GnRH drive is normal, an LH surge takes place and ovulation occurs (middle images). When GnRH drive is insufficient to provoke follicular development or LH surge, the cycle is anovulatory (left images). When GnRH is present but has a reduced drive, luteal-phase insufficiency results (right image). (Reprinted with permission from Berga, S. L., unpublished.)

to life events activate central neuroregulator networks such that there is concomitant metabolic mobilization and reproductive suppression due to disruption of the GnRH pulse generator," or, more simply stated, "a constellation of neuroendocrine aberrations that reflect allostatic adjustments to chronic stress" (Berga & Loucks, 2006). It is psychosomaticism at its finest.

While psychological distress affects biological function, not all women with stress become amenorrheic. Barring extreme situations such as famine or war, metabolic disturbances do not result from normal day-to-day stressors in most women. An individual's emotional valence thus plays a role and determines the extent to which external variables affect internal homeostasis (Bethea et al., 2005; Berga, 2008; Williams, Berga, & Cameron, 2007). A study that investigated this topic discovered that the primary factor that distinguished women with FHA from those with normal ovulatory cycles was the presence of unrealistic expectations (Giles & Berga, 1993). More specifically, they indicated that unachievable ambitions or cognitive distortions that created vulnerability to life's inevitable challenges heightened biologic responsiveness to psychosocial stressors.

Through the years, multiple studies have shown that FHA patients are more depressive, and exhibit more dysfunctional attitudes, disordered eating patterns, higher levels of perfectionism, higher need for social approval, subclinical hypercortisolism, and functional hypothyroidism than those without FHA (Berga et al., 1989; Berga, Daniels, & Giles, 1997; Giles & Berga, 1993; Marcus, Loucks, & Berga, 2001). In a review article evaluating the psychological consequences of infertility, it was reported that indices measuring interpersonal sensitivity, depression, and anxiety were higher in infertile couples (Greil, 1997; Wright et al., 1991). Another study demonstrated the prevalence of a psychiatric disorder in patients seen in infertility clinics to be as high as 40% (Chen, Change, Tsai, & Juang, 2004). The most common diagnosis was anxiety disorder (23%), followed by major depressive disorder (17%). These findings reflect significantly higher levels than the 10–12% seen in the primary care settings. Finally, one study showed that women with FHA had trouble just "relaxing and having fun" (Berga et al., 1989).

Stress also directly impacts fertility rates and pregnancy outcomes. Reproductive function is curtailed when the potential mother is under significant stress, and this teleologically occurs in order to prevent the exposure of the young to an unfavorable environment. In numerous studies, various stress-related hormones that affect placental hormonal secretion were identified (Barnea, Lavy, Fakih, & Decherney, 1986; Barnea, Fares, & Shahar, 1989; Barnea & Kaplan, 1989; Barnea et al., 1989; Barnea, Perlman, Bick, & Hochberg, 1989; Lavy, Barnea, & Decherney, 1987; Tal, Kaplan, Sharf, & Barnea, 1991), and it was determined that communication between the placenta and decidua is impacted by stress factors. Specifically, stress decreases blood flow reaching the decidua and consequently affects implantation, impairs metabolism, and modifies placental function. Stress can also lead to increased levels of pro-inflammatory cytokines, which are implicated in several complications of pregnancy, including premature rupture of membranes and preeclampsia (Coussons-Read, Okun, & Nettles, 2007). Anxiety is also associated with higher numbers of

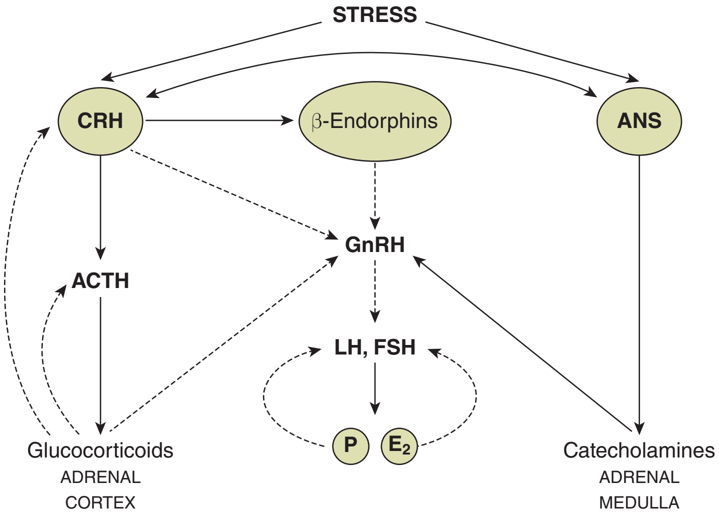

Figure 26.6 The effect of stress on ovarian function. Solid lines represent potentiation; dotted lines represent inhibition.

activated T-cells and decreased rates of implantation, indicating a potential role for an immunological mechanism (Gallinelli et al., 2001).

Two primary systems that mediate the stress response include the HPA axis (with subsequent cortisol and β-endorphin release) and the ANS (which leads to stimulation of the locus ceruleus–adrenal medulla pathway and releases NE) (Chrousos & Gold, 1992). These systems are linked in a positive feedback loop, and thus activation of one potentiates the other. Additionally, each affects the HPO axis (Figure 26.6).

The HPA axis has been shown to be an important mediator of infertility via its inhibitory effects on GnRH release. Remarkable increases in the amplitude and secretory episodes of cortisol have been shown to accompany stress, and data has observed a parallel relationship between levels of circulating cortisol and the degree of GnRH suppression and resultant ovarian quiescence (Loucks, Mortola, Girton, & Yen, 1989). This dose-dependent correlation between stress severity (and resultant hypercortisolemia) and degree of amenorrhea is most eloquently depicted by studies of the effects of caloric intake and energy expenditure on the menstrual cycle.

Body weight, specifically fat level, plays an essential role in the initiation and maintenance of reproductive function in women. This is evident by the positive feedback of leptin on GnRH release. Anorexia nervosa affects 3% of women (Becker, Grinspoon, Klibanski, & Herzog, 1999), and many sufferers develop FHA due to loss of the required minimal-percentage body fat. Authors have proposed that a level of at least 22% body fat is necessary for menstruation (Frisch, & McArthur, 1974), and a mere 10–15% loss has been shown to revert the body to a prepubertal amenorrheic state. Normal gonadotropin secretion and subsequent menses are not restored until fat is re-accumulated and IBW achieved (Boyar et al., 1974).

A study addressing energy consumption quantified the amount of caloric restriction needed to impact GnRH drive. Energy balance was achieved by providing 45 kcal/kg per day. While a deficit of 33% had no impact on GnRH/LH pulse frequency, a deficit of 75% induced a significant decline (Loucks & Thuma, 2003). Furthermore, induction of a state of caloric deprivation (75% deficit) increased cortisol levels by 30%. This confirms that metabolic stress activates the HPA axis.

Insufficient caloric intake is not the only cause for amenorrhea; excessive energy expenditure also plays a role. Running has been associated with a 55% incidence of anovulation (De Souza et al., 1998). It has been determined that the physical stress associated with strenuous activity leads to pituitary and sympathetic nervous system activation within minutes of commencement and the subsequent rise in circulating cortisol, β-endorphins, and NE.

A classic example of the dominant role of the mind/mood in the control of reproductive function is the state of pseudocyesis. This syndrome is characterized by a manifestation of pregnancy-induced changes without an actual conceptus. In this situation, extreme psychological stress impacts an individual and leads to a diminished central nervous system dopamine level. Since DA inhibits GnRH and PRL release, the lack of DA leads to an increase in GnRH pulsatility and elevated PRL secretion (Yen, Rebar, & Quesenberry, 1976). The increased GnRH pulse amplitude maintains high levels of E2 and P, leading to amenorrhea, whereby, with elevated levels of circulating PRL, galactorrhea ensues.

Finally, in FHA, the HPT axis is blunted as a result of hypercortisolemia. TSH does not increase in response to low levels of thyroid hormone, which suggests that central neurotransmission is altered at the level of the hypothalamus (Berga et al., 1989). The thyroid is a critical gland involved in reproduction and, especially, pregnancy, given that the fetal brain requires an appropriate amount of thyroixine for neurogenesis. Since the mother is the sole source of fetal thyroixine in the first trimester, and the major source throughout the second and third, deficits may induce fetal neurodevelopmental compromise (Haddow et al., 1999), and thus thyroid dysfunction needs to be addressed in all FHA patients seeking fertility.

Diagnosis

FHA is a diagnosis of exclusion. Laboratory testing and imaging to rule out other causes of amenorrhea are first necessary. Following that, a lack of menses for three consecutive months, an LH pulse frequency less than 16 pulses per 24 hours, an LH-to-FSH ratio less than 1, and a P level less than 5 ng/mL (indicating lack of ovulation) generally support the diagnosis of FHA.

Treatment

Over the past few decades, new and more efficient techniques to assist infertility have become widely available. These techniques include hormonal stimulation, in vitro fertilization (IVF), intracytoplasmic sperm injection (ICSI), gamete intra-fallopian transfer (GIFT), and zygote intra-fallopian transfer (ZIFT).

Traditionally, first-line pharmacotherapy includes clomiphene citrate (a selective estrogen receptor modulator) and letrozole (an aromatase inhibitor). These agents are ineffective in patients with FHA, as their mechanism is to antagonize E2 action in order to stimulate feedback to the hypothalamus/pituitary, which already is non-responsive to lower E2. Strategies for ovulation induction in such patients typically include exogenous-administration gonadotropins. Ovulation induction is associated with increased risk to the mother and fetus, including ovarian hyperstimulation syndrome (OHSS) and multiple gestations, which in and of itself is associated with increased risks of preterm labor, gestational diabetes, preeclampsia, intrauterine growth restriction, postpartum hemorrhage, cesarean section, and hyperemesis gravidarum (van der Spuy, Steer, McCusker, Steele, & Jacobs, 1988). In addition to the negative perils of attempted ovulation induction, the medicalization of infertility has unwittingly led to a disregard for the emotional and psychosocial well-being of potential mothers who are already overwhelmed and stressed. This could limit parenting skills and subsequently place offspring at risk of poor psychosocial development (Pike & Rodin, 1991).

A popular approach to treating women with FHA who are not interested in immediate fertility is to provide hormone replacement. This is based on the inappropriate presumption that hormone deficiency is the primary problem. Therapies aimed at correcting only reproductive compromise have inherent limitations because they fail to ameliorate the concomitant endocrine changes including activation of the HPA axis, suppression of the HPT axis, and potential health consequences of increased cardiovascular risk, osteoporosis, depression, and dementia, which exogenous hormone exposure does not fully reverse. The key to recovery is to change the behaviors and attitudes that initiated hypothalamic dysfunction and reduced GnRH drive. This will yield the greatest change for neuroendocrine recovery in totality.

Ideal therapy improves psychological equilibrium and reverses the physiological effects of stress. In a large survey of infertility patients, it was found that most patients assumed that psychological aspects of infertility would be addressed by medical personnel as part of their treatment (Schmidt et al., 2003), but they were not. Many infertility patients go online to gather fertility information (Weissman, Gotlieb, Ward, Greenblatt, & Casper, 2000) and even more seek out Internet forums to share personal information about problems and treatment outcomes (Himmel, Meyer, Kochen, & Michelmann, 2005). However, those who relied solely on online resources for support actually had higher levels of distress compared with those who had more diverse means of support (Epstein, Rosenberg, Grant, & Hemenway, 2002).

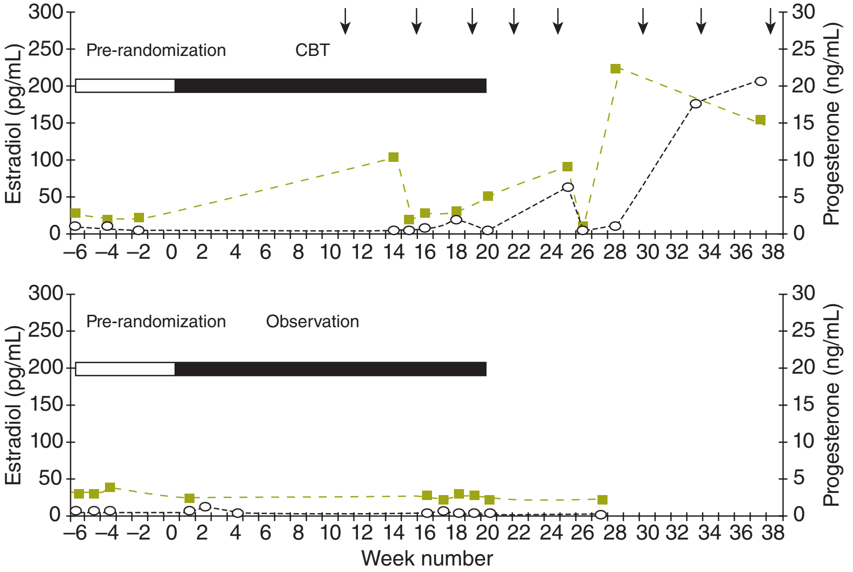

Figure 26.7 The effects of cognitive behavioral therapy (CBT) versus observation on restoration of ovarian function. (Reprinted from Berga et al., 2003, with permission from Elsevier.)

Nonpharmacologic therapies such as stress management, relaxation training, coping skills training, hypnotherapy, psychoeducation, group support, and acupuncture have the potential to produce long-term benefits to mental and physical health as well as resumption of ovulation. In a prospective, randomized controlled trial (RCT) of 16 patients, researchers proved that cognitive behavioral therapy (CBT) was beneficial in restoring ovarian activity in women with FHA (Berga et al., 2003). Patients were randomized to CBT or observation for 20 weeks. Results demonstrated resumption of ovulation in 75% of women treated with CBT versus 25% in the observation group (Figure 26.7). In a follow-up study (Michopoulus, Mancini, Loucks, & Berga, 2013), 17 women with FHA were randomized to either CBT or observation. Similar to the previous study, this trial demonstrated a rate of ovarian recovery in 87.5% of participants in the CBT group, whereas observation resulted in a recovery rate of only 33.3%. In this study, however, CBT also ameliorated hypercortisolism, while observation did not. TSH levels were also increased in the CBT group. A concomitant decrease in cortisol and a rise in TSH following CBT suggest that a change in hypothalamic feedback sensitivity primes thyroidal recovery. Indeed, it has been reported that the HPT axis is the last to recover from stress as HPA has been shown to recover in the presence of incomplete recovery of HPO and only partial HPT (Berga et al., 1997). It is postulated that HPA recovery may actually permit HPO and later HPT recovery (Berga et al., 2003).

The effects of hypnotherapy on resumption of menstruation in patients with FHA have also been studied (Tschugguel & Berga, 2003). Women who met the criteria for FHA underwent a single session of hypnotherapy and were then monitored over a 12-week period. Nine of 12 (75%) resumed menstruation, and all patients reported benefits of increased general well-being and self-confidence. Hypnotic trance has been associated with a decrease in plasma cortisol levels (Sachar, Fisherman, & Mason, 1965; Sachar, 1996), and it is hypothesized that such effects accounted for the results in this study.

Many studies have demonstrated the efficacy of acupuncture for anovulatory-related infertility. Acupuncture is a therapeutic method in Chinese medicine based on the theory that there are pathways in the body which, when triggered, can regulate blood flow and rectify disturbances and dysfunction of organ in the body. In one study, after undergoing acupuncture, the percentage of ovulatory cycles in participants improved from 15% to 66% (Stener-Victorin et al., 2000). Another study demonstrated that more than half of anovulatory cycles became ovulatory when acupuncture was employed (Chen & Yu, 1991). In a third study, researchers conducted an RCT on 45 infertile women suffering from ovulatory dysfunction (Gerhard & Postneek, 1992). The intervention group received acupuncture, while the control group received medical treatment including dexamethasone, levothyroxine, clomiphene citrate, and gonadotropins. Resumption of ovulatory cycles occurred significantly more often in the acupuncture group.

The mechanism of action of acupuncture is not quite understood, but the role of β-endorphin release with subsequent impact on the HPO axis has been suggested (Chen & Yu, 1991). Other studies have demonstrated increased expression of GnRH in the arcuate nucleus following acupuncture (Wang, Zhu, & Jin, 2007). Evidence of the effects of acupuncture on decreasing CRH (Stener-Victorin, 2001) and weight reduction via leptin and thyroid gland regulation (Li, Wei, & Wu, 2007) has also arisen through recent studies. Based on these findings, acupuncture may improve ovulation by modulating the central and peripheral nervous systems, the endocrine system, and metabolism.

There is substantial evidence for an association between psychophysiopathology and the outcomes of assisted reproductive techniques (ARTs). In a prospective study of 151 women undergoing ART for infertility, baseline stress and negative affect was significantly associated with decreased numbers of oocytes retrieved, numbers of oocytes fertilized, number of embryos transferred, conception rates, and live birth deliveries (Klonoff-Cohen, 2001; Klonoff-Cohen & Natarajan, 2004). These authors concluded that patients should receive pretreatment counseling, support, and education

According to a review article, interventions targeting stress reduction appear beneficial toward artificial fertility outcomes (Morreale, Balon, Tancer, & Diamond, 2011). To date, psychotherapy, hypnotherapy, relaxation techniques, and physical perception exercises have led to more positive outcomes in IVF (Poehl, Bichler, Wicke, Dörner, & Feichtinger, 1999). In an RCT conducted to elucidate the benefit and effectiveness of counseling on IVF outcomes, 60 couples were assigned to either counseling intervention or a control group (Terzioglu, 2001). Couples in the intervention group had significantly lower anxiety/depression scores and higher pregnancy rates when compared with controls (43% versus 17%).

Published data from meta-analyses have revealed that acupuncture treatment significantly improves success rates of IVF as well as quality of life in IVF patients (Anderson, Haimovici, Ginsburg, Schust, & Wayne, 2007; Manheimer et al., 2008; Ng, So, Gao, Wong, & Ho, 2008). In the first ever RCT studying the impact of acupuncture on ART, 160 IVF patients were allocated to a treatment group (receive acupuncture 25 minutes before and after ET) or a control group (lay quietly in a room for equivalent time). The clinical pregnancy rate was 42.5% in the treatment group versus 26.3% in the control group (Paulus, Zhang, Strehler, El-Danasouri, & Sterzik, 2002). The mechanism of acupuncture on improved fertility may be related to increased uterine blood flow, inhibition of uterine activity (via blocking COX-2 enzymatic expression), and abatement of anxiety/depression/stress (Huang et al., 2011; Kim, Shin, & Na, 2000).

In general, the anticipatory anxiety of having IVF, often perceived as a "last resort," can persist throughout the entire treatment cycle, resulting in a chronic state of arousal that is further detrimental to attempted conception. In one retrospective study of 86 couples who did not conceive with IVF, 66% of women and 40% of men reported symptoms of depression (Baram, Tourtelot, Muechler, & Huang, 1988). The severity and prevalence of depression increased in proportion to the number of failed IVF cycles (Thiering, Beaurepaire, Jones, Saunders, & Tennant, 1993). Of utmost concern was the finding that as many as 13% of women with a failed IVF cycle passively contemplated suicide (Baram, Tourtelot, Muechler, & Huang, 1988). Pre-fertility technique psychotherapy may diminish the number of treatment cycles needed to obtain pregnancy, require lesser amounts of hormonal stimulation, and even make more invasive assisted reproductive techniques unnecessary. Additionally, given that many couples dealing with fertility complications are overwhelmed by distress, loss of control, a sense of defeat and hopelessness, acquisition of fear, pressure from family, stigmatization/ostracism, a disruption in the developmental trajectory of adulthood, and possibly religious or ethical concerns regarding treatment options, psychotherapy can prepare couples for possible treatment failure.

Summary

In the context of psychoneuroendocrinology, health is dependent on achieving psychological and metabolic harmony. Reproductive processes (in men and women) are detrimentally affected by psychological stress. While hormone replacement is not harmful, more than this is needed to reverse physiological aberrations. Ongoing insults to the brain from chronic stress and subsequent endocrinological cascades on HPO, HPA, and HPT axes are not ameliorated with mere hormone exposure. Thus, it is critical to remember that FHA is more than a disorder of reduced GnRH drive, and that optimal intervention is necessary to reverse the stress process, so that the hypothalamus can recover.

The time course of hypothalamic recovery is HPA $>$ HPO $>$ HPT, and involves a pattern of readjustment and restoration of normal function. Any intervention that ameliorates HPA will likely thus reverse HPO and HPT dysfunction. Because medications targeting underlying anxiety/depression/stress may cause untoward effects on the fetus, and ovulation inducting can be associated with maternal and fetal compromise, psychosocial interventions such as CBT (as well as other stress-reduction techniques such as acupuncture and massage, which offer efficacious infertility treatment while avoiding the pitfalls of pharmacological modalities) should be offered as a first-line treatment option to all couples with FHA-induced infertility. Moreover, restoration of hypothalamic function by CBT (with subsequent amelioration of long-term health consequences that result from FHA such as cardiovascular disease, osteoporosis, and dementia) is a secondary derivative of the therapeutic process. Furthermore, given that women with FHA display hypothyroidism of a magnitude associated with compromised fetal neuropsychological development, CBT can create a more favorable environment for fetal neurodevelopment before conception in attained.

In regards to reproductive techniques, a caustic disposition negatively influences outcomes. However, the majority of women exposed to psychosocial interventions appear to benefit personally and have improved IVF results.

"Hypothalamic hypogonadism is a clinical example of how attitudes, moods, and behaviors can have endocrine consequences and cause clinically evident reproductive compromise" (Berga & Loucks, 2006). While psychogenic stress has a metabolic cost, metabolic stressors augment psychogenic stress as well. Thus, there is a vicious cycle that, if not addressed, will continue to potentiate female infertility. Because of the concomitant endocrine and metabolic disturbances resulting from chronic stress, hypogonadotropic hypogonadism must be regarded as a condition deserving clinical attention, even when fertility is not an immediate goal. While any medical interventions can ameliorate stress-induced neuroendocrine aberrations, psychoeducation has the benefit of sustained effect as it teaches new ways and new perspectives to "immunize" patients from future stressors.

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27

An Integrative Body–Mind–Spirit Approach for Women Experiencing Infertility

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Introduction

An incapability to conceive naturally and the prospect of remaining childless is potentially a source of distress for couples in their childbearing age. Infertility can be defined as “a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse” (Zegers-Hochschild et al., 2009, p. 1522). According to the World Health Organization (2010), infertility affects up to 15% of childbearing-aged couples, and 8–12% of all couples experience some form of infertility during their reproductive lives. Although there is an increasing trend among women in developed countries to delay both marriage and childbearing (United Nations, 2003), motherhood is still closely related to womanhood (Phoenix, Woollett, & Lloyd, 1991) and believed to provide identity and status for women (Arendell, 2000; Miller, 2005; Morell, 1994; Ulrich & Weatherall, 2000).

Jordan and Revenson (1999) conducted a meta-analysis on a mixture of clinical and anecdotal studies, professional opinions, and empirical studies, between 1966 and 1995. They summarized different kinds of emotions experienced by infertile women or couples: anger, surprise, denial, guilt, frustration, isolation, personal and social failure, loss of control, diminished self-worth and life quality, depression, grief, anxiety, and marital dissatisfaction. In cultures that place a great deal of emphasis on childbearing, being involuntarily childless is entangled not only with frustration and disappointment but often with the guilt, shame, and disapproval of the extended family or society. Childlessness per se might not directly cause distress to people, but the pressure arising from the cultural and social expectations certainly

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does (Chan et al., 2002). The meaning of childbearing in these cultures may make it more difficult for couples to cope with childlessness, as some of them may see being able to continue the family line as the prime existential meaning (Chan, C. H. Y., Chan, C. L. W., Ng, S. M., Ng, E. H. Y., & Ho, 2005; Ng, Liu, Chan, C. H. Y., & Chan, C. L. W., 2004). It is not surprising, then, to find that some infertile women or couples are preoccupied with the issue of infertility and undergo all kinds of assisted reproductive technology (ART) for many years (Notman, Rosenthal, & Goldfarb, 1997; Redshaw, Hockley, & Davidson, 2007).

One of the most welcome forms of ART, *in vitro* fertilization (IVF), was introduced in the 1970s, and is widely used by couples with infertility. The advancement of reproductive technology gives people the hope of having children through assisted conception. However, IVF is a meticulously timed procedure that can be physically and emotionally demanding. People usually maintain unrealistically high expectations of pregnancy outcomes after IVF, and the 20–25% success rate may leave many couples frustrated. This statistic implies that there are a significant number of women who fail to get pregnant at each IVF cycle.

No matter if the cycle is successful or not, anxiety from IVF treatment can be seen as a significant predictor of emotional response. Boivin (2003) suggested that stress or negative psychosocial factors can affect a woman's reproductive ability. Increased psychosocial distress prior to or during IVF was also found to be associated with poorer physical responses and/or a reduced pregnancy rate. The somatic responses to the treatment process, the high dose of hormones used during the treatment, the unpredictable outcome, the uncertainty about the side effects, and the additional financial cost can affect mood and may result in mood swings, anxiety, depression, anger, frustration, and exhaustion (Ardenti, Campari, Agazzi, & La Sala, 1999; Chen, Chang, Tsai, & Juang, 2004; Smeenk et al., 2001).

Infertility as a State of Entanglement

Entanglement can be understood as inner captivity, in which the emotive and cognitive mind is preoccupied with a conceptualized idea, hindering the capacity to exercise freedom of choice and causing pain and suffering. From our clinical observation, women who are infertile and undergo infertility treatments suffer from a state of entanglement, in which they experience afflictive emotions, inflexible thoughts, and/or maladaptive behavior.

A woman who is entangled in infertility will have a mixture of emotional responses. Empirical studies on the psychosocial well-being of the infertility experience usually use measurements that tap single emotional constructs such as anxiety, depression, or grief. However, existing instruments of mood can shed light on, but do not fully capture, the phenomenon. Afflictive emotions can be denoted as a mixture of feelings obstructive to people's mind and destructive to their well-being, and ultimately causing suffering. For example, some infertile women said that they

Table 27.1 A state of entanglement in the context of infertility.

Affective Emotions	A mixture of emotional responses obstructive to a woman's mind and destructive to her well-being • *Examples:* • *Enmity, wrath, despondency, guilt, fear, anger, frustration*
Inflexible Thoughts	Over-attachment of unhelpful mental representation of a relationship, value, behavior, attribute, or habit • *Examples:* • *"A complete woman should have the experience of being pregnant."* • *"A complete family should include children."* • *"The more you pay, the more you should get."*
Maladaptive Behaviors	Resistance to change and difficulty of letting go • *Examples:* • *Undergoing or pursuing infertility treatments* • *Ruminating on negative thoughts about ART failures* • *Being unwilling to choose other ways of having a family such as a living without children or adoption*

felt jealous every time they saw a pregnant woman or attended a social gathering at which children were present. In fact, jealousy may be a mixture of feelings related to the self and others such as anger, hatred, sadness, inadequacy, and guilt. Some women expressed despondency after the repeated failure of infertility treatments, which may be another combination of feelings such as hopelessness, discouragement, disappointment, frustration, and despair.

Some women undergoing infertility treatments are over-attached to a value or norm about the structure or meaning of family and children. Then, the treatment outcome becomes a dominant desire and a single pathway to a better future. Such rigid attachment will interfere with a woman's ability to make flexible and appropriate adjustments to the changes in everyday life. The problem of fertility is primarily a physical dysfunctional problem. What causes more problems is the way people interpret the physical problem. From our clinical experience, we have found that women who are infertile are somehow entrapped by the unhelpful representations of infertility, which include a polarized and rigid interpretation of "I'm a failure," "I'll be alone for the rest of my life," or "I'm not a woman." These will further inhibit their ability to appreciate their strengths and capacities in dealing with life stressors.

The advancement of ART can offer hope to women with fertility problems in having children but can also be a source of suffering if women pursue treatment. Unlike other medical conditions, infertility is considered a state of reproductive function at a certain time. There is an uncertainty about, and difficulty in making an accurate diagnosis of, the cause of infertility, which is crucial for choosing effective treatment. Once initiated, however, IVF and other ART treatments are marked by their open-ended nature and lack of finality. Theoretically, a couple can endlessly pursue additional treatment, and it is difficult to pinpoint the best time to stop (Boden, 2007). A woman who is entangled in infertility will find difficult it to recognize and accept her fertility problems or the reality of being childless, resulting in difficulty in letting go and making the decision to end infertility treatments.

Infertility as a Quest for Reconstructing Personal Value and the Meaning of Family

Entanglement is at the root of the concept of *jizhou* in Chinese, denoting "holding on, rigid attachments, and fixation on desirable attributes, values, and behaviours as determined by the individual" (Lee, Ng, Leung, & Chan, 2009, p. 35). Family formation is a developmental stage representing generativity and continuity of one's life (Erikson, 1959), in which infertility presents as a disruption of this normal family life cycle, preventing people from assuming new developmental roles and transiting to another stage of life (Burns & Covington, 2006). Women with infertility may suffer from attachment to the conceptualized idea of children and family, leading to endless infertility treatments and pursuit of the use of reproductive technologies.

Domar and her team (2001) conducted a cross-sectional survey on the effect of spirituality or religiosity on distress in infertile women. Results show that an increased level of spiritual well-being was significantly associated with less infertility distress and fewer depressive symptoms. In another study conducted by Domar and her team (2005), surveying the effect of religion on infertility stress among women undergoing IVF, a link was also found between depressive symptoms and fertility distress in women undergoing infertility treatment. It was suggested that strong religious beliefs can help or interfere with coping and healing. As an implication, healthcare professionals and clinicians should be prepared to discuss religious and spiritual issues with women facing infertility and treatment, as those issues may play an important role in the psychological health of infertile women and even in their response to infertility treatment.

Infertility is not only considered a physical or psychosocial distress but more importantly represents a critical life event that challenges one's underlying values and assumptions, including one's perceptions of self, marriage, family, and life in general. Waldfogel (1997) further explained that an "imbalance of one's biologic, psychologic, social and spiritual dimensions can lead to disease, compounding distress and exacerbating illness" (p. 964). Currently, spirituality is often conceptualized by the meaning and purpose of life, transcendence, connection with others, and spiritual energy (Chiu, Emblen, Van Hofwegen, Sawatzky, & Meyerhoff, 2004; Walton, 1999). Increasing awareness of the importance of spirituality in different study populations among researchers and practitioners is an obvious trend in current research. The effect of spiritual well-being has been studied to examine its influence on physical health, mental health, life attitudes, and health behaviors

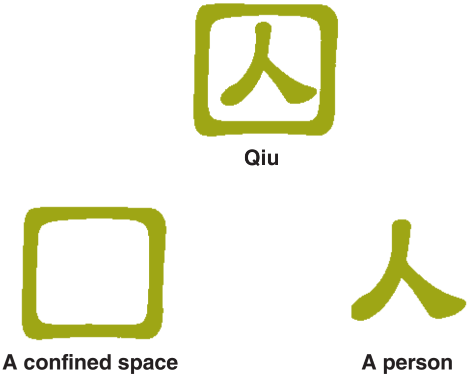

Figure 27.1 The Chinese character for the word "enclosure."

(Anandarajah & Hight, 2001; Cotton, Levine, Fitzpatrick, Dold, & Targ, 1999; Hill & Pargament, 2003). It is generally believed that spirituality contributes to a person's sense of wholeness and wellness. Therefore, holistic health is understood as a balanced integration of body, mind, and spirit (Lee et al., 2009).

Throughout the course of infertility and use of ART, people often said that their life was stuck from moving forward or their whole person was stagnated within the infertility experience. Their subjective experience can be pictorially illustrated in the Chinese word *qiu*, which denotes a state of enclosure or imprisonment. The Chinese character for enclosure, 囚, is a person enclosed in a confined space (Figure 27.1).

Holistic care has been increasingly promoted in healthcare settings. It has been proposed that quality healthcare should cover not only the physical, psychological, and social needs of individuals but also their religious and spiritual needs. This assumes that people may use their religious or spiritual beliefs to cope with crisis and to search for meaning and hope in response to suffering. Although the importance of psychosocial factors in infertility treatment has become widely accepted, the consideration of the spiritual dimension is noticeably absent. Infertility is not only a disease but also reveals attitudes toward the meaning of children, family, and life purpose. As the journey through infertility and its treatment progresses, people have to make many decisions that reflect their personal values and choices. Therefore, spirituality and its effect on responses to infertility cannot be overlooked, and were included in our previous study.

The Concept of the Integrative Body–Mind–Spirit Model

To provide more relevant psychosocial interventions for local Chinese patients, Chan and her colleagues developed an Integrative Body–Mind–Spirit (IBMS) approach for different kinds of clientele in the Chinese community (Chan, 2001; Chan, Ho, & Chow, 2002; Chan, Leung, & Ho, 1999; Lee et al., 2009). Applying Chinese philosophy and concepts of holistic health, the model adopts an empowerment approach aiming to regain balance and harmony at the intrapersonal, interpersonal, and transpersonal levels. The IBMS model on infertility is based on four fundamental assumptions (Chan, C. H. Y. & Chan, C. L. W., 2004; Chan et al., 2012; Chan, Ng, Ho, & Chow, 2006):

1. *Life is a manifestation of physical, emotional, cognitive, social, and spiritual being.* These different domains are interconnected and assimilated to form a whole. Childbearing is related to the personal values and the meaning of life and family. Frustration in fulfilling the preoccupied and unhelpful mental representation of childbearing can lead to a state of entanglement and affect physical and psychological well-being as well as social relationships with the extended family and kin.
2. *Life is the interplay of yin and yang.* The concepts of yin and yang are considered fundamental to the Chinese perspective of the world. Yin and yang are two basic life forces or building blocks that make up life. Energy flows throughout the body to create a harmonious dynamic equilibrium and internal balance within a person. Gains and losses, success and failure, having children, and being childless are part of the dynamics of yin and yang. The ability to cope with the afflictive emotions and make adaptive life adjustments can be enhanced when infertility is taken as an opportunity to reflect on the dynamic changes in life. Internal balance will then be restored.
3. *Restoring harmony not only cures illness and resolves problems, but it also enhances holistic well-being and opens up opportunities for growth and transformation.* Enhanced health increases the individual's resilience to ill health and to other external stressors. The Chinese word for "crisis" consists of two characters: one is for "risk" and the other is for "opportunity." An emphasis on transformation through pain can actually strengthen the capacity among women with fertility issues to embrace adversity.
4. *Healing comes from within.* Each individual is believed to possess his or her own resources that facilitate self-healing. IBMS aims to mobilize the person's own healing power to restore a state of equilibrium. Women can regain their freedom from the infertility experience and control their life. ART focuses on helping women to become pregnant. Even if ART is successful, anxiety and shame may continue to affect the woman's well-being. Thus, a holistic intervention on the total wellness of the individual and the couple is the direction for ART intervention. The psycho–social–spiritual dimension should be introduced as standard practice for ART intervention.

Under these assumptions, physical (bodily functions), psychosocial (emotions and interpersonal relationships), and spiritual (personal values and the meaning of

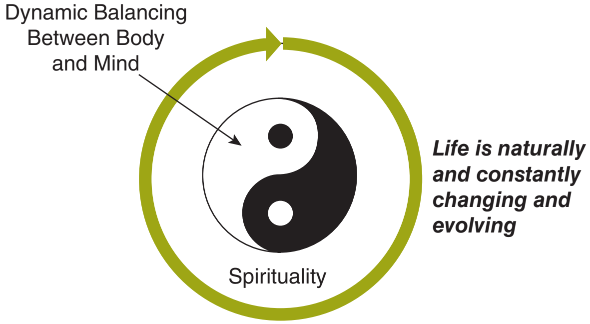

Figure 27.2 The Integrative Body–Mind–Spirit model on infertility.

life and family) well-being are believed to be an integrated whole, and all play a crucial role when encountering stressful life events (Figure 27.2).

The imbalances of this multi-layered system are believed to be the root of all physical and psychological problems. One of the most important aspects of the IBMS model is to facilitate the self-healing process through rebalancing the system and achieving a harmonious dynamic equilibrium within the person and between the person and the environment (Chan et al., 2005; Chan, et al., 2002; Ng, Chan, Leung, Chan, & Yau, 2008). This is achieved through a process of change that builds on the self-healing capacities of individuals. As people can transform a crisis into personal growth, so infertility provides an impetus to create new opportunities; suffering may not be eradicated, but it can co-exist with a sense of peace, contentment, and tranquility. With these frameworks in mind, intervention can be tailored for women and/or couples with infertility.

Based on the IBMS holistic model, specific group intervention for couples undergoing IVF can be carried out in a culturally sensitive manner, with the aim of reducing the level of psychosocial distress that women may experience during the treatment. Randomized controlled studies examining the efficacy of the IBMS model on the psychosocial–spiritual well-being of women undergoing IVF have been conducted. It was found that participating in the IBMS intervention group could not only help alleviate women's anxiety but also improve their spiritual well-being across the treatment stages.

Intervention Components of the IBMS Model

The IBMS model is distinctive in at least two ways. First, it aims at developing a holistic model of psychosocial intervention that gives full recognition to the interconnectedness of body, mind, and spirit. The model adopts a holistic perspective in treatment, involving an orientation to the total context. Second, the model integrates Eastern health practices, such as meditation, yoga, and martial arts (e.g. tai chi) with Western psychotherapeutic techniques. This is also in line with contemporary mind–body medicine, the efficacy of which has been well documented (Bower et al., 2012; Gaylord et al., 2011; Jahnke, Larkey, Rogers, Etnier, & Lin, 2010).

Therapeutic components in the general IBMS model include: (1) mini-lectures on holistic health concepts, viewing health as a state of mind–body–spirit harmony; (2) awareness training coupled with a wide range of physical exercises, meditation, guided imagery, and breathing techniques; (3) reflective activities (such as journal writing and drawing) aimed at the discovery of positive meanings within negative experience, and reading materials taken from ancient Chinese philosophical writings on suffering and the meaning of life; and (4) group sharing of the experiences associated with infertility. The intervention process focuses on the rediscovery of the self and the development of inner strength. The ultimate goal of IBMS intervention, besides the focus on mind–body balance, is the attainment of internal peace and a sense of control over life. The dual goals are two sides of the same coin: resilience pertains to resistance to the disruptions of normal functioning in the face of a crisis such as infertility (Bonanno, 2004), and transformation describes the ability to grow in the aftermath of it (Chan, Chan, & Ng, 2006; Tedeschi & Calhoun, 1995). Therefore, this is an empowerment approach that places much emphasis on self-competence and self-help in response to life's adversities, with a multi-modal intervention approach comprising various techniques working on the body, mind, and spiritual domains (Chan et al., 2005). The themes and content of the IBMS intervention are shown in Table 27.2.

Working on the body: Expanding mind–body awareness and strengthening total well-being

When undergoing a series of investigations and retrieval during IVF treatment, women typically experience pain and discomfort (Cooper, Weaver, & Hay, 2000; Weaver, Clifford, Hay, & Robinson, 1997). The physical complaints can be physiologically related, but some of them are somatized due to psychological distress. It is common for women to become tense during treatment procedures and perhaps not be aware of which part of the body the pain and discomfort come from. Failing to acknowledge and deal with these physical responses will become another source of frustration and suffering.

The techniques in IBMS group intervention are designed to enhance women's awareness of their bodily responses and the interconnectedness between mind and body. For example, a body scan is one of the important techniques used in the earlier sessions of the intervention group. Through a meditational script, women are guided to pay attention to the parts of the body and be aware of bodily sensations. Acknowledging the signals from the body could help people make appropriate responses in dealing with the symptoms.

Table 27.2 Intervention components of the IBMS model on infertility.

Session Themes	*Objectives*	*Core Content*
The interconnectedness of body–mind–spirit	• Introducing the concept of holistic health • Understanding the relationship between physical and emotional well-being • Understanding the nature of stress in infertility and IVF • Understanding and managing bodily symptoms and distress	• Sharing the journey of infertility • Introduction of the concept of holistic health • Introduction of the nature of stress and its effect on the body and mind • Practicing physical exercise and stress relaxation exercise, e.g., breathing exercise, body scan, therapeutic massage
Acceptance and forgiveness	• Strengthening self-help capacity • Understanding the impact of afflictive emotions • Facilitating self-acceptance and forgiveness concerning infertility	• Techniques to manage emotions • Practicing cognitive reconstruction • Facilitating sharing ideas about effective marital communication • Encouraging individuals to discuss with their partners their values and expectations of IVF outcomes
Self-love and letting go	• Enhancing levels of tranquility and internal sense of control • Enhancing internal peace and harmony	• Life planning and mental rehearsal of the IVF treatment procedure • Readjusting expectations of IVF outcomes • Psycho-education about developing a healthy lifestyle • Facilitating self-appreciation • Encouraging individuals to discuss with their partners their perceptions of a complete family
Growth through pain and personal transformation	• Acknowledging and accepting personal constraints and adversity • Revisiting the gains and losses from the journey through infertility • Revisiting and reconstructing the meaning of infertility, life, and family • Planning for the future	• Facilitating sharing of their concept of complete family • Re-examining the concept of a complete family structure and relationships • Sharing of philosophy of life and suffering in a culturally specific manner • Appreciation of self, others, and life • Encouraging individuals to commit to reaching out for others

Infertility is considered invasive and physically demanding. Women with fertility problems are often stuck in a problem situation regarding their reproductive dysfunction and exhaust their body in fulfilling the demands of the treatment. Techniques for nurturing and strengthening the body and connecting bodily functions could help people connect and reconcile with their body; for example, breathing, therapeutic massage, tai chi, psycho-education on a healthy lifestyle, and other physical exercises. Physical exercises are usually designed to maintain internal harmony. Learning to relax from body tension and to re-establish a healthy lifestyle can better prepare infertile women with greater physical and emotional capacity during IVF treatment.

Working on the mind: Harmonizing the emotional responses and restoring flexibility in mind

Women encounter a mixture of emotional responses through the journey of infertility (Chen et al., 2004; Lee & Sun, 2000; Slade, Emery, & Lieberman, 1997; Verhaak et al., 2005). In the IBMS intervention, an entangled state with afflicted emotions is related to a weakening of the immune system and a wide range of bodily imbalances. Therefore, intervention aims to enhance women's psychosocial health by identifying deficient elements and strengthening them through acknowledgement and acceptance of personal constraints and adversity, mental rehearsal of the treatment procedure, activating self-healing power, enhancing marital resilience, and facilitating social support.

According to Chinese philosophical teachings, over-attachment is the root of suffering. Over-attachment is like tightly holding on to something, in this case, the desire or aspiration of having children and the expectation of treatment success. Letting go of these desires relieves the anxiety and distress associated with infertility and releases energy for self-healing; the women are then able to feel more relaxed during treatment. In order to promote the women's internal self-healing powers and to cultivate the states of mind that are conducive to peace and holistic well-being, meditation, guided imagery, and mindfulness exercises were applied during the intervention.

Acceptance and forgiveness are also crucial elements in the intervention. Afflictive emotions due to childlessness and perceived personal failure can be resolved when women learn to love themselves and forgive other people for what they have done or not done in the past or during the infertility experience, such as assigning blame for the couple's fertility problems. Bitterness throughout the infertility experience ended when women accepted life as it was. Sharing Chinese philosophy's concept of suffering could help them accept suffering as part of life. The women were helped to become aware of their personal resources in dealing with their expectations of, and a mixture of destructive emotional responses to, the treatment.

Working on the spirit: Maintaining a state of tranquility and reconstructing the meaning of life

The IBMS holistic model is distinctive with its emphasis on the crucial component: spirituality. Transforming the experience of infertility into personal, interpersonal, and transpersonal growth through the reconstruction of the meaning of life is not clinically uncommon (Lee et al., 2009). With this IBMS holistic concept in mind, instead of using pregnancy rate as the primary target, the focus is on spiritual transformation. The focus emphasizes the reconstruction of a woman's meaning of life by relinquishing her attachment to the concept of the "children-focused ideal family" and the reconstruction of the meaning of life.

Undergoing prolonged sophisticated medical investigation and ART in an attempt to fulfill the mission of having children, infertile couples are vulnerable to emotional turmoil and internal confusion. Being entangled in the infertility experience disrupts the internal balance within the woman. In the IBMS model, meditation for loving kindness and compassion breathing is practiced in order to help women restore a state of tranquility, which is reflected not only by a peaceful state of mind but also a particular bodily condition and attitude toward surrounding life stimuli.

According to Chinese philosophy, suffering is related to possessions and over-attachment. To practice meditation for equanimity, a healthy sense of humility and willingness to let go can be facilitated. Meditation for letting go and non-attachment can also be effective in helping women untangle themselves from an entrapped state of infertility and resolve afflictive emotions and unhelpful mental representations (Figure 27.3).

Infertility may shatter a woman's worldview and self-identity and disrupt the normal family life cycle. Infertility means compromised womanhood to these women, and their femininity will be challenged. Some will consider infertility a

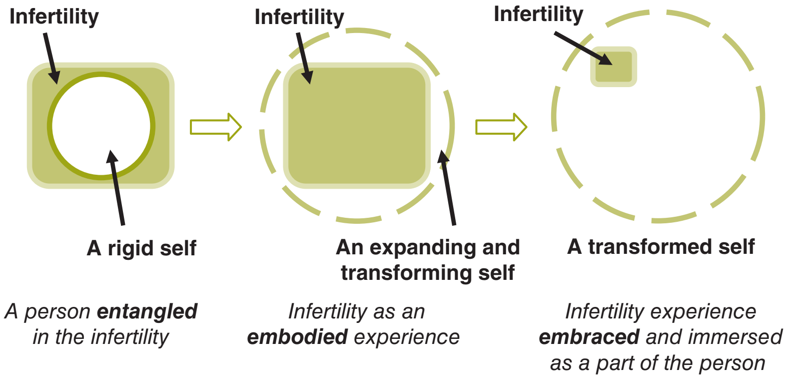

Figure 27.3 Spiritual transformation: From entanglement to embracing.

curse or punishment from God. It also threatens one's long-held values and belief systems, as having children seems to be a normal function for most people. Moreover, when medical treatments cannot help women to conceive, they have to struggle between having further treatment (which may also fail) and accepting the choice of adoption or being childless. The couples become confused and disoriented. The existential balance is challenged, creating both internal disharmony and disharmony with the environment. The process of reconstructing the meaning of life in the context of infertility is undertaken through engaging the couple in finding the benefits of their lives and gains in suffering, thus helping them to make sense of this adverse experience. As a replacement, the concepts of wholeness and resilient family are discussed. Emphases on building a healthy and happy family with harmonious interpersonal relationships became their new meaning of family.

Conclusion

Being diagnosed with infertility potentially has a strong negative effect on a woman's psychosocial and spiritual well-being. However, being infertile and undergoing ART is still a taboo subject in Asian cultures (Blyth & Landau, 2009), so infertile individuals are not receiving the sufficient and effective support they would like to have. The feeling of loss of direction and the sense of powerlessness are well-known emotions experienced by infertile women (Jordan & Revenson, 1999; McCormick, 1980). The physiological and psychological responses are somehow beyond their expectation and control throughout the journey. Even if infertile women put a lot of effort into the treatment process, they will not necessarily get pregnant. Such failure unavoidably leads to a feeling of frustration, disappointment, and severe sense of losing control.

Effective group approaches have been developed for infertile women and couples in Western countries (Domar, Seibel, & Benson, 1990; McNaughton-Cassill et al., 2000). These interventions usually take the form of a support group, during which the group facilitator or the therapist provides stress-reduction training and fosters peer support among patients and their partners. The effectiveness of this form of psychosocial counseling is well established in the literature (Boivin, 2003).

The IBMS model has received much attention in international social work practice. This approach has been applied to different populations, such as divorced women, cancer patients, people with depression, or those who have had traumatic experiences in their lives (Lee et al, 2009). Substantial evidence of the effectiveness of IBMS approach has also been well-documented. By emphasizing restoration of the internal balance with reference to the domains of body, mind, and spirit, it is believed that people can regain freedom in their life by accepting suffering, specifically infertility, as a normal part of living. By utilizing these components in the intervention, we believe that a greater level of self-awareness and improved resilience to the external turmoil can be achieved.

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Behavioral and Psychotherapeutic Interventions in Dermatology

Philip D. Shenefelt

Introduction

Skin disorders often have a significant psychosomatic or behavioral component (Zane, 2003). The skin and the nervous system are both derived from ectoderm in the fetus, develop connections via the peripheral nerves, and remain interconnected throughout life. The cutaneous innervation is vital to skin protection and health. This interrelationship between skin and nervous system (Arck, Slominski, Theoharides, Peters, & Paus, 2006) facilitates the use of non-pharmacological behavioral and psychotherapeutic interventions that can positively affect many skin diseases. The effects on the skin are mediated through the autonomic nervous system, local hormones and neuropeptides, and habit alterations, which change exposures to environmental factors such as sun, heat, cold, or chemicals. Skin disorders may also cause adverse psychosocial effects that alter neurochemistry in the brain. Psychotropic drugs and non-pharmacological behavioral and psychotherapeutic interventions may help to counteract these adverse responses of the psyche to the skin disorder (Fried, 2002). Patients often refuse referral to a psychiatrist or psychologist, leaving any behavioral and psychological treatment up to the dermatologist or family physician. In many cases, it is often necessary to use a multimodal approach with both psychotropic drugs and non-pharmacological behavioral interventions and psychotherapies to obtain optimal results in treating complex psychosomatic and somato-psycho-social problems. The focus in this chapter will be on behavioral and other non-pharmacological methods that can positively affect skin and psyche.

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Biofeedback

Biofeedback provides a real-time signal, usually visual or auditory, for physiological responses that ordinarily are not perceived on the conscious level. It can be a useful adjunct to improve some skin disorders. Examples include conditions that have an autonomic nervous system component, such as biofeedback of galvanic skin resistance (GSR) for hyperhidrosis and biofeedback of skin temperature for Raynaud's syndrome (Sarti, 1998).

Hyperhidrosis with a very low initial GSR at the beginning of treatment improved slowly over 20 sessions combining GSR biofeedback with autogenic relaxation training, a variant of hypnosis, in a young man (Panconese, 1998). At 3 months and 6 months after treatment, during which the patient continued to practice the autogenic training exercises, he continued to show persistent reduction in palmar sweating to near normal levels. Guided by biofeedback, individuals may learn consciously how to alter the autonomic response, and with enough repetition (typically 20–40 sessions) may establish new habit patterns. Hypnosis or autogenic training may enhance the effects obtained by biofeedback (Shenefelt, 2003).

Patients with systemic sclerosis and Raynaud's have been able to increase finger skin temperature by an average of about 4°C using either hypnosis or autogenic training (Seikowski, Weber, & Haustein, 1995). Two of six patients using skin temperature biofeedback combined with autogenic training found that they could shorten the duration of Raynaud's attacks by using the autogenic training. Measurement of finger blood flow in another study with venous occlusion plethysmography, finger temperature, and GSR in patients with Raynaud's disease showed significant elevations in finger blood flow, finger temperature, and GSR conductance level in the patients given finger temperature biofeedback compared with those who received autogenic training but no biofeedback (Freedman, 1989). A study of Raynaud's patients compared learned hand-warming results using different biofeedback methods and found that attention to emotional and cognitive aspects of biofeedback training was important (Middaugh et al., 2001). Another study found that there was a significant correlation between degree of hypnotic ability and ability to lower finger temperature using biofeedback in 30 subjects given the Stanford Hypnotic Susceptibility Scale, Form C (SHSS-C) (Piedmont, 1983). In yet another study, combining biofeedback with hypnosis permitted voluntary control of skin temperature in some individuals with moderate-to-high hypnotic ability as measured by the SHSS-C (Roberts, Kewman, & Macdonald, 1976), permitting increased local peripheral circulation in such conditions as Raynaud's disease. A simple heat-sensitive color-changing square on a card (Barrios, 1985) can also be used for finger skin temperature biofeedback and for learning relaxation.

Biofeedback-assisted relaxation can have a positive effect on inflammatory and emotionally triggered skin conditions such as acne (Hughes, Brown, Lawlis, & Fulton, 1983), atopic dermatitis (Haynes, Wilson, Jaffe, & Britton,, 1979), dyshidrotic dermatitis (Koldys & Meyer, 1979), hyperhidrosis (Duller & Gentry, 1980), lichen planus, neurodermatitis, psoriasis (Benoit & Harrell, 1980), and urticaria. The most common mechanism is through influencing immunoreactivity (Tausk, 1998). Hypnosis may enhance the effects obtained by biofeedback (Dikel & Olness, 1980). Biofeedback of muscle tension via electromyogram (EMG) can enhance teaching of relaxation. Patients who have low hypnotic ability may be especially suitable for this type of relaxation training utilizing EMG biofeedback. Heart rate variability biofeedback with handheld devices such as the emWave Personal Stress Reliever or StressEraser can promote relaxation, improving skin conditions worsened by stress. RespeRate is a device that coaches slowing respirations to music. Simply slowing the breaths to 6 per minute suffices to induce relaxation and a shift from sympathetic to parasympathetic dominance.

Brainwave spectral biofeedback via filtered electroencephalogram (EEG) can alter pain discomfort with multiple repetitions (20–40 sessions) (Sime, 2004) through promoting neuroplasticity, which may reduce chronic postherpetic neuralgia. It also has the potential to correct impulse control disorders and obsessive–compulsive disorders that can manifest in the skin as acne excoriée or neurodermatitis (Shenefelt, 2004). Whether quantitative EEG with neurofeedback will prove sufficiently useful in improving neurogenic chronic pruritus and habit disorders such as acne excoriée, neurodermatitis, trichotillomania, and onychotillomania remains to be determined.

Cognitive Behavioral

Cognitive behavioral methods attempt to alter dysfunctional thought patterns (cognitive) or actions (behavioral) (Levenson, Persons, & Pope, 2000) that damage the skin or interfere with dermatologic therapy. Skin disorders likely to respond include acne excoriée, atopic dermatitis, factitious cheilitis, hyperhidrosis, lichen simplex chronicus, needle phobia, neurodermatitis, onychotillomania, prurigo nodularis, trichotillomania, and urticaria. Adding hypnosis to cognitive behavioral therapy can facilitate aversive therapy and enhance desensitization and other cognitive behavioral methods (Shenefelt, 2003).

In cognitive behavioral therapy, the first step is to identify specific problems by listening to the patient's verbalization of thoughts and feelings such as fear of needles or by directly observing behaviors such as scratching. The second step is to determine the goals of cognitive behavioral therapy, such as a reduction in anxiety about needles or cessation of scratching. The third step is to develop a hypothesis about the underlying beliefs or environmental events that precede (stimulate) or that maintain (reinforce) or minimize (extinguish) these thought patterns and behaviors. The fourth step is to test the hypothesis of cause and effect by altering the underlying cognitions, the behavior, the environment, or all three, and to observe and document the effects on the patient's dysfunctional thoughts, feelings, and actions. The fifth step is to revise the hypothesis if the desired results are not obtained, or to continue the treatment if the desired results are obtained until the goals of therapy are reached (modified from Levenson et al., 2000). A more detailed description of systematic desensitization, aversion therapy, operant techniques, and assertive training as applied to skin disorders is provided by Bär and Kuypers (1973).

The picking behavior in acne excoriée responded in a young adult woman to cognitive behavioral therapy coupled with biofeedback, minocycline, and sertraline (Fried, 2002). A multimodal approach is often beneficial in resistant cases.

Scratching can become a conditioned response in atopic dermatitis (Jordan & Whitlock, 1972, 1974), and may be associated with and exacerbated by feelings of anxiety or hostility. In a study when an itch stimulus was paired with the neutral stimulus of a sound tone (classical conditioning) and the amount of scratching and GSR changes were measured, atopic patients had a significantly higher scratching and GSR response than did a control group. The atopic patients also scored significantly higher in anxiety levels and in levels of suppressed hostility. Most atopic patients report some relief of anxiety or hostility through scratching (operant conditioning). Substituting other activities for scratching, such as sports, music, artwork, meditating, or yoga, can with repetition change the conditioning (Ehlers, Stangier, & Gieler, 1995).

Lip licking or lip biting produces factitious cheilitis (Thomas, Greene, & Dicken, 1983). Topical anti-inflammatory agents combined with cognitive behavioral counseling were effective in producing improvement or resolution.

Severe palmar hyperhidrosis in a 19-year-old woman with social anxiety responded following assertiveness training and systemic desensitization (Bär & Kuypers, 1973). After 12 months, she continued to show no anxiety about social situations and was able to accept the milder hyperhidrosis that she still experienced.

Lichen simplex chronicus (LSC) can arise from repetitive focal rubbing and scratching in those people whose skin tends to thicken with rubbing. Bär and Kuypers (1973) treated a 6-year-old girl with a 3-year history of vulvar LSC by having the mother ignore all scratching but reward non-scratching behavior with a token that the girl exchanged each night for rewards, and by 13 weeks the condition was resolved. They also treated a 33-year-old male with LSC by aversive therapy with resolution of the scratching behavior after 19 days.

For needle phobia, systemic desensitization using participant modeling has been effective (Ferguson, Taylor, & Wermuth, 1978). First, give information about needles and interact with them in a way that shows that the patient's fear is unrealistic or excessive. After modeling the handling of a needle, have the patient join in this performance, starting with situations that provoke relatively little anxiety and culminating in the performance of the feared activity. Then, instruct the patient in self-directed practice to complete the desensitization.

Ratliff and Stein (1968) reported improvement of neurodermatitis in a 22-year-old male using aversion therapy techniques. Rosenbaum and Ayllon (1981) used habit-reversal treatment for neurodermatitis. They taught conscious awareness of scratching, reviewed the inconveniences produced by the habit, developed a competing response practice of isometric exercise by fist clenching that was incompatible with scratching, and did symbolic rehearsal. All three patents had improved and healed at 1 month, and remained healed at 6 months.

Onychotillomania reflects damage to the nails produced by rubbing, picking, or tearing at the proximal and lateral nailfold. This differs from onychophagia, the habit of biting the free ends of the nails (Ameen Sait, Reddy, & Garg, 1985). Onychotillomania can lead to onychodystrophy (Mortimer & Dawber, 1985). Teaching picking awareness, a competing response practice of isometric exercise gripping the hands together and pulling, and rehearsal under observation, can help to reverse this habit.

Trichotillomania is caused by repetitive hair twisting and pulling, resulting in hair loss. Habit-reversal training for trichotillomania involves self-monitoring of the frequency and duration of hair-pulling, habit control motivation by reviewing the inconveniences produced by the behavior, awareness training including situational precursors or triggers, competing response training that substitutes a different motor action to prevent or interrupt hair pulling, relaxation training to reduce stress levels, and generalization training to identify and manage high-risk situations (Stanley & Mouton, 1996). Of three patients, one discontinued hair pulling and the other two noticeably decreased their hair pulling.

Psychosomatically triggered or exacerbated urticaria was reduced in a young professional woman using cognitive behavioral therapy with specific self-talk and relaxation techniques (Fried, 2002). Biofeedback was also used along with multiple-agent antihistamines in a multimodal approach to reduce the urticaria.

Hypnosis may be used in cognitive behavioral therapy with patients of medium-to-high hypnotic ability to produce desensitization, facilitate relaxation, or produce imagined aversive experiences (Dengrove, 1976). It is much easier and safer to have the patient experience virtual aversive stimuli in the imagination rather than in real life. For patients with low hypnotic ability, distraction or biofeedback may be a more appropriate adjunct to cognitive behavioral therapy.

Cranial Electrotherapy Stimulation

Cranial electrotherapy stimulation (CES) was first developed in Russia. Kirsch (2002) subsequently developed the Alpha-Stim in the United States, first focusing on its use for chronic pain as a milder and more effective method than the transepidermal nerve stimulation (TENS) electrical devices that had been developed by Shealy. The Alpha-Stim was also used for CES and was found to be effective in reducing anxiety and depression (Kirsch 2002; Kirsch & Smith, 2007). The Alpha-Stim used with ear clips measurably affects the brain, normalizing the EEG and inducing predominant alpha rhythm using 10–600 microamperes of rectangular wave spiked alternating current at low voltage and at 0.5 hertz and 50% duty cycle powered by a 9 volt battery and applied usually for 20 minutes per session. For chronic problems, usually 30 or more sessions are needed to effect permanent change. Alpha-Stim CES has excellent supportive research documenting reduced anxiety and depression (Kirsch, 2002). CES has produced significant improvement of atopic dermatitis and neurodermatitis, including reduction in scratching behavior (Turaeva, 1967).

Emotional Freedom Technique

Emotional freedom technique (EFT) (Craig, 2008) utilizes tapping on acupressure sites. EFT starts with selecting a negative emotional charged memory or problem area, focusing intently on that thought or memory or condition, pressing on the subclavicular "sore spot," and repeating an affirmation such as "Even though I have this problem with (state the problem), I deeply and completely accept myself" while progressively tapping with the finger on a series of up to 14 specific acupuncture sites on the head, chest, and hand. For infants, toddlers, and preschoolers, this tapping process can be done for them, while older children, adolescents, and adults can be taught to use the technique themselves. EFT can neutralize negative emotional charged memories or problem areas, reducing anxiety and enhancing performance (Craig, 2008). Anecdotally reported improvements or resolution of skin conditions on www.eftuniverse.com (accessed September 21, 2012) include acne, allergic contact dermatitis, atopic dermatitis, herpes simplex recurrences, lupus erythematosis, needle phobia, procedure anxiety, postherpetic neuralgia, psoriasis, and warts. *The Tapping Cure* (Temes, 2006) is an easily accessible quick read for understanding EFT. Reducing emotional distress often results in improvement of inflammatory skin conditions such as acne, atopic dermatitis, and psoriasis.

Eye Movement Desensitizing and Reprocessing

Eye movement desensitizing and reprocessing (EMDR) involves selecting a negative emotional charged memory or problem area, focusing on that thought, and doing an alternating bilateral activity such as following a finger from side to side with the eyes (Shapiro, 2001), hearing alternating left and right tones through headphones, feeling alternating left and right vibrations in handheld paddles, or alternately tapping left and right distal thighs or upper arms. It is slightly more effective than EFT in producing positive benefits in PTSD (Karatzias et al., 2011). EMDR has been reported effective for improving atopic dermatitis and psoriasis (Gupta, M. A. & Gupta, A. K., 2002).

Hypnosis

Hypnosis is the intentional induction, deepening, maintenance, and termination of the trance state for a specific purpose. Trance has been used since antiquity to assist the healing process. In ancient times and even today, shamans, medicine men and women, and other healers have entered trance states themselves and induced trance in their patient to assist with healing. Hypnosis was developed in Europe as a Western approach to utilizing trance. It is a goal-oriented approach to use trance to attempt to improve or fix something. The purpose of medical hypnotherapy is to reduce suffering, to promote healing, or to help the person alter a destructive behavior. Some people are highly hypnotizable, others less so, but most can obtain some benefit from hypnosis.

Defining hypnosis is still somewhat controversial. Marmer (1959) defined hypnosis as a psychophysiological tetrad of altered consciousness consisting of narrowed awareness, restricted and focused attentiveness, selective wakefulness, and heightened suggestibility. Discussions on definitions of hypnosis are available in Crasilneck and Hall (1985) or Barabasz and Watkins (2005).

Hypnosis utilizes the natural trance state. In the waking state, the mind tends to cycle through ultradian rhythms about every 90 minutes, consisting of alternating alertness with dominant beta brainwave activity followed by relaxation with dominant alpha brainwave activity (Rossi, 1982). In the trance state, the mind shifts out of conscious awareness with dominant low alpha and high theta activity (Freeman, Barabasz, A., Barabasz, M., & Warner, 2000). The trance state occurs spontaneously several times daily when the conscious mind is quieted. Being very absorbed in a book or movie or TV show, or focusing on spontaneous thoughts while driving and suddenly realizing that you have travelled a distance without consciously being aware of it, are all everyday spontaneous trance experiences. Clear objective evidence of the trance state has been reported recently through detection of specific changes in eye movement in the trance state related to the so-called “trance stare” (Kallio, Hyona, Revonsuo, Sikka, & Nummenmaa, 2011). These eye movements are distinctly different and cannot be replicated by persons attempting to simulate trance. The other mind states are rapid eye movement (REM) sleep, which is different from the trance state and has dominant lower theta brainwave activity, and deep sleep, which has dominant delta wave activity. Just as an individual can resist or cooperate with entering the sleep state, the individual can resist or cooperate with entering the trance state. The trance state allows access to capabilities and memories that often are not accessible in the conscious state.

In trance, the left prefrontal cortex regional cerebral blood flow decreases, as demonstrated on a positron emission tomography (PET) scan when compared with the alert conscious state (Rainville, Hofbauer, Bushnell, Duncan, & Price, 2002). There is an associated suspension of judgment, suspension of time sense, and often a feeling of connectedness or unity with the universe. Associated with this are higher suggestibility and openness to changing behavior patterns. Suggestions given in the trance state are also more able to alter autonomic function, blood flow, and immune responsiveness. There is also a better ability to block reaction to pain in trance localized to the anterior cingulate cortex (ACC). While everyone can and does transition through alert consciousness, trance, REM sleep, and deep sleep states daily, some individuals have a natural trait of being able to shift into trance easily, while others have a natural trait of less ability to shift into trance. This trait correlates in part with the genetic alleles that code for production of the catechol-o-methyl-transferase (COMT) enzyme that degrades dopamine, an important neurotransmitter (Szekely et al., 2010). About one-quarter of individuals are homozygous for producing the COMT enzyme with methionine at the 158 position and tend to be lower hypnotizable; about one-half of individuals are heterozygous and moderately hypnotizable; and about one-quarter of individuals are homozygous to produce the COMT enzyme with valine and tend to be more highly hypnotizable (Szekely et al., 2010). Hypnotizability tends to be consistent over time as measured by the Hypnotic Induction Profile (HIP) (Spiegel & Spiegel, 2004). The trance state can be induced more easily in high and medium hypnotizables, but even low hypnotizables can often obtain some benefit from trance. Children can respond to hypnotic induction from about age 4 years and older. Hypnotic ability peaks at about ages 7–11 years (Morgan & Hilgard, 1973), and then it declines a little for adolescents and adults.

Persons who have just been injured or who are overwrought with anxiety may shift spontaneously into trance and be more highly suggestible to anything positive or negative that they hear. Even patients under general anesthesia or who are comatose can still hear and subconsciously store the memory of what they heard (Cheek, 1964). Careful selection of words with awareness of their potential effect can be as potent as a drug and have strong positive (placebo) or negative (nocebo) side effects. Often when drugs are tested, the placebo does almost as well as the active drug, indicating the power of the mind to influence the body. As David Spiegel famously said, it is not mind over matter, but mind matters (Spiegel, 2011).

Stress can trigger or aggravate many inflammatory skin diseases, as illustrated in the Griesemer index (Griesemer, 1978; Shenefelt, 2000). The interactions of the CNS and the immune system were well reviewed by Kiecolt-Glaser and colleagues (2002). This interaction permits interventions such as relaxation, hypnosis, and meditation to have positive impacts on many cutaneous diseases. Reducing chronic stress through non-pharmacological methods can help calm inflammatory skin disorders and rebalance the immune response without the adverse side effects often associated with drugs.

The appearance of the skin and hair can significantly affect self-image and social interactions. Skin diseases also affect self-image, social interactions, and behavior. Chronic skin disorders such as acne, alopecia areata, atopic dermatitis, or psoriasis can induce or aggravate depression in susceptible individuals (Gupta, M. A. and Gupta, A. K., 2003). Many skin disorders have a significant psychosomatic or behavioral component.

Hypnosis is a tool, not a therapy in and of itself. Skin diseases responsive to hypnosis are described in the relatively old book by Scott (1960), and in the chapter on the use of hypnosis in dermatological problems in Crasilneck and Hall (1985). Koblenzer (1987) also mentions some of the uses of hypnosis in common dermatologic problems. Grossbart and Sherman (1992) include hypnosis as recommended therapy for a number of skin conditions in an excellent resource book for patients. Examples include acne excoriée, alopecia areata, atopic dermatitis, congenital ichthyosiform erythroderma, dyshidrotic dermatitis, erythromelalgia, furuncles, glossodynia, herpes simplex, hyperhidrosis, ichthyosis vulgaris, lichen planus, neurodermatitis, nummular dermatitis, post-herpetic neuralgia, pruritus, psoriasis, rosacea, trichotillomania, urticaria, verruca vulgaris, and vitiligo (Shenefelt, 2000). Hypnosis can also reduce stress, anxiety, and pain associated with dermatologic procedures. It can also be used to provide immediate and long-term analgesia, improve recovery from surgery, and facilitate the mind–body connection to promote healing. Skin disorders that have responded to hypnotherapy are discussed in the following text. Hypnosis integrates very well with both conventional and alternative therapies and often has a synergistic effect with them in promoting healing and health.

Medical Hypnotherapy

Hypnosis can be used to reduce stress and to reduce psychological or behavioral inhibitors of healing. Hypnosis facilitates supportive therapies that promote ego-strengthening and self-efficacy and improvements through autogentic training, direct suggestion, symptom substitution, and hypnoanalysis (Scott, 1960, 1963, 1964; Hartland 1969). The time needed to screen patients, educate them about realistic expectations for results from hypnosis, and actually perform the hypnotherapy are similar to or less than those for screening, preparing, and educating patients about cutaneous surgery and then actually performing the surgery. Practitioners who prefer to refer patients to hypnotherapists or who desire further information about training in hypnotherapy may obtain referrals or training information from the American Society of Clinical Hypnosis at www.asch.net, or from similar professional organizations.

Some advantages of medical hypnotherapy for skin diseases include non-toxicity, cost-effectiveness, ability to obtain a response where other treatment modalities have failed, and ability of patients to self-treat and gain a sense of control when taught self-hypnosis. The self-hypnosis can be reinforced by using recordings in the form of CDs or MP3s that patients can play back at home. Disadvantages include the practitioner training required, the low hypnotizability of some patients, the negative social attitudes still prevalent about hypnosis, and the lower reimbursement rates for cognitive therapies such as hypnosis when compared with procedural therapies such as cutaneous surgery. Patient selection is an important aspect of successful medical hypnotherapy. With proper selection of disease process, patient, and provider, hypnosis can decrease suffering and morbidity from skin disorders with minimal side effects.

Medical Hypnotherapy for Treating Specific Skin Disorders

Most reports of the effectiveness of hypnosis on specific dermatologic conditions were until recently based on one or a few uncontrolled cases. The trend toward controlled trials has produced more reliable information (Kaschel, Revenstorf, & Wörz, 1991), although randomized controlled trial results are still not available for most skin disorders

Acne flares under stress in some individuals. Picking associated with acne excoriée also intensifies with stress. Posthypnotic suggestion was successful in reducing or stopping the picking associated with acne excoriée in two reported cases (Hollander, 1959). One patient was instructed to remember the word "scar" whenever she wanted to pick her face and to refrain from picking by saying "scar" instead. The author has reported similar success in one case (Shenefelt, 2004).

Alopecia areata commonly flares with stress in some individuals. In a well-conducted clinical case series trial (Willemsen, Vanderlinden, Deconinck, & Roseeuw, 2006), all 21 patients with severe alopecia areata had improvement of anxiety and depression with hypnotherapy. Nine patients had total regrowth of scalp hair, and another three had better than 75% regrowth.

Stress frequently exacerbates atopic dermatitis. In a non-randomized controlled clinical trial, Stewart and Thomas (1995) treated 18 adults with extensive atopic dermatitis who had been resistant to conventional treatment with hypnotherapy that included relaxation, stress management, direct suggestion for non-scratching behavior, direct suggestion for skin comfort and coolness, ego strengthening, posthypnotic suggestions, and instruction in self-hypnosis. The results were statistically significant ($p < .01$) for reductions in itch, scratching, sleep disturbance, and tension. Topical corticosteroid use decreased by 40% at 4 weeks, 50% at 8 weeks, and 60% at 16 weeks.

A complete clearing of congenital ichthyosiform erythroderma of Brocq in a 16-year-old boy was reported following direct suggestion for clearing under hypnosis (Mason, 1952). Similar though less spectacular results were confirmed with two sisters aged 8 and 6 years (Wink, 1961), with a 20-year-old woman (Schneck, 1966), and with a 34-year-old father and his 4-year-old son (Kidd, 1966).

Stress is a common trigger factor for dyshidrotic dermatitis. Reduction in severity of dyshidrotic dermatitis has been reported with using hypnosis as a treatment (Tobia, 1982).

The author reported a case of erythema nodosum that had failed to resolve with medical treatment for 9 years but which resolved following hypnoanalysis (Shenefelt 2007).

There is a case report of successful treatment of erythromelalgia in an 18-year-old woman using hypnosis alone, followed by self-hypnosis (Chakravarty, Pharoah, Scott, & Barker, 1992), in which permanent resolution occurred.

A 33-year-old man with a negative self-image and recurrent multiple *Staphylococcus aureus* containing furuncles occurring since age 17 had been unresponsive to multiple treatment modalities. Hypnosis and self-hypnosis with imagined sensations of warmth, cold, tingling, and heaviness brought about dramatic improvement over 5 weeks, with full resolution of the recurrent furuncles (Jabush, 1969). The patient also had substantial mental improvement. In unusually resistant cases with significant psychosomatic overlay such as this, use of hypnosis may help to end the chronic susceptibility to recurrent infection.

Oral pain such as glossodynia may respond well to hypnosis as a primary treatment if there is a significant psychological component (Golan, 1997). With organic disease, hypnosis may give temporary relief from pain.

Discomfort relief from herpes simplex is similar to that for postherpetic neuralgia (see the following text), and reduction in the frequency of recurrences of herpes simplex following hypnosis has also been reported (Bertolino, 1983). In cases with an apparent emotional stress trigger factor, hypnotic suggestion may be useful.

Hypnosis or autogenic training may be useful as adjunctive therapy for hyperhidrosis (Hölzle, 1994). Stress is a common trigger or exacerbator of hyperhidrosis.

A 33-year-old man with ichthyosis vulgaris that was better in summer and worse in winter began hypnotic suggestion therapy in the summer and was able to maintain the summer improvement throughout the fall, winter, and spring (Schneck, 1954).

Stress is a definite exacerbating factor in lichen planus. Pruritus and lesions of lichen planus may be reduced in selected cases using hypnosis (Scott, 1960; Tobia, 1982).

Some cases of neurodermatitis or psychogenic dermatitis have resolved and remained resolved with up to 4 years of follow-up using hypnosis (Kline, 1953; Sacerdote, 1965; Collison, 1965; Lehman, 1978). Stress is a major factor in increasing scratching or picking of the skin in these patients.

Reduction of pruritus and resolution of lesions of nummular dermatitis has been reported with the use of hypnotic suggestion (Scott, 1960; Tobia, 1982).

Pain from herpes zoster and post-herpetic neuralgia can be reduced by hypnosis (Scott, 1960; Tobia, 1982). Hypnosis may be useful as a therapy for postherpetic neuralgia. The author had a patient whose life had been disrupted for 6 years with postherpetic neuralgia that greatly limited his quality of life. He had been a highly successful attorney and had retired before he had anticipated at age 65 due to the postherpetic neuralgia. After he learned self-hypnosis, he regained a sense of control over his life. He could diminish the pain, and it no longer ruled over his activities.

Pruritus typically increases with stress. Hypnosis can modify and lessen the intensity of pruritus (Scott, 1960). A man with chronic myelogenous leukemia had intractable pruritus that was much improved with hypnotic suggestion (Ament & Milgram, 1967).

Stress and emotions are a common exacerbating factor in psoriasis. Hypnosis and suggestion have been demonstrated to have a positive effect on psoriasis (Kantor, 1990; Winchell & Watts, 1988; Zachariae, Oster, Bjerring, & Kragballe, 1996). A 75% clearing of psoriasis was reported in one case using a hypnotic sensory-imagery technique (Kline, 1954). A patient with extensive, severe psoriasis of 20 years duration had marked improvement using sensory imagery to replicate the feelings in the patient's skin that he had experienced during sunbathing (Frankel & Misch, 1973). Another patient with severe psoriasis of 20 years duration recovered fully with a hypnoanalytic technique (Waxman, 1973). Tausk and Whitmore (1999) performed a small randomized controlled trial using hypnosis as adjunctive therapy in psoriasis with significant improvement only in the highly hypnotizable subjects and not in the moderately hypnotizable subjects.

The vascular blush component of rosacea has been reported to improve in selected cases of resistant rosacea where hypnosis has been added (Scott, 1960; Tobia, 1982). Stress and emotions can increase blushing.

Several reports of successful adjunctive treatment of trichotillomania with hypnosis have been published (Galski, 1981; Rowen, 1981; Barabasz, 1987). Stress is an exacerbating factor.

Two cases of urticaria with stress as a trigger factor responded to hypnotic suggestion in one study. An 11-year-old boy who had an urticarial reaction to chocolate could have the hives blocked by hypnotic suggestion, so that hives appeared on one side of his face but not the other in response to hypnotic suggestion (Perloff & Spiegelman, 1973). In 15 patients with chronic urticaria of 7.8 years average duration, hypnosis with relaxation therapy resulted within 14 months in six patients being cleared and another eight patients improved, with decreased medication requirements reported by 80% of the subjects (Shertzer & Lookingbill, 1987).

Many reports confirm the efficacy of hypnosis in treating warts (McDowell, 1949; Ullman & Dudek, 1960; Vickers, 1961; Surman, Gottlieb, & Hackett, 1972; Ewin, 1974; Clawson & Swade, 1975; Tasini & Hackett, 1977; Johnson & Barber, 1978; Dreaper, 1978; Straatmeyer & Rhodes, 1983; Morris, 1985; Spanos, Stenstrom, & Johnston, 1988; Noll, 1988; Spanos, Williams, & Gwynn, 1990; Ewin, 1992; Noll, 1994). One study (Tenzel & Taylor, 1969) that tried to replicate the remarkable success reported in *Lancet* (Sinclair-Gieben & Chalmers, 1959) of using hypnotic suggestion to cause warts to disappear from one hand but not the other in persons with bilateral hand warts was unsuccessful. A well-conducted randomized controlled study resulted in 53% of the experimental group having improvement of their warts 3 months after the first of five hypnotherapy sessions, while none of the control group had improvement (Surman, Gottlieb, Hackett, & Silverberg, 1973).

Having vitiligo can be very stressful to some individuals, especially those with naturally dark skin tone. Vitiligo has improved using hypnotic suggestion as supportive therapy (Scott, 1960; Tobia, 1982), but it is unclear whether the recovery was simply spontaneous. Hypnosis may also be appropriate as a supportive treatment for the psychological impact of having vitiligo.

Medical Hypnotherapy for Reducing Procedure Stress and Anxiety

Hypnosis can reduce stress, anxiety, needle phobia, and pain during cutaneous surgery, as well as reduce postoperative discomfort and enhance postoperative healing. Fick and others (1999) used self-guided imagery to help 56 non-selected patients referred for percutaneous interventional procedures in the radiology procedure suite. A standardized protocol and script was used to guide patients into a state of self-hypnotic relaxation followed by suggestion to go where they would rather be. All 56 patients developed an imaginary scenario, and the imagery they chose was highly individualistic, making recorded suggested scenarios or provider-directed imagery likely to be less effective than self-directed imagery. The author has used this technique with good success in dermatology patients (Shenefelt, 2003).

Lang and colleagues (2000) conducted a randomized trial of adjunctive non-pharmacological analgesia for invasive percutaneous vascular radiologic procedures consisting of three groups: standard care (control group), structured attention, and self-hypnotic relaxation. While pain increased linearly with time in the standard and the attention group, pain remained flat in the hypnosis group. Anxiety decreased over time in all three groups, but more so with hypnosis. Conscious sedation drug use was significantly higher in the standard group than in the structured attention and self-hypnosis groups. Hemodynamic stability was significantly higher in the hypnosis group than in the attention and standard groups. Procedure times were significantly shorter in the hypnosis group than in the standard group, with the attention group intermediate. Cost analysis of this study (Lang & Rosen, 2002) showed that the cost associated with standard conscious sedation averaged US$638 per case while the cost for sedation with adjunct hypnosis was US$300 per case, making the latter considerably more cost-effective.

The author conducted a randomized controlled trial of hypnotically induced relaxation with self-guided imagery among 39 patients undergoing dermatologic surgery. Patients were randomly assigned to live induction, recorded induction, and control groups. The live induction group had significantly ($p < .05$) less anxiety by 20 minutes than the controls, with the recorded induction group being close to the controls in response (Shenefelt, 2013).

A meta-analysis of hypnotically induced analgesia found that hypnosis can significantly relieve pain in patients with headache, burn injury, heart disease, cancer, dental problems, eczema, and chronic back problems (Montgomery, DuHamel, & Redd, 2000). For most purposes, light and medium trance is sufficient, but deep trance is required for hypnotic anesthesia for surgery (Barabasz & Watkins, 2005). Pain reduction mediated by hypnosis localized to the mid-anterior cingulate cortex in a study (Faymonville et al., 2000) using positron emission tomography (PET).

For hypnosis to be useful, patients must be mentally intact, not psychotic or heavily intoxicated, motivated, not resistant, and preferably medium or high hypnotizable as rated by the Hypnotic Induction Profile (Spiegel, H. & Spiegel, D., 2004) or Stanford Hypnotic Susceptibility Scale and its variants. However, for hypnotic induction with self-guided imagery, a moderate or high degree of hypnotizability is not critical to success, and allowing the patient to choose his or her own self-guided imagery permits most individuals to reach a state of relaxation during procedures. Both the patient and the physician can benefit from a more pleasant experience attended by fewer complications during the procedure.

Hypnoanalysis

Hypnoanalysis may help some patients with skin disorders unresponsive to other simpler approaches. Using hypnoanalysis, results may also occur much more quickly than with standard psychoanalysis (Scott, 1960). Non-psychiatrist physicians have focused on the body and how the mind interacts with the body. To differentiate this from the type of hypnoanalysis used by psychologists and psychiatrists, the author has coined the term "psychosomatic hypnoanalysis" (Shenefelt 2007). Seven key factors were identified by Cheek and LeCron associated with psychosomatic issues (Cheek & LeCron, 1968). The key issues, listed in slightly modified form by the author (Shenefelt, 2010), are **C**onflict, **O**rgan language, **M**otivation or secondary gain, **P**ast experiences or traumatic conditioning, **A**ctive identification, **S**uggestion, and **S**elf-punishment. The C.O.M.P.A.S.S. method of identifying seven trigger or exacerbating psychosomatic root causes is well described in Ewin and Eimer (2006). Ideomotor signaling is used for non-verbal communication (Ewin & Eimer, 2006; Shenefelt, 2011). Uncovering the initiating or trigger or exacerbating factors and neutralizing the associated negatively charged emotion often leads to the resolution of the psychosomatic aspects of the problem. Dr. Ewin used psychosomatic hypnoanalysis for a series of 41 patients with recalcitrant warts that had failed to respond to ordinary hypnotic suggestion and achieved resolution in 33 of the 41 patients (Ewin, 1992). In these cases, a psychological blocking factor had inhibited the delayed cellular immune system from eliminating the warts until the negative emotional blockage was removed. A patient who had persistent erythema nodosum for 9 years with no apparent physical trigger factors had resolution of the lesions after hypnoanalysis (Shenefelt, 2007). Another patient had resolution of resistant neurodermatitis on the face (Shenefelt 2010). This C.O.M.P.A.S.S. method can be used to screen for psychosomatic factors. Although not empirically demonstrated, experience has taught that if all of the C.O.M.P.A.S.S. factors are negative, there is likely not a significant psychosomatic component associated with the disease process. If one or two factors are positive, appropriate neutralizing suggestions may be sufficient treatment. If three or more factors are positive, referral to an appropriate psychologist or psychiatrist or other experienced mental health worker would be appropriate (Shenefelt, 2007).

Mindfulness Meditation

Mindfulness meditation has a focus on emotional non-attachment but broad awareness of many objects, sounds, other sensations, or thoughts. Concentrative meditation, by comparison, has a focus on one object such as a candle flame or mandala, image, sound, word, or mantra. Both forms of meditation involve entering a trance state. The mindfulness trance maintains external awareness while remaining calmly centered, similar to alert–awake hypnotic trance, while the concentrative trance reduces external awareness similar to internally focused hypnotic trance. The relaxation response, a form of concentrative meditation, was introduced by Herbert Benson (Benson, 1975). The health benefits of the relaxation response have been extensively researched, with positive results in areas such as cardiovascular health.

Mindfulness meditation has been shown as an adjunct to help improve psoriasis. Originally associated with Buddhism, and in particular Zen, it has been adapted for medical use for stress reduction. Jon Kabat-Zinn (Kabat-Zinn, 1990, 1994) developed the mindfulness-based stress reduction program. The 8-week course had weekly 2-hour classes where techniques of breath, awareness of body sensations, and stretching yoga were taught, along with a half day of meditation and daily homework (of 45 minutes taped guided meditation or 30 minutes of meditation on their own). Gentle coaching helped patients to develop non-judgmental, moment-to-moment awareness, attention monitoring, and acceptance. He also performed a study (Kabat-Zinn, 1998) that randomized psoriasis patients undergoing ultraviolet B (UVB) or psoralen plus ultraviolet A (PUVA) light treatments into two groups, those listening to mindfulness meditation tapes and those who were controls. Patients in the mindfulness meditation tape group reached the halfway point in clearing and the complete clearing point significantly more rapidly than the controls for both UVB and PUVA treatments. The mindfulness meditation worked synergistically with the UVA or PUVA to promote healing.

Placebo

Positive placebo expectations and a positive doctor–patient relationship can affect the patient's experience of treatment, can reduce pain, and may influence outcome. Negative expectations can produce negative nocebo results (Speigel, 2004). Research on the placebo effect illustrates that the natural healing capacities of individuals can be enhanced and nurtured (Di Blasi & Reilly, 2005). The placebo effect for some common dermatologic conditions such as acne and urticaria is about 30% (Gupta, M. A. & Gupta, A. K., 1996). Those disorders higher on the Griesemer scale (Shenefelt, 2000) are more likely to have a significant placebo effect.

Suggestion

Suggestion used to promote healing is as old as language. It can be used to change subjective perceptions and to reduce pain. Suggestion may influence outcome. Bloch (1927) and Sulzberger and Wolf (1934) used suggestion to treat verrucae successfully. The efficacy of suggestion in treating verruca vulgaris (warts) has been confirmed numerous times to a greater or lesser degree (Obermayer & Greenson, 1949; Ullman, 1959; Dudek, 1967; Sheehan, 1978) and failed to be confirmed in a few studies (Clarke, 1965; Stankler, 1967). A study that showed negative results was criticized for using a negative suggestion of not feeding the warts rather than a positive suggestion about having the warts resolve (Felt et al., 1998).

Conclusion

Skin disorders can significantly affect the psyche, and the psyche through psychoneuroimmunoendocrine and behavioral mechanisms can significantly affect skin disorders. Since many inflammatory skin disorders are triggered or aggravated by stress, teaching patients to practice safe stress using non-pharmacological behavioral and psychological methods, supplemented if necessary with anxiolytic standard drugs or herbal alternatives, deserves more attention in treatment planning. Adding non-drug psychocutaneous treatments such as biofeedback, cognitive behavioral methods, CES, EFT, EMDR, hypnosis, mindfulness meditation, placebo effect, or suggestion often enhances the effectiveness of treatment. A multidimensional approach often optimizes the treatment response.

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Psychocardiology

Mechanisms and Management of Psychosocial and Behavioral Risk Factors in Patients with Coronary Heart Disease

Thomas Meyer and Christoph Herrmann-Lingen

Psychocardiology – Studying the Interplay between Heart and Brain

The evolving field of evidence-based psychocardiology focuses on the study of psychosocial factors involved in the emergence, course, and treatment of cardiac diseases. It covers a broad spectrum of diverse methodological approaches, ranging from basic biochemical research to epidemiological and clinical studies and intervention trials. New techniques have led to recent advances in our understanding of the role of psychosocial and behavioral factors in the context of human heart diseases. Virtually all cardiac disease entities, such as coronary heart disease, chronic heart failure, and cardiac arrhythmias, can be accompanied by affective symptoms and, conversely, mental diseases may manifest themselves as heart-related symptoms. Furthermore, psychosocial factors have been identified as risk factors for the development of chronic heart disease and the onset of acute cardiac events. Both emotional sequelae of organic heart disease and psychosocial risk factors therefore deserve proper identification and treatment. Best studied in this field is probably the impact of social inequality, emotional stress, anxiety, depression, and vital exhaustion on the initiation and course of coronary heart disease. In this chapter, we will highlight some recent developments in the field of psychocardiological research, with special emphasis on studies addressing the epidemiology, management, and treatment of psychosocial and behavioral risk factors for coronary heart disease.

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Identifying Psychosocial Risk Factors in the Development of Coronary Artery Disease

Various psychosocial risk factors strongly influence the course of coronary arteriosclerosis and promote the development and clinical manifestation of ischemic heart disease. Among them, the experience of chronic stress and associated unhealthy lifestyle behaviors, such as overeating, physical inactivity, and smoking, have tremendous impact on global public health (Rozanski, Blumenthal, & Kaplan, 1999). An impressive body of epidemiological research has shown that cardiovascular disease remains the leading cause of death and a major cause of morbidity and disability in developed countries.

In addition to traditional risk factors as reported in the Framingham study, including hypertension, smoking, diabetes mellitus, and hyperlipoproteinemia, numerous psychosocial risk factors have been identified in the last few decades, and there is no doubt that this has extended our knowledge on the impact of individual emotional symptoms and personality traits for promoting the development of coronary heart disease. Identification of novel cardiac risk factors will be beneficial not only from a pathophysiological standpoint but, more importantly, also for the evaluation of promising intervention strategies for the prevention of cardiac events and the treatment of arteriosclerotic diseases. It is well known that unhealthy lifestyle behaviors tend to aggregate disproportionately among individuals exposed to chronic stressors (Perk et al., 2012). Such clustering of risk factors may lead, probably via mechanisms involving excessive sympathetic nervous system activation, to endothelial dysfunction and exacerbation of coronary arteriosclerosis (Rozanski, Blumenthal, Davidson, Saab, & Kubzansky, 2005).

A variety of adverse life circumstances can influence the extent to which individuals engage in high- or low-risk adverse health behaviors. For instance, social isolation or lack of emotional support, work-related stress, and/or low socioeconomic status, alone or in combination, contribute to a higher frequency of adverse health behaviors such as poor diet, fat intake, obesity, and smoking, all of which promote atherogenesis and most probably act in a synergistic manner. In particular, when low socioeconomic status is clustered together with traditional cardiovascular risk factors, the incidence of coronary artery disease and/or future cardiac events rises substantially (Winkleby, Fortmann, & Barrett, 1990; Lynch, Everson, Kaplan, Salonen, R., & Salonen, J. T., 1998; Hemingway, Shipley, Macfarlane, & Marmot, 2000). Independently of whether socioeconomic status was measured by education, income, or occupation, many investigators have consistently uncovered its role as a significant contributor to increased incidence and poor prognosis of coronary heart disease. Stress at work and in family life has also been shown to predict incident coronary artery disease (Yusuf et al., 2004). Low perceived social support has been linked to increased incidence and progression of coronary artery disease (Vogt, Mullooly, Ernst, Pope, & Hollis, 1992; Orth-Gomér, Rosengren, & Wilhelmsen, 1993; Lett et al., 2005; Wang, Mittleman, & Orth-Gomér, 2005; Barth, Schneider,

& von Känel, 2010; Roohafza, Talaei, Pourmoghaddas, Rajabi, & Sadeghi, 2012), and is associated with increased morbidity and mortality in coronary artery patients, independent of the severity of cardiac disease (Chandra, Szklo, Goldberg, & Tonascia, 1983; Ruberman, Weinblatt, Goldberg, & Chaudhary 1984; Wiklund et al., 1988; Case, R. B., Moss, Case, N., McDermott, & Eberly, 1992; Williams et al., 1992; Jenkinson, Madeley, Mitchell, & Turner, 1993; Woloshin et al., 1997; Angerer et al., 2000; Barth, Schneider, & van Känel, 2010; Knox et al., 2000). Conversely, the presence of family affiliations, a higher number of close friends, and active participation in group and organizational affairs have beneficial effects by conferring a low risk for future cardiac events.

The impact of psychosocial risk factors for global health was addressed by the INTERHEART study, a standardized case-control study of acute myocardial infarction in 15,152 cases and 14,820 controls conducted in 52 countries, which aimed at predicting the impact of potentially modifiable risk factors on the development of myocardial infarction (Rosengren et al., 2004; Yusuf et al., 2004). The most surprising finding of this investigation was that psychosocial risk factors, including perceived chronic stress at home and at work, financial stress, major life events in the past year, depression, and low locus of control, were responsible for almost one-third (32.5%) of the population attributable risk (PAR) for myocardial infarction, which was only slightly lower than that for smoking (35.7%), and higher than that for hypertension (17.9%), abdominal obesity (20.1%), or diabetes (9.9%). The strikingly high PAR observed for psychosocial factors was noted in both sexes, across all age groups, and in all regions of the world. The PAR, which estimates the reduction in the incidence of myocardial infarction that would occur if the risk factor could be completely eliminated, is based on both the prevalence and the strength of the risk factor, with a highly prevalent predictor having a more profound effect on PAR.

Epidemiologic Links between Depression and Coronary Artery Disease

Among mental disorders, depression has been most frequently studied for its impact on the development and prognosis of coronary heart disease. There is a growing body of evidence indicating that depression is an important predictor of incident coronary heart disease (Rugulies, 2002; Wulsin & Singal, 2003; Nicholson, Kuper, & Hemingway, 2006; Blumenthal, 2008), as well as morbidity and mortality in patients with coronary heart disease, particularly after myocardial infarction (Pratt et al., 1996; Barth, Schumacher, & Herrmann-Lingen, 2004; van Melle et al., 2004; van der Kooy et al., 2007; Das & O'Keefe, 2008; Doyle, Conroy, & McGee, 2012). About 20% of post-myocardial-infarction patients experience a major depressive episode, and an approximately equal percentage of patients report on minor depressive symptoms within the first year after myocardial infarction. Most investigations have shown that depressive episodes in post-myocardial infarction are associated with an increased risk of all-cause mortality, cardiac mortality, and the development of new cardiovascular events. Among depressed patients with coronary artery disease, there is a higher rate of hospitalization and emergency room visits, and a trend toward increased healthcare use (Frasure-Smith et al., 2000; Rutledge, Reis, Linke, Greenberg, & Mills, 2006; Reese et al., 2011). Interestingly, post-myocardial depressive disorders also predict slower recovery and, not unexpectedly, poor health-related quality of life (Carney & Freedland, 2008).

Although depression has been linked to both physiological and behavioral changes that are deleterious to the cardiovascular system, the mechanisms underlying this connection still remain largely unclear. Due to methodological difficulties, epidemiological studies addressing this relationship have shown mixed results, probably because it is often unclear whether behavioral changes occurring in the context of depression in cardiovascular patients mediate the effect of depression or merely function as confounders. Up to now, we cannot completely rule out the possibility that depression reflects some still-unidentified physiological consequences of advanced cardiac disease or, alternatively, that depression and coronary heart disease are the phenotypic consequences of common causes, for example, genetic profiles, and, equally interestingly, psychosocial factors, such as personality traits, low socioeconomic status, or chronic stress (Frasure-Smith & Lespérance, 2010). However, there is evidence that depression is related to a variety of factors known to be related to the onset and progression of coronary disease. For example, depression has been associated with alterations in autonomic and neuroendocrine regulation, as well as with peripheral changes in plasmatic coagulation, inflammation, endothelial function, proliferative processes, etc. (Rozanski et al., 2005).

Because the identification of patients with major depression requires a formal interview performed by trained professionals with a psychological or psychiatric background, there are only a limited number of studies on cardiovascular patients with diagnosed major depression. In contrast, a variety of investigations using validated self-rating scales for depressive symptoms have revealed a strong consistent gradient between the severity of depressive symptoms, biological markers, and the likelihood of adverse cardiac events, beginning at subclinical symptom levels (Lespérance, Frasure-Smith, Talajic, & Bourassa, 2002). Even mild-to-moderate depressive symptoms that are not sufficient in magnitude to meet the criteria for major depression according to the *Diagnostic and Statistical Manual of Mental Disorders* are nevertheless associated with an increased incidence of future cardiac events (Hance, Carney, Freedland, & Skala, 1996; Penninx et al., 2001). Core symptoms of depression include depressed mood and markedly decreased interest in all former activities, accompanied by additional symptoms such as feelings of guilt or worthlessness, psychomotoric retardation, sleep disturbance, fatigue, and often suicidal idealization. Hopelessness, a frequently observed emotional symptom in depressed patients, has been linked to decreased heart rate variability (Schwarz, Schächinger, Adler, & Goetz, 2003), arterial hypertension (Everson, Kaplan, Goldberg, & Salonen, 2000), and sudden cardiac death (Anda et al., 1993; Everson et al., 1996; Rozanski et al., 1999; Das & O'Keefe, 2008). Interestingly, one study has reported on men experiencing high levels of hopelessness who have an accelerated progression of carotid arteriosclerosis, as determined by an increase in the ultrasonographically measured intima-media thickening (Everson, Kaplan, Goldberg, Salonen, & Salonen, 1997). In middle-aged women, increasing hopelessness was significantly related to greater subclinical arteriosclerosis levels, independent of other depressive symptoms and cardiovascular risk factors (Whipple et al., 2009). Similar correlations have been reported between carotid arteriosclerosis and both anger (Matsumoto et al., 1993) and hostility (Julkunen, Salonen, Kaplan, Chesney, & Salonen, 1994; Matthews, Owens, Kuller, Sutton-Tyrrell, & Jansen-McWilliams, 1998; Angerer et al., 2000; Knox et al., 2000; Newman et al., 2011).

Vital Exhaustion and Anxiety Syndromes in Cardiovascular Patients

Vital exhaustion, a psychological concept originally developed to distinguish a state of unusual fatigue from depression in the context of risk factors for cardiac events, encompasses a transient emotional state that is characterized by a combination of impaired mental and physical energy, tiredness, increased irritability, anhedonia, and feelings of hopelessness. Despite a considerable overlap with depression including sleep alterations, feelings of weakness, and anhedonia, vitally exhausted individuals rarely express sadness, guilt, and feelings of worthlessness, typically observed in depressed patients, thus reflecting a state of demoralization rather than lowered self-esteem. Similar to a depressive mood, vital exhaustion predicts the manifestation and progression of cardiovascular disease, and has been reported to precede and follow myocardial infarctions, even after controlling for recognized traditional risk factors, such as elevated blood pressure, serum cholesterol, or smoking (Appels & Mulder, 1988, 1989; Schuitemaker, Dinant, van der Pol, & Appels, 2004; Schuitemaker, Dinant, van der Pol, Verhelst, & Appels, 2004). Excess fatigue is among the most prevalent precursors not only of myocardial infarction, but also of sudden cardiac death (Cole, Kawachi, Sesso, Paffenbarger, & Lee, 1999; Prescott et al., 2003), and, furthermore, has been identified as an independent risk factor for first stroke (Schwartz, Carlucci, Chambless, & Rosamond, 2004). Feelings of general malaise have been reported to increase the risk of cardiac events after successful percutaneous transluminal coronary angioplasty (Kop, Appels, Mendes de Leon, de Swart, & Bar, 1994).

Compared to depression and vital exhaustion, the relationship between anxiety syndromes and coronary disease is less well studied, and data linking anxiety to progressive arteriosclerotic lesions are limited (Haines, Imeson, & Meade, 1987; Kawachi et al., 1994; Kawachi, Sparrow, Vokonas, & Weiss, 1994; Kubzansky, Davidson, & Rozanski, 2005; Rutledge et al., 2009; Martens et al., 2010; Meyer, Buss, & Herrmann-Lingen, 2010; Nabi et al., 2010; Roest et al., 2010; Watkins et al., 2010; Roest, Zuidersma, & de Jonge, 2012). Individuals with anxiety disorders may be more prone to sudden cardiac death but not myocardial infarction, suggesting that a dysbalance in the autonomic nerve system with impaired vagal control and increased sympathetic stimulation may trigger the occurrence of life-threatening ventricular arrhythmias. However, the lack of association between anxiety disorders and fatal myocardial infarction suggests a more complex, multifactorial interaction of anxiety symptoms on preexisting arteriosclerosis and requires further prospective investigation on the delineation of other underlying pathophysiological states. Psychologically, it can be assumed that a certain amount of anxiety may exert beneficial behavioral effects on, for example, self-care and heart-healthy behavior, thus counterbalancing the adverse effects of autonomic arousal in the majority of patients with stable heart disease.

Personality Traits and the Risk of Coronary Heart Disease

Aside from the evaluation of traditional risk factors, many efforts have been made to link behavior patterns and personality traits to the incidence and progression of coronary artery disease. The type A behavior, first described by the two cardiologists Meyer Friedman and Ray Rosenman in the late 1950s, was defined as a psychological construct characterized by social competition, hostility, and exaggerated commitment to work, and since then has been extensively studied for its association with coronary heart disease (Roseman et al., 1964, 1966). Although the Western Collaborative Group Study had initially reported that type A behavior approximately doubled the risk of coronary heart disease and was associated with a fivefold increased risk of recurrent myocardial infarction over an 8.5-year follow-up (Roseman et al., 1975), a series of subsequent studies failed to reproduce these results and found no positive correlation (Dimsdale, Hackett, Hutter, Block, & Catanzano, 1978; Dimsdale et al., 1979; Case, R. B., Heller, Case, N. B., & Moss, 1985; Shekelle, Gale, & Norusis, 1985; Shekelle et al., 1985). Most contradictory was a long-term analysis from the Western Collaborative Group Study after 22 years of follow-up, which demonstrated an unexpected lower mortality among type A patients who survived an initial myocardial infarction as compared to type B patients (Ragland & Brand, 1988). The better prognosis of type A post-myocardial-infarction patients has cast doubts on the validity of this psychological construct as a predictor for worse outcome in cardiovascular patients (Ragland & Brand, 1988; Shoham-Yakubovich, Ragland, Brand, & Syme, 1988). Because type A behavior is a composite of several dimensions, for example, competitiveness, excessive drive, enhanced sense of time urgency, hostility, and anger, each of these constituting components may have unique effects on the progression of arteriosclerotic lesions. More recently, anger proneness and hostility have been found to be associated with physiological risk factors and coronary disease. One can therefore assume that these traits may constitute the pathogenic components of the type A construct (Kawachi et al., 1994; Kawachi, Sparrow, Spiro, Vokonas, & Weiss, 1996; Williams et al., 2000; Cole et al., 2001; Chida & Steptoe, 2009). However, more studies are needed to confirm this assumption.

Another promising psychological construct linked to the prognosis of coronary heart disease is the distressed (type D) personality, which was described by Denollet and colleagues. Individuals classified as type D have elevated scores on two (typically self-rated) personality traits, namely negative affectivity defined as the general tendency to experience negative emotions, and, secondly, social inhibition, which means the suppression of self-expression in social interactions (Denollet & Brutsaert, 1998; Denollet, Vaes, & Brutsaert, 2000; Denollet, Pedersen, Vrints, & Conraads, 2006). Numerous investigations, most of which were published from Denollet's group, have reported that type D personality is associated with poorer outcome in patients with cardiac disease, suggesting that vulnerability to chronic psychological distress, as defined by the type D construct, has adverse prognostic value. However, some recent attempts at replicating these findings have failed to detect a positive relationship between type D and objective outcomes of heart disease (Larson, Barger, & Sydeman, 2013; Grande et al., 2011; Coyne et al., 2011; Romppel, Herrmann-Lingen, Vesper, & Grande, 2012; Williams, O'Connor, Grubb, & O'Carroll, 2012). More prospective research in clinically well-defined study samples is necessary to clarify these inconsistent results and refine this personality typology by strictly focusing on its two constituents, negative affectivity and social inhibition (Grande, Romppel, & Barth, 2012).

Primate Models for the Study of Psychosocial Factors in Coronary Heart Disease

There is no doubt that behavioral studies have significantly contributed to our recent knowledge on molecular mechanisms behind psychosocial aspects of coronary artery arteriosclerosis, in part by offering important clues as to the neuroendocrine mediation of behavior. Besides epidemiological studies in human populations, animal experiments are most suitable to decipher the impact of behavioral changes on the progression of coronary artery disease. Given the overwhelming volume of literature on the pathophysiological basis of psychosocial risk factors, we will restrict ourselves to some observational studies from experimental animal models and briefly discuss outstanding clinical investigations in humans, but will not focus on pure biochemical and pathophysiological studies.

Our current understanding of how chronic psychosocial stress can lead to development and exacerbation of coronary heart disease has very much profited from animal experiments using the group-living cynomolgus monkey *Macaca fascicularis*. This cercopithecine primate has long been established as an experimental model for behavioral research in cardiovascular medicine, because these monkeys normally live in multiple-male groups with strict dominance hierarchies and can readily be housed under laboratory conditions. Additionally, it has been recognized that the distribution of arteriosclerotic lesions in the large epicardial coronary arteries of these animals closely resembles the arterial lesions found in human beings (Malinow et al., 1976; Bond, Bullock, Bellinger, & Hamm, 1980; Clarkson, Kaplan, Adams, & Manuck, 1987).

Cynomolgus monkeys exhibit elaborate patterns of competitive social interaction, including generation-spanning networks of affiliation, mutual support, and alliance based on asymmetries in their power and status relationships, some of which are reminiscent of human behaviors. Whereas adult male monkeys in high-ranking positions behave despotically and combat each other from time to time, the ranks of the females remain more stable. In the early 1980s, Kaplan and colleagues showed that socially stressed adult male macaques developed more extensive arteriosclerotic coronary artery lesions than unstressed controls, when fed on a low-cholesterol diet (Kaplan, Manuck, Clarkson, Lusso, & Taub, 1982; Kaplan et al., 1983, 1993). Psychosocial stress induced by periodical reorganization of group membership led to exacerbation of coronary artery arteriosclerosis, particularly in those male monkeys who were habitually dominant in their social groups (Manuck, Kaplan, Adams, & Clarkson, 1988; Manuck, Marsland, Kaplan, & Williams, 1995). Interestingly, the observed differences in lesion extent between male monkeys in stressed and non-stressed social environments were independent of differences in physical parameters, such as serum lipids, blood pressure, serum glucose, or body weight.

Whereas males in dominant ranks are prone to development of coronary lesions, subordinate males are protected from progressive arteriosclerosis, even when housed in an unstable social setting with rotating group memberships. The extent of coronary artery lesions in dominant males in these reorganized groups is about twice as high as in those housed in stable social groups. The observation that unstable social environment potentiates coronary artery disease exclusively in dominant males, but not in subordinate males, may seem surprising in view of the prevailing belief that low-ranking males are under greater social pressure than dominates (Kaplan & Manuck, 1999; Manuck et al., 1995). However, active suppression of the subordinates seems to be associated with pronounced sympathoadrenal activation in dominant males and reflects the behavioral demands of retaining preeminence in unstable social environments.

When grouped together, female monkeys organize themselves into linear social status hierarchies that define dominant and subordinate positions. Compared to dominant females, lower-ranking female group members are exposed to more aggression, show more vigilant behavior, and spend more time alone or in fearful scanning of the social environment. Female animals in subordinate positions respond to a standardized social stressor with higher heart rates than their dominant group members (Manuck, Kaplan, Adams, & Clarkson, 1989). Typically, they have elevated cortisol levels and, in response to adrenocorticotropin stimuli, secrete greater amounts of glucocorticoids into the circulation (Shively, Musselman, &

Willard, 2009). Furthermore, social subordination stress was found to be associated with heavier adrenal glands and slightly elevated plasma glucose levels as compared to dominates (Shively & Kaplan, 1984). Female monkeys commonly respond to stress associated with low social status not only with perturbations in the hypothalamic–pituitary–adrenal (HPA) axis and autonomic nervous system, but also with metabolic changes, such as higher plasma lipid concentrations and lower mean peak luteal phase progesterone levels, suggesting an impaired ovarial function (Clarkson et al., 1987; Manuck et al., 1989; Watson, Shively, Kaplan, & Line, 1998; Kaplan & Manuck, 1999). Moreover, there is evidence of altered monoaminergic functions in female subordinates, as demonstrated from lower prolactin responses to haloperidol challenge in subordinates as compared to dominants (Shively, 1998).

In contrast to males, social subordination stress or change of social positions favors the development of coronary arteriosclerosis in group-living female cynomolgus monkeys (Shively & Clarkson, 1994). Moreover, there is evidence of social-stress-associated behavioral depression in subordinate female monkeys, consistent with the hypothesis that, in the primate model, depression is linked to the development of coronary artery arteriosclerosis (Willard & Shively, 2012). The comorbidity of depression-like behavior and coronary arteriosclerosis observed in these animals make female macaques a suitable model for future studies on the relationships between social stress, depression, and coronary heart disease.

Pathophysiological Mechanisms behind Psychosocial Risk Factors

The lessons that we have learned from the behavioral studies in primates so far can help us to better understand the biological impact of psychological factors, including personality traits, on coronary artery disease in human populations and, in addition, may predict the effects of behavioral interventions on the course and impact of comorbid depressive episodes in cardiovascular patients. It is well known that, similar to the case in monkeys, so also in humans, emotional disturbance, such as depressive mood, and chronic social stress appear to promote coronary arteriosclerosis (Richardson et al., 2012).

Further evidence for a stress-induced susceptibility to cardiac mortality comes from a transgenic mouse model undergoing application of chronic stress. Recently, Carnevali and co-workers reported that knockout mice lacking the expression of the serotonin (5-HT) 1A receptor show an altered autonomic regulation of cardiac function under acute and chronic stress conditions (Carnevali et al., 2012). During acute stress, mice with a genetic loss of 5-HT 1A receptor displayed a higher tachycardic stress response and a larger reduction in vagal modulation of heart rate than their wild-type counterparts. More than a quarter of the knockout animals died from cardiac arrest when exposed to a protocol of chronic psychosocial stress, indicating that mice with an altered serotonergic neurotransmission have an increased susceptibility to a stress-induced rise in heart rate and sudden cardiac death.

Also in humans, chronic autonomic imbalance with sympathetic predominance is a significant predictor for sudden cardiac death. Strong, sudden emotions can predispose to life-threatening ventricular arrhythmias resulting from autonomically mediated repolarization changes, as has been shown in Taiwanese earthquake survivors (Huang, Chiou, Ting, Chen, Y. T., & Chen, S. A., 2001), in Israeli citizens during Iraqi missile attack in the first days of the Gulf War (Meisel et al., 1991), and in New York City residents following the September 11, 2001, terrorist attacks (Steinberg et al., 2004). Episodic negative emotions, such as anxiety (Friedman & Thayer, 1998) and depression (Kemp et al., 2010), have also been related to reduced heart rate variability, although the multiplicity of measures and study designs does not yet allow any estimation of the clinical relevance of this association.

Severe emotional stress leads to changes in the HPA axis and the autonomic nervous system, which act in concert. Psychosocial stressors activate the HPA axis, leading to hypercortisolemia and elevated corticotropin-releasing hormone concentrations in the cerebrospinal fluid of depressed subjects (Nemeroff et al., 1984). Hypercortisolemia, observed in a subset of patients with depression, is associated with insulin resistance, favors accumulation of visceral fat, and contributes to the clinical presentation of diabetes mellitus and diverse cardiovascular complications. Raising cortisol secretion into the circulation is important for the ability to adequately respond to an acute stressor, but may be dysfunctional in the context of chronic exposure to unbearable social stressors or maltreatment. The neuroendocrine alterations commonly found in individuals with altered stress reactivity suggest that HPA hyperactivity is engaged in linking depression to increased risk for arteriosclerosis, diabetes mellitus, and osteoporosis, particularly in older patients (Brown, Barton, & Lambert, 2009; Stetler & Miller, 2011). Thus, cortisol functions as a mediating factor by directly linking emotions to cardiovascular effects.

Heightened physiological stress responses and activation of stress pathways facilitate adaptation to new psychosocial and behavioral challenges, and may also increase vulnerability toward physical and mental health problems depending on the stressor onset, intensity, and chronicity. Under conditions of repeated and high levels of perceived stress, elevated secretion of cortisol may contribute to increased arteriosclerosis as a consequence of a suppressed glucocorticoid attenuation of stress-induced inflammation. Recently, a model has been proposed wherein exposure to prolonged stressors results in glucocorticoid receptor resistance that, in turn, results in failure to downregulate inflammatory responses (Cohen et al., 2012). The molecular pathways for glucocorticoid receptor resistance, which paradoxically lead to accelerated immune reactions, have not yet been extensively studied. It will be interesting to know whether, in chronically stressed or depressed patients, expression of glucocorticoid receptors are downregulated, and what distal signal components (e.g., microRNAs, heat-shock proteins, and transcriptional regulators) are involved in suppressing the anti-proliferative and immune-modulating effects of glucocorticoids.

Enhanced local production of proinflammatory cytokines, as reported for macrophages localized in arteriosclerotic plaques, may play a crucial role in the onset and progression of comorbid diseases in patients under stress, thereby providing an explanation for the clinically observed association of depressive symptoms with inflammatory processes in the vessel wall (Schieffer et al., 2000; Daugherty, Webb, Rateri, & King, 2005). Both depressed patients and patients with severe arteriosclerotic lesions have increased circulating levels of cytokines, acute phase proteins, and chemokines, which promote leukocyte adhesion to the endothelium with their subsequent transmigration. The treatment of depressed patients with selective serotonin reuptake inhibitors (SSRIs) attempts to ameliorate mood symptoms, and numerous, but not all, studies have reported that SSRIs also affect immune functions, as shown by a reduction in the circulating proinflammatory cytokines interleukin (IL)-1β, IL-6, and tumor necrosis factor-α (TNFα) (Tuglu, Kara, Caliyurt, Vardar, & Abay, 2003; Tucker et al., 2004; Basterzi et al., 2005; De Berardis et al., 2010; Henje Blom et al., 2012).

Heart Disease as a Stressor

While considerable evidence links emotional stress to cardiovascular disease outcomes, heart disease itself typically acts as a stressor in affected persons. Given the high physiological and emotional relevance of the heart, it is little surprising that heart disease often leads to profound anxiety, depression, and even posttraumatic symptoms and disorders. Besides such psychological factors, inflammatory processes involved in the cardiovascular disease process lead to feelings of fatigue and lower the threshold for development of depressive disorders. Emotional maladjustment is a major source of suffering in cardiac patients. It often leads to higher cardiac symptom reporting and a decline in quality of life sometimes exceeding the changes brought about by the heart disease itself. It is associated with poor control of risk factors, increased healthcare utilization and costs, poorly indicated medical procedures, inability to work, and increased rates of complications. The vicious circle of distress causing heart disease and of heart disease causing distress requires an individualized, holistic treatment approach specifically addressing both somatic and psychosocial aspects of the disease in each patient.

Studies on Psychoeducation and Stress Reduction to Improve Heart Disease Outcomes

Given the link between stress and CAD, therapeutic approaches aimed at modifying psychosocial risk factors promise to have a major impact on the prevention of myocardial infarction. Linden and co-workers (2007) identified 43 randomized controlled trials on this issue, and approximately half of them ($n = 23$) included mortality data. The striking finding of this meta-analysis was that psychological treatment, offered in addition to usual care, reduced mortality for at least the first 2 years after study enrolment. Interestingly, psychological treatment initiated within 2 months of a cardiac event had no positive impact on survival, whereas benefit was reported in studies that had recruited their study participants later. Mortality benefits were identified only in men, and were usually associated with small concomitant changes in negative affect. These data underlined the conclusion from an earlier meta-analysis, which had reported that cardiac rehabilitation programs were more successful in reduction of cardiac mortality and recurrence of myocardial infarction, if they had yielded positive effects on systolic blood, smoking behavior, physical exercise, and/or emotional distress (Dusseldorp, van Elderen, Maes, Meulman, & Kraaij, 1999). In contrast, Whalley et al. (2011) found no strong evidence that psychological interventions reduced all-cause mortality, incident nonfatal infarctions, risk of revascularization, or need for cardiac surgery. However, there was evidence that psychological interventions may produce small-to-moderate reductions in cardiac mortality, depression, and anxiety.

However, several recent studies, not covered by these reviews, have yielded promising results. In the Stockholm Women's Intervention Trial for Coronary Heart Disease (SWITCHD), Orth-Gomér et al. (2009) found that a gender-specific cognitive behavioral group intervention with emphasis on coping with stress resulted in a significant reduction in mortality at the end of the follow-up period (mean duration 7.1 years). The authors concluded that a group-based psychosocial intervention, focusing on psychosocial risk factors, significantly prolongs life in women who had survived myocardial infarction or presented for coronary revascularization. Another randomized controlled trial of cognitive behavioral therapy (CBT) from Sweden, the Secondary Prevention in Uppsala Primary Health Care Project (SUPRIM), confirmed these findings (Gulliksson et al., 2011). The 1-year CBT intervention program on stress management in coronary artery patients was associated with a significantly more favorable cardiovascular outcome during 94 months of follow-up as compared to the reference group, who had only received the usual care. In summary, numerous studies have reported on the beneficial effects of psychological interventions targeting psychosocial risk factors to improve the prognosis of the underlying heart disease. In the following paragraph, we will discuss our current knowledge on the treatment of comorbid depression: does it also have positive effects on survival?

Treatment for Depression in Patients with Coronary Heart Disease

Several trials have addressed comorbid depression in coronary artery patients using psychotherapy and antidepressant medication as well as collaborative care and preference-based interventions. The ENhancing Recovery in Coronary Heart

Disease (ENRICHD) trial examined whether mortality and recurrent myocardial infarction can be reduced by treating patients for depression and low perceived social support with CBT, which was supplemented with an SSRI antidepressant when indicated (Berkman et al., 2003). The intervention tested was an individually tailored CBT-based treatment initiated at a median of 17 days after myocardial infarction and continued for a median of 11 sessions over 6 months. In addition, patients scoring higher than 24 on the Hamilton Rating Scale for Depression (HRSD) or having less than 50% reduction in Beck Depression Inventory scores after 5 weeks were eligible to receive antidepressant medication. The results of the ENRICHD trial showed that the intervention did not increase the event-free survival, although significant improvements in psychological outcomes at 6-month follow-up were achieved for patients in the treated group as compared to the usual care group. Whereas the ENRICHD investigators had failed to show beneficial effects of psychosocial intervention on mortality and recurrent myocardial infarction, a follow-up analysis confirmed that depression was an independent risk factor for death after acute myocardial infarction, when a subsample of the initially enrolled depressed ENRICHD patients were compared to an independent sample of non-depressed patients (Carney et al., 2003). Further subgroup analyses showed that patients whose depression did not improve during treatment had a particularly poor prognosis (Carney et al., 2009). White men only seemed to benefit from the trial intervention in terms of cardiac prognosis (Schneiderman et al., 2004).

The Sertraline Anti-Depressant Heart Attack Trial (SADHART), which was the first randomized clinical study to investigate the safety and efficacy of sertraline treatment for major depressive disorders in patients with myocardial infarction or unstable angina, has demonstrated that this antidepressant drug can safely be used in patients with ischemic heart disease, who are free of other life-threatening medical conditions (Glassman et al., 2002). Unexpectedly, this SSRI was not extremely effective for the pharmacological treatment of depression in this sample, although it was statistically superior to placebo on the Clinical Global Impression Improvement scale (CGI-I, $p = 0.049$) measured over 24 weeks, which was used as a secondary outcome. However, sertraline resulted in significantly greater improvement than placebo in quality of life and functioning as well as depressive symptoms in predefined subgroups with recurrent or severe depression (Swenson et al., 2003; Glassman, Bigger, Gaffney, Shapiro, & Swenson, 2006). Although the impact of sertraline treatment on hard endpoints still remains unclear, in a substudy, the SADHART investigators reported that this drug was associated with a reduced release of β-thromboglobulin and P-selectin from platelets into the circulation, suggesting that, in larger studies, sertraline might confer a morbidity and mortality advantage (Serebruany et al., 2003). However, more recently, bleeding complications reported under SSRI medication, especially in coronary patients often receiving dual anti-platelet therapy, have shed some doubt on this assumption.

The objective of the Canadian Cardiac Randomized Evaluation of Antidepressant and Psychotherapy Efficacy (CREATE) study was to evaluate the short-time efficacy of citalopram and interpersonal psychotherapy in improving depressive symptoms in patients with coronary artery disease and comorbid major depression. The trial documented the superiority of SSRI treatment over placebo in reducing 12-week Hamilton Depression Rating Scale HAM-D scores, although the medium effect size of 0.33 was small (Lespérance et al., 2007). In contrast, short-term interpersonal psychotherapy was not better in reducing depression levels than enhanced clinical management with weekly supportive sessions.

The first randomized trial aimed at assessing the effectiveness of a collaborative care strategy for treating depression following an acute cardiac event was Bypassing the Blues (BtB) (Rollman et al., 2009). A total of 302 depressed patients and a comparison group of 151 randomly sampled patients without depression were enrolled prior to hospital discharge after coronary artery bypass graft (CABG) surgery. Depressed post-CABG patients were randomized to either the usual care arm ($n = 152$) or the treatment arm ($n = 150$), which consisted of 8-months telephone-delivered collaborative care provided by nurses working with patients' primary care physicians and supervised by an internist and a psychiatrist. The results from the BtB trial revealed the superiority of collaborative care treatment over usual care: patients randomized to intervention showed significantly improved health-related quality of life, physical functioning, and severity of depressive symptoms at 8-month follow-up. Given the benefit of collaborative care interventions on these outcomes, it is conceivable that, in the near future, such approaches will make their way into routine clinical practice and may become widespread aids in an integrated treatment of patients who have survived an acute cardiac event (Rollman & Belnap, 2011).

TEAM-care, a collaborative treatment program for depressed outpatients with poorly controlled diabetes and/or coronary heart disease, also demonstrated the superiority of collaborative care management over usual care in patients with stable coronary disease (Katon et al., 2010). Treatment of multiple disease risk factors provided by physician-supervised nurses significantly improved depressive symptoms, somatic risk factors, and, additionally, reduced the mean healthcare costs per patient (Katon et al., 2012).

The COPES (Coronary Psychosocial Evaluation Studies) trial of problem-solving therapy was the first to report a significant reduction in major adverse cardiac events following a stepped-care treatment approach of depression (Davidson et al., 2010). In this prospective multicenter study, a total of 237 patients with unstable angina or myocardial infarction and a Beck Depression Inventory (BDI) score ≥ 10 were enrolled, including 157 persistently depressed patients randomized to the intervention arm or usual care. The study participants in the intervention group were treated with problem-solving therapy and/or pharmacotherapy, according to individual preferences. This initial treatment was followed by a stepped-care approach. Expectedly, patients in the treatment arm reported on substantially better satisfaction with depression care and reduction in depressive symptoms. Moreover, the COPES investigators found a marginally significant lower risk of major cardiovascular events and all-course mortality in the treatment group during the course of the intervention. Although not powered for this outcome, and despite low effect sizes, this finding of a lower risk in the intervention group warrants future studies to refine stepped-care models of depression in order to improve cardiac prognosis (Whang et al., 2010).

Thus, despite a paucity of data examining the impact of depression treatment on cardiac outcome, the promising results from these clinical trials encourage future large-scale interventions to improve the effectiveness of psychotherapy (e.g., Albus et al., 2011) and team-based care management programs for treating comorbid depression in cardiac patients. In addition to cardiac outcomes, these investigations should also examine putative benefits on psychosocial factors, such as improved quality of life, social relationships, and work performance (Wang, Hoffman, & Blumenthal, 2011).

Recent Concepts for the Integrated Treatment of Psychocardiological Inpatients

The proven benefits of collaborative care protocols point to the fundamental role of personal interactions between patients and professional healthcare providers with regard to the outcome of cardiac rehabilitation programs. Novel concepts in the treatment of cardiovascular patients with comorbid mental diseases go far beyond simple recommendations for behavior changes, such as smoking cessation, stress reduction, and adherence to diet and medication. Rather, they include integrated treatment strategies provided by multiprofessional treatment teams (Herrmann-Lingen, 2011). Originating from established concepts of consultation–liaison psychiatry and psychosomatics, interdisciplinary teams have been developed, jointly led by an experienced psychosomaticist or psychologist and an interventional or rehabilitative cardiologist. Such teams now exist in many inpatient rehabilitation centers in Germany and some acute-care hospitals. The team approach appears most suitable to address the anxieties and hidden emotions of cardiac patients with mental comorbidity and, simultaneously, offers high-standard medical and psychological treatment. In Germany, our department at the University Hospital of Göttingen was among the first academic departments to implement such an integrated concept for "holistic" treatment of cardiac patients, including a dedicated psychocardiological ward, immediately neighboring the regular cardiology wards. Now we look back on more than 3 years of clinical experience with inpatients treated in this ward. In addition to interactional group psychotherapy, our integrated treatment is based on individual psychotherapy, which is offered twice a week by physicians or clinical psychologists with expertise in either psychodynamic or cognitive behavioral psychotherapy. Nurses with clinical experience in psychocardiology, who are part of the multiprofessional treatment team, manage patient care twice a day to support the patients in their daily life in the ward and encourage them to regain psychosocial competence. Furthermore, patients are invited to participate in weekly psychoeducational programs, which mainly focus on psychocardiological issues of general interest. To regain an active lifestyle, we routinely encourage our patients to participate in accompanying individual and group art therapy and practice daily physical training, including gym and ergometer training (Herrmann-Lingen, 2011). Progressive relaxation is practiced daily under the supervision of experienced team members, and biofeedback can be prescribed if individually indicated. There is always a cardiologist in the team, and a senior cardiologist serves as a regular consultant. Social counseling is provided by a social worker if needed. Daily team meetings and weekly case conferences as well as regular external team supervisions are essential conceptual achievements in the treatment of our in-patients. Within the German healthcare system, treatments in this ward, which typically last up to 6 weeks, are paid for by the statutory health insurance system. Preliminary data on the short-term outcome following interactional group treatment encourage us to continue and refine our integrated treatment approach. Based on our first and promising experiences, we found that this collaborative, interdisciplinary treatment appears beneficial not only for inpatients with coronary heart disease, but also for patients with other severe cardiac diseases, such as heart failure or arrhythmias complicated by mental comorbidity. Experiences from our department and other departments of psychosomatic medicine in Europe suggest that such integrated models of care might also be beneficial for patients suffering from other organic diseases triggered or complicated by psychological factors.

Transfer of Psychocardiological Skills to Routine Medical Treatment

Several practice guidelines nowadays recommend addressing psychosocial factors during routine treatment in cardiology. Physicians need to emphasize the role of psychosocial risk factors while counseling their patients, and should assist and motivate them in modifying their individual risk profile. Given the comparably high number of psychosocial risk factors and their complex interaction, the identification of clinically relevant risk factors in the medical setting can often be challenging (Albus, Jordan, & Herrmann-Lingen, 2004). To foster psychocardiological expertise in physicians and psychologists, we developed a certified 80-hour curriculum, covering various aspects of integrated treatment for cardiac patients. The course, termed *Psychokardiologische Grundversorgung* (Basic Care in Psychocardiology), is held under the auspices of the German Society of Cardiology. Its aim is to sensitize cardiologists for the psychological problems of their patients and psychologists to understand the medical background. Course participants learn to further develop their clinical and interactional skills necessary for an up-to-date person-centered care management. By bringing together cardiologists and psychologists with their specific expertise, mutual exchange leads to a lively group atmosphere, an enhanced professional identity, and better "holistic" understanding of patients with both their medical and psychological problems.

Concluding Remarks

In summary, a substantial body of research in the interdisciplinary field of psychocardiology has established the contribution of diverse psychosocial factors to the development and progression of cardiovascular disease. In turn, heart disease itself and its treatment may serve as stressors and lead to increased rates of psychological and social adaptation problems and mental comorbidity. While a measurable reduction in the severity of depressive symptoms achieved by behavioral or psychotherapeutic interventions does not necessarily lead to reduced cardiac mortality, improvement in patient-reported outcomes typically achieved by such interventions is in itself a reasonable treatment goal. However, in order to further improve the prognostic efficacy of behavioral interventions, it is important to know more about the pathophysiological and psychobiological mechanisms behind the interactions between the heart and the brain, to continue developing better treatment concepts and to test them in adequately funded clinical research.

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30

Biobehavioral Interventions in Heart Failure

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Heart failure (HF) is a medical condition in which the heart loses its ability to pump blood efficiently. Nearly 6 million Americans suffer from HF (Lloyd-Jones et al., 2010), with another 670,000 new cases diagnosed each year (Roger et al., 2012; Rosamond et al., 2007). Many of these patients have symptoms that significantly limit their functional capacity and quality of life. HF is the most costly diagnosis in the Medicare population, and also the most common cause for hospitalization in patients over the age of 65 years. In the United States, the annual direct and indirect cost for HF care is in excess of US$39 billion (Delgado-Passler & McCaffrey, 2006; Lloyd-Jones et al., 2010). There is an urgent need for the development of innovative programs for HF management.

The present chapter focuses on HF due to systolic dysfunction of the left ventricle, which is the most common and widely studied type of HF (Chatterjee & Massie, 2007). It begins with an introduction to HF and its treatment, including medical management, biomarkers of disease severity and progression, and the effects of HF on quality of life, written to orient the behavioral interventionist to the complex world of HF treatment, and to illustrate the need for behavioral interventions in HF treatment. This is followed by a review of biobehavioral HF interventions, such as comprehensive disease management programs, telehealth interventions, and exercise programs. Next, talk therapies, such as motivational interviewing and cognitive behavioral therapy, are discussed. The chapter concludes with future directions for biobehavioral interventions.

The Handbook of Behavioral Medicine, First Edition. Edited by David I. Mostofsky.

Introduction to HF: Complications and Treatments

Systolic HF is characterized by depressed left ventricular (LV) contractile function (Julius & Johnson, 1985). In an effort to compensate for this impairment, the sympathetic nervous system (SNS) and renin–angiotensin–aldosterone system are activated, and secretion of antidiuretic hormone is increased. These neurohumoral changes serve to augment cardiac output by increasing heart rate and enhancing ventricular contractility, and to maintain arterial pressure by increasing systemic vascular resistance and intravascular volume (Cohen et al., 1997). However, while initially adaptive, this response ultimately contributes to further pathology including progressive LV remodeling and an increase in LV mass (Coryell, 1988). This restructuring of the left ventricle places additional demands on its oxygen supply, increases vulnerability to potentially fatal arrhythmias, and causes geometric alterations that impair, rather than facilitate, systolic function (Bart et al., 1997). This cascading pathophysiology underlies the rapid deterioration of the typical HF patient (Dalack & Roose, 1990).

The New York Heart Association (NYHA) Functional Classification provides a simple way of classifying the degree of HF. It places patients in one of four categories based on how much they are limited during physical activity, ranging from NYHA class I (no symptoms or limitations during ordinary activities) through class IV (severe limitations and symptoms at rest). The 6-minute walk test is another widely used and inexpensive indicator HF severity, and has been shown to predict hospitalizations and mortality (Curtis, Rathore, Wang, & Krumholz, 2004). Both NYHA class and 6-minute walk are employed as important outcome variables in HF, and are responsive to effective disease management (Galbreath et al., 2004).

Pharmacotherapy typically includes use of diuretics to optimize fluid balance, angiotensin converting enzyme (ACE) inhibitors, angiotensin receptor blockers, and/or aldosterone antagonists to block the renin–angiotensin–aldosterone system, and beta-blockers to protect the heart from sympathetic nervous system hyperactivity (Yancy, 2005). Heart failure treatment guidelines include significant lifestyle changes as well (Hunt, 2005; Swedberg et al., 2005). Diuretics are prescribed in combination with dietary sodium restriction, with close monitoring for changes in weight (i.e., daily weighing at home; reporting of sudden weight changes) or clinical status. Exercise training is recommended for all stable outpatients to improve physical conditioning, enhance quality of life, reduce neurohumoral system activation, and attenuate the process of vascular remodeling. Supervised exercise training and home-based walking programs have been found to be both safe and effective in improving HF functional status as measured by 6-minute walk performance (Andersen, Jonsdottir, Sigurethsson, & Sigurethsson, 2006; Corvera-Tindel, Doering, Woo, Khan, & Dracup, 2004).

Heart Failure Biomarkers

The progression of HF over time, and the response to HF treatments, can be quantified with biomarkers. Because some of these biomarkers may be unfamiliar to behavioral interventionists, a brief overview is provided in the following text.

Left ventricular ejection fraction (LVEF)

The prognostic importance of echocardiographic measures of left ventricular function in patients with HF is well established. An inverse relationship between LVEF and cardiovascular mortality has been demonstrated over a wide range of HF severities, and therapies that improve long-term outcomes do so in part by improving ventricular function (Eriksson, 1995; Konstam et al., 1995; the SOLVD Investigators, 1992). Left ventricular remodeling, impaired left ventricular filling, left atrial enlargement, right ventricle dysfunction, and mitral and tricuspid regurgitation are also predictors of morbidity and mortality.

B-type natriuretic peptide (BNP)

BNP and N-Terminal proBNP (NT-proBNP) are naturally occurring hormones that are synthesized in the cardiac ventricles and released from cardiac myocytes in response to increased ventricular load and neurohumoral activation. In addition to being an important diagnostic test for HF disease, several recent studies have demonstrated that BNP and NT-proBNP are strongly related to clinical outcomes, including mortality and hospitalizations for patients with HF at all stages of disease (Doust, Lehman, & Glasziou, 2006; Doust, Pietrzak, Dobson, & Glasziou, 2005; Sherwood et al., 2007). BNP is also responsive to HF therapeutic interventions, making it a useful tool for monitoring treatment response and guiding decisions on further treatment (Troughton & Richards, 2006).

Vascular endothelial function

Arterial vasodilatory regulation by the endothelial system, as indexed by acetylcholine infusion and by brachial artery flow-mediated dilation (FMD), is impaired in HF patients (Dean et al., 2005). Impaired FMD is a robust predictor of cardiovascular events (Mancini, 2004) and a sensitive early marker of atherosclerotic disease (Corretti et al., 2002). In a recent study of 149 NYHA Class II–III HF patients, impaired FMD predicted mortality over a 30-month follow-up period, independent of traditional risk factors including age, etiology of HF, functional class, and LVEF (Katz et al., 2005). FMD as an HF biomarker is also sensitive to interventions in HF patients, showing improvements with HF pharmacotherapy using ACE inhibitors (Hryniewicz et al., 2005; Tavli & Gocer, 2002) and increased physical activity (Moyna & Thompson, 2004). In patients with coronary heart disease (CHD), endothelial response as measured by FMD is attenuated by acute stress (Gottdiener et al., 2003), and is impaired in association with depression (Sherwood, Hinderliter, Watkins, Waugh, & Blumenthal, 2005), while stress-reduction interventions have been found to result in improved FMD (Blumenthal et al., 2005; Sivasankaran et al., 2006).

Heart rate variability (HRV)

HRV is widely recognized as an important index of autonomic function that is a useful prognostic indicator of risk in patients with HF. Reduced 24-hour HRV independently predicts mortality in patients with HF (Aronson, Mittleman, & Burger, 2004; Hadase et al., 2004; Nolan et al., 1998). In HF patients, reduced HRV is a powerful predictor of outcome and predicts mortality and sudden cardiac death (SCD) above and beyond the risk predicted by conventional predictors such as LVEF and age (Aronson et al., 2004; Hadase et al., 2004; Nolan et al., 1998). When compared with other predictors of mortality (LVEF, arrhythmia history), low HRV was the best predictor of progressive HF death in a cohort of 433 outpatients with chronic HF (Nolan et al., 1998). Furthermore, low HRV is linearly related to HF severity and to risk. For example, a study of 433 patients with chronic HF (Nolan et al., 1998) annual mortality rates were 5.5% for those with HRV>100 msec, 12.7% for those with HRV 50–100 msec, and 51.4% for patients with HRV<50 msec.

The reduction in HRV characteristic of high-risk HF patients is secondary to attenuation of parasympathetic drive (Binkley, Nunziatta, Haas, Nelson, & Cody, 1991; Nihei et al., 2005; Porter et al., 1990). This reduction in parasympathetic activity leads to loss of regulation in a number of other neural and paracrine systems that may contribute to poor prognosis in HF patients. For example, low parasympathetic activity not only reduces HRV and baroreflex control, but also leads to an excessive release of catecholamines from sympathetic nerves due to loss of the stimulation of muscarinic receptors on adrenergic nerve terminals that regulate norepinephrine release (Azevedo & Parker, 1999; Porter et al., 1990). This results in an inverse relationship between circulating catecholamine levels and the magnitude of HRV in HF patients (Stein, Rich, Rottman, & Kleiger, 1995). In addition, because the parasympathetic nerves are important in the regulation of immune responses, low parasympathetic activity leads to amplified inflammatory responses (Tracey, 2002) and contribute to the high levels of proinflammatory cytokines observed in HF patients (Straburzyska-Migaj et al., 2005). Low parasympathetic control is also associated with downregulation of neuronal nitric oxide synthase, an important determinant of optimal vascular function (Binkley, Nunziatta, Liu-Stratton, & Cooke, 2005). In HF patients, dietary, exercise, and medical interventions have been associated with improved HRV (Adamson, Kleckner, VanHout, Srinivasan, & Abraham, 2003; Larsen et al., 2004; Radaelli et al., 2006; Yee, Pringle, & Struthers, 2001).

Inflammatory markers

Pro-inflammatory cytokines are often upregulated in patients with HF and may play an important role in the development and progression of left ventricular dysfunction. In experimental models, tumor necrosis factor alpha (TNF-α) provokes myocyte hypertrophy and apoptosis, blunts adrenergic responsiveness, impairs endothelial function, and suppresses myocardial contractile function. Similarly, interleukin-6 (IL-6) promotes myocardial hypertrophy and dysfunction (Bozkurt et al., 1998; Gulick, Chung, Pieper, Lange, & Schreiner, 1989; Krown et al., 1996; Murray & Freeman, 1996; Yokoyama et al., 1997). In humans, observational studies have demonstrated that TNF-α, IL-6, and high-sensitivity C-reactive protein (hsCRP) predict HF in individuals with no apparent heart disease, and are associated with a poor prognosis in HF patients (Deswal et al., 2001; Kaneko et al., 1999; Rauchhaus et al., 2000). Moreover, hsCRP is elevated in patients with depression, suggesting a possible mechanism whereby this psychological disorder may increase the risk of cardiovascular events (Ford & Erlinger, 2004; Penninx et al., 2003; Tiemeier et al., 2003). Although the effects of behavioral and medical interventions on inflammation and HF are not well characterized, a recent report suggests that the decreases in hsCRP, IL-6, and TNF-α receptor 2 observed with statin therapy are associated with improvements in left ventricular function (Sola, Mir, Lerakis, Tandon, & Khan, 2006).

Quality of Life (QoL) in Heart Failure

HF symptoms including dyspnea, fatigue, and edema contribute to significant physical limitations in many patients with HF (Barnes et al., 2006). Due in part to an impaired functional capacity limiting the activities of daily living, QoL is compromised in HF patients to a greater degree than in other cardiac patients (Hawthorne & Hixon, 1994). Age, perhaps by moderating expectations, appears to be related to QoL, with younger HF patients expressing greater dissatisfaction than older patients (Baas, Beery, Fontana, & Wagoner, 1999). Uncertainty about HF as a disease and its associated treatment are also related to distress and negative affect in HF (Hawthorne & Hixon, 1994). QoL has gained acceptance as an important aspect of overall health status in HF. In the SOLVD trial, self-reported instruments assessing QoL in 5,025 HF patients independently predicted mortality and HF-related hospitalizations after adjusting for age, treatment, NYHA class, and EF (Konstam et al., 1996).

An aspect of QoL that is especially relevant for HF patients, with important prognostic significance, is the presence of elevated depressive symptoms. A meta-analytic review observed prevalence rates among HF patients of 20.3% for depression diagnosed by clinical interview, formal diagnosis, or moderate-to-severe score on a validated depression symptom questionnaire, and 35.5% when mild depression is included (Rutledge, Reis, Linke, Greenberg, & Mills, 2006). Rates of depression in HF patients are higher than in other cardiac patients (Thomas, Friedmann, Khatta, Cook, & Lann, 2003). Vaccarino and colleagues (Vaccarino, Kasl, Abramson, & Krumholz, 2001) assessed depression using the Geriatric Depression Scale in 391 patients with HF and found that over 75% of HF patients had significant depressive symptoms. Using a structured diagnostic interview, Koenig (Koenig, 1998) found clinically significant symptoms of depression in 58% of hospitalized

HF patients. In a sample of 682 hospitalized HF patients, Freedland and colleagues (Freedland et al., 2003) found that 20% met DSM-IV criteria for a current major depressive episode, 16% for a minor depressive episode, and 51% scored 10 or greater on the Beck Depression Inventory (BDI).

Younger patients with HF are more likely to experience depression than older patients; patients under the age of 60 are almost twice as likely to become depressed as those 60 and older (Freedland et al., 2003; Koenig, 1998). Physical impairment and the adaptations to that impairment are also strong predictors of depression in HF patients (Koenig, 1998; Murberg, Bru, Aarsland, & Svebak, 1998; Turvey, Klein, Pies, & Arndt, 2003). Turvey et al. in 2006 found that attitudes about impairment predicted depression, and that physical impairment *per se* did not predict depression after controlling for attitudes (Turvey, Klein, & Pies, 2006). This observation suggests useful psychotherapeutic strategies for treating depression in HF patients.

Depression is associated with a substantial increased risk of adverse outcomes for patients with established HF. In a study by Jiang and colleagues (Jiang et al., 2001) of 374 patients hospitalized with HF who underwent screening for depression, those with major depression were approximately twice as likely to die or be rehospitalized within 1 year. Similarly, Vaccarino and colleagues (2001) reported that the severity of depressive symptoms was related to death or functional decline at 6-month follow-up in 391 hospitalized HF patients. Murberg and colleagues (Murberg & Furze, 2004) reported 6-year follow-up of 119 HF patients in whom symptoms of depression at baseline were predictive of mortality. Because depression in HF patients is related to disease severity, there has been uncertainty as to the extent to which depression, independent of HF severity, is related to adverse clinical outcomes. However, Sherwood and colleagues (Sherwood et al., 2007), in a prospective study of 204 HF outpatients, found depression to predict adverse clinical outcomes (death or hospitalization) with a hazard ratio of 1.56, even after controlling for disease severity biomarkers, including NT-proBNP, EF, as well as HF etiology, age, and medications. A follow-up to this study evaluated prospectively the clinical impact of changing depression symptoms in HF patients (Sherwood, Blumenthal et al., 2011). Depressive symptoms were assessed with the BDI, at baseline and 1 year later. Patients with a marked increase in depressive symptoms (defined as a three-point or more increase in BDI score) were found to be at twice the risk of cardiovascular hospitalization or mortality compared with patients showing minimal change (HR: 2.12, 95% CI: 1.31–3.43, $p = .002$). These findings have been confirmed by a secondary analysis of 2,331 HF patients enrolled in the HF-ACTION trial, which showed that worsening depressive symptoms (BDI-II increase of 10 points) were associated with a 21% increased risk for all-cause hospitalization or death, whereas improving depressive symptoms (BDI-II decrease of 10 points) were associated with an 8% reduction in risk over a 4-year follow-up period (Blumenthal et al., 2012). Thus, depressive symptoms in HF patients appear to fluctuate over time, and these fluctuations, especially where symptoms are worsening, may serve as important indicators of an impending adverse change in the patient's HF disease trajectory. Moreover, these findings suggest that treating depression may help improve risk and result in more favorable clinical outcomes.

Biobehavioral Interventions for Heart Failure

Because HF is such a major cause of morbidity, mortality, and healthcare expenditures, it is especially important to develop evidenced-based therapies to improve clinical outcomes (Bonow et al., 2005). The standard treatment regimen for HF is a demanding one, requiring patients to follow complex medication regimens, make meaningful lifestyle changes, and monitor symptoms. Efforts to achieve medication adherence are complicated by depression and poor functional health. Non-compliance with medication and poor symptom monitoring are a significant contributor to HF hospital re-admissions (Ambardekar et al., 2009; Annema, Luttik, & Jaarsma, 2009), and have been shown to account for as much as one-third of HF hospital re-admissions (Stromberg & Martensson, 2003). Biobehavioral interventions for HF aim to facilitate treatment adherence, address obstacles to treatment such as depression, and/or target specific biomarkers to improve outcomes.

HF disease management programs

Interventions that seek to improve heart failure outcomes by addressing factors such as patient discharge planning, compliance with medication and dietary regimens, and HF symptom monitoring are broadly classified as "disease management programs" (DMP) (Desai, 2012). HF DMPs are typically nurse-led interventions that incorporate elements of HF education, case management, and symptom monitoring, sometimes include a clinic-based or multidisciplinary component, and are delivered over time and often by telephone (Takeda et al., 2012). For example, Blue and colleagues randomly assigned 81 patients hospitalized with HF (NYHA class II–IV) to receive a 12-month nurse-led HF DMP intervention or usual care (Blue et al., 2001). The intervention consisted of HF education, self-management training (including medication adherence, diet, exercise, and symptom monitoring), and monitoring by specialist study nurses, delivered both in person (at an initial inpatient visit, and at home visits within 48 hours of discharge, at 1, 3, and 6 weeks, and at 3, 6, 9, and 12 months) and through scheduled phone calls (at 2 weeks, as well as 1, 2, 4, 5, 7, 8, 10, and 11 months). After 12 months of treatment, participants in the treatment condition had lower rates for the composite endpoint of death or HF-related hospitalization (OR $= 0.61$, $p = .033$). Krumholz and colleagues (Krumholz et al., 2002) found that an education and support program in 44 HF patients was associated with a 39% decrease in readmission rate compared to usual care, with an associated savings of over US$7,515 per patient over 1 year.

The variability across HF DMPs is illustrated by a recent meta-analytic review of 25 RCTs comparing the effects of HF DMPs to usual care (Takeda et al., 2012). Studies that relied exclusively on cardiac rehabilitation or telehealth interventions were excluded from the review. The HF DMPs differed in format, content, and intensity. The authors characterized 17 interventions as primarily "case management" (intensive monitoring over time, often by phone, and typically by a nurse), six as primarily "clinics" (management by an HF clinic, run by cardiologists or specialist nurses), and two as "multidisciplinary" (addressing medical, psychosocial, behavioral, and financial needs by a team of professionals). Of the 25 included studies, 20 incorporated telephone follow-up, 16 addressed sodium restrictions or other dietary advice, 14 emphasized the importance of weight monitoring, 10 encouraged exercise, and four specifically offered social support. The authors judged eight interventions to be "high intensity" (e.g., a 24-month intervention consisting of repeat visits to a cardiologist-led specialty clinic, with between-clinic support and additional intervention through both study-initiated and optional patient-initiated telephone contact with a study nurse, designed to optimize discharge planning, HF treatments, doctor–patient communication, and treatment adherence [Del Sindaco et al., 2007]), and five interventions to be "low intensity" (e.g., a 12-month pharmacist-led intervention consisting of an educational interview on the day of discharge, and nine follow-up phone calls for problem-solving [Lopez Cabezas et al., 2006]).

Takeda and colleagues (Takeda et al., 2012) found a significant effect of HF DMPs on all-cause mortality (24 studies, OR $= 0.74$, $p = .0003$) and HF-related hospitalization (12 studies, OR $= 0.57$, $p < .0001$). The effects of treatment on all-cause mortality varied by intervention intensity, with particularly strong effects for "high-intensity" interventions (eight studies, OR $= 0.67$, $p = .002$), and no discernible effects for the "low-intensity" interventions (five studies, OR $= 1.08$, $p = .72$). Results by intervention types (i.e., case management, clinic, and multidisciplinary) were less consistent, and were complicated by a combination of small sample sizes and high levels of statistical heterogeneity. It is noteworthy that an earlier meta-analytic review of 33 trials found similar positive effects for DMPs on all-cause mortality (28 studies, OR $= 0.80$, $p = .003$), all-cause hospitalization (32 studies, OR $= 0.76$, $p < .00001$), and HF-related hospitalization (20 studies, OR $= .58$, $p < .00001$) (Roccaforte, Demers, Baldassarre, Teo, & Yusuf, 2005). Taken together, there is ample reason for confidence that HF DMPs reduce hospitalization rates, and that higher-intensity DMPs reduce mortality as well.

Telehealth interventions in HF

Telephone-based and telemonitoring-based disease management interventions extend the reach of more traditional HF DMPs by delivering symptom management, medicine management, and lifestyle education to HF patients in the home (Clark, Inglis, McAlister, Cleland, & Stewart, 2007). Telephone-based interventions use telephones and self-report as the primary modality for monitoring and intervention. Telemonitoring intervention programs use technologies such as electronic weighing scales, blood pressure cuffs, and electrocardiographic measures to extend the reach of nurse-led disease management programs by allowing for the transmission of physiologic data directly from a patient's home to his or her medical provider (Clark et al., 2007). Inglis and colleagues conducted a meta-analysis of 30 randomized clinical trials comparing the beneficial effects of telehealth HF case management to usual care (Inglis et al., 2010). Interventions occurring primarily via telephone were associated with reduced all-cause mortality (18 RTCs, risk ratio = 0.85, $p = .02$), reduced all-cause hospitalizations (12 RCTs, risk ratio = 0.90, $p = .003$), and reduced HF-related hospitalizations (14 RTCs, risk ration = 0.77, $p < .0001$). Telemonitoring interventions were associated with lower all-cause mortality (14 RCTs, risk ratio = 0.68, $p < .0001$) and lower HF-related hospitalizations (6 RCTs, risk ratio = 0.76, $p = .0006$), and a trend toward lower all-cause hospitalization (11 RCTs, 0.94, $p = .09$), compared to usual care.

However, there is controversy about the effectiveness of HF interventions that rely primarily on telehealth (Desai, 2012), and some relatively large and recent studies have produced mixed or negative results. For example, 1,518 Argentinean HF patients in the DIAL trial were randomly assigned to either a telephone-based nurse management condition or to usual care (GESICAInvestigators, 2005). Participants in the intervention group received four phone calls from nurses trained in the management of heart failure over the first 2 weeks, with variable follow-up thereafter. Phone calls addressed topics including adherence to diet and medications, symptom monitoring, fluid retention, and exercise. After an average follow-up period of 16 months, participants in the intervention group were less likely to be hospitalized for heart failure or die (26.3%), compared to participants in the control condition (31%; $p = .03$). However, mortality rates were similar between the treatment and control conditions.

DeBusk and colleagues (DeBusk et al., 2004) compared the effects of a telephone-based intervention to usual care among 462 American hospitalized HF patients in the Kaiser Perminente HMO. The telephone intervention consisted of a series of phone calls (weekly for 6 weeks, biweekly for 8 weeks, monthly, and bimonthly thereafter), delivered by nurses, to address lifestyle and medication management. After 1 year, there were no observed differences in rehospitalitzation, the primary endpoint. The telephone treatment condition was associated with a trend toward a lower mortality compared to the control condition (21% vs 29%), but this was not statistically significant. The authors noted that the absence of a beneficial effect for rehospitalization may be related to the high level of care that all Kaiser Permenente HF patients receive.

DeWalt and colleagues (DeWalt et al., 2012) recently reported the results of a 1-year RCT in which 605 patients with diagnosed HF (NYHA Class II-IV) were randomly assigned to one of two conditions: (1) a 40-minute in-person HF self-management education session, or (2) a 40-minute HF self-management session plus follow-up telephone support to promote mastery of the information (average number of calls: 14; average call length: 12 minutes). The intervention was specifically designed to accommodate patients with low literacy levels, and randomization was stratified by health literacy. At 1 year, there were no between-group differences in all-cause hospitalization or death, the composite primary outcome. However, there was a significant treatment by literacy interaction effect ($p = .048$); among patients with low literacy levels, education plus telephone support was associated with reduced risk for all-cause hospitalization and death, compared to education alone. Also, there were no between-group differences in HF-specific hospitalization rates, but there was a significant treatment by literacy interaction ($p = .005$) in which, among patients with low literacy levels, education plus telephone support was associated with reduced risk, compared to education alone. The authors concluded that intensive telephone support may be beneficial for traditionally underserved populations.

Mortara and colleagues reported the results of Home or Hospital in Heart Failure (HHH), a multisite trial in which 461 HF patients were randomly assigned to either usual care or to one of three 12-month treatment conditions: (1) monthly telephone evaluations by a study nurse; (2) monthly telephone contact plus weekly transmission of vital signs; or (3) monthly telephone contact, weekly transmission of vital signs, and biweekly 24-hour recording of cardiorespiratory activity (Mortara et al., 2009). Clinical data gathered in the treatment conditions were shared with appropriate medical providers, whose responses were not guided by the study. After 12 months, there were no observed differences in hospital days or cardiac death plus HF hospitalization.

Chaudhry and colleagues reported the results of Telemonitoring to Improve Heart Failure outcomes (Tele-HF), a large multisite clinical trial in which 1,653 HF patients within 30 days of hospitalization were randomized to either daily symptom monitoring via a telephone-based interactive voice response system, or to usual care (Chaudhry et al., 2010). After 6 months, there were no significant differences between the two conditions with regard to the primary composite outcome of hospital admission or all-cause mortality, or any of the secondary outcomes, including HF hospitalization. Of note, adherence to the voice response system was poor, with only 55% of study participants using it three times per week.

A meta-analysis by Inglis and colleagues demonstrated that HF DMPs delivered via telehealth modalities had positive effects on hard endpoints. The DIAL trial further suggests that even low-intensity telephone-based interventions can have a positive effect on hospitalization rates (GESICAInvestigators, 2005). The findings reported by DeBusk and colleagues and DeWalt and colleagues suggest that telehealth interventions may be particularly beneficial for traditionally underserved populations who may lack access to excellent HF medical care (DeBusk et al., 2004; DeWalt et al., 2012). Finally, the results from HHH and Tele-HF suggest that simply collecting medical data and transmitting it to healthcare providers is not enough (Chaudhry et al., 2010; Desai, 2012; Mortara et al., 2009). Because telephone-based interventions have been found to be both effective and cost-saving, there is a need to further develop and refine these approaches (Chaudhry et al., 2007). Studies are needed to identify the biological and behavioral mechanisms by which these interventions improve outcomes. Also, follow-up periods typically have been brief, sometimes not extending beyond the intervention period, and research designed to evaluate optimal approaches to achieving extended effects on clinical outcomes would be of value (Dunagan et al., 2005). Finally, and perhaps most importantly, studies are needed to examine the kinds of responses from the interventionists that most benefit patients (e.g., feedback, information, direct intervention, etc.).

Aerobic exercise in HF

HF treatment guidelines recommend exercise training for all stable HF patients (Hunt, 2005; Swedberg et al., 2005). Davies and colleagues conducted a Cochrane meta-analytic review of 19 RCTs comparing the effects of exercise to usual care for patients with diagnosed HF, no previous history of cardiac rehabilitation, and a minimum of 6 months follow-up (Davies et al., 2010). Exercise typically occurred in a center, and was often augmented with home-based exercise. The frequency and intensity of exercise varied widely, from 15 to 120 minutes in duration per occasion, from two to seven occasions per week, and at an intensity of 40–85% of maximal oxygen uptake (VO_2 max), over a period of 24–52 weeks. Exercise was associated with reduced HF hospital admissions (seven trials, RR $= 0.72$, $p = .04$), but not all-cause hospital admissions (eight trials, RR $= 0.79$, $p = .13$), or reduced mortality (13 trials, RR$= 1.02$, $p = 0.90$), compared to usual care at 6–12 months follow-up. Also, HF symptom burden questionnaires improved considerably for exercise interventions compared to usual care (10 studies, effect size $= 0.56$, $p < .00001$). Not only were patients with HF symptoms such as dyspnea, fatigue, and diminished exercise tolerance able to participate in exercise, but exercisers experienced a reduction in their HF symptoms.

The largest clinical trial of exercise for HF patients was the recently completed HF-ACTION trial, a multicenter RCT comparing the effects of exercise training to guideline-based usual care in 2,331 patients with HF (O'Connor et al., 2009; Whellan et al., 2007). Participants exercised in a structured group format, three sessions per week, for 3 months, and then transitioned to home-based exercise, and were followed for up to 4 years (median follow-up was 30 months). The duration and intensity of the supervised exercise increased from 15 minutes at 60% of heart rate reserve (sessions 1–5) to 30–35 minutes at 70% of heart rate reserve. The home-based exercise target training regimen was five sessions per week, 40 minutes per session, at an intensity of 60–70% of heart rate reserve. Home-based exercise was primarily supported through phone calls that occurred twice a month for the first 9 months, monthly until 24 months, and quarterly thereafter. During the supervised exercise portion of the study, patients in the exercise group exercised for a median of 76 minutes per week (target = 90 minutes per week). During the home-based portion of the study, exercise time initially increased to a median of 95 minutes per week, but then declined to 74 minutes per week by months 10–12, and 50 minutes per week by year 3 (home-based target = 120 minutes per week).

Participants in the exercise condition exhibited a trend toward reduced risk for the combined endpoint of all-cause mortality or hospitalization (HR = 0.93, $p = .13$), which reached statistical significance when the analyses were adjusted for risk factors including baseline exercise capacity, left ventricular ejection fraction, baseline depression severity, and history of atrial fibrillation or flutter (HR = 0.89, $p = .03$). Similarly, there was a trend toward reduced risk for HF mortality or HF hospitalization (HR = 0.87, $p = .06$), which became statistically significant after controlling for baseline predictors (HR = 0.85, $p = .03$). Furthermore, exercise was associated with a modest improvement in HF-specific quality of life (measured by the Kansas City Cardiomyopathy Questionnaire) at 3 months compared to usual care ($p < .001$), and this difference did not attenuate over the next 2.5 years (Flynn et al., 2009). Finally, exercise was associated with a modest reduction in depressive symptoms at 3 months ($p = .002$) and at 12 months ($p = .01$), compared to usual care controls (Blumenthal et al., 2012). Larger effects were observed among patients with clinical depression (i.e., BDI-II scores > 14); among the exercisers, the number of minutes of exercise per week was inversely associated with declines in depression severity scores. Ninety minutes of exercise per week appeared sufficient to significantly reduce depressive symptoms. Taken together, these findings suggest that even modest amounts of exercise constitute an effective intervention for patients with stable HF, and can produce significant improvement in disease-related outcomes, functional well-being, and QoL.

Whereas participants in HF-ACTION engaged in supervised exercise for 3 months followed by 18 months of home-based exercise, Karapolat and colleagues (Karapolat et al., 2009) compared the effects of an 8-week hospital-based supervised exercise program to a home-based exercise regimen for 74 patients with HF (NYHA class II-III). All patients exercised for 45–60 minutes per session, three sessions per week, which included 30 minutes of treadmill training to 60–70% of heart rate reserve and 13–15 on the Borg scale. Home-based exercisers tracked their performance with heart rate monitors and reviewed their progress with an exercise physiologist via weekly phone calls. Both groups improved in measures of fitness (6-minute walk test, Peak VO_2), health-related quality of life (SF-36, BDI), and LVEF by echocardiography ($p < .05$), and the effects were similar between the two groups ($p > .05$). The authors concluded that home-based cardiac rehabilitation appears to be as safe and effective as compared to hospital-based exercise programs. These findings serve to further reinforce the safety and effectiveness of home-based exercise for patients with HF.

Cognitive behavioral therapy (CBT)

Among the “talk-therapies” that have been shown to be effective for the treatment of a variety of clinical issues, perhaps none has been more extensively studied and widely used in clinical practice than cognitive behavioral therapy. The central tenet of CBT is that emotional and behavioral symptoms (e.g., depression, anxiety, overeating, medical non-adherence, etc.) are often mediated by maladaptive cognitions that can be modified (Beck, 1995). CBT has been the subject of numerous randomized clinical trials and meta-analytic reviews, and has been shown to be a particularly effective treatment for depressive disorders, anxiety disorders, and chronic pain (Butler, Chapman, Forman, & Beck, 2006), and to enhance the effectiveness of diet and exercise in promoting weight loss (i.e., as compared to diet and exercise alone) (Shaw, O'Rourke, Del Mar, & Kenardy, 2005).

The beneficial effects of CBT have also been examined in patients with heart disease. For example, the ENRICHD trial randomly assigned 2,481 post-MI patients with either depression or low perceived social support to CBT or to education and usual care (Berkman et al., 2003). At the 6-month evaluation, both groups exhibited considerable improvement in depressive symptoms, although the CBT group was associated with a modest beneficial effect for depression relative to the control condition. The SMART-HEART study randomly assigned 134 patients with exercise-induced myocardial ischemia to one of three 16-week conditions: a weekly CBT-based stress management treatment group, aerobic exercise (three 35-minute sessions per week), or usual care (Blumenthal et al., 2005). After 16 weeks, exercise and stress management were associated with reduced general distress and lower depression scores, as well as a reduction in myocardial ischemia during mental stress and greater improvements in flow-mediated dilation, compared with usual care.

Despite the overwhelming evidence that CBT is an effective treatment for depression in general, and the evidence that it is specifically effective for the treatment of depression among patients with heart disease, the effects of CBT for patients with HF has rarely been the subject of study. Kostis and colleagues (Kostis, Rosen, Cosgrove, Shindler, & Wilson, 1994) compared the effects of a 12-week multimodal non-pharmacologic intervention to digoxin in 20 HF patients on ACE inhibitors. The intervention included exercise, CBT and stress management, and dietary modification to reduce both sodium and caloric consumption. Compared to the other treatment groups, the behavioral intervention was associated with significantly better functional capacity and mood. In another report, Luskin (Luskin & Newell Ka, 1999) found that patients trained in stress management exhibited improved ability to cope with stress. A subsequent study in a small ($n = 29$) cohort (Luskin, Reitz, Newell, Quinn, & Haskell, 2002) demonstrated that patients who completed stress management training had greater improvements in perceived stress and 6-minute walk performance, as well as greater reductions in emotional distress and depression, compared to controls. Chang and colleagues (Chang et al., 2005) examined the effects of the relaxation response compared to cardiac education and usual care in 95 HF patients. Although results did not reach statistical significance, the relaxation group tended to exhibit better emotional quality of life. There was no group difference on quality of life, however, and there was no assessment of the impact of the interventions on clinical outcomes.

Smeulders and colleagues compared the effects of a nurse-led CBT-based group intervention (six weekly sessions to promote self-efficacy for disease self-management) to usual care for 317 patients with chronic HF (NYHA class II-III) (Smeulders et al., 2009, 2010). Compared to usual care, CBT was associated with increased self-reported walking for exercise (175 minutes per month difference; $p = .03$) at post-treatment, and a trend toward increased walking at 6 months ($p = .07$), compared to usual care (Smeulders et al., 2009). However, there were no between-group differences in self-reported exercise behaviors at 12 months. CBT was associated with improved coping with symptoms ($p < .0001$) and increased self-reported adherence to HF medication-, dietary-, and symptom-monitoring guidelines ($p = .008$) at 16 weeks compared to usual care, but not at 6 months or 12 months (Smeulders et al., 2010). In a secondary analysis of treatment completers (85.5% of the sample), the beneficial effects of CBT on coping were evident at the 6-month and 12-month follow-up as well. There were no between-group differences on measures of depression, anxiety, or self-efficacy (Smeulders et al., 2010), and there were no between-group differences in hospitalizations (Smeulders et al., 2009). The authors hypothesized that the effects of CBT compared to usual care may have been minimized by the excellent Netherlands healthcare system (Smeulders et al., 2010). Also, it is noteworthy that the CBT intervention did not specifically target depressive symptoms, which may explain the null finding for depression.

Gary and colleagues (Gary, Dunbar, Higgins, Musselman, & Smith, 2010) randomly assigned 74 patients with HF (NYHA class II-III) and significant depressive symptoms (BDI = 10 or greater) to one of four 12-week conditions: Exercise (home-based, 3 days per week, moderate-intensity walking, supported by weekly visits from a study nurse), CBT (12 1-hour sessions targeting depressive symptoms), Combined (Exercise and CBT), or Usual Care. Depressive symptoms improved similarly for all groups. The Combined condition had the lowest depression severity scores at 12 weeks and 24 weeks, but the effect was not statistically significant. The Combined group had significantly better 6-minute walk test outcomes at both 12 weeks and 24 weeks compared to the other groups ($p = .001$). Walk test distance improved from baseline to 24 weeks for the Combined group, remained essentially unchanged for the Exercise and CBT groups, and declined for the Usual Care group. The groups were similar in health-related quality of life. In post-hoc analyses, the beneficial effects of the Combined group were greater for depressive symptoms and 6-minute walk test for those patients with moderate-to-severe depressive symptoms.

Powell and colleagues (Powell et al., 2010) conducted the Heart Failure Adherence and Retention Trial (HART) to evaluate the effects of self-management counseling, compared to an education attention control, in 902 patients with mild-to-moderate HF. The treatment condition consisted of 18 group sessions of 2 hours, delivered over the course of 1 year. Group sessions provided information on HF self-management topics such as medication adherence, weight monitoring, sodium restriction, and exercise, as well as training in five cognitive behavioral self-management skills: self-monitoring, environmental restructuring, elicitation of support from family and friends, cognitive restructuring, and relaxation training. Participants in the control condition received 18 HF information sheets via mail, as well as follow-up phone calls from study staff to answer questions about the information sheets. After a median of 2.56 years, there were no between-group differences in time to death or HF hospitalization, the primary outcome. However, there was a positive income by treatment group interaction ($p = .02$); among participants with an income of less than US\$30,000 per year, counseling was associated with reduced risk of death or HF hospitalization, compared to education. After 1 year, average dietary sodium intake had improved for both conditions, with more improvement in the counseling condition ($p = .02$). Depression severity scores (measured by the Geriatric Depression Scale) improved by approximately 20% for both conditions at 1 year, suggesting that the attention control condition may have been more therapeutic than anticipated. The authors concluded that self-management training may be particularly beneficial for low-income patients, and that future studies should combine self-management interventions with telehealth monitoring.

Motivational interviewing

Motivational interviewing (MI) was originally described by Miller (Miller, 1983) and more fully discussed in a seminal text by Miller and Rollnick (Miller & Rollnick, 1991), and has been used extensively in the addiction field (Heather, Rollnick, Bell, & Richmond, 1996; Kadden, 1996; Miller & Rollnick, 1991; Rollnick, Heather, Gold, & Hall, 1992). More recently, there has been considerable interest from public health and medical practitioners in adapting MI to address various health-related behaviors (Baskin, Resnicow, & Campbell, 2001; Berg-Smith et al., 1999; Colby et al., 1998; Dunn, Deroo, & Rivara, 2001; Emmons & Rollnick, 2001; Ershoff et al., 1999; Miller, 1999; Smith, Heckemeyer, Kratt, & Mason, 1997; Stott, Rollnick, & Pill, 1995; Velasquez et al., 2000). A number of randomized trials have demonstrated its clinical efficacy for improving adherence to pharmacotherapy treatments as well as for chronic disease behaviors (Burke, Arkowitz, & Menchola, 2003; Dunn et al., 2001; Stott et al., 1995; Velasquez et al., 2000). MI is an egalitarian, empathetic "way of being" that manifests through specific techniques and strategies, for example, reflective listening and agenda setting. One of the goals of MI is to assist individuals in working through ambivalence about behavior change, and MI appears to be particularly effective for individuals who are initially less ready to change (Rollnick & Miller, 1995). In MI, counselors establish a supportive climate where patients feel comfortable expressing both the positive and negative aspects of their current behavior. Unlike psychotherapy models that rely heavily on transference or traditional patient education programs that provide medical information, in MI the patient is expected to take a more active role in their treatment. MI counselors rely heavily on reflective listening and positive affirmations. The assumption is that behavior change is affected more by motivation than information. Employing a neutral yet inquisitive tone, the MI counselor addresses discrepancies in patients' knowledge, beliefs, or behaviors without instilling defensiveness or attempting to refute the patient's position. Whereas the essence of MI lies in its spirit, there are specific techniques and strategies that, when used, effectively help ensure that such a spirit is evoked. Core MI techniques include the use of reflective listening, allowing the patient to interpret information, agenda setting, rolling with resistance, building discrepancy, and eliciting self-motivational statements or "change talk." In standard medical practice, practitioners often provide information about the risks of continuing a behavior or the benefits of change with the intent of persuasion. With regard to the HF patient, a statement may include "it is very important that you watch your diet before it becomes a bigger problem." In contrast, in the MI approach, information is presented in a more neutral manner, and the patient is asked to interpret what it means for them. For example; "what does this information mean to you" or "what do you make of this?" MI practitioners avoid persuasion with "pre-digested" health messages and instead allow patients to process information and find their own personal relevance. Confronting patients can lead to defensiveness, rapport break, and poor outcomes (Miller, 1983). Therefore, MI counselors avoid argumentation and instead "roll with resistance," and MI encounters resemble a dance more than a wrestling match (Rollnick, Mason, & Butler, 1999).

MI has been used to improve adherence to exercise, medication, and dietary regimens in healthy patients as well as patients with conditions such as hypertension, diabetes, and asthma (Rubak, Sandbaek, Lauritzen, & Christensen, 2005). However, it has rarely been studied in the context of HF. Brodie and colleagues (Brodie & Inoue, 2005; Brodie, Inoue, & Shaw, 2008) sought to examine the effects of motivational interviewing to increase physical activity on 60 HF patients (age 65 years or older; HF NYHA class II–IV). Patients were randomly assigned to either standard care (specialist nurse advising patients to participate in a structured exercise program), motivational interviewing (eight 1-hour sessions targeting increased activity level), or both. At the 5-month follow-up assessment, average self-reported physical activity increased modestly for participants in the MI and combined conditions (2.4 and 2.3 kcal/kg/day respectively; $p < .01$), but not the standard care condition. All three groups improved in 6-minute walk test distances ($p < .0001$), but there were no significant between-group differences (Brodie & Inoue, 2005). Also, significant improvement was observed for all three conditions in health-related quality-of-life (SF-36 scales Role Limitations, Social Functioning, and Change in Health Status) and in HF-specific quality of life (Minnesota Living with HF Questionnaire) ($p < .05$). In post-hoc comparisons, the standard care group consistently showed the least change, and the MI condition consistently showed the most change ($p = .006$–$.03$). The authors noted that the combined group actually received less MI than the MI-only group, which may explain the findings that the MI-only group performed better than the combined group on some outcomes, most notably the Minnesota LHFQ (Brodie et al., 2008).

Summary and Future Directions

No studies to date have examined the effects of an intervention that combines CBT, MI, and telehealth. Coping Effectively with Heart Failure (COPE-HF) (Sherwood, O'Connor, et al., 2011) is an ongoing clinical trial in which 200 HF patients (NYHA class II–IV) are randomly assigned to one of two 16-week telephone-based interventions: Coping Skills Training (CST), or an HF health education (HFE) attention control condition. The CST condition includes four sessions of MI to improve adherence to low-sodium dietary guidelines, medications, daily weighing, and exercise, as well as nine sessions of CBT to address maladaptive cognitions, promote daily stress management practices (e.g., progressive muscle relaxation), promote behavioral activation, and practice effective problem-solving techniques. Outcomes include HF disease biomarkers, physical functioning, health behaviors, and quality of life, as well as death or hospitalization over a 3-year follow-up period. Ongoing and future studies should help establish optimal combinations of the elements of behavioral interventions, and the most cost-effective methods for their delivery, which will maximize the health and quality-of-life benefits for patients with HF.

HF is an increasingly common disorder associated with significant physical limitations, reduced quality of life, depression, recurrent hospitalizations, and mortality. Furthermore, HF self-management is demanding, and patient non-adherence with complex medication regimens, dietary sodium restriction, symptom monitoring, and exercise recommendations are significant contributors to negative outcomes. Biobehavioral interventions can help improve HF management by promoting treatment adherence and lowering barriers to successful self-management. Traditional HF disease management programs provide ongoing education about HF management, facilitate symptom monitoring, and provide HF patients with ongoing advice. With the advent of telehealth approaches, HF education can be provided via telephone, and symptom monitoring can be conducted electronically from the patient's home. Despite the sometimes considerable symptom burden, patients with stable HF can safely participate in regular exercise, which can in turn improve functional ability, quality of life, and markers of disease progression. MI may be useful in promoting adherence to medications, dietary recommendations, symptom monitoring, and exercise guidelines. Although research on the effects of MI in HF is limited, MI provides a useful model through which behavioral interventionists other than physicians and nurses can promote medical adherence among HF patients. CBT may also help promote health behaviors and reduce depression. Together, these behavioral interventions may improve both quality of life and life expectancy in HF patients.

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31

Behavioral Rehabilitation Approaches in Osteoarthritis

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Introduction

Osteoarthritis (OA) is a painful chronic joint disease typically affecting the joints of the knee, hip, hand, and spine. It is the most common of all the rheumatic diseases affecting a substantial proportion of the older adult population, particularly women (Pereira et al., 2011). OA is characterized by whole-joint structural changes, including loss of articular cartilage, development of osteophytes, synovial inflammation, subchondral bone changes, muscle weakness, and ligamentous laxity. These structural changes result from a complex interplay of genetic, metabolic, biomechanical, and biochemical factors. For the affected individual, OA is associated with pain, disability, and reduced quality-of-life.

This chapter will review the role of behavioral rehabilitation approaches in OA. OA in general will be covered where possible, but knee OA will be a primary focus, given that this is the most common lower limb joint affected and that the majority of OA rehabilitation research involves the knee joint. Spinal OA will not be covered, given the non-specific nature of back and neck pain and the difficulty in defining pain arising from spinal OA. The first section of this chapter will provide a brief overview of the personal impact of OA, including pain and physical and psychological dysfunction together with their inter-relationship as well as general management principles. Following this, education, self-help, and patient-driven treatments will be discussed, in particular, formal self-management programs, exercise, and weight-loss. While there is evidence to support the use of these treatment approaches, issues around adherence can influence treatment outcomes in clinical practice. The next section will then cover gait retraining to reduce knee load during walking in people

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with knee OA. Gait retraining involving biofeedback devices, and incorporation of motor learning principles has been of recent interest, given that higher knee load is associated with faster progression of structural disease. The final section will describe formal psychological interventions that have been specifically studied in people with OA.

Individual Impact of OA

Pain is the primary complaint of people with OA. Pain is often aggravated by use of the joint but can also be present at night. A qualitative study revealed two distinct types of pain – a dull, aching pain that becomes more constant over time, punctuated increasingly with short episodes of a more intense, often unpredictable, emotionally draining pain (Hawker et al., 2008). Central sensitization may contribute to pain in OA, with some patients presenting with symptoms typically associated with neuropathic pain such as burning and pins and needles (Hochman, Gagliese, Davis, & Hawker, 2011). The exact causes of pain in OA are unclear but are likely to represent a range of structural, physical, and psychosocial factors. However, given that the extent of structural joint damage in OA is not well correlated to severity of pain, other factors are likely to play a more important role in the pain experience.

People with OA have difficulty performing activities of daily living, the exact nature of which depends upon the involved joint. For OA involving the lower limb joints, walking, climbing stairs, rising from a chair, and getting in/out of a car are often impaired. Hand OA affects manual dexterity and fine motor control, making tasks such as grasping objects, turning keys, opening doorknobs, and writing difficult.

In addition to pain and impaired function, there are a number of other sequelae of OA. Musculoskeletal impairments include muscle weakness and restricted range of motion. Higher levels of depression and anxiety have been reported in people with OA (Parmelee, Harralson, McPherron, & Schumacher, 2012). Work productivity is affected, with greater levels of absenteeism (Hubertsson, Petersson, Thorstensson, & Englund, 2012). Fatigue and problems with sleep are common. Furthermore, many patients with OA are overweight or obese (Grotle, Hagen, Natvig, Dahl, & Kvien, 2008), and suffer from a range of co-morbid diseases that further increases their likelihood of poor physical function (Guh et al., 2009).

There is a complex inter-relationship between the various impairments in OA. Muscle weakness is associated with higher levels of pain and greater declines in physical function (Eitzen, Holm, & Risberg, 2009; Sharma et al., 2003). Psychological impairments including pain catastrophizing, poor pain-coping strategies, anxiety, depression or depressed mood, and social isolation can also be related to higher pain levels in people with OA (Edwards, Cahalan, Mensing, Smith, & Haythornthwaite, 2011). Furthermore, bi-directional relationships exist between pain and physical and psychological impairments, whereby pain can influence, and in turn be influenced by these factors, leading to a downward cascade in physical and

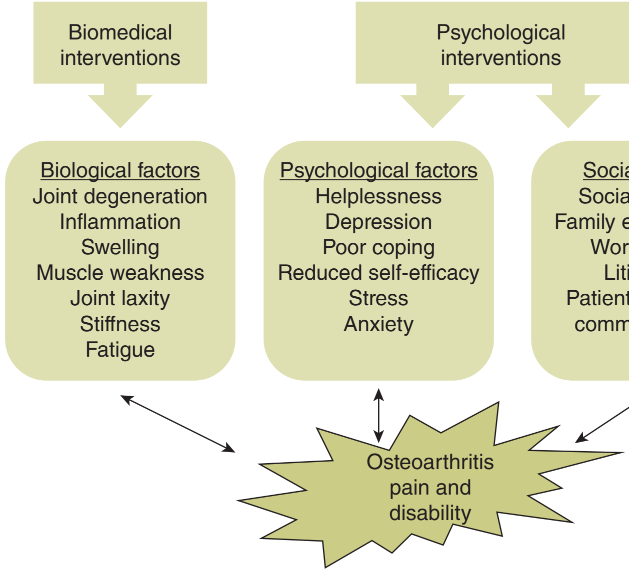

Figure 31.1 The biopsychosocial model of osteoarthritis pain and disability. Adapted from F. J. Keefe & V. Bonk (1999) "Psychosocial assessment of pain in patients having rheumatic diseases." *Rheumatic Disease Clinics of North America*, 25(1), 81–103, with permission from Elsevier.

mental functioning. There are also various mediators of these relationships. For example, OA pain has been shown to determine subsequent depressed mood through its effect on fatigue and disability (Hawker et al., 2011). It is apparent then that OA has wide-reaching effects on the affected individual.

Management of OA

Given the broad impact of OA and in accordance with a biopsychosocial approach to the management of chronic pain, it is logical that both biological and psychosocial factors should be addressed in people with OA (Figure 31.1). Clinical guidelines recommend a range of non-pharmacological conservative interventions that may assist in the management of people with OA (Hochberg et al., 2012; Zhang et al., 2007; Zhang et al., 2010). For OA, core conservative treatments for all patients should include patient education and exercise. In addition, weight loss is also recommended for those with lower limb OA who are overweight/obese. It is apparent that the key treatments for OA (exercise and weight loss) require behavioral changes, and it is well known that these changes are difficult to initiate and maintain. As such, a behavioral approach to treatment is needed, underpinned by one of the many behavior change models including social cognitive theory, transtheoretical theory, or the health action process approach. To ensure safe and effective delivery of the many conservative non-drug treatments suitable for knee OA, a multidisciplinary approach is needed, based upon patient need and the healthcare setting. Treatment should be individualized and patient-centered, involving shared decision-making between the patient and health practitioner, taking into account the patient's preferences and wishes.

Patient Education and Self-management

Patient education is an integral component of chronic pain treatment. It can be delivered by a variety of methods, including informal discussion with the healthcare provider, provision of written materials, support groups, websites, as well as referral to self-management programs. Self-management programs can take various forms, with differences in the content, mode of delivery (individual, group-based, telephone, Internet), program length, and expertise of those delivering the material (lay leaders, healthcare professionals). Motivational interviewing is often used as a tool to facilitate self-management (see Chapter 21). Self-management programs typically include coping with behavioral change, educational information, and self-management techniques. The topics can cover problem-solving, pain management, exercise, diet, modeling, social persuasion, weekly goal-setting, and cognitive therapy (see Table 31.1). An important component of education is for patients to

Table 31.1 Topics that may be covered in self-management programs for OA.

Potential topics for patient education in OA
• Information about OA
• Information about the neurophysiology and neurobiology of pain
• Principles of self-management
• Exercise
• Healthy eating and weight management
• Joint care and protection
• Conservative non-drug treatment options
• Medications
• Joint injections
• Surgery
• Communication with healthcare providers
• Involvement of significant others
• Complementary and alternative medicine
• Stress management and relaxation
• Fatigue and sleep
• Mood
• Problem-solving, goal-setting, behavioral change

understand the neurophysiology and neurobiology of pain, and there is evidence that an educational strategy specifically addressing this can have a positive effect on chronic musculoskeletal pain (Louw, Diener, Butler, & Puentedura, 2011). When held in a group setting, the programs can also bring with them the benefits of peer support, providing social interaction with others with OA.

In general, however, the reported effects of isolated self-management programs for OA have often been small or non-significant A meta-analysis published in 2003 involving 17 trials found an effect size of 0.12 for pain and 0.07 for disability (Warsi, LaValley, Wang, Avorn, & Solomon, 2003). Since this systematic review, there have been other randomized controlled trials (RCTs) investigating self-management for OA. In one study, a health-professional-led program, conducted in a group setting with six weekly sessions of 2.5 hours, significantly improved pain, quality of life, and function at 8 weeks and 6 months from baseline, compared to a control group in people with knee OA (Coleman et al., 2012). In another study, an educational program delivered via 12 monthly telephone calls to people with hip or knee OA produced moderate improvements in pain, particularly when compared with a health education control group (Allen et al., 2010). An RCT in the UK primary care setting found no difference in pain or function between a self-management course including an educational booklet compared with administration of the educational booklet alone (Buszewicz et al., 2006). Another RCT in the primary care setting in France found that standardized medical consultations that included education about OA and advice about exercise and weight loss led to significantly greater weight reduction, compared with usual care but no difference in pain (Ravaud et al., 2009). A more recent systematic review with studies up to January 2009 also reported small but significant effects of patient education and self-management (Zhang et al., 2010). The relatively small effect size of self-management programs and patient education in isolation highlights that they should form just one component of an overall treatment plan. Furthermore, while self-management programs for OA are available in many countries, health practitioners do not necessarily refer patients. A qualitative study found a number of barriers and enablers to general practitioner referral of people with OA to self-management programs in Australia (Pitt, O'Connor, & Green, 2008). These barriers and enablers could be targeted to increase referral to, and uptake of, such programs in the primary medical care setting.

Health practitioners have a role to play in providing education and/or in referring patients to appropriate educational sources. With the increasing use of technology, patients are often turning to the Internet to access information to assist them in managing their condition. A 2010 study assessed the quality and variability of health information on chronic pain websites (Kaicker, Debono, Dang, Buckley, & Thabane, 2010). It located 161 unique sites, most of which were in English. Overall, the quality levels of the sites were moderate but variable. Given this, health practitioners should assist patients to access only up-to-date evidence-based information from the Internet.

Exercise

Exercise is an integral component of conservative non-pharmacological management of OA, and is advised for all patients, irrespective of disease severity, age, co-morbidity, pain severity, or disability (see also Chapter 25). Many forms of exercise have been described in the literature for people with OA, including muscle strengthening/resistance training, stretching/range of motion, cardiovascular/aerobic conditioning, neuromuscular exercise, balance training, and tai chi. Recent clinical guidelines for managing OA, published by the American College of Rheumatology in 2012 (Hochberg et al., 2012), strongly recommend that people with knee and hip OA participate in cardiovascular and/or resistance land-based exercise, as well as aquatic exercise. These recommendations are based on meta-analyses of clinical trials that demonstrate small-to-moderate effect sizes with these types of exercise for pain and function in people with knee and hip OA (Bartels et al., 2007; Fransen & McConnell, 2008; Fransen, McConnell, Hernandez-Molina, & Reichenbach, 2009). These beneficial effects are similar in magnitude to those observed with analgesics and non-steroidal anti-inflammatory drugs (Zhang et al., 2010). Participation in tai chi programs is also conditionally recommended for people with knee OA (Hochberg et al., 2012). Although this style of gentle, low-impact exercise is gaining popularity among people with OA, there are few well-designed clinical trials of tai chi (Escalante, Saavedra, Garcia-Hermoso, Silva, & Barbosa, 2010), with these suggesting potential symptomatic benefits of tai chi for knee OA. There are no clinical recommendations as yet regarding balance exercises (either alone, or in combination with strengthening exercises) for people with OA, due to the limited evidence available (Chaipinyo & Karoonsupcharoen, 2009).

For people with OA, outcomes from exercise are most likely optimized when the exercise program is prescribed, and initially supervised, by an appropriately qualified health professional with expertise in exercise prescription (such as a physiotherapist). Given the varied clinical presentation of patients with OA regarding pain severity, number of joints affected, functional ability, muscle strength, and comorbidities, an exercise program should be individually prescribed, in order to maximize effectiveness and to be tailored to the individual goals, needs, and interests of the patient. Supervision, at least in the initial stages of an exercise program, can ensure safe and correct exercise technique, and ensure that the dosage of the exercise is appropriate for the patient's physical ability and overall goals of the program. Research demonstrates the importance of supervised exercise. A Cochrane review has shown that, in people with knee OA, 12 or more directly supervised exercise sessions with a health professional significantly improves pain and function more when compared with less than 12 sessions (Fransen & McConnell, 2008).

Home-based exercise is an important component of the rehabilitation of any patient with OA. Given the chronic nature of the disease, exercise must be maintained over the long term for ongoing clinical benefits, and unsupervised home exercise is both feasible and potentially sustainable for the vast majority of patients.

Research shows that home exercise programs are effective in reducing pain and improving function in people with knee OA. Although effect sizes for home exercise appear smaller than for class-based programs and individual supervised exercise treatments, the differences in effect size between delivery modes did not reach statistical significance in a Cochrane review (Fransen & McConnell, 2008). In clinical practice, patients are almost always prescribed a home exercise program, even if they are attending supervised individual or class-based exercise sessions on a regular basis. This is to ensure that people with OA perform exercise at a frequency required to achieve the desired aims of the program (see Table 31.2).

Recently, integrated rehabilitation that combines both exercise and self-management interventions has been advocated for OA (Hurley & Walsh, 2009). Traditionally, these interventions are usually delivered separately; theoretically, the benefits of each strategy individually may be additive. Thus, it is possible that an integrated approach may optimize patient outcomes. Additionally, although

Table 31.2 General guidelines for training parameters in people with OA, as developed by the American Geriatrics Society.

Exercise type	*Intensity*	*Volume*	*Frequency*
Flexibility			
Static stretching initially	Stretch to subjective sensation of resistance	1 stretch/muscle group; hold 5–15 sec	Once daily
Flexibility			
Longer-term goal	Stretch to full range of motion	3–5 stretches/muscle group; hold 20–30 sec	3–5/week
Strengthening			
Isometric	Low–moderate: 40–60% MVC	1–10 submax contractions/muscle group; hold 1–6 sec	Daily
Strengthening			
Isotonic	Low: 40% 1 RM Moderate: 40–60% 1 RM High: >60% 1 RM	10–15 reps 8–10 reps 6–8 reps	2–3/week
Endurance			
Aerobic	Low–moderate: 40–60% of VO_2 max/HRmax RPE: 12–14 = 60–65% VO_2 max	Accumulation of 20–30 min/day	2–5/week

1 RM = one repetition maximum; MVC = maximal voluntary contraction; RPE = rating of perceived exertion; HRmax = age-predicted heart rate maximum; VO_2 max = maximal aerobic capacity

Source: Copyright (2001) Wiley. Used with permission from American Geriatrics Society Panel on Exercise and Osteoarthritis, Exercise Prescription for Older Adults With Osteoarthritis Pain: Consensus Practice Recommendations: A Supplement to the AGS Clinical Practice Guidelines on the Management of Chronic Pain in Older Adults, *Journal of the American Geriatrics Society*, John Wiley & Sons Publishing.

self-management programs for OA typically emphasize the importance of exercise for OA, most programs do not have a participatory exercise component. Furthermore, healthcare professionals delivering exercise interventions typically do not address the wider aspects of self-management of OA. A cluster randomized trial in the United Kingdom evaluated the efficacy of an integrated rehabilitation program that included an individualized progressive exercise regime, education, and self-management strategies to alter behavior and dispel inappropriate health beliefs (Hurley et al., 2007; Hurley, Walsh, Mitchell, Nicholas, & Patel, 2012). Over 400 people with chronic knee pain participated, and self-reported physical functioning was evaluated immediately following the 6-week intervention, as well as 6, 18, and 30 months later. Results showed that participants undergoing integrated rehabilitation (delivered by a physiotherapist either individually or in groups) had better functioning than those receiving only usual primary care following intervention. Although improvements in function declined over time, the integrated program still resulted in better function, and was more cost-effective, than usual care at 30 months.

Despite the vast research evidence demonstrating the beneficial effects of exercise for people with knee OA, and the publication of clinical guidelines by numerous international rheumatology bodies advocating exercise for OA (Hochberg et al., 2012; Jordan et al., 2003; Zhang et al., 2008), exercise is under-utilized by medical practitioners as a treatment for OA. For example, a recent Canadian survey evaluated the quality of care for people with OA (Li et al., 2011). Regarding the quality indicator "advice to exercise," only 25% of the people who required advice to exercise had actually seen a physiotherapist or attended a land- or pool-based exercise program or had used fitness facilities over the past year (Li et al., 2011). It is not clear whether the poor uptake of exercise in this study was because people had not received advice to exercise in the first place, or because people chose not to undertake the advised exercise. Given that a French survey of general practitioners showed that less than 15% would prescribe exercise for knee OA as a first-line therapeutic approach (Chevalier, Marre, de Butler, & Hercek, 2004), it is likely that at least part of the problem lies with medical and healthcare practitioners failing to recognize the importance of exercise.

Patient adherence is a key factor in determining outcome from exercise therapy in patients with knee OA (Mazieres et al., 2008; Pisters, Veenhof, Schellevis, De Bakker, & Dekker, 2010b). Although patient adherence to exercise is often good when commencing an exercise program, it typically declines over the longer term. Although not well studied, a complex array of factors can influence adherence to exercise programs in individuals with OA. A qualitative phenomenological study of people with symptomatic and radiographic OA of the knees, hips, spine, hands, and other joints identified both internal and external facilitators and barriers to exercise (Figure 31.2) (Petursdottir, Arnadottir, & Halldorsdottir, 2010). Internal factors include individual attributes (motivation, personality, self-image, health attitude, exercise attitude, exercise history, and disease knowledge) and personal experience (effect of pain, stiffness and fatigue, finding suitable exercise, perceived exercise

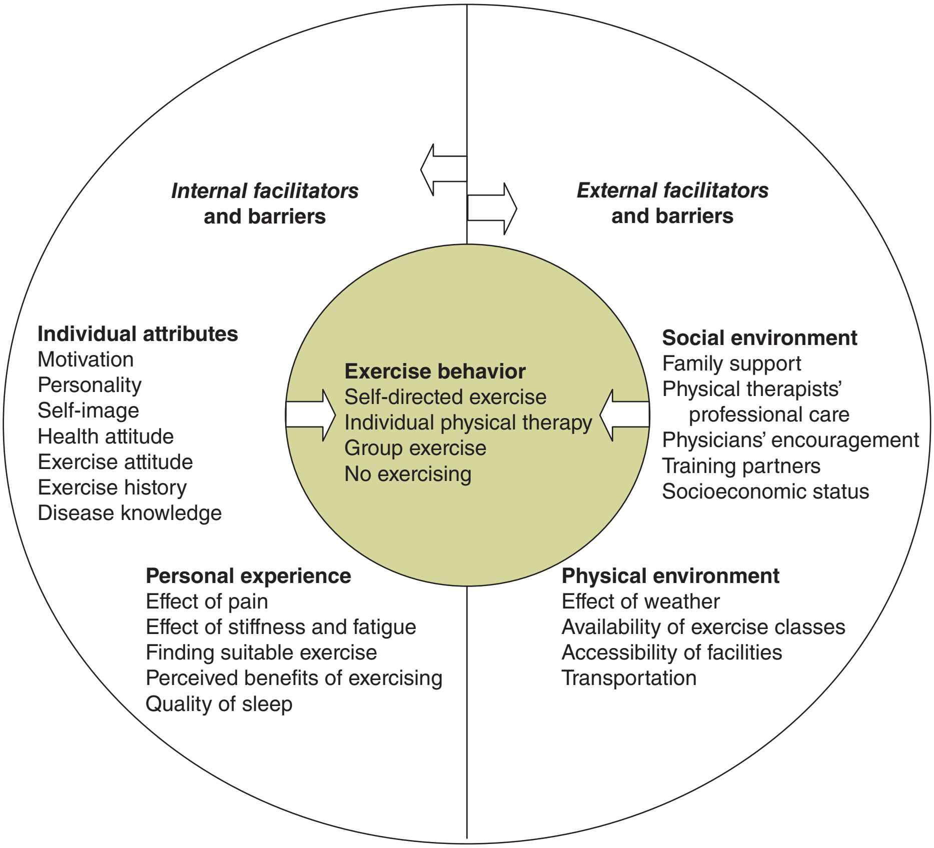

Figure 31.2 Model representing the internal and external facilitators and barriers to exercising among people with osteoarthritis.
Reprinted from U. Petursdottir, S. A. Arnadottir, S. Halldorsdottir (2010) "Facilitators and barriers to exercising among people with osteoarthritis: a phenomenological study." *Physical Therapy, 90*: 1014–1025, with permission of the American Physical Therapy Association. This material is copyrighted, and any further reproduction or distribution requires written permission from APTA.

benefits, and quality of sleep). External factors include the social environment (family support, physical therapists' care, physicians' encouragement, training partners, and socioeconomic status) and physical environment (effect of weather, availability of exercise classes, accessibility of facilities and transportation). Based on this information, Petursdottir et al. (2010) constructed a checklist of barriers and facilitators that influence exercise behavior among people with OA (Table 31.3).

Participants who are influenced mainly by facilitators are more successful in integrating exercise into their lifestyle, compared to participants who are predominantly influenced by barriers. This checklist may be useful for health professionals to identify potential factors that may adversely influence exercise adherence in their

Table 31.3 Checklist of facilitators and barriers influencing exercise behavior among people with osteoarthritis.

The individual

Barriers		Facilitators
Negative	**Personality**	Positive
Weak	**Self-image**	Strong
Negative	**Health attitude**	Positive
Negative	**Exercise attitude**	Positive
Weak	**Motivation by enjoyment**	Strong
Weak	**Motivation by results**	Strong
Negative	**Exercise history**	Positive
Little	**Disease knowledge**	Substantial

↓

Influencing factors

Barriers		Facilitators
Great	**Pain**	None
Great	**Stiffness and fatigue**	None
Unsuitable	**Type of exercise**	Suitable
None	**Perceived benefits of exercise**	Great
Poor	**Quality of sleep**	Good
Poor	**Family support**	Great
Poor	**Physical therapists' professional care**	Great
Poor	**Physicians' encouragement**	Great
Lack of	**Training partner (if needed)**	Existing
Low	**Socioeconomic status**	High
Problematic	**Personal hygiene**	No problem
Unfavorable	**Weather conditions**	Favorable
Little	**Availability of exercise classes**	Great
Problematic	**Transportation**	No problem

Source: Reprinted from U. Petursdottir, S. A. Arnadottir, S. Halldorsdottir (2010). "Facilitators and barriers to exercising among people with osteoarthritis: a phenomenological study." *Physical Therapy, 90*: 1014–1025, with permission of the American Physical Therapy Association. This material is copyrighted, and any further reproduction or distribution requires written permission from APTA

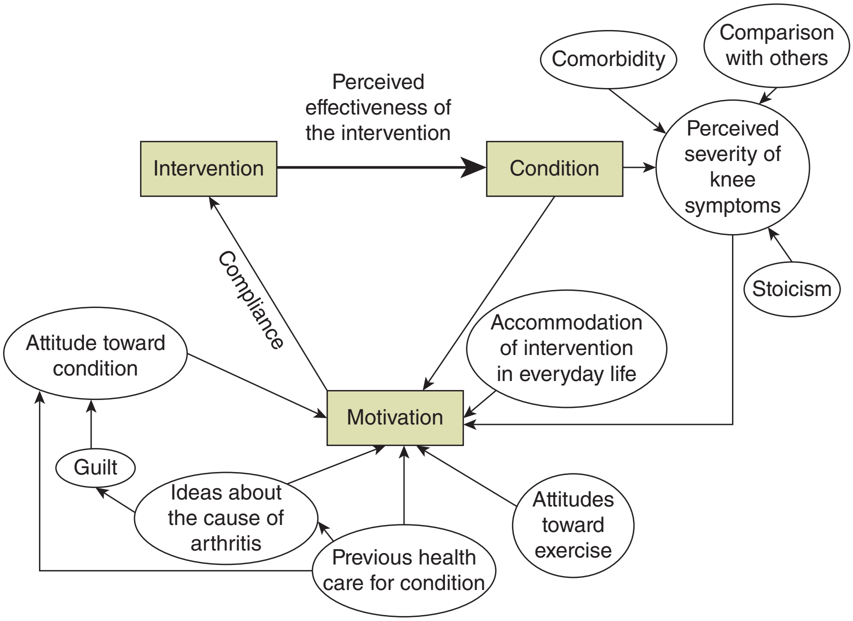

Figure 31.3 Model of continued exercise adherence proposed by Campbell et al., reproduced from R. Campbell, M. Evans, M. Tucker, B. Quilty, P. Dieppe, J. L. Donovan, *Journal of Epidemiology & Community Health*, *55*, 132–138, copyright notice 2001 with permission from BMJ Publishing Group Ltd.

patients with OA. Another qualitative study exploring factors related to non-adherence with physiotherapy exercises in people with knee OA highlights the importance of attitude toward exercise and understanding of OA (Campbell et al., 2001) in influencing adherence to exercise. This study showed that a positive disposition toward exercise could increase motivation to exercise. People who thought that OA was caused by unmodifiable factors such as age and "wear and tear" found it difficult to believe that exercise could be beneficial, and this weakened their resolve to adhere to the prescribed program. Other reasons identified for poor adherence included inability to accommodate exercises into everyday life, perceived symptom severity, and prior experience with other treatments (Figure 31.3).

In the literature, numerous strategies have been suggested to help improve adherence to exercise interventions in people with OA (Table 31.4) (Jordan, Holden, Mason, & Foster, 2010; Mazieres et al., 2008; Roddy et al., 2005). Individualizing the exercise program to the unique clinical presentation, goals, and preferences of the patient is paramount, as is ensuring the availability of resources needed to undertake the prescribed program. Education about the disease process and benefits of exercise is critical, and it is important that advice to exercise comes from medical practitioners involved in the primary care of the patient, as well as the professionals prescribing the exercise program (Dexter, 1992). While regular monitoring from a

Table 31.4 Strategies that may assist in improving adherence to exercise in people with OA.

STRATEGY
• Patient-centered and individually tailored exercise programs with respect to exercise capacity, pain levels, goals, and interests, rather than standardized non-specific programs
• Supervised exercise sessions rather than unsupervised where possible
• Supplementing a home-based program with group exercise
• Long-term monitoring/review by a health professional (phone, mail, or visits)
• Patient education regarding the importance and benefits of exercise
• Inclusion of spouse/family in the exercise program
• Self-monitoring by means of an exercise diary or pedometer
• Support from family and friends to incorporate exercise into lifestyle
• Intermittent "booster" or "refresher" exercise sessions with a health professional
• Ensuring access to appropriate exercise resources and facilities

healthcare professional may be beneficial in promoting adherence over the long term, patients may also utilize their own social support networks to ensure exercise is integrated into their daily routine (Minor & Brown, 1993). Other strategies that may promote adherence to exercise include self-monitoring, reinforcement by other individuals, telephone and/or mail contact, as well as participating in exercise with spouse or other family members (Roddy et al., 2005). Integration of behavioral-graded activity principles and "booster sessions" into exercise programs also seems to result in better adherence and a more physically active lifestyle (Pisters, Veenhof, de Bakker, Schellevis, & Dekker, 2010a).

Hurley et al. (2010) explored the effects of an integrated exercise and self-management program on the health beliefs, experiences, and expectations of people with chronic knee pain, using semi-structured interviews and thematic analysis. Following the program, most participants described improvements in pain, physical and psychosocial functioning, and greater knowledge and understanding of their condition and treatment options and in their ability to use exercise to control symptoms. Although beliefs about the cause and prognosis of knee pain were unchanged, concerns about potential dangers of exercise had reduced, and there was an appreciation of how exercise could be used to reduce symptoms. Participants considered supervision essential for enhancing helpful exercise beliefs and self-efficacy.

It is important to ensure that healthcare professionals prescribing exercise for people with OA facilitate the behavioral changes required to incorporate exercise into a long-term management plan. A recent UK study utilized semi-structured interviews to explore physical therapists' beliefs and attitudes regarding exercise for people with knee OA (Holden, Nicholls, Young, Hay, & Foster, 2009). Although exercise adherence was deemed important, it was viewed by therapists as the patient's responsibility. It was also apparent that many therapists largely worked under a "biomedical" model of care of knee pain, whereby knee OA was viewed as a progressive degenerative disease. A paternalistic approach to exercise was evident, where therapists tended to blame patients for not exercising, rather than trying to understand reasons for poor adherence and implement strategies to overcome barriers. The authors of this study suggest that a more equal partnership between exercise providers and patients, which acknowledges the complex nature of adherence and includes a range of educational and behavioral adherence-enhancing strategies, may be beneficial in supporting patients to maintain exercise.

Weight Loss

Being overweight or obese is an important risk factor for the development and progression of knee OA, with less effect at the hip. Greater body weight could have detrimental effects on joint structure by placing greater loads on the lower limb joints during walking and other daily activities, as well as via general increases in substances that can directly degrade the joint or increase the amount of joint inflammation.

Clinical guidelines recommend weight loss for those who are overweight or obese and suffering from lower-limb OA (Hochberg et al., 2012; Zhang et al., 2008). However, there are few RCTs evaluating the effect of specific weight loss programs in OA, all of which have been performed in people with knee OA. A meta-analysis of four trials concluded that the amount of weight loss was associated with improved self-reported physical disability, but not with reduced pain in knee OA (Christensen, Bartels, Astrup, & Bliddal, 2007). More specifically, disability could be significantly improved when weight is reduced over 5% or at a rate of >0.24% reduction per week over a 20-week period. A high-quality RCT also showed that weight loss improved all-cause mortality in overweight/obese people with knee OA by 10% (Shea et al., 2010). Furthermore, a computer simulation model of knee OA and obesity using national US census and obesity data showed that a reduction in mean body mass index of only 0.6 units (about a 1.7-kg reduction for a person about 1.7 m tall) would reduce total knee replacements over the remaining lifespan of this population by 1.9% (Losina et al., 2011). This reduction would equate to considerable health cost savings.

Weight loss can be obtained by dietary restriction to reduce caloric intake, but exercise can also play a role by increasing energy expenditure and changing body composition. Methods of weight loss have been compared in people with knee OA. In the 18-month ADAPT trial involving 316 people with knee OA, an exercise-only group lost 3.5 kg or 3.7% of their baseline body weight compared with 5.2 kg (5.7%) and 4.6 kg (4.9%) for the diet plus exercise group and diet only group, respectively (Messier et al., 2004). The combination of modest weight loss plus moderate exercise provided better overall improvements in self-reported measures of function and pain and in performance measures of mobility compared with either intervention alone. Ottawa Panel guidelines have been developed specifically for overweight or obese people with OA. These guidelines also demonstrate that a combination of physical activity (aerobic exercise plus or minus strength training) and diet (caloric restriction) produce the most beneficial results compared with either intervention alone or control on a range of clinical outcomes with highest-level recommendations for pain relief, functional status, strength, and quality of life (Brosseau et al., 2011). The Panel recommends weight loss prior to implementing weight-bearing exercise to maintain joint integrity.

Despite the clinical benefits, losing weight and maintaining weight loss is difficult, and a number of behavioral strategies are used to assist patients achieve weight loss goals. These include behavioral and education sessions delivered in both group and individual formats, providing advice on food selection, meal portions, dietary fat control, relapse prevention, and teaching self-monitoring techniques such as keeping a food diary. The interventions used in the ADAPT trial, where patients with knee OA successfully lost weight over 18 months, were based largely on social cognitive theory (involving three constructs – self-efficacy around diet and exercise, outcome expectations, and incentives) and group dynamics, given that the interventions were delivered in group settings (Messier et al., 2004). The interventionists were trained in social cognitive behavioral strategies and reviewed patient programs with a health psychologist biweekly to develop strategies to use with patients who were finding it difficult to adhere. Over the 18 months, adherence was 73% for the healthy lifestyle control group, 72% for the diet-only group, 60% for the exercise-only group and 64% for the diet-plus-exercise group. It is evident that weight loss is challenging and requires considerable time and effort on behalf of both patients and health professionals. Incorporating weight management interventions into the management of OA is challenging, as it requires considerable time and effort on behalf of both the patient and the health provider. Furthermore, to be effective, the health provider needs to be cognizant of behavioral change techniques. Further information to assist clinicians is found in Chapter 5, which discusses how to promote physical activity for the management of obesity, while motivational interviewing, a technique that can assist patients to change behavior around weight loss, is discussed in Chapter 19.

Gait Retraining

Increased knee joint loading during walking has been found to be associated with faster progression of knee OA structural disease (Bennell et al., 2011; Miyazaki et al., 2002). Given this, there has been increasing interest in identifying treatments that can reduce knee load and hence slow disease progression and reduce symptoms. One such behavioral treatment is gait modification via retraining – that is, teaching patients ways of modifying the way they walk.

A recent systematic review investigated the effect of gait modification strategies on the external knee adduction moment (Simic, Hinman, Wrigley, Bennell, & Hunt, 2011). The external knee adduction moment can be measured during 3D gait analysis and provides an indication of the amount of load passing through the medial (inner) knee joint compartment compared to the lateral (outer) knee joint compartment during walking (Erhart, Dyrby, D'Lima, Colwell, & Andriacchi, 2010; Zhao et al., 2007). The review included 24 studies exploring 14 different gait modifications with sample sizes generally small, ranging from 1 to 88. The majority of the studies assessed the immediate effects of the gait modification on knee load ($n = 22$), while only two studies investigated their effects over time. Furthermore, the majority of the studies were performed in healthy individuals ($n = 14$), with only six studies involving people with knee OA. The gait modification strategies that were found to reduce medial knee load were: using a cane in the hand opposite to the affected leg; walking with legs further apart (increased step width); walking in a manner whereby one tries to bring the thighs and knees closer together (called medial knee "thrust"); transferring the weight more toward the inside part of the foot when it is placed on the ground; and leaning the trunk away from the affected leg when it is placed on the ground (lateral trunk lean). Walking with the knees excessively bent or using Nordic walking poles in both hands were associated with increases in the medial knee load, suggesting a potential detriment to their use. The effects of walking with shorter strides as well as increasing or decreasing walking speed, or how much the foot is turned in (pigeon toe) or out, were inconsistent across the studies and gait cycle.

While there is evidence to show that particular gait strategies can reduce knee load in the short-term, based on the principles of motor relearning, internalization of a new gait pattern requires systematic training. Such training should incorporate extrinsic feedback initially to facilitate learning of the required gait modification followed by gradual removal of the feedback over time. Practice is a key component of motor relearning. Few studies have evaluated the effect of systematic training of gait modifications relevant to knee OA over time. A recent study, albeit only in young, healthy individuals with varus ("bow legs") knee alignment (a risk factor for knee OA), evaluated the effect of eight gait retraining sessions lasting 15–30 minutes that focused on achieving a reduction in the amount of dynamic knee varus during walking (by bringing the thighs and knees closer together) (Barrios, Crossley, & Davis, 2010). Verbal instruction has not been deemed sufficient on its own to achieve the precise gait changes required for this and other modifications, and in any case would require close supervision by a therapist for some time. Therefore, in this and other studies, visual feedback was provided. In this case, the amount of knee varus angle (measured by a laboratory-based real-time motion analysis system) was displayed to participants on a screen as they walked on a treadmill. A fading feedback design was used over the retraining sessions, whereby feedback was provided for 100% of the time during the first four sessions, reducing to 10% by the final session. Results showed a 20% decrease in medial knee load during the modified gait following the retraining, which was maintained 1 month later. However, natural gait at that time was not different from baseline, indicating that participants had not subconsciously adopted this gait pattern. These results contrast with those of a case study whereby one trained individual with knee OA, mild varus alignment, and pain was unable to revert back to their pre-training gait following 9 months of practice (Fregly, Reinbolt, Rooney, Mitchell, & Chmieleswki, 2007). This could suggest that a longer period of training is needed for sustained gait changes. The pain reduction experienced by this patient with the modification was also presumably important in reinforcing long-term change. The first study was conducted in a laboratory setting with real-time 3D motion analysis used to provide feedback to participants; the single patient in the second study was a biomechanical engineering researcher with intimate knowledge of the gait strategy. As such, it is not possible to generalize the findings to routine clinical practice. Therefore, it is not currently known whether it is possible to permanently alter gait in people with knee OA in order to ultimately achieve symptomatic and structural benefits.

While the majority of the studies have attempted to retrain a specific standardized gait parameter in the whole sample, it is possible that a "one-size-fits-all" approach is not optimal. An alternative approach that requires further investigation in people with OA is to provide them with a *range* of potential gait modifications that have been shown to be effective for load reduction, and allow them to converge on a strategy that works best for them in reducing knee load, while not being too awkward (Wheeler, Shull, & Besier, 2011). However, the modification a person chooses in his or her early training sessions may not be the most effective modification for pain and load reduction in the longer term.

While gait retraining is a promising intervention in terms of reducing knee load, there are a number of questions that currently prevent gait retraining being a practical and accepted strategy for the management of knee OA in the clinical setting. First, how do we select the appropriate patients from clinically measurable parameters? Those with high knee joint load are the primary targets for gait modification, but biomechanical laboratory testing to identify such patients is not widely feasible, and joint loading is not currently measurable by practical portable sensors (Wrigley, 2011). While some observable features such as knee varus malalignment can be inferred to be associated with increased loading, further work is necessary to find more precise and practical ways of inferring knee load clinically using minimal equipment (Favre, Hayoz, Erhart-Hledik, & Andriacchi, 2012; Hunt & Bennell, 2011; Wrigley, 2011). Second, what are the most effective and practical gait modifications, alone or in combination, to target for retraining? A number of gait modifications have been identified, but it is not known which is going to be the most effective in reducing knee load, easiest to adopt in the long term, and unlikely to be associated with adverse effects. Third, how can we best provide feedback to facilitate retraining, and what movement-related parameter associated with the desired modification should be fed back to the patient? While biofeedback has a significant history in rehabilitation (Huang, Wolf, & He, 2006), technology limitations have hindered its use; therefore, relatively little is known about what forms (visual, auditory, mechanical/vibration/tactile) are most effective in the clinic. There are also other questions related to which practical sensing systems are amenable to measuring the required movement parameters, and if these sensing and feedback systems can also be used in the home and outdoors to facilitate training outside the clinic. This is likely to be important in order to generalize movement patterns in one setting (such as during a rehabilitation setting) to everyday life. Fourth, can we achieve permanent changes in gait patterns and joint load with gait retraining? To date, this has not been studied in a cohort of people with knee OA. Fifth, are there beneficial clinical effects of gait retraining? Ultimately, the purpose of gait retraining is to permanently reduce knee load with the presumption that this will reduce pain and slow disease progression. This is not yet known, and studies investigating immediate effects of gait retraining on pain cannot evaluate whether long-term benefits are achievable. Furthermore, studies investigating whether knee load is associated with pain and symptoms are conflicting. Last, are there any negative effects of gait modifications at other joints? This is particularly important, as changes in walking patterns will ultimately alter the amount and distribution of load in a range of areas, given that the lower limb is a linked chain. For example, it is not known whether leaning the trunk to the side away from the affected leg, while beneficial for knee load, might give rise to back or hip pain. Further research is needed to address these clinically relevant questions.

Psychological Interventions

A number of psychological interventions are available to treat chronic pain covering operant, cognitive, and respondent approaches, with many interventions combining these approaches. Of the psychological interventions, cognitive behavioral therapy for pain management/pain coping is the most extensively researched for chronic pain and has the strongest evidence base. However, research into the effectiveness of psychological interventions in OA specifically is limited, and mostly focuses on pain-coping-skills training. Self-management programs, which generally also include a behavioral component, have been discussed earlier in this chapter.

Pain-coping-skills training for OA typically consists of three components. The first component involves providing an educational rationale (e.g., the gate control theory, neuromatrix) that helps patients better understand how their thoughts, feelings, and behaviors can influence pain, and how in turn their own efforts to manage pain can influence the pain experience. The second component involves therapist-guided training in cognitive and behavioral coping strategies such as progressive relaxation training, brief relaxation methods, goal setting, activity pacing, imagery, and strategies for altering overly negative thoughts related to pain. A key aspect of training is behavioral rehearsal, in which patients have the opportunity to have the therapist model skills practice and then rehearse skills, and are provided with feedback on their performance. The third component involves home practice with coping skills and learning how to apply those skills to individual pain-related situations (Keefe, Somers, & Martire, 2008). These components are outlined in Table 31.5.

Table 31.5 Typical elements of cognitive behavioral pain-coping-skills training for OA.

Element	*Description*
Behavioral	
Progressive muscle relaxation	Exercises designed to reduce muscle tension and nervous system arousal through systematic tensing and relaxing of major muscle groups
Brief muscle scan	A 30-second exercise that teaches patients to quickly identify and release muscle tension throughout the body
Activity pacing	Patients learn how to break down activities that are painful into periods of limited activity, followed by limited rest, with the goal of gradually increasing activity and decreasing rest time
Pleasant activity scheduling	Patients gradually increase the frequency of pleasant activities by identifying potentially pleasurable and meaningful activities, developing activity goals and monitoring and reinforcing accomplishment of goals
Problem-solving	A technique that teaches patients to identify actual or potential problems that may exacerbate pain and other symptoms, generate solutions to address problems, and implement solutions with increasing mastery until problem resolution is achieved
Communication and assertiveness skills	Systematic training in social skills that help patients to better communicate their needs to healthcare providers, family, and members of their social support network. Typically uses a role-play format with extensive rehearsal of skills and therapist feedback and guidance
Relapse prevention training	A strategy that teaches awareness and modification of situations that interrupt continued practice of cognitive behavioral therapy skills
Cognitive	
Cognitive restructuring	Treatment involves methods to help patients identify and alter overly negative and distorted thoughts that increase pain and emotional distress and lead to maladaptive behaviors that exacerbate pain
Imagery	Strategy that involves deliberately focusing on a pleasant scene to divert attention from pain and other stressful events
Distraction	Training in the use of focal points and auditory stimulation as distraction methods

The first RCT of pain-coping-skills training for OA was published in 1990 by Keefe and colleagues (1990a, 1990b). In this trial, 99 older adults with persistent knee OA pain were randomized into a 10-session pain-coping-skills training intervention, a 10-session OA education/information intervention, or usual care. Results showed that patients who received the pain-coping-skills training showed significant improvements in pain and psychological disability compared to those in the other groups. These improvements were more likely if patients reported increases in perceived control over pain (pain control and rational thinking) over the course of the pain-coping-skills training intervention. The study provided initial support for the efficacy of psychological interventions in those with chronic OA pain.

Based on the notion that pain can influence and be influenced by significant others, involving spouses or family members of people with OA in pain-coping-skills training has also been investigated (Keefe et al., 1996, 1999, 2004). In this protocol, patients attended treatment sessions with their spouses, and the training involved not only instruction in pain-coping skills but also couple skills designed to supplement and reinforce learned pain-coping skills. Results showed that patients who received spouse-assisted coping skills training had better outcomes compared to those treated on their own with conventional pain-coping-skills training, while the patients in an arthritis education social support group had the poorest outcome (Keefe et al., 1996, 1999). A more recent RCT also found that spouse-assisted coping skills training produced improvements in coping and self-efficacy (Keefe et al., 2004). The evidence suggests that spouse-assisted coping skills may be particularly beneficial for patients with OA.

While pain-coping-skills training may be efficacious, there are subgroups of individuals who respond differently. Not all individuals approach psychological interventions with positive expectations of benefit (Broderick, Junghaenel, Schneider, Bruckenthal, & Keefe, 2011). A recent study found that patients who are psychologically distressed and are less optimistic about engaging in treatment may benefit from and need pretreatment motivational interviewing in order to enhance their uptake of pain-coping skills (Broderick et al., 2011). Strategies to assist with longer-term adherence may also be needed following a pain-coping-skills training program as the initial gains in pain relief for some patients with OA after the program are not always maintained (Keefe et al., 1990b). One promising strategy is the use of a telephone-based, automated maintenance enhancement program that has been shown to reduce opioid and non-steroidal anti-inflammatory drug analgesic use in patients with chronic musculoskeletal pain (Naylor, Naud, Keefe, & Helzer, 2010). Other strategies such as booster sessions need further research.

Behavioral-graded activity is an operant treatment approach based on the principles of operant conditioning with a traceable theoretical justification. The operant principles include reinforcement of healthy behaviors and withdrawal of attention to pain behaviors to increase the time of performance of daily activities. This approach has only been evaluated in one study in OA, a cluster RCT performed in the Netherlands (Veenhof et al., 2006a). In this study, 200 people with hip and knee OA were randomized into a behavioral-graded activity program or usual exercise therapy, delivered by physical therapists. Both treatments consisted of a 12-week period, with a maximum of 18 sessions, while the behavioral-graded activity program also involved five preset booster periods with a maximum of seven sessions (in weeks 18, 25, 34, 42, and 55) (Table 31.6). The results showed similar benefits for pain and functional status from both treatments at 23, 39, and 65 weeks. Long-term follow-up at 5 years also showed no differences between treatments on the primary outcome measures (Pisters et al., 2010b). However, in patients with hip OA, significantly fewer hip replacement surgeries were performed in the behavioral-graded activity group, compared with the usual exercise therapy group. A further benefit of the behavioral-graded activity program was that patients had significantly better exercise adherence and higher physical activity levels than those in the usual exercise therapy group (Pisters et al., 2010a). Given this and the fact that it was no more costly than usual exercise therapy (Coupe et al., 2007), behavioral-graded activity may be a useful treatment for patients with OA, particularly those with a relatively low level of physical function in whom greater benefits were found (Veenhof et al., 2007). If therapists wish to employ this approach, the results of a qualitative study highlight the importance of active involvement by patients from the outset and the need for therapists to better understand the patient's initial motives in undergoing the intervention (Veenhof et al., 2006b).

There has been some research into tailored activity pacing for people with OA (Murphy et al., 2011; Murphy, Lyden, Smith, Dong, & Koliba, 2010). In one study, the intervention was designed to enhance arthritis self-efficacy by individually tailoring the use of activity-pacing strategies to the context of where and when the strategies may be most useful for an individual. Based on social cognitive theory (Bandura, 2004), by tailoring activity-pacing instruction to one's real-life routines and activities, there is a greater chance for learning to occur and for self-efficacy to be enhanced, given the greater proximity of the pacing schedule to real-life and personally relevant activities (Murphy et al., 2011). In a pilot study of 32 patients with knee OA, a tailored activity-pacing intervention led to less fatigue interference than a general pacing intervention (Murphy et al., 2010) and less fluctuations in activity levels consistent with the message to maintain a steady pace and avoid extremes of activity (Murphy, Smith, & Lyden, 2012).

Other cognitive behavioral approaches, including emotional disclosure, which involves a series of formal writing and talking sessions in which patients are asked to disclose thoughts and feelings associated with their disease, pain, or with other stressful experiences, and meditation-based approaches such as mindfulness meditation training and forgiveness interventions (e.g., loving kindness meditation), have not yet been formally studied in people with OA.

In accordance with a biopsychosocial approach to the management of chronic pain, it is logical that both physical and psychological impairments as well as

Table 31.6 Description of the behavioral graded activity intervention tested in people with hip and knee osteoarthritis.

Content	Three phases: • *Starting phase:* provision of educational messages, selection of problematic activities and treatment goals, and determination of baseline values • *Treatment phase:* increase of selected activities, gradually and in a time-contingent way by means of an exercise program that is reproduced in the performance charts • *Integration phase:* support and reinforcement of the behavioral change, and integration of the increased level of activities in the patient's daily life
Educational messages	Not pain relief, but improvement of functioning is the primary goal of treatment
Activities	Problematic activities (maximum of three) are selected by patients on activity list. Individually tailored exercises to improve impairments limiting the performance of these activities are selected
Goals	Short- and long-term goals are set for each activity and each exercise and recorded in a treatment agreement form
Baseline values	Patients perform the selected activities until pain tolerance, during 1 week, and record these in a diary
Gradually increasing exercise program	An individually based scheme is made on a time-contingent basis for each activity and exercise, starting slightly under baseline values and gradually increasing toward the pre-set short-term goal. Patients should neither underperform nor overperform this gradually increasing scheme
Visual reproduction	Performance charts are used to record and visualize the performance of activities and exercises
Reinforcement	Positive reinforcement is given toward healthy and active behavior: pain behavior is extinguished
Stopping rule	The gradual increase of activities has to be interrupted when an active inflammatory process is suspected or diagnosed (e.g., redness, increased knee effusion). Hereafter, the increase starts at a lower level. In case of recurrent inflammatory processes, the treatment goals need to be changed and the rate of increasing activities decelerated
Duration	Maximum of 18 sessions within the first 12 weeks. Additional booster sessions: Maximum of seven sessions in five determined booster sessions in week 18, 25, 34, 42, and 55

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co-morbidities be addressed in people with knee OA. Two studies (Hunt et al., 2012; Keefe et al., 2004), one of which was a pilot feasibility study only (Hunt et al., 2012), have examined the effects of a combined program of pain-coping-skills training and exercise in those with knee OA. One study compared, in 72 participants with knee OA, a 12-week intervention of spouse-assisted pain-coping-skills training alone, exercise training alone, combined intervention, or standard care (Keefe et al., 2004). The results showed that each of the interventions had specific benefits. Spouse-assisted training, either alone or combined with exercise, produced improvements in coping and self-efficacy, whereas exercise training, either alone or combined, produced improvements in physical fitness and strength. Thus, when one combines interventions, improvements seem to be obtained across a much broader range of outcomes than can be achieved through either intervention alone. This has potentially important implications for multicomponent treatment programs for people with OA. However, one issue in this study was the time-intensive nature of the treatment. Patients in the combined intervention were required to attend a total of 4 hours per week of therapy delivered by two different health professionals, in addition to home practice. From a practical perspective, this requires a considerable time commitment from patients, and in reality may involve substantial treatment costs that would not necessarily be sustainable in everyday practice. Conversely, in the pilot study by Hunt et al. (2012), the exercise and pain-coping-skills training were delivered in the same sessions by one health professional, which may prove to be more feasible for the patient.

Pain-coping-skills training has also been combined with other treatments addressing different co-morbidities in OA (Somers et al., 2012; Von Korff et al., 2012). A recent RCT by Somers et al. (2012) examined the long-term efficacy of a 6-month intervention that combined pain-coping-skills training and lifestyle behavioral weight management in 232 overweight and obese patients with OA. The group receiving combined treatment demonstrated significantly better treatment outcomes in terms of pain, physical disability, stiffness, activity, weight self-efficacy, and weight when compared to either intervention alone or standard care. The combined group also did significantly better than at least one of the other groups in terms of psychological disability, pain catastrophizing, and arthritis self-efficacy. The benefits of the combined intervention were sustained and apparent at 2-year follow-up. A recent published protocol for an RCT described a 6-week group intervention that addressed insomnia and pain in OA via combined pain-coping-skills training and sleep-enhancement techniques (Von Korff et al., 2012). Further research is needed to evaluate whether other combined interventions provide more comprehensive long-term benefits.

Psychological interventions are generally delivered by psychologists specializing in pain management. However, given that there can be limited availability of psychologists in the pain management field, it may be beneficial to utilize other healthcare professionals who have undergone appropriate training. Indeed, a recent pilot study reported on the feasibility of training physical therapists to deliver a pain-coping-skill-training intervention for people with knee OA under the supervision of a psychologist (Hunt et al., 2012). Several large RCTs are also currently underway in knee OA patients (Bennell et al., 2012; Riddle et al., 2012), whereby physical therapists have been trained to deliver a psychological intervention. In one trial, the aim is to determine if a pain-coping-skills training program, delivered prior to total knee arthroplasty, effectively reduces function-limiting pain following the procedure in patients with high levels of pain catastrophizing (Riddle et al., 2012). In the other trial, the aim is to determine whether an integrated program of pain-coping-skills training and exercise is more effective in reducing pain and improving function than either delivered alone (Bennell et al., 2012). In both, health economic analyses have been incorporated. The results of these trials will provide insights into the benefits of pain-coping-skills training delivered by other healthcare professionals in patients with knee OA ,as well as its cost effectiveness.

The costs and transportation issues associated with individualized training are issues that researchers and clinicians are continually trying to address. For this reason, there has been interest in different forms of delivering psychological treatments utilizing the Internet (Rini, Williams, Broderick, & Keefe, 2012). Internet interventions for pain can either be therapist-guided or unguided (automated), and delivered through the desktop computer or mobile platforms. An important benefit of delivering psychological pain treatments via the Internet is that patients can use the programs at their own pace, with access not limited by time, location, and availability of therapists. Furthermore, they can augment limited healthcare resources and have the potential to allow clinicians to reach larger segments of the population (Rini et al., 2012). As promising as they are, Internet interventions have not been evaluated specifically in patients with OA, and hence their efficacy, feasibility, and acceptability in this patient group are currently unknown.

Conclusion

OA is a chronic painful condition commonly affecting older individuals. Management of the condition requires a multidisciplinary approach to address the physical and psychological factors associated with it. There are a number of conservative non-drug interventions that can reduce pain and improve function in people with OA. As with any chronic condition, patient self-management and enhancing adherence to treatment is vital. This requires a behavioral approach to initiating and maintaining lifestyle changes, particularly around exercise and weight loss. Altering the way someone walks is a behavioral rehabilitation technique utilizing the principles of motor relearning to attempt to reduce knee load during walking. This could have benefits in slowing the progression of structural knee OA disease. Formal psychological interventions have not been well studied in people with OA, with most of the studies investigating cognitive behavioral therapy, and specifically pain-coping-skills training. Given the co-existence of psychological impairments in OA and their inter-relationships with pain, function, and quality of life, addressing these impairments would seem prudent. Further research is needed to evaluate behavioral rehabilitation strategies in patients with OA, particularly those with OA affecting joints other than the knee.

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Behavioral Factors in Management of Asthma

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In the United States, as of 2009, asthma affects 24.6 million people, that is, 8.2% of the population, and annually accounts for 1.75 million emergency department visits and 446,000 hospitalizations (Akinbami, Moorman, & Liu, 2011). Using 2007 data, the incremental direct cost of asthma in the United States was estimated as US$3,259 per person per year, with an incremental total cost of over US$50 billion (Barnett & Nurmagambetov, 2011). Worldwide, the prevalence, morbidity, and mortality of asthma in industrialized countries have increased over the past two decades, again with huge associated costs. Accordingly, both in the United States and worldwide, improving asthma treatment has become a top public health priority, and numerous high-quality, evidence-based guidelines have been developed (Anonymous, 2000; BTS/SIGN, 2003). Behavioral factors play an important role in asthma, its morbidity, and treatment.

What Is an Asthma Exacerbation, and How Is It Treated?

Asthma tends to be an intermittent disease, with periodic exacerbations mostly caused by various allergens and airway irritants. Although between exacerbations individuals with mild or moderate asthma may experience few or no symptoms, even people with mild asthma can experience loss of control and suffer a potentially life-threatening asthma attack. Asthma exacerbations can be debilitating and, indeed, life threatening. Using US surveillance data from 2008, the Centers for Disease Control and Prevention (CDC) reported that 52.6% of people having asthma reported having at least one asthma exacerbation in the past 12 months, and, during that same time frame, 13.6% of people with asthma required treatment

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for an asthma attack in an emergency room, urgent care center, or hospital (MMWR, 2011). Symptoms of asthma most commonly include coughing, bronchial congestion, chest tightness, and dyspnea. Ancillary symptoms can include fatigue, hyperventilation, irritability, anxiety, and panic (Brooks et al., 1989). Some sufferers may experience a severe flare after long symptom-free periods. The airways tend to be inflamed in people with asthma, and the inflammation is thought to increase airway sensitivity to various irritants, and thereby increase vulnerability to exacerbations. An asthma exacerbation usually involves several changes in the lung, including excess mucus secretion and constriction of the smooth muscles of the airways, both of which can restrict airflow. The smooth muscles, located primarily in the central airways, are under primary parasympathetic control, such that increased parasympathetic activity activates them. The small lower airways, on the other hand, have little or no influence from smooth muscle, but are directly affected by inflammation, although beta-2 sympathetic stimulation is known to dilate them. Once begun, an asthma flare may compound in intensity by recruiting various inflammatory, autonomic, and emotional processes, such that the resulting cascade of events becomes increasingly difficult to abort. These processes interact, and thereby generate an asthma flare. Although asthma flares may erupt suddenly, they usually tend to increase in intensity gradually over minutes or hours.

Standard medical treatments are targeted at both promptly stopping asthma flares once they have occurred as well as preventing them (National Heart Lung and Blood Institute [NHLBI], 2007b). Accepted treatment regimens call for a combination of "controller" and "rescue" medications. Rescue medication, primarily the beta-2 sympathetic drug, albuterol, is indicated for relief of acute exacerbations. This medication dilates the airways, and tends to work quickly. However, overuse of this medication can lead to cardiac complications, so it is not recommended as a monotherapy for asthma of more than the mildest severity. Longer-acting sympathetic stimulants, such as salmeterol, and parasympathetic blocking agents, such as ipratropium, tend to work more slowly, and thus are ineffective as rescue medication. They are particularly useful as a component in treating nocturnal asthma, although they are ineffective as monotherapies in preventing severe exacerbations. There is evidence that exclusive reliance on salmeterol can predispose asthma sufferers to life-threatening asthma flares.

The most commonly used anti-inflammatory drugs for asthma treatment are various forms of inhaled corticosteroids (ICSs), although other anti-inflammatory drugs such as leukotreine inhibitors are commonly used as second-line drugs, as supplements to ICSs, or as replacements in cases of steroid intolerance. Although anti-inflammatory therapies are slow-acting, and hence ineffective in treating acute exacerbations, they are highly effective in preventing exacerbations clinically, and rendering the airways less reactive to laboratory challenges with histamine or methacholine (NHLBI, 2007b). For maximum effectiveness, these drugs must be taken regularly irrespective of symptom levels, although gradual titration downward, under a provider's close supervision, is recommended after extended symptom-free periods. Although some mild autonomic and psychoneurological side effects are common with these medications, they are usually well tolerated by the large majority of asthma sufferers. Severe asthma flares are generally treated with oral corticosteroids, often prednisone, which usually can be titrated away within a few days or weeks, but must be taken chronically by some individuals with severe asthma. These medications can produce devastating side effects, including neuropsychiatric symptoms, weight gain, bone loss, and increased susceptibility to infection.

Despite their demonstrated effectiveness, non-adherence to controller regimens is very high, and resort to alternative therapies with little or no evidence of effectiveness is widespread. Various studies report that over 50% of asthma patients fail to take prescribed inhaled steroids (Milgrom et al., 1996; Strunk, Ford, & Taggart, 2002; Williams et al., 2004; World Health Organization, 2003). The CDC recently reported that only 33.5% of persons with asthma living in the United States currently use a controller medication (MMWR, 2011). There also is some concern that long-term reliance on inhaled steroids may predispose some individuals to osteoporosis (Dam et al., 2010), and other steroid-related problems (Toogood, 1998).

Furthermore, solid evidence exists linking poor adherence to adverse asthma outcomes (Milgrom et al., 1996; Williams et al., 2004). Unfortunately, interventions to improve adherence have shown, at best, limited success in improving patient behavior in clinically relevant and/or sustainable fashions (Bender, Milgrom, & Apter, 2003; Haynes, McDonald, Garg, & Montague, 2002; Lemanek, Camps, & Chung, 2001; McDonald, Garg, & Haynes, 2002; Toelle & Ram, 2004). The reasons for such poor adherence to prescribed ICSs are complex, and appear to include concerns about medication cost and safety, beliefs that asthma severity was not sufficient to require daily treatment, lack of immediate effects, worry about dependence or diminished effectiveness from long-term use of medication, and a general distrust of the medical establishment (Bender, & Bender, 2005).

Although asthma is not generally thought of as a psychosomatic or stress-related disorder, some experts suggest that it should be, because of its relationship with various psychological factors. Its symptoms can be exacerbated by stress, and asthma symptoms themselves also can be stressful, so a vicious spiral of effects can occur. This relationship has been described in several review articles (Bloomberg & Chen, 2005; Wright, Rodriguez, & Cohen, 1998).

Given this situation, in the remainder of this chapter, we will review two behavioral-based strategies for dealing with this clinical conundrum: promotion of optimal self-management behavior, and non-traditional, breathing-based therapies for asthma.

Psychosocial Factors Associated with Asthma

Asthma has been found to be associated with several domains of mental health (Goodwin, Messineo, Bregante, Hoven, & Kairam, 2005; Goodwin, Pagura, Cox, & Sareen, 2010; Hayatbakhsh et al., 2010; Scott et al., 2007). This relationship was confirmed in a large survey that covered 17 countries, indicating that this link is not due to cultural factors (Scott et al., 2007). The following sections will review how socioeconomic status, ethnicity, mental health, and other factors can be associated with asthma.

Stress

Several studies suggest that there is a potential association between stress, asthma onset, and asthma exacerbations. A high-stress home environment has been associated with increased susceptibility to lung function effects of air pollution (Islam et al., 2011). Also, stress at work and the inability to relax are positively associated with asthma prevalence (Loerbroks, Gadinger, Bosch, Sturmer, & Amelang, 2010). Another study found that people with stressful jobs are twice as likely to have current asthma and 50% more likely to have adult-onset asthma than those with less stressful jobs (Eng, Mannetje, Pearce, & Douwes, 2011). Another study found that stressful life events such as the illness of a family member, marital problems, divorce, separation, and conflicts with a supervisor are associated with the onset of asthma in adulthood (Lietzen et al., 2011).

On the other hand, asthma severity also increases psychological distress. One study suggests that patients with severe asthma have more psychological distress and difficulty coping with their disease, both emotionally and behaviorally, when compared to patients with moderate asthma (Lavoie et al., 2010). Uncontrolled asthma may also impact the patient's functioning and sleep to a significantly greater degree than well-controlled asthma (Dean et al., 2010). These coping difficulties can create a spiral effect where distress increases and asthma becomes increasingly uncontrolled.

Various psychological factors are known to affect symptom perception, healthcare utilization, and treatment adherence, leading to disorganized self-care behaviors (Feldman et al., 2005; Siddique et al., 2000, 2001). Psychological factors can also lead to stress-related exacerbations by autonomic or inflammatory pathways. A model proposed by Chen and Miller (2007) describes how stress can amplify the immune response to asthma triggers by activating various pathways such as the hypothalamic–pituitary–adrenal (HPA) axis, the sympathetic–adrenal–medullary (SAM) axis, and both the sympathetic (SNS) and parasympathetic (PNS) nervous systems. These processes, in turn, influence inflammatory processes. This occurs when stressors are appraised as threatening and unmanageable, increasing negative emotions and decreasing positive emotions. The increased inflammatory response can lead to increased frequency, duration, and severity of asthma symptoms.

However, not all kinds of stress provoke the same reactions on asthma symptoms. Chronic exposure to stress can make it more difficult to regulate airway inflammation, and situations that involve high levels of social evaluation eliciting self-conscious emotions can trigger the HPA axis, leading to changes in inflammation (Chen & Miller, 2007). Laboratory findings suggest that decreases in pulmonary function as a result of exposure to stress occurs during passive responses to stressors, such as criticism of performance, while stressors requiring active coping, such as mental arithmetic, appear to produce bronchodilation (Lehrer, 1998; Lehrer et al., 1996). Nevertheless, it is possible that some asthma sufferers tend to inhibit the expression of anger because it may exacerbate their disease (Lehrer, 1998).

Panic disorder

Panic disorder (PD) and asthma share many similarities, and the comorbidity between these two conditions is well known (Chen & Lin, 2011). PD is characterized by both catastrophic thinking and somatic symptoms. Many of the somatic symptoms experienced during panic are related to hyperventilation. Similar symptoms produced by hypocapnia and dyspnea are also experienced by asthma patients (Meuret & Ritz, 2010). Confusion can occur between the two diseases, leading to incorrect medical self-management of symptoms. Studies of individuals with asthma indicate that psychological factors can affect both airway obstruction and the ability to perceive diminished airflow in asthma. Patients with PD often overperceive asthma symptoms, leading to overmedication, or occasionally undermedication, where asthma exacerbations are perceived as panic.

There also is some evidence that patients with more severe asthma tend to have higher intensity of catastrophic interpretation of body sensations and more severe symptoms of both panic and depressive symptoms (Potoczek, 2011a). There is an elevated tendency for more catastrophic interpretations with elevated severity of both panic and depressive symptoms in patients with specific levels of asthma severity (Potoczek, 2011b). Other studies show that symptoms of "behavioral apnea" (breath dissatisfaction, feelings of dyspnea, and decreased respiratory regularity of cycles) developed well before the manifestation of asthma and persisted in its remission, suggesting that the clinical manifestation of asthma is extended by signs of panic attacks, and that symptoms of anxiety and panic attacks worsen the duration and outcome of asthma (Vashadze, 2011). In addition, in another study, illness-specific panic-fear was related to poorer health-related quality of life and more primary care office visits for asthma, and generalized panic-fear was associated with restriction of activities due to asthma and use of rescue medication for asthma regardless of asthma severity (Feldman, Siddique, Thompson, & Lehrer, 2009). Nevertheless, an association of objective measure of airflow limitation to generalized anxiety and panic has been found (Spitzer, Glaser, et al., 2011). In another study, panic was also a predictor of unscheduled visits to the doctor for asthma (Schneider et al., 2008).

General anxiety and depression

Several studies have shown that youth and young adults with asthma are more likely to have an anxiety disorder than those without the condition (Bruzzese, Fisher, Lemp, & Warner, 2009; Feldman, Ortega, Koinis-Mitchell, Kuo, & Canino, 2010; Goodwin & Marusic, 2004; Goodwin et al., 2005; Katon et al., 2007; Meuret & Ritz, 2010; Rockhill et al., 2007). A study in Russia with asthma patients found that 39% of their sample had subclinical anxiety and depression, and that 50% had clinically significant anxiety and depression (Vashadze, 2011). Henkin et al. (2011) found that having a respiratory disease was significantly associated with psychological acculturation, depression, high perceived stress score, and current smoking among adult Puerto Ricans in Massachusetts. They also found significant inverse associations with a high level of language acculturation and physical activity.

Other studies suggest that depression symptoms have a significant negative association with asthma quality of life (Schneider et al., 2008), and greater anxiety has been associated with increased perception of asthma-specific panic-fear and hyperventilation symptoms during asthma exacerbations (Deshmukh, Toelle, Usherwood, O'Grady, & Jenkins, 2008; Feldman et al., 2009). Furthermore, hyperventilation symptoms are linked to a lower perceived health in asthma patients, perhaps because hyperventilation symptoms cannot be controlled by using asthma medication, thus compromising perceived control over the management of asthma (Ritz, Rosenfield, Meuret, Bobb, & Steptoe, 2008). Lavoie et al. (2010) found that more severe asthma is associated with more severe levels of pessimism, cognitive dysfunction, anxiety, and impaired coping. More recent models are gearing toward an integration of behavioral, neural, endocrine, and immune processes (Di Marco, Santus, & Centanni, 2011).

Posttraumatic stress disorder

In a study of medical history and spirometric lung function, 1,772 adults from the general population were administered a posttraumatic stress disorder (PTSD) interview, and assigned to three groups: no trauma; trauma, but no PTSD; and trauma with PTSD. Subjects with PTSD had significantly greater odds ratios for most asthma-related symptoms than PTSD-negative participants (OR 3.2–8.8). The mean ratio of forced expiratory volume in 1 sec (FEV_1) to forced vital capacity (FVC) was lowest in the PTSD group and highest in those without trauma exposure, as was, independently, FEV_1. The authors conclude that there is an association between trauma exposure and airflow limitation, perhaps mediated by inflammatory processes (Spitzer, Koch, et al., 2011).

Alexithymia

Alexithymia, the inability to experience and communicate emotions, can be a complicating factor in the management of asthma. Some studies have related alexithymia scores to impairment in health-related quality of life, poor adherence, and more severe asthma (Axelsson et al., 2009; Chugg, Barton, Antic, & Crockett, 2009; Vázquez, Sández et al., 2010). Other studies suggest an association between alexithymia, severe exacerbations, and hospitalizations in severe asthma (Plaza et al., 2006; Serrano et al., 2006). Vázquez et al. (2010) suggest that the difficulty identifying feelings is associated with more emergency room visits and more asthma symptoms during exacerbations (Feldman, Lehrer, & Hochron, 2002). Difficulty in identifying feelings may also lead to misinterpretation of the somatic feelings and increased use of healthcare services (Vázquez Sández et al., 2010). Also, patients with near-fatal asthma have shown more difficulties describing and communicating feelings (11.36 vs. 8.90; $p = .002$) (Vázquez Sández et al., 2010). They also have reduced sensitivity to respiratory sensations associated with hypoxia, including dyspnea. Poor sensitivity to internal body sensations may either be a marker of poor respiratory regulation in these individuals (Kikuchi et al, 1994), or make them less likely to perceive the need for rescue medication when it is needed. Difficulty identifying feelings is also associated with increased report of emotional panic–fear symptoms as well as physical symptoms (fatigue) (Feldman, Lehrer, & Hochron, 2002). The causative pathway for the effect of alexithymia on asthma remains unclear.

Community and Family Factors: The Importance of Early Intervention

The risk and protective factors associated with asthma can be divided in three major levels: community, maternal/family, and individual (Yonas, Lange, & Celedon, 2012). At a community level, the literature suggests that a low socioeconomic status, exposure to violence, crime, poor housing, high traffic, pollutants in the area, an inner city environment, and exposure to other social toxins can all have a negative effect on asthma.

At the maternal/family level, parental psychopathology, housing conditions, and indoor pollution, among others, can affect the condition. The psychological characteristics of children with asthma and their caregivers appear to contribute to the course and possibly to the onset of the condition (Tibosch, Verhaak, & Merkus, 2011). Childhood adversities also have been related to *adult* onset asthma (Scott et al., 2008). The onset, remission, or persistence of asthma across the life course may be influenced by exposure or cumulative exposure to toxic biologic or social factors over critical periods of development, beginning *in utero* or early childhood (Wright, 2011). In utero and perinatal exposure to maternal stress has been associated with alterations to the HPA axis and autonomic nervous system, (SAM axis), possibly leading to poor stress regulation, changes in immunomodulation (cortisol, epinephrine, and norepinephrine), and increased vulnerability to other environmental toxins, thus increasing risk for asthma and allergy (Kozyrskyj, Bahreinian, & Azad, 2011; Wright, 2011; Wright, 2009). Low maternal childhood socioeconomic status

(SES) and repeated wheeze appear to have a significant indirect association, operating through adult SES, prenatal cumulative stress, and pollution (Sternthal, Coull, Chiu, Cohen, & Wright, 2011). Also, children of mothers experiencing intimate partner violence chronically show an increased risk of developing asthma, although the ability to maintain positive caregiving processes may buffer the effects on child asthma risk (Breiding & Ziembroski, 2011; Suglia, Enlow, Kullowatz, & Wright, 2009, Wright, 2009).

Anxiety disorders and acculturative stress have been associated with childhood asthma (Feldman et al., 2010). Early-onset depressive/anxiety disorders independently predict adult-onset asthma (Scott et al., 2008). Also, a study of Puerto Rican households found that adults with an anxiety disorder are more likely to have a lifetime history of asthma attacks versus youth/young adults without an anxiety disorder (Feldman et al., 2011). The psychological status of the principal caregiver and caregiver burden are additional factors that can profoundly affect asthma management of children. Caregivers of asthma patients with exacerbations have been found to be more likely to have major depression than caregivers of participants without them (Feldman et al., 2011). Paternal PTSD symptoms, depression, and antisocial behavior are associated with increased asthma symptoms at age 1 year, with maternal depressive symptoms also associated with an increased risk of asthma hospitalizations at that age (Lange et al., 2011). The burden of asthma also can impact the emotional condition of caregivers as well as that of the asthma patients (Vila et al., 2003).

Behavioral Self-Management Strategies for Asthma

To successfully manage and control asthma, current guidelines stress that patients with asthma, and in many important regards other members of their household, must engage is specific behaviors falling into two major domains: daily routines and rescue procedures. An excellent patient education guide summarizing these recommendations entitled “So You Have Asthma” is available from the National Heart Lung and Blood Institute (NHLBI, 2007c). Solid asthma self-management skills are crucial for treatment success, since trained providers are almost never on hand when asthma flares occur and virtually all aspects of optimal asthma outcomes are mediated by patient behaviors (Creer, 2008; Kaptein, Klok, Moss-Morris, & Brand, 2010).

Daily medication-taking routines

Because asthma is now viewed primarily as an inflammatory disease, the primary medication treatment is daily use of anti-inflammatory therapy, typically an ICS. An important paradox for patients is, why to continue daily use of medication when they are not experiencing any symptoms. This situation is further complicated by the fact that ICS medications usually have no noticeable beneficial effects until they are taken regularly for several weeks, and during this time frequently have minor, but nonetheless disconcerting, side effects, such as throat irritation or hoarseness. This is strikingly different from the effects of inhaled rescue medications, like albuterol, which provide very fast relief of symptoms, and hence much stronger as a positive reinforcement for their ongoing use.

An often-neglected behavioral aspect of asthma therapy is making sure that patients can use their inhalers with proper technique (NHLBI, 2007b). There currently are several types of inhalers on the market, and several of them require different techniques for proper use. Since the patient must perform a coordinated multistep behavioral task to properly administer medication, providers must do more than just hand the patient a prescription and assume that they will be able to use the medication appropriately. Indeed, studies suggest that over 50% of patients do not properly perform the steps to medication delivery using asthma inhalers (Virchow et al., 2008).

The most common strategy to promote adherence with ICSs is education about the nature of asthma, in particular its inflammatory basis and the use of ICS medication as a controller treatment. When done well, and especially when individualized to the specific patient so as to be maximally relevant, such education has been shown to be effective in controlled trials (Gibson, Ram, & Powell, 2003; Janson, McGrath, Covington, Cheng, & Boushey, 2009). However, these gains do not appear to be reflected in long-term differences in real-life asthma outcomes, as comprehensive and individualized asthma education programs are hard to maintain once the funding of evaluation trial ends (Bender, Milgrom, & Apter, 2003). Therefore, ongoing education and pragmatic discussions of patient's difficulty taking daily ICS medication is recommended at each visit with the patient's asthma provider (NHLBI, 2007b), although evidence suggests that this worthy goal is rarely met (MMWR, 2011).

In patients not responding with well-controlled asthma to properly prescribed asthma medication therapy, a good strategy is to inquire about the cognitive and emotional interpretations that patients make about their illness, known as the patients' "illness perceptions" (Kaptein et al., 2010). One way to do this relies on Kleinman's classic questions to elicit patients' "explanatory models of illness" (Kleinman, 1988). According to Kleinman, patient behaviors, when confronted with an illness, will be determined by how they make several key decisions, recently adapted to the context of adolescents' decision-making regarding use of ICS medication for asthma (Wamboldt, Bender, & Rankin, 2011).

First, do they agree that they have the illness that their provider has diagnosed? Patients often do not associate certain symptoms, such as coughing or nighttime awakening, as due to asthma, as they may not view these symptoms as "breathing" symptoms. Similarly, patients may not view their asthma as "severe" enough to warrant daily treatment. Compounding this problem, there are no established techniques capable of quantifying airways inflammation in the absence of clinical symptoms, in distinction to other prevalent chronic illnesses such as hypertension, with measurement of high blood pressure, or diabetes, with measurement of high blood sugar.

Second, do they agree that they need to have some type of daily treatment? Patients who agree that they do have asthma may still not agree with the need for regular treatment due to such things as a belief that "medication should not be used unless one has symptoms," the so-called "no symptoms, no asthma" belief system (Halm, Mora, & Leventhal, 2006), or because they have learned that they can manage their asthma without daily ICS therapy by just using ICS medication promptly when symptoms start or when they are entering risky periods of time (e.g., after onset of an upper respiratory infection). There is even some solid empirical support for this latter approach (Boushey et al., 2005), although population-level outcomes appear less good for those employing this strategy. This latter belief likely has been fostered by the current line of high-potency ICS medications that continue to have some degree of protective "coverage" for longer periods of time after daily use is discontinued. Even once the period of "coverage" has lapsed, patients will not necessarily develop asthma symptoms, unless they are exposed to an environmental risk (e.g., an inhaled irritant or allergen). This situation is analogous to the situation of a woman who forgets to take her birth control pill for several days. She will not automatically become pregnant – to become pregnant during this time of lost "coverage," she has to be exposed to a specific "environmental risk."

Third, do they agree that their daily treatment should be ICS therapy? Many patients have significant reservations about taking a "steroid" medication (Bender & Bender, 2005). The beliefs that underlie such reservations range from the finding that they "stunt" the growth of children, albeit by no more than 1–2 centimeters (Childhood Asthma Management Program Research Group, 2000), to specific mistrust of "steroid" medications, often a misconception based on the established risks of body builders and athletes who use anabolic steroids, to a more general distrust of medications – "there are lots of approved medications that we later learn hurt people." Even if the patient is willing to take a daily ICS medication, it is a very unfortunate situation that, in the United States, as opposed to the rest of the developed world, many patients who are under- or uninsured are unable to afford these medications, since low-cost generics do not exist. Indeed, in 2008, nearly half (40.3%) of the uninsured could not afford to purchase their asthma medications (MMWR, 2011).

Fourth, for patients who are willing to take daily medication, the challenge is how to support this behaviorally. For those patients having well-established daily health promotion routines, it can be recommended that they link their daily ICS use with that routine, for example, taking ICS medications right before they brush their teeth. Unfortunately, there are large numbers of patients who live more variable, at times even chaotic, lives, without regular routines. Cramer (1995) has demonstrated the effectiveness of "cue-dose training" in such situations. In this technique, patients are asked about the existence of daily behaviors that are fairly regularly established and attempts to pair the taking of ICS medication with those behaviors (e.g., leaving the inhalers on the kitchen table or near the family's primary television, and prompting the patient to use the inhaler when they have finished a meal or are watching television). If the patient does not acknowledge the presence of any behavior that recurs with sufficient regularity, the provider can work with that person to create such a routine.

Finally, since asthma is a highly variable illness, guidelines stress the importance of patients' establishing ongoing, long-term partnerships with their asthma provider to monitor the status of their asthma, as well as to provide supervision of changes in controller therapy. Successful patient–provider partnership involves shared and collaborative decision-making (Creer, 2008; Wamboldt et al., 2011). Given that many patients discover that they can "control" their asthma by being less than optimally active, given that exercise is a common asthma trigger, one additional very important role of the provider is to "nudge" their patients with asthma to recognize that their asthma is not really "under control" until they can live an active, vigorous lifestyle without having asthma symptoms (Walders-Abramson, Wamboldt, Curran-Everett, & Zhang, 2009; Wamboldt et al., 2011).

Regular avoidance of factors known to worsen asthma

As stated in the preceding text, controller treatments prevent asthma by providing "coverage" to protect against environmental factors known to worsen asthma. However, rather than relying of controller therapy alone, patients are often instructed to actively avoid various inhaled irritants and allergens that serve as "asthma triggers." Of these, the most important is tobacco smoke. Indeed, 20% of all asthma attacks in children can be attributed to exposure to tobacco smoke within their homes (DiFranza & Lew, 1996). Accordingly, all patients with asthma should be actively discouraged from starting smoking and urged to stop if they are already smokers, with similar instructions given to members of their household. Smoke is a powerful respiratory irritant that will cause airways inflammation and asthma symptoms. It also has effects within the airways that make ICS therapy less effective, counteracting its function as a controller (Chalmers et al., 2002; Chaudhuri et al., 2006; Chaudhuri et al., 2003; Thomson, Chaudhuri, & Livingston, 2004; Tomlinson et al., 2005). Finally, patients with asthma who smoke show accelerated decline in lung function compared to non-smokers with asthma, which may cause them to be especially likely to develop chronic obstructive pulmonary disease later in life (Thomson et al., 2004). Despite these factors, we know that at least 25% of adults with asthma smoke (Thomson et al., 2004), and more than half are regularly exposed to secondhand smoke (Eisner et al., 2005). Less common respiratory irritants also exist, for example, isocyanates, whose exposure typically occurs in occupational or at times home hobby situations.

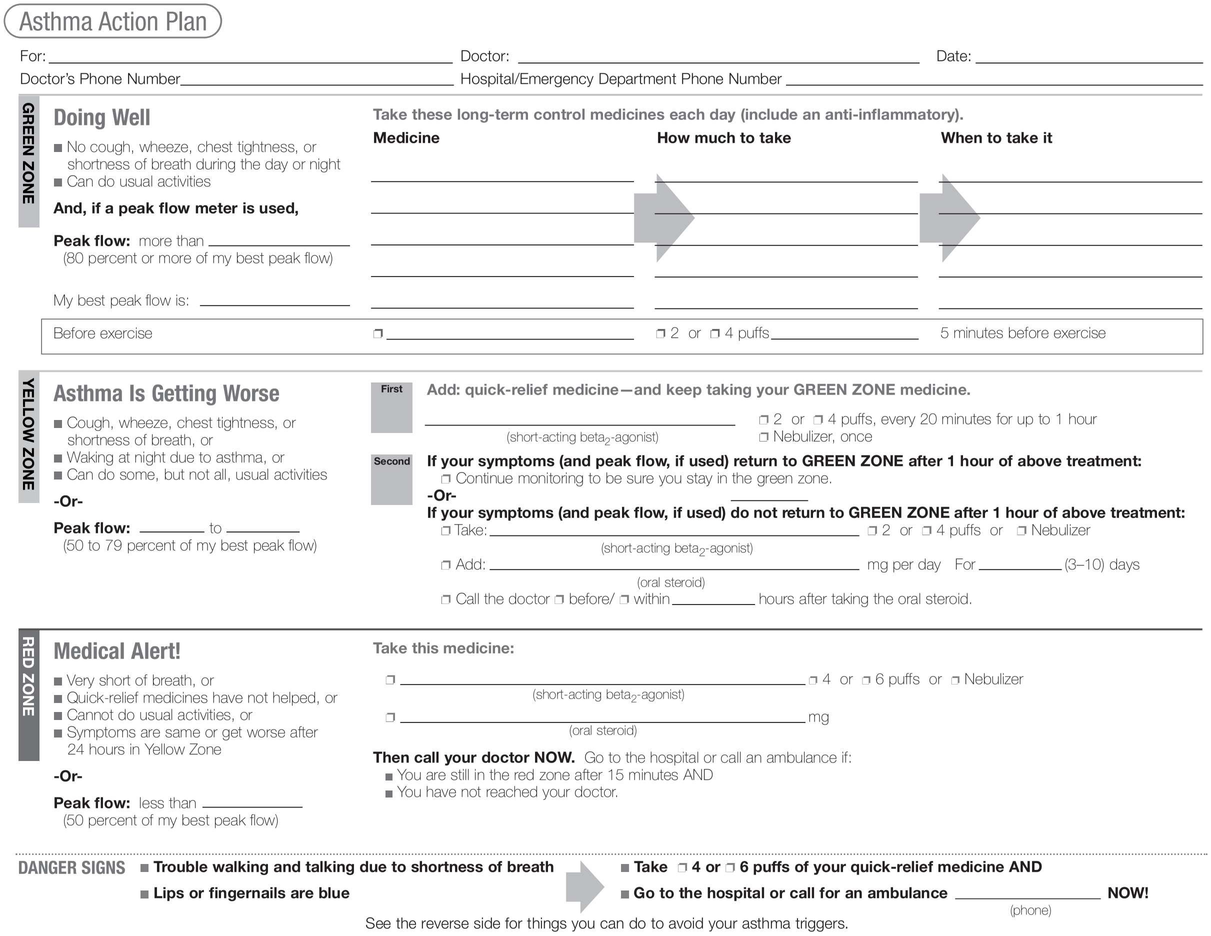
A second, important class of asthma triggers is respiratory allergens – particles that, after being inhaled into the lungs, cause an inflammatory immune reaction. These include exposure to pets with fur and/or feathers, molds, plants, and vermin (dust mites, cockroach, and rodents). Exposure to these classes of allergens is highly stratified by social class, with vermin and molds being much more prevalent in the homes of poor families, where they are a major factor contributing to the health disparities faced by disadvantaged communities (Crain et al., 2002; Morgan et al., 2004). Somewhat paradoxically, exposure to pet allergens is much more common in families with greater resources (Wamboldt et al., 2002).

It is interesting, and perhaps a little counterintuitive, that the specific behavior related to successful asthma management – that is, taking daily ICS therapy, avoiding smoke, and avoiding allergens – appear to have different antecedents. Hence, patients often can be good at performing some of these behaviors, but not good at others, requiring the clinician to specifically inquire about how well any given patient and family is at accomplishing each specific behavioral task (Wamboldt et al., 2002).

Rescue Procedures

The second major set of behaviors related to successful asthma management involves having a clear understanding of what to do when asthma symptoms occur. Current guidelines operationalize these rescue procedures via a written asthma action plan (NHLBI, 2007b) (e.g., see Figure 32.1). These plans empirically classify severity of current asthma control either through self-monitoring of asthma symptoms, peak expiratory flow rates, or a combination of the two. Peak flow meters are devices that measure maximal air velocity and therefore reflect the degree to which the patient's airways are open or closed, once a patient has established his or her "personal best" flow rates. Peak flow measurements can be especially useful for patients who have less clear-cut symptoms, as well as those who are somewhat "clueless" to bodily signs (Creer, 2008). Many action plans utilize the metaphor of a traffic light with green, yellow, and red zones to indicate the danger level of a patient's current asthma control, with specific rescue behaviors prescribed for each zone (see Figure 32.1 – an asthma action plan developed by NHLBI [2007a]). All action plans should be tailored using specific knowledge of the patient's history of asthma flares. Typically, patients in the "green zone" are simply instructed to continue to regularly self-monitor their symptoms and/or peak flows. Patients entering the "yellow zone" often receive instructions about how much albuterol to take, how long to wait before repeating self-monitoring of asthma control, and what to do if control is not re-established after this period of time – for example, take additional puffs of albuterol, call the provider's office for further instructions, etc. Patients in the "red zone" are usually given instructions concerning the emergency procedures to take, for example, immediately go to an emergency room.

Despite the well-established evidence that written action plans significantly decrease asthma morbidity, mortality, and urgent healthcare utilization (Gibson et al., 2003), current surveillance data suggest that only 34.2% of patients actually receive an action plan (MMWR, 2011).



Asthma Action Plan

For: ____ Doctor: ____ Date: ____

Doctor's Phone Number ____ Hospital/Emergency Department Phone Number ____

GREEN ZONE

Doing Well

- No cough, wheeze, chest tightness, or shortness of breath during the day or night
- Can do usual activities

And, if a peak flow meter is used,

Peak flow: more than ____
(80 percent or more of my best peak flow)

My best peak flow is: ____

Take these long-term control medicines each day (include an anti-inflammatory).

Medicine	How much to take	When to take it
Before exercise ☐ ____	☐ 2 or ☐ 4 puffs ____	5 minutes before exercise

YELLOW ZONE

Asthma Is Getting Worse

- Cough, wheeze, chest tightness, or shortness of breath, or
- Waking at night due to asthma, or
- Can do some, but not all, usual activities

-Or-

Peak flow: ____ to ____
(50 to 79 percent of my best peak flow)

First **Add: quick-relief medicine—and keep taking your GREEN ZONE medicine.**

____ (short-acting beta$_2$-agonist) ☐ 2 or ☐ 4 puffs, every 20 minutes for up to 1 hour
☐ Nebulizer, once

Second **If your symptoms (and peak flow, if used) return to GREEN ZONE after 1 hour of above treatment:**
☐ Continue monitoring to be sure you stay in the green zone.

-Or-

If your symptoms (and peak flow, if used) do not return to GREEN ZONE after 1 hour of above treatment:
☐ Take: ____ (short-acting beta$_2$-agonist) ☐ 2 or ☐ 4 puffs or ☐ Nebulizer
☐ Add: ____ (oral steroid) mg per day For ____ (3–10) days
☐ Call the doctor ☐ before/ ☐ within ____ hours after taking the oral steroid.

RED ZONE

Medical Alert!

- Very short of breath, or
- Quick-relief medicines have not helped, or
- Cannot do usual activities, or
- Symptoms are same or get worse after 24 hours in Yellow Zone

-Or-

Peak flow: less than ____
(50 percent of my best peak flow)

Take this medicine:

☐ ____ (short-acting beta$_2$-agonist) ☐ 4 or ☐ 6 puffs or ☐ Nebulizer
☐ ____ (oral steroid) mg

Then call your doctor NOW. Go to the hospital or call an ambulance if:

- You are still in the red zone after 15 minutes AND
- You have not reached your doctor.

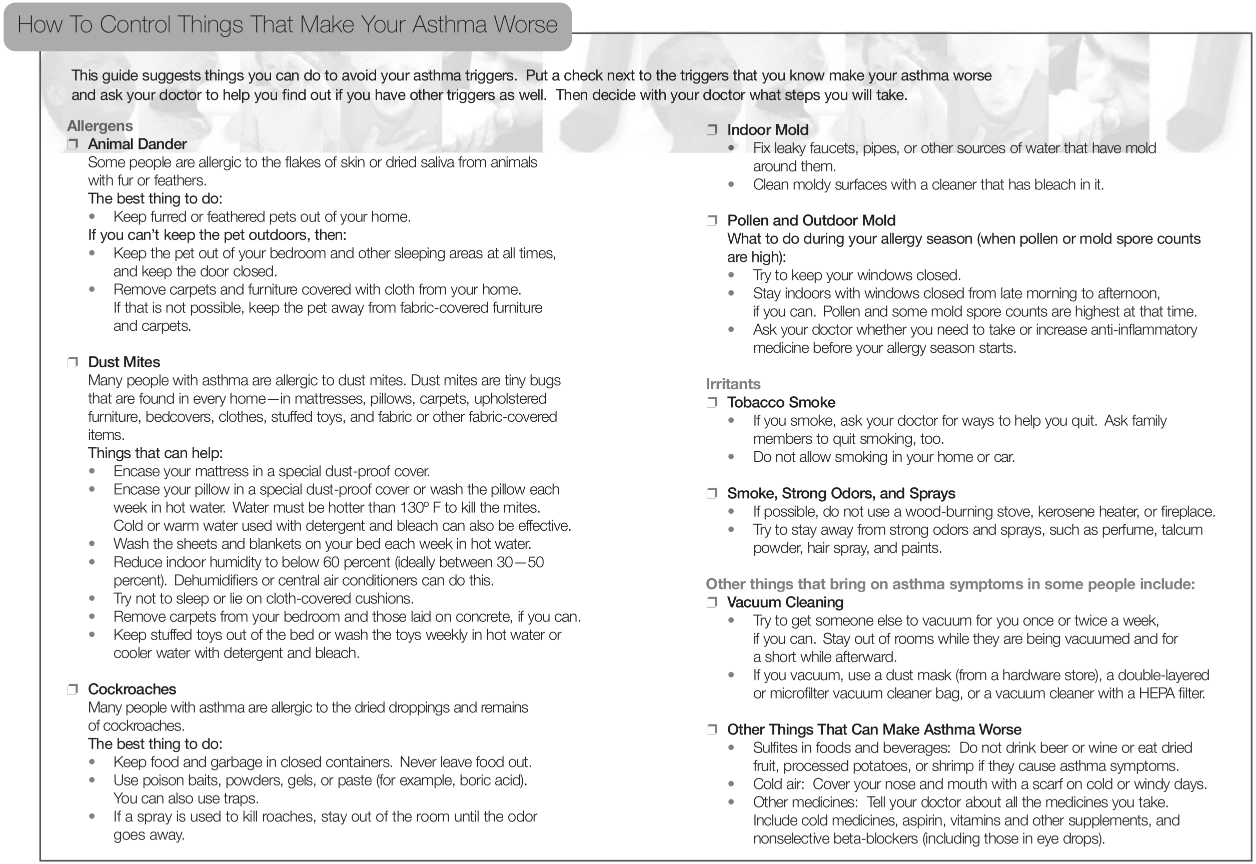
DANGER SIGNS

- **Trouble walking and talking due to shortness of breath**
- **Lips or fingernails are blue**

- **Take ☐ 4 or ☐ 6 puffs of your quick-relief medicine AND**
- **Go to the hospital or call for an ambulance ____ (phone) NOW!**

See the reverse side for things you can do to avoid your asthma triggers.

Figure 32.1 National Heart Lung and Blood Institute (NHLBI). (2007c). So you have asthma. Retrieved September 5, 2011 from http://www.nhlbi.nih.gov/health/public/lung/asthma/have_asthma.htm.



How To Control Things That Make Your Asthma Worse

This guide suggests things you can do to avoid your asthma triggers. Put a check next to the triggers that you know make your asthma worse and ask your doctor to help you find out if you have other triggers as well. Then decide with your doctor what steps you will take.

Allergens

☐ **Animal Dander**

Some people are allergic to the flakes of skin or dried saliva from animals with fur or feathers.

The best thing to do:

- Keep furred or feathered pets out of your home.

If you can't keep the pet outdoors, then:

- Keep the pet out of your bedroom and other sleeping areas at all times, and keep the door closed.
- Remove carpets and furniture covered with cloth from your home. If that is not possible, keep the pet away from fabric-covered furniture and carpets.

☐ **Dust Mites**

Many people with asthma are allergic to dust mites. Dust mites are tiny bugs that are found in every home—in mattresses, pillows, carpets, upholstered furniture, bedcovers, clothes, stuffed toys, and fabric or other fabric-covered items.

Things that can help:

- Encase your mattress in a special dust-proof cover.
- Encase your pillow in a special dust-proof cover or wash the pillow each week in hot water. Water must be hotter than 130° F to kill the mites. Cold or warm water used with detergent and bleach can also be effective.
- Wash the sheets and blankets on your bed each week in hot water.
- Reduce indoor humidity to below 60 percent (ideally between 30—50 percent). Dehumidifiers or central air conditioners can do this.
- Try not to sleep or lie on cloth-covered cushions.
- Remove carpets from your bedroom and those laid on concrete, if you can.
- Keep stuffed toys out of the bed or wash the toys weekly in hot water or cooler water with detergent and bleach.

☐ **Cockroaches**

Many people with asthma are allergic to the dried droppings and remains of cockroaches.

The best thing to do:

- Keep food and garbage in closed containers. Never leave food out.
- Use poison baits, powders, gels, or paste (for example, boric acid). You can also use traps.
- If a spray is used to kill roaches, stay out of the room until the odor goes away.

☐ **Indoor Mold**

- Fix leaky faucets, pipes, or other sources of water that have mold around them.
- Clean moldy surfaces with a cleaner that has bleach in it.

☐ **Pollen and Outdoor Mold**

What to do during your allergy season (when pollen or mold spore counts are high):

- Try to keep your windows closed.
- Stay indoors with windows closed from late morning to afternoon, if you can. Pollen and some mold spore counts are highest at that time.
- Ask your doctor whether you need to take or increase anti-inflammatory medicine before your allergy season starts.

Irritants

☐ **Tobacco Smoke**

- If you smoke, ask your doctor for ways to help you quit. Ask family members to quit smoking, too.
- Do not allow smoking in your home or car.

☐ **Smoke, Strong Odors, and Sprays**

- If possible, do not use a wood-burning stove, kerosene heater, or fireplace.
- Try to stay away from strong odors and sprays, such as perfume, talcum powder, hair spray, and paints.

Other things that bring on asthma symptoms in some people include:

☐ **Vacuum Cleaning**

- Try to get someone else to vacuum for you once or twice a week, if you can. Stay out of rooms while they are being vacuumed and for a short while afterward.
- If you vacuum, use a dust mask (from a hardware store), a double-layered or microfilter vacuum cleaner bag, or a vacuum cleaner with a HEPA filter.

☐ **Other Things That Can Make Asthma Worse**

- Sulfites in foods and beverages: Do not drink beer or wine or eat dried fruit, processed potatoes, or shrimp if they cause asthma symptoms.
- Cold air: Cover your nose and mouth with a scarf on cold or windy days.
- Other medicines: Tell your doctor about all the medicines you take. Include cold medicines, aspirin, vitamins and other supplements, and nonselective beta-blockers (including those in eye drops).

Figure 32.1 (*Continued*)

Herbal Remedies

Many patients seek non-medication treatments for asthma (Langmack, 2001). A survey of 4,741 asthmatic patients from the United Kingdom showed that 59% of these patients tried non-pharmaceutical treatments (Ernst, 1998). The most common techniques used were breathing-based therapies (30%), homeopathy (12%), herbalism (11%), yoga (9%), and acupuncture (7%). When asked about the extent that these therapies provided improvement in their asthma, 10% stated that symptoms improved to a great extent, 23% somewhat, 26% slight, and 17% none. Similarly, in an interview study of 601 adult asthmatics, 8% reported reliance on herbal remedies, 6% on use of tea and coffee, and 6% on OTC epinephrine or ephedrine at some point in the prior year to control their asthma (Blanc, Kuschner, Katz, Smith, & Yelin, 1997). This level of reliance on alternative treatments occurs despite little to no evidence concerning the safety and efficacy of such methods. Indeed, reliance on herbal remedies, tea, and coffee has been associated with more than a twofold increased risk of an asthma hospitalization (Blanc et al., 1997).

Mind–Body Therapies

This section will focus on various breathing and relaxation exercises that are also widely used for treating asthma, and on the variety of these methods that has been applied to asthma, and evaluate evidence for their effectiveness.

Progressive muscle relaxation

Stemming in part from sizable evidence for a relationship between asthma and psychological stress, a number of studies have examined progressive muscle relaxation as an asthma treatment. This technique involves learning to recognize and control very low levels of skeletal muscle tension that usually accompanies states of anxiety and psychological stress (Jacobson, 1938). The technique has sometimes been used in combination with surface EMG biofeedback, which gives added information to subjects about muscle tension, which can be used for developing such control (Lehrer, Carr, et al., 1997; Lehrer, Hochron, McCann, Swartzman, & Reba, 1986; Wamboldt et al., 2002). Progressive muscle relaxation is usually taught as a way of controlling general tension throughout the body, under the assumption that dramatic decreases in muscle tension will lead to associated decreases in sympathetic arousal, through the more recently documented muscle–sympathetic reflex network (Mitchell & Victor, 1996; Wallin, 2007), and thereby decrease associated parasympathetic hyperreactivity. Other proponents of muscle relaxation have focused more narrowly on teaching relaxed abdominal breathing, decreasing involvement of accessory respiratory muscles, and generally decreasing the work of breathing, which can cascade to more general physiological arousal through interactions between the muscles and the autonomic nervous system (Holloway & West, 2007). Another approach has been to focus specifically on relaxation of the facial muscles, because of the well-known interactions between trigeminal and vagus nerve activity (Diamond et al., 2011; Schaller, 2004). This approach assumes that decreases in facial muscle tension will lead to decreased vagus nerve activity through the vagal–trigeminal reflex system, and that this will lead to relaxation of the smooth muscles from decreased parasympathetic stimulation (Glaus & Kotses, 1983; Kotses & Glaus, 1981; Kotses et al., 1991).

Several studies of progressive muscle relaxation found statistically significant improvements in various indices of asthma (Lehrer et al., 1994; Lehrer, Hochron, McCann, Swartzman, & et al., 1986; Vázquez & Buceta, 1993). Consistent with the vagal–trigeminal hypothesis, one study of surface EMG biofeedback concluded that facial muscle relaxation produced measurable improvements in pulmonary function in asthma patients, whereas biofeedback training for relaxation of the arm produced no effects (Glaus & Kotses, 1983). Nevertheless, exhaustive literature reviews have concluded that the effects of progressive relaxation on pulmonary function are unreliable and generally not of clinical significance, although often mildly positive (Richter & Dahme, 1982; Ritz, 2001). This is consistent with our own experience, where we found small but statistically significant improvements in mid-expiratory flow over several months of training (Lehrer et al., 1994), but not in the more bedrock measure of FEV_1, which is defined as the volume of air exhaled during the first second of a forced expiratory maneuver from maximum vital capacity. Acute effects of relaxation appear to be deleterious to asthma: decreased sympathetic arousal, and a parasympathetic rebound effect, which correlates with decreases in pulmonary function, presumably through constriction of smooth muscles in the central airways (Aboussafy, Campbell, Lavoie, Aboud, & Ditto, 2005a; Lehrer, Hochron, et al., 1997). Indeed, on the contrary, we found that mentally involving laboratory tasks, such as mental arithmetic, produced *improvements* in pulmonary function, correlated with evidence of vagal withdrawal (Lehrer, Hochran, Carr, & Edelberg, 1996). Similarly, patients with high levels of panic symptoms, whether asthmatic or not, tended to show better pulmonary function on average than corresponding individuals without panic, although these differences disappeared during exposure to laboratory tasks, where pulmonary function improved only in individuals without panic (Carr, Lehrer, Hochron, & Jackson, 1996). Chronic sympathetic arousal in the panic group may be responsible for the effect. Sympathetic arousal and/or vagal withdrawal may have had its maximum effect *chronically* on the lung in panic patients, so that additional autonomic effect from psychological tasks could have no further effect. Other research on stress-induced effects on asthma suggest that asthma patients are parasympathetically hyperreactive, such that they respond to stressful situations more with parasympathetic than sympathetic arousal (Aboussafy et al., 2005a; Feldman, Lehrer, Hochron, & Schwartz, 2002). Such a pattern is characteristic during exposure to uncontrollable stress, or in behavioral withdrawal from active coping in the face of overwhelming stress, as in the "play dead" response characteristic of vasovagal stress reactions (Engel, 1978; Labus, France, & Taylor, 2000; van Lieshout, Wieling, Karemaker, & Eckberg, 1991). However, there is little evidence that asthma patients have a more passive approach to stress than others (Roeder, Kroonenberg, & Boekaerts, 2003), and it is unclear whether the association between asthma and the parasympathetic stress response is due to psychological factors, inborn psychophysiological patterns of response stereotypy, the effect of asthma on dampening active coping responses (through experience of fatigue, exercised-induced exacerbations, etc.), effects of stress on the inflammatory system, medication effects, or other factors involving these autonomic, immune, pulmonary, and behavioral systems. Nevertheless, it should be noted that incidence of psychopathology, particularly anxiety and depression, is elevated in asthma (Goodwin, Fergusson, & Horwood, 2004; Goodwin, Jacobi, & Thefeld, 2003; Hasler et al., 2005; Katon et al., 2007; Rietveld & Creer, 2003), and associated with greater asthma morbidity (Feldman, M. et al., 2005; Siddique et al., 2000). A number of behavioral and physiological factors may play a role in this association, and these will not be exhaustively treated here. There is a small amount of uncontrolled evidence that treatment of comorbid psychiatric disorders may improve asthma condition, perhaps by improving medical care and treatment adherence (Lehrer et al., 2008).

Autogenic training

Autogenic training (Linden, 2007) uses self-hypnotic suggestions to affect and control various physiological processes. Although designed as a technique to foster self-regulation, there is evidence that it functions as a relaxation technique (Freedman et al., 1988). Several studies have found modest improvements in asthma, with effects similar to those achieved by other relaxation therapies (Deter & Allert, 1983; Groller, 1991, 1992; Henry, de Rivera, Gonzalez-Martin, & Abreu, 1993; Schaeffer & Freytag-Klinger, 1975; Stetter & Kupper, 2002).

Yoga

A number of psychophysiological approaches to asthma have used controlled breathing methods. Primary among them appears to be yoga, particularly pranayama methods, which, in some controlled studies, have shown statistically and clinically significant short- and long-term improvements in asthma, as assessed both by symptoms and by measures of pulmonary function (Bidwell, Yazel, Davin, Fairchild, & Kanaley, 2012; Holloway & Ram, 2000; Manocha, Marks, Kenchington, Peters, & Salome, 2002). However, other studies have found no effects (Sabina et al., 2005). A possible interpretation of these discrepant findings is that some yoga components are indeed effective in controlling asthma, but that the yoga technique is not standardized, so that some practitioners may teach a method that is effective in asthma control, and others not. The research literature does not permit evaluation of these possibilities.

Buteyko method

The Buteyko method originated in Russia, and is used by Buteyko practitioners throughout the world to treat asthma (Bruton & Lewith, 2005; McHugh, Aitcheson, Duncan, & Houghton, 2004; McHugh, Duncan, & Houghton, 2006). The method draws upon the common observation of hyperventilation symptoms in asthma patients. Indeed, there is evidence for increased respiratory drive in many asthma patients, which seems to overcompensate for effects of bronchoconstriction. The Buteyko method assumes that hyperventilation contributes to asthma physiology and symptomatology. It teaches patients to breathe regularly, shallowly, and slowly to decrease pCO_2. However, although there is evidence that the method produces decreases in asthma symptoms (Prem, Sahoo, & Adhikari, 2013) and, less consistently, increases in various measures of pulmonary function (Cowie, Conley, Underwood, & Reader, 2008), it does not appear to produce any changes in end-tidal CO_2 (Courtney & Cohen, 2008). Thus, although elements of the Buteyko method may be effective in treating asthma, the mechanism for the method appears to be incorrect.

Papworth method

This method, widely used by physical therapists, particularly in the United Kingdom, involves a combination of relaxation, asthma education, and slow relaxed breathing methods (Holloway & West, 2007). It includes some elements of the Buteyko method, including training in appropriate minute and tidal volume, and reduction in yawning and sighing, which are known contributors to hyperventilation. It also includes training in diaphragmatic breathing and reduced use of accessory muscles of breathing, and elimination of hyperinflation and exposure to cold room air through slow nasal breathing. It additionally includes training in relaxation and other "stress management" methods, and training patients to integrate these techniques into daily life. Several studies have found significant improvements in asthma symptoms from this method, but no acute or enduring changes in pulmonary function have been documented (Cowie et al., 2008; Holloway & West, 2007). This pattern is similar to that produced by placebo interventions (Wise et al., 2009). Indeed, it is possible that the sheer number of components in this method may lead to insufficient training in any single one that may be more effective. On the other hand, a method that reduces suffering, even if the mechanism is one of expectancy, as in the placebo response, should be considered seriously by those interested in helping patients with this disease, whether or not the underlying disease process is affected.

Biofeedback methods

In addition to the surface EMG biofeedback method used in conjunction with progressive relaxation, as mentioned in the preceding text, two other biofeedback methods have received some attention from researchers: biofeedback training to decrease respiratory resistance and biofeedback training to increase heart rate variability.

Biofeedback to decrease respiratory resistance

Continuous measures of respiratory resistance, allowing immediate feedback of moment-to-moment changes in respiratory resistance, can be conveniently obtained through the method of forced oscillation pneumography. In this method, a sound is used to generate oscillations in air pressure in the lung through a loudspeaker connected through a tube to the mouth. The amplitude and frequency of these oscillations reflect various characteristics of pulmonary function, including resistance of the airways. A number of studies, reviewed thoroughly elsewhere (Ritz, Dahme, & Roth, 2004), have used this method, with small but relatively consistent effects in reducing respiratory resistance. At present, equipment to perform this type of biofeedback is expensive and not readily available to most biofeedback practitioners.

Heart rate variability biofeedback

The amplitude and complexity of heart rate oscillations is known to reflect the body's state of general regulation, because they reflect the functioning of various modulatory reflexes affecting the autonomic nervous system (Bar et al., 2009; Folino et al., 2007; Giardino, Lehrer, & Feldman, 2000; Hilz & Dutsch, 2006). More complex patterns reflect larger amplitude in a greater number of compensatory reactions. Decreased amplitude and complexity of oscillations in heart rate are related to a variety of diseases and disorders, including hypertension (Giardino et al., 2000), heart failure (Cygankiewicz, Zareba, & de Luna, 2008; Valentini & Parati, 2009), generalized inflammation, diabetes (Schonauer et al., 2008), chronic pain (del Paso, Garrido, Pulgar, & Duschek, 2011; Faye et al., 2010; Guignard, 2006; Hummel & van Dijk, 2006; Oberlander & Saul, 2002; Tan et al., 2009), anxiety (Licht, de Geus, van Dyck, & Penninx, 2009), and depression (Boettger et al., 2008; Catipovic-Veselica et al., 2007; Kemp et al., 2010; Tonhajzerova et al., 2010; Udupa et al., 2007). There is some evidence that heart rate variability also is depressed in asthma

(Vaschillo, Vaschillo, & Lehrer, 2006), perhaps reflecting decreased adaptability, but a few studies found increased high-frequency heart rate variability, suggesting greater vagal activity, particularly where there is a relationship between emotional characteristics and asthma (Aboussafy, Campbell, Lavoie, Aboud, & Ditto, 2005b; Campbell et al., 2006; Miller & Wood, 1997).

In the 1980s and 1990s, researchers and clinicians in Russia began teaching people to increase their heart rate variability by breathing at a slow rate, where respiratory effects on heart rate, known as respiratory sinus arrhythmia, interact with effects of the baroreflex, which triggers compensatory changes in heart rate in response to changes in blood pressure. Although observations on asthma were uncontrolled, they suggested a consistent therapeutic effect among children with the disease (Lehrer, Smetankin, & Potapova, 2000).

After reviewing these data, we performed a small controlled trial, comparing heart rate variability (HRV) biofeedback with both a relaxation condition and no treatment, and found that biofeedback produced a significantly greater decrease in respiratory resistance than both comparison groups (Lehrer, Carr, et al., 1997). In a later study of 94 asthma patients (Lehrer et al., 2004), where medication was strictly controlled by blinded physicians, clinically significant improvement occurred in all aspects of asthma: patients took less asthma medication (prescribed by blinded pulmonologists according to a 13-step medication protocol), and had fewer symptoms, and lower respiratory resistance. On the average, their clinical condition improved from moderate asthma to mild persistent asthma. Several patients previously taking chronic doses of oral steroids were able to stop taking medication altogether while showing an improvement in clinical condition. Strikingly, *no* participants given the biofeedback procedure had an asthma exacerbation requiring increases in asthma medication, while individuals in three control groups did experience them to a significantly greater degree. Although the clinical findings were strong, however, the mechanisms for the effects remain obscure. There was no correlation between asthma improvement and changes in HRV. Indeed, older individuals, who showed smaller changes than younger people in HRV, showed greater improvement in asthma (Lehrer et al., 2006). Possibilities yet to be explored include biofeedback effects on airway inflammation, effects of mechanical stretching of the airways, undiscovered autonomic effects, or possible mediation by stress reduction. In another study, we examined the effects of HRV biofeedback on experimentally induced systemic inflammation, by injection of inflammatory cytokines, and found decreases in the autonomic blockade caused by the cytokines, but no changes in inflammation per se (Lehrer et al., 2010), suggesting that the pathway for improvement was not through an anti-inflammatory effect.

Summary

Although not strictly speaking a “psychosomatic” disease, asthma is closely associated with emotion and psychopathology. Depression and anxiety are more common among people with asthma and their caretakers, with probable bidirectional causality. Some panic symptoms have great similarity to asthma symptoms, and the two are often confused, sometimes with disastrous consequences. Some self-regulation techniques that are commonly used to treat emotional problems also may help asthma, particularly methods involving slow deep breathing. Of these, evidence for effects of heart rate variability biofeedback is particularly strong, but the pathways for efficacy have not been established.

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Behavioral Interventions for Youth with Type 2 Diabetes

Tatyana Buynitsky and Erinn T. Rhodes

Introduction

Diabetes mellitus is a chronic illness that has a growing global impact, affecting an estimated 285 million people, or 6.4% of the global population (Shaw, Sicree, & Zimmet, 2010). In the United States, over 18 million people have been diagnosed with diabetes, and an estimated additional 7 million have undiagnosed diabetes (Centers for Disease Control and Prevention, 2011). Diabetes is also one of the most expensive chronic illnesses. Based on adult modeling studies, the diabetes population and the related costs are expected to at least double in the next 25 years (Huang, Basu, O'Grady, & Capretta, 2009).

While type 1 diabetes remains the predominant form of diabetes mellitus in youth, the incidence and prevalence of type 2 diabetes have increased over the past several decades (Fagot-Campagna et al., 2000), a trend assumed to be at least in part related to the increase in childhood obesity during this time (Ogden, Carroll, Kit, & Flegal, 2012). In the SEARCH for Diabetes in Youth study, which has characterized youth in the United States with diabetes, the prevalence of type 2 diabetes in 10–19-year-old youth in the United States ranged from 0.18/1000 among non-Hispanic Caucasian youths to 1.45/1000 among Navajo youth. The incidence ranged from 3.7/100,000/year among non-Hispanic Caucasian youth to 27.7/100,000/year among Navajo youth (Bell et al., 2009; Dabelea et al., 2009). While the absolute number of youth with type 2 diabetes remains relatively small, the potential health consequences of type 2 diabetes in youth are dire (Rhodes, Prosser, et al., 2012). Adolescents and young adults with type 2 diabetes lose approximately 15 years from their average remaining life expectancy, frequently already have evidence of diabetes

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complications at the time of diagnosis, and may experience severe, chronic complications of type 2 diabetes by their 40s (Rhodes, Prosser, et al., 2012; TODAY Study Group, 2013).

Both type 1 and type 2 diabetes are caused by insulin deficiency. Insulin is a hormone produced by the pancreas, which is responsible for controlling the level of glucose in the blood. Type 1 diabetes is characterized by absolute deficiency of insulin, which usually results from autoimmune destruction of pancreatic beta cells (American Diabetes Association, 2012a). In contrast, type 2 diabetes results from a combination of insulin resistance and a relative deficiency of insulin (American Diabetes Association, 2012a; American Diabetes Association, 2000). Children with type 2 diabetes are typically overweight or obese and have a first- or second-degree relative with type 2 diabetes (Liu et al., 2010; American Diabetes Association, 2000), reflecting the contribution of both genetic and lifestyle factors to the development of type 2 diabetes. While there is no cure for either type of diabetes, maintaining blood glucose levels near to normal via both medication and lifestyle management is important to reduce the risk of diabetes complications and to ensure a good quality of life.

The American Diabetes Association (ADA) recommends targeted screening of children at increased risk for type 2 diabetes (American Diabetes Association, 2012b). While the details of the medical care of type 2 diabetes are beyond the scope of this chapter, the ADA recommends that individuals with diabetes be treated by a team of clinicians including physicians, diabetes nurse educators, dieticians, and mental health providers, who work together with the patient and his or her family to address issues stemming both directly and indirectly from the concerns arising from diabetes (American Diabetes Association, 2012a).

The intensity of medical treatments for type 2 diabetes needed to reduce the risk of long-term complications has been informed over time by large clinical trials performed in adults. The United Kingdom Prospective Diabetes Study (UKPDS) was one of the largest studies to evaluate treatment of adults with type 2 diabetes (UK Prospective Diabetes Study Group, 1998a; UK Prospective Diabetes Study Group, 1998b). The study followed over 5,000 newly diagnosed adult patients with type 2 diabetes to determine the benefits, if any, of intensive blood glucose management. Like the Diabetes Control and Complications Trial (DCCT), which looked at similar questions in type 1 diabetes (Diabetes Control and Complications Trial Research Group, 1993), the UKPDS completely changed the goals and philosophies of diabetes treatment of type 2 diabetes (Genuth et al., 2003). The UKPDS showed that lowering blood glucose levels and blood pressure would result in lower morbidity and mortality as well as fewer complications for patients with type 2 diabetes (UK Prospective Diabetes Study Group, 1998a; UK Prospective Diabetes Study Group, 1998b), just like the DCCT did for patients with type 1 diabetes (Diabetes Control and Complications Trial Research Group, 1993). Based on these observations in adults, recent data suggest that intensive diabetes control for youth with type 2 diabetes is also likely to improve outcomes (Rhodes, Prosser, et al., 2012); however, the optimal treatment regimens for youth are still unclear

(Zeitler et al., 2012). With these studies in the 1990s demonstrating significant benefit from intensive blood glucose control in reducing the long-term risk, "seemingly overnight, large numbers of patients were expected to follow a demanding, intensive treatment regimen that previously had been recommended only for those who were most highly motivated and diligent in their diabetes self-management" (Gonder-Frederick, Cox, & Ritterband, 2002). These expectations placed an enormous burden on healthcare providers, who may not have been adequately trained or prepared to manage large numbers of patients in this way (Gautier, Beressi, Leblanc, Vexiau, & Passa, 1996). Effective use of a behavioral medicine approach, in conjunction with currently accepted medical interventions, could serve to fill this gap (Mostofsky, 2010).

Behavioral Medicine for Youth with Type 2 Diabetes

Studies suggest that lifestyle differences between and across cultures may affect the changing epidemiology of diabetes, and that Westernization has played a role in the developing world (Ogden, Carroll, Kit, & Flegal, 2012; Ravussin, Valencia, Esparza, Bennett, & Schulz, 1994; Zimmet, McCarty, & de Courten, 1997). This suggests a potentially strong behavioral and environmental impact on diabetes prevalence and puts clinicians who care for patients with diabetes in the position to make substantial changes in the lives of their patients (Delamater, 2007). A study of adolescents with or at risk of type 2 diabetes has demonstrated that health-related quality of life in this group is influenced by factors such as severity of obesity, family conflict, and burden of diabetes care (Rhodes, Goran, et al., 2012). Poor glycemic control is also related to lower health-related quality of life (Naughton et al., 2008; Plack, Herpertz, & Petrak, 2010) and depressed mood (Lawrence et al., 2006) in youth with diabetes. Therefore, treatment of diabetes, particularly type 2 diabetes, in youth requires not only attention to a choice of medical regimen but also an implementation approach that acknowledges the adolescent in his or her biopsychosocial context, including the family and lifestyle.

As the epidemiology reflects, the burden of treating type 2 diabetes in youth is relatively new to clinicians compared to either its adult counterpart or type 1 diabetes in children. Treating youth with type 2 diabetes, therefore, provides both challenges and opportunities. Few behavioral change strategies have been carefully studied among youth with type 2 diabetes (Johnson et al., 2010; TODAY Study Group, 2009). However, opportunities exist to learn from effective intervention strategies used to treat youth with type 1 diabetes, to treat adults with type 2 diabetes, and to address weight management across the age spectrum.

Like all adolescents coping with a chronic disease, adolescents with both type 1 and type 2 diabetes are navigating a path to independence in their day-to-day lives while they are also learning to care for their health (Rubin, 2002). Adherence to medication or self-management tasks and family conflict are factors that challenge both of these populations (Borus & Laffel, 2010; Rhodes, Goran, et al., 2012;

Rothman et al., 2008; Williams, Laffel, & Hood, 2009). However, unlike youth with type 1 diabetes, who can experience almost immediate, even life-threatening, consequences from non-adherence with their treatment, youth with type 2 diabetes can omit their medications for extended time periods without experiencing adverse health effects (Mulvaney et al., 2006; Rothman, et al., 2008). However, the long-term effects of non-adherence in type 2 diabetes can lead to serious disability or death (Rhodes, Prosser, et al., 2012). Complications can include neuropathy in some cases resulting in amputations, as well as blindness, kidney failure, and heart disease (Rhodes, Prosser, et al., 2012). While these consequences would appear to be sufficiently dire to motivate behavior change, their impact on adolescents may be variable (Rhodes et al., 2011). A survey of youth with or at risk of type 2 diabetes demonstrated that adolescents rated treatments and sequelae of diabetes as significantly worse than their parents (Rhodes, et al., 2011). However, heterogeneity in preferences for the type 2 diabetes health states suggests that management discussions need to be tailored to the individual needs and circumstances of each adolescent.

Adolescents are not simply small adults, and their treatment requires more than simple adaptation of adult management plans (Klassen, Hartling, Craig, & Offringa, 2008; Shea, 2008). Age as well as maturity are needed for adolescents to manage their own illness, and the timing of transition to independence will vary among individuals (Wolfsdorf, 2002). As healthcare responsibilities shift from the parent to the adolescent, deterioration in glycemic control, an increase in both acute and chronic complications, as well as emerging psychological issues are commonly observed. It is the role of the family as well as the healthcare team to monitor the pace of this transition and support the adolescent's adherence to diabetes regimens (Wolfsdorf, 2002). Studies of adolescents with diabetes have shown that children, who have the most support from their family and the least family conflict, adapt and adhere best to their treatment regimen, and have the most success managing their diabetes (Hamlett, Pellegrini, & Katz, 1992; Leonard, Garwick, & Adwan, 2005; Pereira, Berg-Cross, Almeida, & Machado, 2008; Wilson et al., 1986). It is important for families to be educated and counseled on how to best provide this support for their children.

Although the family plays a vital support role in both type 1 and type 2 diabetes, the majority of youth with type 2 diabetes have families with direct experience with diabetes (Centers for Disease Control and Prevention, 2011; Fagot-Campagna, 2000; Pinhas-Hamiel et al., 1999). The behavior changes being targeted in this adolescent population are, therefore, usually relevant for the whole family (Anderson, Cullen, & McKay, 2005; Pinhas-Hamiel, et al., 1999). Therefore, including the whole family when creating a treatment plan for these adolescents can support adherence (Wysocki, 2006). Parents of adolescents with type 2 diabetes report many barriers to managing their child's illness, including difficulties with monitoring glucose, medication adherence, proper diet, and sufficient levels of exercise (Anderson, Miller, Auslander, & Santiago, 1981; Mulvaney, et al., 2006). Parents who have type 2 diabetes are able to both positively and negatively influence their affected child. Parents with type 2 diabetes who are obese and do not manage their illness well may need additional guidance (Mulvaney, et al., 2006; Young-Hyman, 2002) and education (Cullen & Buzek, 2009) before they are ready to be partners in the care process. Parents may lack sufficient skills to promote behavior change, such as rewards, verbal praise, or encouragement, and will need provider support to promote a successful family dynamic (Wysocki, 2006; Young-Hyman, 2002). Finally, it is important to note that type 2 diabetes in the United States is a disorder that differentially affects youth of racial/ethnic minority groups and lower socioeconomic status (Fagot-Campagna, et al., 2000; Mayer-Davis et al., 2010). Limited resources to support behavior change must be considered in developing a realistic care plan (Young-Hyman, 2002).

Type 2 Diabetes Treatment in Youth: The Care Team

Establishing a good rapport with adolescents is critical to a successful patient–provider relationship. The diabetes care team must be multidisciplinary. Both the specialist and the primary care physician are important members of the medical team (Copeland et al., 2013). Additional support from their primary care physician can be particularly helpful especially for adolescents who are overweight or obese, and providers should constantly strive to improve care collaboration. In an international partnership to improve the outcomes of diabetes, the DAWN (Diabetes Attitudes, Wishes, and Needs) Program, a survey of more than 5,000 patients reported that only 51% of their healthcare providers talked to each other (Skovlund & Peyrot, 2005). Youth with type 2 diabetes need evaluation, guidance and support not only from physicians but also from nutritionists, diabetes nurse educators, and, ideally, specialists in behavioral medicine and physical activity.

Expert Committee Recommendations on the management of overweight and obesity in children recommend that physicians review lifestyle factors during annual visits including diet, consumption of sweetened beverages, and exercise (Barlow, 2007). A four-stage approach for the management of overweight or obese children has been recommended. The stages include: (1) provide diet and exercise recommendations and monitor monthly; continue to the next stage if body mass index (BMI) worsens or stays the same over 3–6 months; (2) create a plan that includes a healthful proper diet, daily exercise, minimal television watching, and self-monitoring logs; monitor progress in this stage with regular follow-ups, and proceed to the next step if progress is not made in 3–6 months; (3) provide a comprehensive, multi-disciplinary intervention; and (4) refer to a specialty team to provide intensive tertiary-care intervention (Barlow, 2007). Only 12% of pediatricians report feeling a high degree of self-efficacy when it comes to treating overweight and obese patients (Rao, 2008). It is important for pediatricians and healthcare professionals caring for adolescents with type 2 diabetes to feel comfortable supporting adolescents around diet and lifestyle changes.

Adolescents spend the greater portion of their day at school. Therefore, advocating for patients in schools is very important (Clarke et al., 2012). Adolescents can perform better when school staff have some education about diabetes (Clarke et al., 2012). With the appropriate permission, creating an alliance with the school nurse or a guidance counselor can be a helpful part of the treatment.

Behavioral Approaches to Enhance Treatment Effectiveness

National standards for diabetes self-management education and support have recently been published by a multidisciplinary team (Haas et al., 2012) and highlight the need for personal strategies to address health and behavior change; incorporating nutrition management and physical activity into lifestyle; and using the results of blood glucose monitoring for self-management decision-making as core topics of a comprehensive curriculum. Behavioral skills that have been used to address these aims include goal setting, coping skills, and problem-solving, as well as management of any mental health issues (Peyrot & Rubin, 2007). In adults, diabetes education has been associated with overall better self-management, patient satisfaction, and improved glycemic control (Berikai et al., 2007; Duncan et al., 2009; Rubin, Peyrot, & Saudek, 1993). There is less direct evidence of this association in youth, but family programs in youth with type 1 diabetes support this approach (Anderson, Brackett, Ho, & Laffel, 1999; Laffel et al., 2003).

While the cost-effectiveness of behavioral medicine interventions in treatment of diabetes is still being evaluated (Songer et al., 2006; Venditti, 2007), the potential benefits of such interventions include reductions in direct cost due to reduced complications as well as improvements in health-related quality of life. A meta-analysis of adult behavioral medicine techniques used to manage chronic illnesses found that hospital illnesses managed with behavioral techniques had hospital stays that were approximately two and a half days shorter and $2,205 less expensive per person (Chiles, Lambert, & Hatch, 1999). While the translation to adolescent healthcare for type 2 diabetes will require further investigation (Songer, et al., 2006), these youth will develop complications of diabetes earlier in life (Rhodes, Prosser, et al., 2012), and therefore the economic benefits may be substantial.

The following sections will highlight behavioral treatment strategies and counseling techniques that can be incorporated into clinical practice. Methods that have been studied in youth with type 2 diabetes along with approaches that have been successful in adults and youth with type 1 diabetes that are relevant to youth with type 2 diabetes are presented.

Successful management of type 2 diabetes involves balancing multiple factors including lifestyle changes focused on nutrition and exercise, adherence to medication, and self-monitoring. Each of these areas may pose challenges for the adolescent patient. While some practical approaches for clinicians to use to address these challenges with their adolescent patients are described separately, it is likely that a combination of approaches addressing these issues will lead to the greatest success (Wing et al., 2001). The clinician will need to individualize a treatment approach based on the needs of each patient.

Approach to diabetes self-management

Type 2 diabetes is like many other chronic illnesses in which a key to success is adherence to specific health behaviors. The clinician can help the adolescent patient to engage with his/her family in a way that will support the adolescent's ability to manage his or her own illness. In addition to following a prescribed medication regimen, managing type 2 diabetes requires knowledge about monitoring of blood glucose levels, changes in physical activity, healthful eating, and regular medical visits, as well as skills to cope with situations such as dealing with friends and school (Grey, Schreiner, & Pyle, 2009; TODAY Study Group, 2009).

The ADA recommends that diabetes clinicians provide diabetes self-management education as part of their routine care (American Diabetes Association, 2012b). A patient-centered, motivation-enhancing approach is the current standard (Glasgow, Peeples, & Skovlund, 2008; Haas, et al., 2012). Key concepts promoted here are readiness to change (Helitzer, Peterson, Sanders, & Thompson, 2007; Kaugars, Kichler, & Alemzadeh, 2011), shared decision-making, and collaborative goal-setting (Fleischman & Rhodes, 2009; Skinner & Cameron, 2010). These are not unique to the adolescent diabetes population and reinforce the importance of establishing both a shorter-term and longer-term view of success in working with adolescents with chronic illness.

Saunders and Pastors (2008) provide a practical guide for the clinician working with diabetes patients including 10 tips for lifestyle management that have been adapted here, where appropriate, to guide management with adolescents and their families.

(1) Take a complete history focusing on lifestyle assessment nutrition, weight history, physical activity, and a mental health screen As will be discussed later, pediatric weight management programs are typically most successful when they are multidisciplinary (Grey, et al., 2009; McGovern et al., 2008; TODAY Study Group, 2009). A team approach is the standard for diabetes care (American Diabetes Association, 2012b). A complete history may be obtained by multiple providers working together. However, having the adolescent set the agenda creates a collaborative environment and sets priorities for the visit (Rubin, 2002).

(2) Assess the patients' readiness to change their behavior using a non-directive method A 10-point scale can be used to obtain this information for both general readiness and the desire to change specific behaviors (Zimmerman, Olsen, & Bosworth, 2000). Patients who may not be ready to commit to behavior changes may be willing to think about behavior change. Those indicating motivation to change

can explore barriers to further progress, which may increase their confidence in making the behavior change.

(3) Focus on behaviors and not outcomes The patient cannot directly control the clinical outcomes, but can alter the behaviors that affect outcomes. Making sure that the adolescent recognizes the distinction between these is important. Adolescents may not have the maturity to make or understand decisions that impact the future (Steinberg et al., 2009). Therefore, linking behavior change to longer-term benefits may not always be effective in counseling adolescents.

(4) During the assessment phase, the clinician should only collect information All care ultimately needs to be individualized for the specific patient and family. Advice should be reserved until after the clinician has collected information that allows the patient's goals to be put in a holistic context. Adolescents with type 2 diabetes report logistical barriers to healthful behaviors, such as limitations in access to appropriate food choices, support structures, or the environment for physical activity (Rothman, et al., 2008). These are important issues to understand before the development of a collaborative plan.

(5) Share decision-making responsibility with the patient Although the typical medical model involves provider-directed care, diabetes is an illness that requires self-management. If the patient is hesitant to select a goal, the provider can suggest several possible goals and have the patient select the most important one. Britto et al. (2004) surveyed adolescents with chronic illness who reported a preference that physicians communicate directly with them. Respect/trust, control, and caring were other key themes that adolescents linked to a perception of care quality. Ongoing efforts to promote patient/family-centered communication, as the adolescent with diabetes assumes greater responsibility for his or her own care, may enhance self-management and lead to improved adherence (Croom, et al., 2011).

(6) Help the patient set goals that are geared toward success Focus should be on setting realistic, tangible goals such as keeping a food journal or exercising a specific number of times per week. The acronym FIRM is useful in this situation, standing for **F**ew in number, **I**ndividualized to the patient, **R**ealistic, and **M**easurable. Failure to reach a goal can be discouraging. Realistic goal-setting with positive reinforcement can be a successful strategy (Epstein, Paluch, Kilanowski, & Raynor, 2004; TODAY Study Group, 2009).

(7) Give the patient a written copy of all of the behavioral objectives determined during visits Patients can often recall a very small portion of the goals set during a clinical encounter and often incorrectly recall them (Parkin & Skinner, 2003). Therefore, it is important for them to leave the visit with a printed copy to reference at home. Older adolescents, who come for visits alone, can also share this with their family in order to enlist help. The clinician should keep a copy in the patient's chart.

(8) Teach the patients ways to keep a written record of their behavior Examples include a food log, exercise log, or record of blood glucose measurements. This will allow patients to track their progress individually and also to discuss any necessary changes at their appointments. Adolescents may find electronic methods preferable and more motivating (Hanauer, Wentzell, Laffel, & Laffel, 2009; Harris, Hood, & Mulvaney, 2012).

(9) Maintain follow up Ensuring follow up is important, as this will allow the provider to give reinforcement for successful adherence to goals as well as to adjust any goals if it becomes clear that they are not realistic. Although in-person contact is ideal, other forms of contact may be needed in between clinic visits. Telehealth interventions, for example, have been used in adults (Polisena et al., 2009), and are being increasingly explored in youth with type 1 diabetes (Harris, et al., 2012).

(10) Create a multi-disciplinary team that includes specialists in the patient's area of need As already mentioned, a team approach is critical for successful diabetes care. Adolescents with type 2 diabetes often report stress, sadness, and other emotions as barriers to lifestyle changes (Rothman, et al., 2008). Including a mental health professional as part of the team, when appropriate, is important.

Ultimately, the approach to diabetes self-management for youth with type 2 diabetes will need to be individualized to the specific needs of the patient and family and to the unique challenges they face. In a study of older adolescents and young adults with cystic fibrosis, another chronic illness that, like diabetes, requires daily medications, four broad themes were identified with respect to barriers and facilitators of self-management (George et al., 2010). These themes included: barriers to self-management (e.g., treatment burden [identified by 64% of patients], accidental or purposeful forgetting [60%], and no perceived benefit [56%]), facilitators of self-management (e.g., clinic visits [76%], social support [68%], and perceived benefit [68%]), substitution of alternative approaches to conventional management (36%), and planned non-adherence (32%). For an individual patient, understanding these views can have a direct impact on the choice of behavioral intervention and goals.

Medication adherence

Research has yet to establish the optimal medical therapy for youth with type 2 diabetes (Zeitler, et al., 2012). In adults, common factors associated with non-adherence to diabetes medication include lack of knowledge about diabetes, low socioeconomic status, side effects, and lack of beliefs that the medication was helping the patient's current or future health (Adeyemi, Rascati, Lawson, & Strassels, 2012; R. W. Grant, Devita, Singer, & Meigs, 2003). Among children and adolescents with type 2 diabetes, rate of adherence to medication is not consistent in the literature (Adeyemi, et al., 2012; Rothman, et al., 2008); however, adolescents are reported to have lower rates of adherence than children less than 12 years of age (Adeyemi, et al., 2012). Youth with type 2 diabetes often report barriers to adherence associated with interpersonal situations relating to peers and family (Mulvaney et al., 2008).

Unlike treating adults, the clinician cannot have the expectation that adolescents have developed the skills to take responsibility for overseeing a medication regimen. Therefore, family-based approaches must be used, with education of both the patient and family about why the patient is taking the medication, and counseling on basic skills for successful implementation, such as taking their medication at the same time daily, pairing administration with a recurring task such as tooth-brushing or a specific meal, keeping a log of each medication administration, and taking the medication even when the patient does not experience any symptoms, in order to enhance the likelihood that the adolescent will remember to take his or her medication, (Gorenoi, Schonermark, & Hagen, 2008; Grey, et al., 2009). For adolescents, text messaging is one method that has been shown to enhance adherence with weight management and type 1 diabetes management in adolescents (Franklin, Waller, Pagliari, & Greene, 2003; Mulvaney, Anders, Smith, Pittel, & Johnson, 2012; Woolford et al., 2011; Woolford, Clark, Strecher, & Resnicow, 2010).

Intentional (i.e., planned) non-adherence to treatment is also something that must be considered in adolescents (George, et al., 2010). Youth with type 1 diabetes, for example, may intentionally omit insulin for the purpose of weight loss (Kelly, Howe, Hendler, & Lipman, 2005; Young et al., 2012). In an internet survey of US adults with either type 1 or type 2 diabetes using insulin, 57% reported intentionally skipping insulin injections (Peyrot, Rubin, Kruger, & Travis, 2010). Characteristics associated with intentional insulin omission included being a student, having type 2 diabetes, greater frequency of injections, and perceiving that injections interfered with daily activities, were painful, or were embarrassing (Peyrot, et al., 2010). Adolescents may be particularly concerned about their schedule and their peer group (Mulvaney, et al., 2008). Therefore, exploring how the individual's treatment regimen affects his or her schedule can be very important.

To fully engage with patients and families around issues related to medication adherence, it is important to recognize not only the patient- and therapy-specific barriers to adherence, but also any socioeconomic and healthcare system factors that influence medication adherence (Krueger, Berger, & Felkey, 2005). In some cases, access to treatment can be a barrier to adherence due to problems with insurance coverage or medication costs (Osterberg & Blaschke, 2005).

Type 2 diabetes is more common among racial/ethnic minorities, and it is important that culture, language, and literacy also be considered when developing educational materials and patient/family treatment plans (Haas, et al., 2012). Health literacy is the ability to understand, accept, and use health information properly; and numeracy is the ability to understand numbers, particularly with respect to implementing proper health management behaviors (Osborn et al., 2011). Both factors can influence medication adherence and have been identified as contributors to racial/ethnic disparities in medication adherence (Cavanaugh et al., 2008; Osborn, et al., 2011; Osborn, Cavanaugh, Wallston, White, & Rothman, 2009; Osborn, Paasche-Orlow, Davis, & Wolf, 2007; Waldrop-Valverde et al., 2010).

A recent systematic review of interventions tailored to the needs of people with diabetes from ethnic minority groups found that these interventions, when tailored by integrating culture, language, religion, and health literacy skills, had a positive influence on clinically relevant outcomes (Zeh, Sandhu, Cannaby, & Sturt, 2012). For example, a study of Hispanic adults with type 2 diabetes showed that utilization of community health workers, who were able to provide culturally appropriate and bilingual educational resources, as liaisons between healthcare providers and members of the community was successful in improving treatment adherence, including adherence to medication (Babamoto et al., 2009).

Finally, understanding the contributors to difficulties with medication or treatment adherence requires good patient–provider communication. Motivational interviewing (see Chapter 19) can be a simple way to facilitate treatment engagement (Miller & Rollnick, 2002). A patient-centered approach allows for two-way communication (Hall, Gibbie, & Lubman, 2012; Schoenthaler, Schwartz, Wood, & Stewart, 2012) and has been successfully used to promote adherence in adolescents with chronic illnesses such as asthma and diabetes (Borrelli, Riekert, Weinstein, & Rathier, 2007; Borus & Laffel, 2010; Riekert, Borrelli, Bilderback, & Rand, 2011). Motivational interviewing is a technique where the clinician gathers information about the patient's goals, beliefs, and his or her perceived barriers to treatment, and then presents the information back to the patient in a non-judgmental way, along with treatment suggestions.

While mastering motivational interviewing may take practice, the basic steps follow the acronym RULE: "1) Resist the righting reflex; 2) Understand and explore the patient's own motivations; 3) Listen with empathy; and 4) Empower the patient" (Dellasega, Anel-Tiangco, & Gabbay, 2012). Motivational interviewing theory states that the clinician should not see the patient as an entity to be fixed but rather as a person with whom to work to identify what he or she deems important to work on (Miller & Rollnick, 2002). During a motivational interviewing session, the patient should be doing the majority of the talking. The clinician should avoid closed-ended questions, and not be afraid to allow for a period of silence before the individual feels ready to answer the question. Clinicians can utilize techniques such as agenda-setting and an assessment of readiness to change (as discussed earlier) to guide the exploration of the patient's motivations (Welch, Rose, & Ernst, 2006). Agenda-setting can be facilitated by a simple chart where adolescents can select which aspect of their treatment they are most ready to work on, allowing the provider to target specific goals.

Lifestyle change

Healthy lifestyle changes, including weight management and physical activity, are standard recommendations for the treatment of type 2 diabetes (American Diabetes Association, 2012b). As with the behavioral strategies used for diabetes self-management, some of the key strategies include self-monitoring, realistic and collaborative goal-setting, and motivational techniques (TODAY Study Group, 2009). For the longer-term success of lifestyle changes that support weight management, problem-solving and involvement of the family are critical (Mulvaney, et al., 2008).

Consistent exercise is an important part of the regimen for individuals with type 2 diabetes. Adults who exercise are less likely to develop type 2 diabetes (Fulton-Kehoe, Hamman, Baxter, & Marshall, 2001) and those with diabetes performing moderate to vigorous exercise have a reduced risk of complications and mortality after diagnosis (Blomster et al., 2013). Studies have also found a reduced risk of diabetes complications in adolescents with type 2 diabetes who exercise, regardless of actual weight loss (Robertson, Adolfsson, Scheiner, Hanas, & Riddell, 2009), and that physical activity increases glucose sensitivity in overweight adolescents (Shaibi et al., 2006).

As with other aspects of diabetes management, the clinician is in a unique position to counsel adolescents about the benefits of exercise. Clinicians can use techniques such as motivational interviewing, described in the previous section, to enhance their patients' motivation to engage in physical activity. Clinicians must work with their patients to find an exercise program that the patient can enjoy, accomplish easily, afford, and which will provide visible benefits to keep the adolescent motivated and to help form a lifelong habit. Goals must be realistic. Family-based approaches to increasing exercise and reducing sedentary time improves adherence and can be particularly helpful for adolescents with multiple family members affected by type 2 diabetes (Pinhas-Hamiel et al., 1999; Wrotniak, Epstein, Paluch, & Roemmich, 2004). Clinicians can begin by encouraging simple activity such as taking the stairs instead of an elevator or walking more frequently (Andersen et al., 1999). Helping to identify specific resources in the community and tracking physical activity in a log are effective strategies for adults (van Rooijen, Rheeder, Eales, & Becker, 2004).

Involvement of the family is an important component of pediatric weight management (Davis et al., 2007). Parents can be taught to utilize contingency management, which involves reinforcing children when they behave in an agreed upon way (Petry, 2011; Raiff & Dallery, 2010), such as if they exercise an agreed upon number of times per week. Parents can give small rewards in close proximity to when a goal is reached. Alternatively, a token economy can be set up where each instance of the target behavior is rewarded with a token such as a checkmark or a sticker and then can be traded in for items of larger value when enough tokens are collected. Most importantly, parents must consistently provide positive reinforcement including verbal praise, whether based on a contingency contract or just general positive health behavior, to ensure the highest level of success (Davis et al., 2007). The TODAY Study, a multicenter trial of treatment options for type 2 diabetes in youth, which included an intensive lifestyle intervention for one of its treatment arms, utilized this form of contingency reinforcement for achievement of lifestyle goals (TODAY Study Group, 2009). In adults, economic incentives for weight loss have been studied and were found to be effective (Volpp et al., 2008).

Like physical activity, changing dietary patterns requires changes in multiple environmental settings, including the home and school. Adjusting the food prepared at home also requires special attention to family and cultural dynamics and socioeconomic status. Overweight or obese children are more likely to skip breakfast, to eat out, and to consume larger portions of food than is developmentally appropriate compared to non-obese children (Davis, et al., 2007). A higher frequency of family meals is associated with consumption of higher-quality foods (Davis, et al., 2007). Parents should establish a protective environment in the home where they substitute healthier foods for less healthy foods. Health care providers working with adolescents with type 2 diabetes should support this goal and refer to outside clinicians, such as nutritionists, as necessary.

There is no consensus on the optimal dietary approach to pediatric weight management (August et al., 2008; Barlow, 2007). At present, general dietary guidelines include avoiding consumption of calorie-dense, nutrient-poor foods; reducing intake of dietary saturated fat; and increasing intake of dietary fiber, fruits, and vegetables (August, et al., 2008). In the TODAY study, an adaptation of the Traffic Light Diet called the Traffic Light Plan was used to guide dietary modification and included labeling categories of foods as "Red" if they were to be decreased (e.g., sugary cereal, foods with 5 grams of fat or more); "Yellow" if they were "good for you" but portion sizes needed to be monitored (e.g., starchy foods), and "Green" if they were "go" foods and their consumption should be increased (e.g., highly nutritious and low calorie density) (TODAY Study Group, 2009). However, the specific food choices were allowed to be flexible to accommodate the cultural and ethnic backgrounds of study participants. Clinicians should keep both access to healthy foods and patient preferences in mind when developing goals for dietary change.

Self-monitoring and goal-setting are common techniques utilized in weight management programs and, for adolescents, the use of technology may be a helpful motivator (Woolford, et al., 2010, 2011). A program that has been tested and deemed feasible for use with adolescents is a food record created by taking a photograph of every item before it is consumed (Six et al., 2010). Other available technologies available include free mobile phone applications that can input food items and report calories consumed and energy expenditure from exercise. These applications can be particularly useful to adolescents if they include analytics that can track their progress over time (Kumar, Wentzell, Mikkelsen, Pentland, & Laffel, 2004). This use of technology to manage diet can be expanded for other health behaviors, including exercise and blood glucose levels (Mulvaney et al., 2012). For some individuals, this can serve as guide to help to develop positive eating habits (Lee, Tatara, Arsand, & Hartvigsen, 2011). Recognizing that challenges with problem-solving are a reported barrier to diabetes care, Mulvaney et al. developed YourWay, an Internet-based self-management intervention for adolescents with type 1 diabetes designed to enhance problem-solving barriers to self-management. In as-treated analyses, the intervention group showed significant improvement in self-management and prevented deterioration in HbA1c (Mulvaney, Rothman, Wallston, Lybarger, & Dietrich, 2010). An adaptation for youth with type 2 diabetes is currently being evaluated (Rothman, 2009).

Finally, the adolescent or the family unit may lack the support of other families and relatives around lifestyle change (James, 2004). Providing positive reinforcement and helping patients and their families avoid negative interpretations of small lapses in adherence are important to establishing the regularity of healthful lifestyle habits and the goals of long-term success (Davis, et al., 2007).

Mental Health Comorbidities

As is the case with many other chronic illnesses, type 2 diabetes in youth is frequently complicated by depression and other mental health disorders (Anderson et al., 2011; Levitt Katz et al., 2005; Wilfley et al., 2011). The ADA recommends including assessment of a patient's psychological and social situation as an ongoing part of the medical management of diabetes (American Diabetes Association, 2012b). Psychosocial screening and follow-up can include assessment of attitudes about the diabetes, expectations for medical management and outcomes, affect/mood, general and diabetes-related quality of life, resources (financial, social, and emotional), and psychiatric history. Such assessment is particularly important if there is a deterioration in the patient's glycemic control.

Stress

Managing type 2 diabetes involves not only controlling medication, diet, exercise, and blood glucose levels but also considering family and cultural issues. Adults with diabetes report greater stress when they are unable to cope with the demands of their illness (Karlsen, Idsoe, Dirdal, Rokne Hanestad, & Bru, 2004). Stress, in turn, can make both lifestyle and blood glucose more difficult to manage (Delamater, 2007; Morris, Moore, & Morris, 2011). Adolescents may already find adjustment to social settings stressful. The addition of diabetes may lead some adolescents to feel distant from their peers in social situations if they are unable to consume the same foods or must take a medication or injection at specific times of the day. Adolescents are more likely to succeed within a treatment regimen if their clinician addresses these issues upfront by helping them schedule their treatment around their lives instead of vice versa (Rubin, 2002). Adolescents with type 2 diabetes, who are also overweight or obese, may also experience stigmatization and bullying (Janssen, Craig, Boyce, & Pickett, 2004; Latner & Stunkard, 2003). Clinicians must work with the family and, in some cases, the school authorities, when these situations arise.

The use of relaxation techniques, such as yoga, relaxation therapy that works on slow movements and controlled breathing, and biofeedback, have been found to help manage stress in people with diabetes and may improve the control of their blood glucose (Morris, et al., 2011). Cognitive behavioral therapy (see

Chapter 9) has also been effective for individuals with diabetes, in both decreasing levels of stress, depression, and facilitating other behavioral improvements (Welschen et al., 2013).

The purpose of cognitive behavioral therapy is to change the way patients think, and it uses techniques such as thought stopping, guided imagery, or cognitive restructuring (Morris, et al., 2011; Welschen, et al., 2013). Cognitive behavioral therapy begins with a session in which the patient shares specific problems and goals that are used to plan future sessions, homework assignments, and to determine the most useful tools for the patient (Martin, 2012). Cognitive behavioral therapy typically includes four components: (1) identification of issues to be worked on; (2) awareness of thoughts, emotions, and beliefs about the situations that result in them – this step may include journaling; (3) identification of thinking patterns that are negative, and the physical, emotional, and behavioral responses that accompany them; and (4) challenging these thinking patterns. This may involve discussion of specific situations to help the patient determine that their thinking habits are inaccurate (Mayo Clinic, 2012). Like motivational interviewing, many practitioners can learn to implement cognitive behavioral therapy.

Depression

Depression is a common comorbidity of type 2 diabetes in youth (Anderson, et al., 2011; Levitt Katz, et al., 2005), and has been shown to be associated with poor treatment regimen adherence and greater difficulty with control of blood glucose (La Greca, Swales, Klemp, Madigan, & Skyler, 1995; Monaghan, Singh, Streisand, & Cogen, 2010; Reddy, Ford, & Dunbar, 2010). Among youth with type 2 diabetes in the TODAY study, 14.8% had clinically significant symptoms of depression (Anderson, et al., 2011), with higher rates among youth with binge eating (Wilfley, et al., 2011). These findings support the need for the screening and identification of depression as part of the clinical care of youth with diabetes (American Diabetes Association, 2012b). The relationships between diabetes, obesity, and depression are not entirely clear. Individuals who are diagnosed with depression early in life have a higher likelihood of a later diagnosis of type 2 diabetes (Carnethon et al., 2007; Katon et al., 2004). The relationship between psychological issues and obesity is similar (Griffiths, Parsons, & Hill, 2010; Puder & Munsch, 2010).

Depression in patients with type 2 diabetes has been treated successfully with counseling and medication as needed (Peyrot & Rubin, 2007). Cognitive behavioral therapy has also been found to be effective for treating depression in this population (Lustman, Griffith, Freedland, Kissel, & Clouse, 1998; Peyrot & Rubin, 2007). However, it is important that referrals to additional treatment happen as soon as necessary, so that the patient and family have access to all the resources they need, especially since patients with depression may have worsening symptoms as they approach adulthood (Anderson, et al., 2011).

Access to resources and homelessness

Ensuring adequate access to healthcare is critical for successful diabetes management. In adults with diabetes, lack of healthcare coverage is associated with poor glycemic control, and low utilization of health services is associated with both poor glycemic and blood pressure control (Zhang et al., 2012). In the United States, low-income children are more likely than middle–high-income children to have their parents report a greater problem getting necessary care or a referral to a specialist (Simpson et al., 2005).

In an extreme example, chronic illnesses, including type 2 diabetes (Trevena, Nutbeam, & Simpson, 2001), asthma, and obesity (R. Grant et al., 2007), may be observed at higher rates among the homeless than in the general population. For adolescents in families that are living on the streets or in a shelter, lifestyle management is a constant struggle, and lack of money and other resources often leave the patients without necessary medication, with inadequate medical care, and with a poor diet (Ensign & Santelli, 1997; Hwang & Bugeja, 2000; Richards & Smith, 2007). Clinicians managing patients in these settings must ensure that patients have complete documentation of their medical history in order to secure all of the required medical services.

Conclusion

Many behavioral techniques are available to clinicians who wish to support their patient's diabetes management and improve their outcomes. As the rates of adolescents with type 2 diabetes rise, research with this population will help clarify the effectiveness of these individual techniques. However, establishing a strong patient–provider connection through which to provide counseling, motivation, and support, even during brief sessions, is a fundamental requirement for successful management of type 2 diabetes in youth.

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34

Behavioral Factors in Headache Management

Frank Andrasik and Dawn C. Buse

Introduction

Headache is a common medical condition affecting 91% of males and 96% of females at some point during their lifetime (Rasmussen et al., 1991). The majority of headaches are benign, and less than 0.1% of the lifetime prevalence of headache is associated with life-threatening conditions (Silberstein & Lipton, 1993). The two most common primary headache conditions are migraine and tension-type headache (TTH). These can be chronic conditions, which are associated with significant disability to the individual and cost to society. The chronic conditions of migraine and TTH are also associated with significant medical and psychiatric comorbidity.

Headache disorders are best conceptualized within a biopsychosocial framework (Andrasik, Flor, & Turk, 2005) and managed with a coordinated multimodal approach (Lemstra, Stewart, & Olszynski, 2002). The biopsychosocial model assumes that the experience and expression of headache (like all chronic illnesses) is a complex interaction among biological, psychological, and social variables, and that their interactions all play significant roles in the experience and outcomes of headache disorders.

This chapter reviews empirically supported and efficacious behavioral approaches to the treatment and management of migraine and TTH and their comorbidities. Evidence-based behavioral medicine treatments for migraine include cognitive behavioral therapy (CBT) and biobehavioral training (biofeedback, relaxation training, and stress management). These techniques have demonstrated efficacy when learned and practiced correctly and may be used individually or in conjunction with

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pharmacological and other interventions. Other significant behavioral components for effective headache management include patient education as well as enhancement of patient self-efficacy, motivation, and adherence.

Headache Diagnosis

Classification and diagnosis are important for guiding treatment efforts and identifying subtypes that present special challenges. Non-physician healthcare providers are urged to ensure that all patients in their practice have been properly evaluated by a medical healthcare professional and to maintain a close working relationship with a medical headache specialist even after a patient has been cleared by a headache specialist, as any patient may *subsequently* develop an underlying physical problem needing attention. Although most headaches are benign, 1–3% can be life-threatening (Evans, 2001). Dodick (2003) has developed a list of "red flags" or "danger signs," captured in the clever mnemonic "SNOOP," which suggests the presence of a serious underlying medical condition and the possible need for immediate referral to a medical headache specialist (see Table 34.1).

The International Classification of Headache Disorders (ICHD) system is the standard for classification and diagnosis (ICHD-2, Silberstein et al., 2004). The ICHD-2 classification system is comprised of three parts: (1) primary headache disorders (i.e., headaches not attributable to another medical condition), which has four major categories and 57 subtypes; (2) secondary headaches (i.e., headaches attributable to another medical condition), which has eight major categories and 152 subtypes and subforms; and (3) cranial neuralgias, facial pain, and "other headaches yet to be defined." Primary headache disorders can be subdivided into migraine, TTH, cluster headache and other trigeminal autonomic cephalalgias, and other primary headaches. The IHS-2 classification is not static, and criteria and descriptions for certain types of headaches are continuing to be refined as new findings emerge. Migraine and tension-type headaches are the two most common

Table 34.1 SNOOP Criteria

Systemic signs of illness (e.g., fever, pregnancy, co-occurring cancer, vomiting that persists or is progressive, stiff neck, compromised immunology)
Neurologic signs/symptoms (e.g., altered mental status, focal neurological signs/symptoms, papilledema, seizures)
Onset that is new or sudden, especially in individuals aged 40 and above
Other associated symptoms (e.g., headache that occurs following head/neck trauma, awakens the person from sleep, or becomes worse by Valsalva maneuvers)
Prior headache history that is markedly different from the current headache (e.g., symptom pattern is different, severity and frequency have increased substantially)

Source: Adapted from Dodick, D. W. (2003). Clinical clues and clinical rules: Primary versus secondary headache. *Advanced Studies in Medicine, 3*, S550–S555.

primary headache disorders, and are those most likely to be seen by behavioral medicine healthcare providers. This chapter will focus on these two headache types, with brief discussions of other subtypes and complications of headache.

Tension-type headache

The primary features of TTH are bilateral location (pain on both sides of the head), non-pulsating quality, and mild-to-moderate pain intensity, although features may vary by individual. It typically remains unchanged or improves with physical activity. Stress is a very common trigger for TTH. It can be subdivided into: (1) infrequent episodic (headaches occurring less frequently than 1 day per month), (2) frequent episodic (headaches on 1–14 days per month), and (3) chronic daily headache (headaches on 15 or more days per month). In a large, population-based study, the 1-year period prevalence of episodic tension-type headache (ETTH) was 38.3%, and chronic tension-type headache (CTTH) was 2.2% (Schwartz, Stewart, Simon, & Lipton, 1998).

Migraine

Migraine is a neurological condition that includes moderate-to-severe headache. Pain is most often unilateral, pulsating in quality, and aggravated by movement and/or activity. Nausea and vomiting are frequently present, as are photo-, phono-, and osmophobia (sensitivity to light, sound, and smell, respectively). Some migraineurs experience a distinct aura before the onset of pain, which is characterized by focal neurologic features/symptoms that precede the headache for up to 1 hour. These auras are most typically visual in nature, such as seeing flickering lights, spots or lines, or losing a portion of the visual field, but other neurological manifestations may occur as well (numbness and feelings of "pins and needles"). Migraine can be disabling, burdensome, and affect all life aspects (e.g., occupational, academic, social, familial, and personal) (Buse et al., 2009; Lipton, Buse, & Sollars, 2013).

Based on headache days, migraine is divided into episodic migraine (EM), with <15 headache days per month, and chronic migraine (CM), with ≥ 15 headache days per month (Headache Classification Committee of the International Headache Society, 2004). Episodic migraine affects an estimated 12% of the population, including 18% of females and 6% of males (Lipton et al., 2007). CM affects 1–2% of the population, and is also more common in females (Buse et al., 2012a). Migraine is associated with increased odds for a number of comorbid psychiatric conditions including depression, anxiety, panic disorder, obsessive–compulsive disorder, bipolar disorder, childhood abuse and neglect, post-traumatic stress disorder (PTSD), and suicide attempts (Baskin & Smitherman, 2009; Breslau & Davis, 1993; Buse et al., 2013; Jette et al., 2008). In a cross-sectional analysis, the gender-adjusted odds ratios for migraineurs for these disorders ranged from 2.6 for phobias to 6.6

for panic disorder. Migraine and depression are bidirectional, and each places those who experience one at a higher risk for the other (Breslau & Davis, 1993). Migraine also negatively impacts quality of life and can result in significant headache-related disability, and lost time and productivity during work, family, and leisure-time activities (Dueland et al., 2004; Lipton et al., 2003). This extra burden occurs not only during attacks, but also interictally (Buse et al., 2007). Individuals with chronic migraine have greater impairment in health-related quality of life, greater headache-related disability, worse healthcare costs and lost productivity, and more medical and psychiatric comorbidities than do those with episodic migraine (Buse et al., 2010, 2012b, 2013).

Approximately 2.5% of individuals with EM progress to CM over the course of 1 year. There are several variables that have been associated with the progression to CM. Many of these are psychological and behavioral, and provide targets for behavioral intervention (Lipton et al., 2013). Knowledge of risk factors associated with migraine progressing from EM to CM can be useful when intervening. Some known risk factors are non-remediable (sex, age, race, socioeconomic status, traumatic brain injury), but others may serve as good targets for behavioral interventions, including frequency of migraine attacks, obesity, acute medication overuse, caffeine overuse, stressful life events, depression, anxiety, and sleep disorders (Bigal & Lipton, 2006, Lipton et al., 2013).

Cluster headache

Cluster headache (CH) is characterized by sharp, agonizing pain in or around the eye. This headache has been referred to as "suicide headache" due to the extreme pain (Markley & Buse, 2006). Cluster headaches typically last about an hour and occur in multiple episodes or "clusters" over 2 weeks to 3 months (however, a small percentage experience nearly continuous or "chronic" CH). Cluster headache is much less common, but extremely debilitating and is experienced by men between four to seven times more often than women (Finkel, 2003). The limited epidemiological studies have suggested prevalence rates of between 56 and 326 people per 100,000 (Torelli et al., 2006). Treating patients who have cluster headache chiefly by non-pharmacological treatments has met with limited success (Blanchard, Andrasik, Jurish, & Teders, 1982). However, non-pharmacological approaches may still be of value in helping cluster sufferers cope with the overwhelming distress that often results from repeated, intense headache attacks and psychological comorbidity (Andrasik, 1990; Robbins et al., 2012).

Medication overuse and medication-overuse headache

Several medications that are commonly prescribed for headache patients, namely opioids, barbiturates, triptans, caffeine-containing combinations, and ergotamine preparations, can lead to what was originally termed "rebound" headaches if overused (Kudrow, 1982; Saper, 1987). The term "rebound" refers both to the gradual worsening of the headache as the medication wears off and the extreme exacerbation that often accompanies abrupt discontinuation of the medication (withdrawal-like phenomenon). This sequence "seduces" patients into taking ever-increasing amounts of medication, establishing a vicious cycle (Saper, 1987). Kudrow (1982) was able to demonstrate that medication overuse actually lessened the effectiveness of medications that would otherwise be effective. More recent research has confirmed these findings regarding medication overuse and its interference potential (Andrasik, Grazzi, Usai, Buse, & Bussone, 2009; Grazzi, Andrasik, Usai & Bussone, 2009; Blanchard, Taylor, & Dentinger, 1992; Mathew, Kurman, & Perez, 1990; Michultka, Blanchard, Appelbaum, Jaccard, & Dentinger, 1989). In addition, overuse or high use of some of these medications is related to an increased risk of progression from EM to CM (Bigal et al., 2008). In addition to the risk for rebound headache, opioid use has been linked to several other negative outcomes, including more severe headache-related disability, symptomology, comorbidities (depression, anxiety, and cardiovascular disease and events), and greater healthcare resource utilization for headache (Buse et al., 2012a).

Patients often find it very difficult to discontinue the offending medications (Saper & Sheftell, 2000). Psychological intervention is extremely helpful in treating medication overuse (Andrasik, Buse, & Grazzi, 2009; Andrasik et al., 2009; Lake 2006; Saper et al., 2005, Saper & Lake, 2006). As an early example, Kudrow (1982) required his patients to withdraw abruptly on their own and encountered high rates of dropout in the process. Regular therapist contact and support, concurrent provision of appropriate prophylactic medication as necessary, and beginning instruction in behavioral coping skills may help patients to be more successful in completing a needed medication washout period (Worz, 1983). Grazzi and colleagues (2002) found it necessary to hospitalize a group of refractory drug-induced headache patients in order to withdraw them from their offending medications and to start them on an appropriate prophylactic course. Some of the patients received behavioral treatment in addition to detoxification. At the first planned follow-up, both groups revealed similar levels of improvement. However, at the 3-year follow-up, patients receiving the combined treatment showed greater improvement on 2–3 measures collected prospectively, and significantly lower rates of relapse (13 versus 42%). This condition has since been renamed "medication overuse headache," and diagnostic criteria for it may be found in Table 34.2. Patients with medication overuse headache are also more likely to have multiple psychiatric conditions that warrant treatment, including depression and anxiety (Radat et al., 2005).

Behavioral Treatments for Headache

Non-pharmacological treatments for migraine and chronic TTH can be broadly divided into the categories of behavioral treatments (CBT and biobehavioral

Table 34.2 Revised criteria for medication overuse headache.

A. Headache present on ≥15 days/month
B. Regular overuse for >3 months of one or more acute/symptomatic treatment drugs as defined under sub forms of 8.2
   1. Ergotamine, triptans, opioids, **or** combination analgesic medications on ≥10 days/month on a regular basis for >3 months.
   2. Simple analgesics **or** any combination of ergotamine, triptans, and analgesics opioids on ≥15 days/month on a regular basis for >3 months without overuse of any single class alone.
C. Headache has developed or markedly worsened during medication overuse.

Source: Headache Classification Committee, 2006. Reproduced with permission of Sage Publications.

training, i.e., biofeedback, relaxation training, and stress management), physical therapies, and education, including lifestyle modification. Some of these interventions benefit all patients with headache, while only patients with chronic or severe headache conditions may require some interventions. Behavioral therapies may be offered individually or in conjunction with a medicine regimen. A combination of pharmacological and non-pharmacological approaches has been demonstrated to be more effective than either approach on its own (Holroyd et al., 1995; Holroyd et al., 2001) to help maintain positive outcomes (Grazzi et al., 2002) and to improve treatment adherence (Rains et al., 2006a, 2006b).

In this chapter, we will review the empirically supported and efficacious behavioral approaches. Empirically supported or "evidence-based" behavioral medicine is defined as "The conscientious, explicit and judicious use of current best evidence in making clinical decisions about the care of patients . . . thereby integrating individual clinical care with the best available clinical evidence" (Eddy 2001). Behavioral treatments with demonstrated empirical efficacy for headache management have become standard components of specialty headache centers and multidisciplinary pain management programs. They are endorsed by the American Medical Association, the World Health Organization, and the National Institutes of Health, as well as many other professional organizations (Goslin et al., 1999).

Behavioral treatments have been the subject of many evidence-based reviews. These include quantitative (via statistical or meta-analysis) and qualitative (study-by-study reviews conducted by evidentiary panels applying strict methodological design criteria) reviews. Meta-analyses abound and uniformly support the utility of these approaches (see Andrasik, 2007, for a historical summary, and Nestoriuc & Martin, 2007, Nestoriuc et al., 2008, for recent examples). The most recent meta-analysis (Nestoriuc et al., 2008) is contained in a comprehensive efficacy ("White Paper") review of existing investigations of biofeedback for migraine and TTH. Efficacy recommendations were provided, according to guidelines jointly established by the Association for Applied Psychophysiology and Biofeedback (AAPB) and the International Society for Neurofeedback and Research (ISNR)

(LaVaque et al., 2002). Effect sizes were computed for various biofeedback treatment conditions in nearly 100 outcome studies, which included approximately 3,500 subjects, all of whom met rigid inclusion criteria. Fifty-six investigations focused on migraine, with a mean number of 40 subjects per study. Forty-five studies investigated TTH, with a mean of 29 subjects per study. Seven studies included both headache types.

Mean effect size scores supported the utility for various biofeedback treatments for headache in adults, with effects being maintained over an average follow-up period of 14 months. These results were confirmed when "intent-to-treat" analyses were performed, something not always included in meta-analyses. Effect size scores for electromyogram (EMG), temperature, combinations of biofeedback and relaxation, and blood volume pulse (BVP) biofeedback treatment for migraine ranged from approximately 0.40 to 0.70, with BVP showing the largest effect size. EMG was the only biofeedback modality with a sufficient number of trials to examine for TTH, and effect size scores for various pain outcome measures (including medication reduction) all ranged from approximately 0.40 to 0.80. The review also included "fail safe analyses" to examine for potential biases due to the "file drawer" effect. Four thousand studies would have to exist with zero effects to reduce the mean effect size scores found in this analysis to zero. One hundred forty-eight studies with zero effects would be needed to reduce the mean effect score to small (0.20) for migraine, while 168 studies with zero effects would be needed to reduce the mean effect score to small (0.20) for TTH. Thus, the results obtained by Nestoriuc and colleagues (2008) provide strong support for the efficacy of biofeedback treatments for headache.

Nestoriuc and colleagues (2008) also examined effects for secondary variables as well, something not included in prior analyses. Biofeedback was found to lead to significant improvements in perceived self-efficacy, symptoms of depression and anxiety, and medication use, as well. The authors concluded that biofeedback can be supported as an efficacious treatment option for migraine with a confidence of Level 4 evidence (efficacious) and for TTH as Level 5 (efficacious and specific) according to the AAPB/ ISNR criteria, which corresponds to a grade of 1A+ according to van Kleef and colleagues (2009). An earlier, more expanded meta-analysis of non-pharmacological treatments for migraine alone, sponsored by the US Agency for Healthcare Research and Quality (AHRQ), identified 355 studies of behavioral and physical treatments (Goslin et al., 1999). A few of these (70 of 355) were controlled trials of behavioral treatments and fewer yet (39 of 355) met criteria for inclusion in their meta-analysis. Nonetheless, similar levels of support were found for biobehavioral treatments of migraine.

A number of expert panels have conducted consensus-based reviews for behavioral treatments, with the most ambitious of these being commissioned by the US Headache Consortium. A large panel of experts was composed from representatives of several medical societies: the American Academy of Family Physicians, American Academy of Neurology, American Headache Society, American College of Emergency Physicians, American College of Physicians – American Society of Internal Medicine, American Osteopathic Association, and National Headache Foundation

(Campbell et al., 2000). The US Headache Consortium was tasked to develop "scientifically sound, clinically relevant practice guidelines on chronic headache in the primary care setting," and to "propose diagnostic and therapeutic recommendations to improve the care and satisfaction of migraine patients" based on a review of the current literature (Goslin et al., 1999). The consortium utilized a quality of evidence grading system, developed by Fiore and colleagues (1996), which closely approximates the scheme of van Kleef and colleagues (2009):

- *Grade A*: Multiple well-designed randomized clinical trials, directly relevant to the recommendation, yielded a consistent pattern of findings.
- *Grade B*: Some evidence from randomized clinical trials supported the recommendation, but the scientific support was not optimal (e.g., either few randomized trials existed, existing trials were somewhat inconsistent, or trials were not directly relevant to the recommendation).
- *Grade C*: The consortium achieved consensus on the recommendation in the absence of relevant randomized controlled trials.

The consortium awarded Grade A to the following treatments: relaxation training, thermal biofeedback combined with relaxation training, electromyographic biofeedback, and CBT for the prevention of migraine. Grade B evidence was assigned for behavioral therapy combined with preventive drug therapy to achieve added clinical improvement for migraine. If the consortium updated their review, they likely would assign an "A" grade now to the combination of behavioral and pharmacological treatment, due to the subsequent publication of some large-scale trials showing such additive effects (Holroyd et al., 2001, 2010). Studies directly comparing behavioral to prophylactic pharmacological treatments, although few in number, have typically found equivalent outcomes. Using meta-analytic techniques, treatment conditions from disparate studies can be pooled for head-to-head statistical analyses. When performed, all have shown very similar outcomes for behavioral and drug treatments (Holroyd & Penzien, 1990; Holroyd, Penzien, & Cordingley, 1991; Holroyd, Penzien, Rokicki, & Cordingley, 1992; Penzien et al., 1990). A review of some techniques is provided in the following text.

Patient Education and Motivation and Adherence

Patient education

Patient "buy-in" and active engagement are essential for all behavioral interventions, as patients make the majority of decisions about what technique(s) to apply and when to do so. Education alone can lead to significant improvements in pain outcomes, functional status and quality of life, and decreased symptoms of depression and service utilization (Blumenfeld & Tischio, 2003; Harpole et al., 2003; Lemstra et al., 2002; Rothrock et al., 2006). Brief patient education has been shown to improve adherence and efficacy for pharmacological treatment alone (e.g., abortive medications) (Holroyd et al., 1989).

No discipline has a corner on the educational market, and conveyance of the material may take on varied formats – individual consultation, formal group classes, or patient self-guided learning. Helpful information designed specifically for headache patients may be found on an online forum sponsored by the American Headache Society (American Council for Headache Education – ACHE, online at www.achenet.org). Here, patients are informed about the relationship between their behaviors and lifestyle choices, which can enhance self-efficacy, promote a more internal locus of control, and strengthen the patient–provider collaborative relationship. The following are among the most important areas to include in patient education:

- Provision of a basic understanding of headache pathology
- Education about the typical course of the chronic nature of headache
- Reassurance of the benign nature of headaches (once other causes have been ruled out)
- Instruction about the proper application of medication, if indicated
- Point out the pivotal importance of patient involvement and exactly what is required for successfully applying behavioral techniques

Patients who understand the mechanisms of their prescribed medications and how they fit with their treatment plan are twice as likely to fill the prescription (Cameron, 1996). Frank conversations with patients help set the occasion to discuss the potential for medication overuse headache, adverse effects of medications, and possible deleterious drug interactions, as well as the effects and interactions of any over-the-counter agents and herbal treatments they may be taking. The importance of this will become more evident in a subsequent section. Having patients maintain detailed daily headache records can aid them in learning the relationship between their thoughts, behaviors, emotions, and lifestyle choices.

The degree of patient understanding and agreement needs to be evaluated by requesting feedback and employing specific communication strategies. The "Ask–Tell–Ask" strategy has been used with great effect in the American Migraine Communication Study – 2 (Hahn et al., 2008). This strategy acknowledges that effective education requires assessing what the patient already knows and believes, then building on (or correcting when necessary) this understanding. The "Ask–Tell–Ask" technique relies upon open-ended questions, active listening, and "being fully present" with the patient.

Rains and colleagues (2006b) make the following suggestions for effective education and enhancing adherence:

- Limit instructions to three to four major points during each discussion
- Use simple, everyday language, especially when explaining diagnoses and treatment instructions (model or demonstrate, when possible)

- Supplement oral instructions with written materials
- Involve the patient's family members or significant others
- Ask patients to restate recommendations back to you ("I want to make sure I am being clear and that you understand what I am saying, so please tell me in your own words what we just covered")
- In conclusion, repeat and reinforce the concepts that were discussed

Adherence and motivation

Adherence refers to an active and collaborative involvement by the patient when implementing a therapeutic regimen. Compliance, on the other hand, refers to the degree to which patients follow medical recommendations of their provider (Rains et al., 2006a; Urquhart, 1996). Although these terms are often used interchangeably, we much prefer the term *adherence* within the headache care arena, as it emphasizes the importance of patient participation in effective treatment. Non-adherence can pose a significant barrier to effective headache management in many ways: lead to misuse of medication (including unfilled, overused, underused, incorrectly used, and non-advised discontinuation of prescribed medications or treatments) (Gallagher & Kunkel, 2003), inconsistent appointment keeping (Edmeads et al., 1993; Spierings & Miree, 1993), failure to maintain headache diary records, and an unwillingness or inability to follow clinical suggestions. Improper medication use may not only limit effectiveness but may also aggravate the primary headache condition when taken to excess (Rains et al., 2006a).

Rates of adherence with behavioral recommendations – such as dietary modifications, weight loss, exercise, smoking cessation, and alcohol or substance use, some of the adjunctive components of behavioral headache management – are even lower than rates of adherence with prescribed medication regimens (Claxton et al., 2001). Sociodemographic factors play a role in predicting adherence, but even more important is a patient's perceived level of self-efficacy (Bandura, 1977, 1986).

Most models addressing health-related behaviors hypothesize that health-related behavior change and motivation are based upon the following basic components/concepts (Elder et al., 1999; Jensen, 2002; Miller & Rollnick, 2002):

- The patient's readiness for change.
- Self-efficacy.
- Outcome efficacy.
- Skills or knowledge alone are not sufficient to ensure behavior change.
- The patient must want to change, believe that he or she can, and believe that the necessary actions will accomplish the desired goal(s).

Application of the transtheoretical model (Miller, 1996; Prochaska et al., 1997) may be helpful in deciding the best initial course of action to pursue with a given patient. In this model, a patient's readiness and motivation for change can be categorized into one of five stages:

- Stage 1: *Precontemplation* (The individual does not recognize a problem exists, and is not even thinking about changing behavior.)
- Stage 2: *Contemplation* (The individual recognizes a problem and begins to think about changing behavior; he or she may even be in the process of developing a plan, but has yet to take any action.)
- Stage 3: *Preparation* (The individual has completed the needed research, developed a plan, and may begin making minor changes or actions.)
- Stage 4: *Action* (The individual is now actively engaged in behavior change or new actions.)
- Stage 5: *Maintenance* (The individual is continuing behaviors necessary to maintain changes.)

Thus, therapists need to consider an individual's stage of readiness for change and tailor their interventions, clinical advice, and education accordingly. Rains and colleagues (2006a) provide several behavioral strategies to enhance patient adherence and maximize headache management that readers may find helpful. Finally, it is important to remember that patients do not always progress through these stages in an orderly manner and, at times, may loop back to lower stages before significant change or upward progress is made.

Biofeedback

Biofeedback involves monitoring physiological processes of which the patient may not be consciously aware and/or does not believe that he or she has the ability to voluntarily control. The goal is to increase patient awareness of, and bring under voluntary control, specific physiological functions associated with or presumed to underlie headache (Buse & Andrasik, 2009; Penzien & Holroyd, 1994). Biological or physiological information is detected by special externally placed sensors, the information is converted into a signal that is understandable to the patient, and it is then "fed back" to the patient via some type of display to facilitate learning and gaining voluntary control (audible sound, displays on a monitor). Specific modalities are used for certain conditions, but often multiple modalities are combined.

Biofeedback takes one of two general approaches. The first is designed to facilitate overall relaxation and is often termed "biofeedback-assisted relaxation." Feedback of muscle tension levels, hand temperature (believed to provide an indirect measure of sympathetic arousal), and sweat gland activity (more directly tied to the sympathetic nervous system) can be especially helpful in this regard as well. When used in this manner, training in various relaxation skills is often added (such as autogenic training, diaphragmatic breathing, and visualization or guided imagery), designed to reduce sympathetic nervous system activity and activate the parasympathetic nervous system. Recent investigations on the neurophysiology of migraine and fMRI studies of pain networks suggest that behavioral interventions can influence neuromodulation (Andrasik & Rime, 2007).

The second approach targets specific response systems that are linked more conceptually to the underlying physiology of headache: muscle tension when obvious abnormalities exist and blood volume pulse (BVP) and electroencephalography (EEG) biofeedback for migraine.

BVP biofeedback involves monitoring blood flow in the temporal artery and providing feedback to teach patients how to decrease or constrict blood flow in this region. This approach, as first envisioned (Friar & Beatty, 1976), can be thought of as the non-pharmacologic counterpart to an abortive agent. The accumulated body of research is now sufficient to establish this as an evidence-based approach, but one that is likely to operate via mechanisms other than those originally thought (peripheral vasoconstriction) (see later sections for further detail).

The second focuses on EEG activity and takes a totally different tactic. The first form of EEG biofeedback derives from research examining the links between certain EEG frequency bands and the experience of pain (Jensen et al., 2008). This research suggests that the experience of pain is associated with lower amplitudes of slow brain wave activity (delta, theta, and alpha) and higher amplitudes of faster brain wave activity (beta). Several uncontrolled series have appeared, but better controlled investigations are needed before making specific claims.

The second form of EEG biofeedback takes a different approach, focusing on a specific evoked potential – the contingent negative variation response (CNV). The CNV is a slow cortical event-related potential that examines EEG activity occurring between presentation of a warning stimulus followed by an imperative stimulus presented a few seconds later (i.e., a stimulus requiring a response by the individual). This potential reflects resource mobilization (e.g., expectation, attention, motivation, and motivation) (Elbert, 1993), with its amplitude arising from activation in the striato–thalamo–cortical loop (Elbert & Rockstroh, 1987). Studies with children and adults reveal that migraineurs have a heightened CNV response (i.e., increased amplitude) to novel stimuli and that they do not habituate as readily over repeated trials as do non-migraineous controls (Kropp et al., 2002). The CNV response is regarded as reflecting anticipation of a migraine attack because its amplitude and habituation patterns change during the headache-free interval. Abnormalities gradually increase in the days before a migraine attack, with the most pronounced changes occurring just prior to the attack (Siniatchkin et al., 2006).

One study (but one study only) has explored whether child migraineurs could learn, via biofeedback, to alter their CNV activity and further if this favorably impacted the subsequent course of migraine attacks (Siniatchkin et al., 2000). Ten child migraineurs, without aura, were provided with CNV biofeedback, where they were taught how to decrease as well as increase EEG negativity (as some assume that bidirectional control of a physiological response reflects a greater overall level of self-regulation skills). Following 10 sessions of treatment, children showed they could regulate their CNV activity, but only when feedback was provided. The number of biofeedback sessions administered was low, considering that EEG treatment investigations for other conditions typically utilize 20–40 sessions. A greater number of sessions may have led to greater response generalization. Of more interest is the finding that baseline or tonic levels of CNV negativity changed over treatment, so much so that the child migraineurs were no longer distinguishable from a matched sample of healthy controls (suggesting their level of cortical excitability may have diminished). CNV biofeedback led to improvements on most measures of headache activity when compared to a group of child migraineurs who comprised a waiting list control group. These preliminary findings add to those briefly mentioned for other EEG biofeedback approaches, suggesting that further investigations are warranted.

Relaxation training

Relaxation techniques focus on minimizing overall physiological responses to stress and decreasing sympathetic arousal. The classic procedure called progressive muscle relaxation training (PMRT), first introduced by Jacobson in a publication in 1938, is based on muscle discrimination training and is implemented by systematically tensing and relaxing various muscle groups while taking note of the contrasting sensations. By exaggerating and then relaxing muscle tension levels, the patient learns how better to discriminate various tension states and the associated feelings. Also, when vigorous contractions are stopped, the muscles reflexively return to a lower state of tension (process of homeostasis), further enhancing discrimination learning. As patients become increasingly aware of rising tension states, they can then engage in strategies to counteract tension build-up. Because it is impossible to experience tension and relaxation at the same time, Wolpe (1958) used PMRT as part of his desensitization procedure for treatment of phobias. Soon afterwards, PMRT became an essential tool in the treatment of phobias, anxiety, and related disorders, and now is used for a variety of conditions characterized by hyper-arousal.

Other commonly utilized clinical relaxation techniques include visual or guided imagery, cue-controlled relaxation, diaphragmatic breathing, hypnosis (therapist- or self-applied), meditation, prayer, yoga, listening to pleasant music, autogenic training (Luthe & Schultz, 1969), the "relaxation response" (Benson, 1975), and any other method the patient finds effective for quieting the mind and body (Hall, 2011; Rime & Andrasik, 2011). Relaxation training is often taught by clinical professionals, but it can also be self-taught by patients with print, audio, or DVD support materials. Guided visual imagery and diaphragmatic breathing exercises are available free of charge at www.dawnbuse.com. Regular practice in the patient's day-to-day setting is required in order to gain full benefits and implement the strategies when needed (Smith, 2005).

Cognitive behavioral therapy (CBT)

CBT is comprised of cognitive and behavioral strategies. Cognitive strategies focus on identifying and challenging maladaptive or dysfunctional beliefs, thoughts, and responses to stress (Beck et al., 1979; Holroyd & Andrasik, 1982; McCarran & Andrasik, 1987). Behavioral strategies are designed to help patients identify and modify behaviors that may precipitate, increase, or maintain undesirable or unhealthy states. In the case of headache, this includes modifying suspected triggers and promoting healthy lifestyle habits. CBT, some argue, has the added advantage of also being effective in treating depression, anxiety, panic attacks, obsessive–compulsive disorder, eating disorders, and sleep disorders, among other conditions – all common comorbidities of migraine. Cognitive targets of CBT for headache management include enhancing self-efficacy (Bandura, 1977), reducing "catastrophizing" (Holroyd et al., 2007) (a pattern of thinking that is hopeless and overwhelming and has been shown to predict poor outcome and reduced quality of life), and helping patients adopt an internal versus an external locus of control (i.e., a belief that the mechanism for change lies within oneself and not with the physician, medication, or medical procedures) (French et al., 2000; Heath et al., 2008). Other targets of CBT for headache may include assertiveness training, increased coping and problem-solving skills, and stress management – anything and everything presumed to be related to headache onset, exacerbation, or maintenance.

For some migraineurs, attacks can be fairly predictable. For these patients, particular triggers, time periods, and prodromal symptoms (including auras, as mentioned earlier) provide windows of opportunity in which to apply behavioral tools as a way to stop or slow the process of migraine early, even before headache onset. It is important for patients to use a diary to note these associations. Some triggers cannot be changed or avoided, such as the menstrual cycle, in which case patients should be aware of their vulnerability to headache during this time and protect themselves by following a very healthy lifestyle. By doing so, they may reduce the number of headache attacks, although it is unlikely that they will disappear altogether. Patients may be able to modify or eliminate other triggers as well.

Mindfulness-based cognitive therapy (MBCT) and mindfulness-based stress reduction (MBSR) have also been used recently for headache along with other chronic pain conditions (Day et al, 2013). MBCT is based on traditional cognitive approaches to treatment combined with mindful meditation practice (Kabat-Zinn et al., 1985). It has also been demonstrated to have a positive effect on anxiety and depression (Coelho, 2007). One study examined magnetic resonance imaging (MRI) obtained from 17 participants in an 8-week MBSR program and found that participation was associated with changes in gray matter concentration in brain regions involved in learning and memory processes, emotion regulation, self-referential processing, and perspective taking (Hölzel et al., 2011).

Conclusion

There is a large, growing body of scientific evidence demonstrating efficacy and support for the use of behavioral therapies for headache. Evidence-based non-pharmacological treatments for migraine and chronic headache management include biofeedback, relaxation training, CBT, education, and lifestyle modification. These behavioral treatments may be used individually or in conjunction with pharmacological treatment. In some cases, a combination of pharmacological and non-pharmacological approaches has been demonstrated to be superior to either approach on its own, to help maintain positive outcomes and to improve treatment adherence.

All individuals with migraine and chronic headache can benefit from education, trigger identification, healthy lifestyle practices, stress management, enhancement of self-efficacy, motivation for health management, and adherence to treatment. In addition, some patients with headache require CBT biofeedback and relaxation training administered by professionals. Behavioral treatments are especially important in the effective treatment of medication overuse headache and other complicated headache conditions.

Patients can be taught ways to modify thoughts, feelings, and behavior with CBT. CBT aids in headache management by making patients more aware of triggers including the relationship between stress and headache, and by identifying and challenging counterproductive or self-defeating beliefs and ideas. In addition, CBT teaches patients to adopt an internal locus of control and actively participate in the management of their condition, including trigger identification, stress management, and maintaining healthy lifestyle habits. Biofeedback and relaxation training help provide individuals an awareness of and mastery over the physiological reactions to stress by reducing sympathetic activity.

Stress, depression, anxiety, and other psychological conditions are highly comorbid with migraine and chronic headache. Patients should be routinely assessed and appropriately treated for these conditions. Interventions including CBT have proven efficacy for headache management as well as the treatment of depression, anxiety, and other psychological conditions. Improvements in psychological comorbidities may translate into improvements in headache status, and vice versa. Once learned, patients can benefit from these strategies for the rest of their lives. Encouraging patients to train their physiology through biofeedback and relaxation, adopt healthy lifestyle habits, and recognize and mediate the effects of stress can positively affect all aspects of their lives.

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35

The Neuromatrix in Behavioral Medicine

Ronald Melzack and Joel Katz

We all know that pain has many valuable functions. It often signals injury or disease and generates a wide range of behaviors to end it and to treat its causes. Chest pain, for example, may be a symptom of heart disease, and may compel us to seek a physician's help. Memories of past pain and suffering also serve as signals for us to avoid potentially dangerous situations. Yet another beneficial effect of pain, notably after serious injury or disease, is to make us rest, thereby promoting the body's healing processes. All of these actions induced by pain – to escape, avoid, or rest – have obvious value for survival.

Despite these beneficial aspects of pain, there are negative features that challenge our understanding of the puzzle of pain. What is the benefit of chronic phantom limb pain to an amputee whose stump has healed completely? The pain, not the physical impairment, prevents them from leading a normal life. Likewise, most backaches, headaches, muscle pains, nerve pains, pelvic pains, and facial pains serve no discernible purpose, are resistant to treatment, and are a catastrophe for the people who are afflicted.

Pain may be the warning signal that saves the lives of some people or animals, but it destroys the lives of countless others. Chronic pains, clearly, are not a warning to prevent physical injury or disease. They *are* the disease – the result of neural mechanisms gone awry (Niv & Devor, 2004; Siddall & Cousins, 2004; Woolf, 2004). The neuromatrix concept suggests the brain mechanisms that may underlie some kinds of chronic pain and points to new forms of treatment.

Phantom Limbs and the Concept of a Neuromatrix

The gate control theory of pain highlighted the role of spinal and brain mechanisms in acute and chronic pain (Melzack & Wall, 1965, 1996). However, as historians of

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science have pointed out, good theories are instrumental in producing facts that eventually require a new theory. And this is what has happened: it is possible to make adjustments to the gate control theory so that, for example, it includes long-lasting activity (Melzack & Wall, 1996). However, there is a set of observations on pain in paraplegics that just does not fit the theory. This does not negate the gate theory, of course. Peripheral and spinal processes are obviously an important part of pain, and we need to know more about the mechanisms of peripheral inflammation, spinal modulation, midbrain descending control, and so forth. However, the data on painful phantoms below the level of total spinal section (Melzack & Loeser, 1978) indicate that we need to go beyond the foramen magnum and into the brain.

The sensory thalamus and cortex are important, of course, but they mark just the beginning of the neural activities that underlie perception. The cortex, as White and Sweet (1966) have made amply clear, is not the pain center, and neither is the thalamus. The areas of the brain involved in pain experience and behavior are extensive. They must include somatosensory projections as well as the limbic system. Furthermore, because our body perceptions include visual and vestibular mechanisms as well as cognitive processes, widespread areas of the brain must be involved in pain. However, the plain fact is that we do not have an adequate theory of how the brain works.

Melzack's analysis of phantom limb phenomena (Melzack, 1989, 1990) has led to four conclusions that point to a new conceptual nervous system. First, because the phantom limb (or other body part) feels so real, it is reasonable to conclude that the body we normally feel is subserved by the same neural processes in the brain; these brain processes are normally activated and modulated by inputs from the body, but they can act in the absence of any inputs. Second, all the qualities we normally feel from the body, including pain, are also felt in the absence of inputs from the body; from this, we may conclude that the origins of the patterns that underlie the qualities of experience are in neural networks in the brain; stimuli may trigger the patterns but do not produce them. Third, the body is perceived as a unity and is identified as the "self," distinct from other people and the surrounding world. The experience of a unity of such diverse feelings, including the self as the point of orientation in the surrounding environment, is produced by central neural processes and cannot derive from the peripheral nervous system or spinal cord. Fourth, the brain processes that underlie the body-self are, to an important extent that can no longer be ignored, "built in" by genetic specification, although this built-in substrate must, of course, be modified by experience. These conclusions provide the basis of the new conceptual model.

Outline of the theory

The anatomical substrate of the body-self is comprised of a large, widespread network of neurons that consists of loops between the thalamus and cortex as well as between the cortex and limbic system. Melzack has labeled the entire network, whose spatial distribution and synaptic links are initially determined genetically and are later sculpted by sensory inputs, as a *neuromatrix* (Melzack, 1989, 1990). The loops diverge to permit parallel processing in different components of the neuromatrix and converge repeatedly to permit interactions between the output products of processing. The repeated *cyclical processing and synthesis* of nerve impulses through the neuromatrix imparts a characteristic pattern: the *neurosignature*. The neurosignature of the neuromatrix is imparted on all nerve impulse patterns that flow through it; the neurosignature is produced by the patterns of synaptic connections in the entire neuromatrix. All inputs from the body undergo cyclical processing and synthesis so that characteristic patterns are impressed on them in the neuromatrix. Portions of the neuromatrix are specialized to process information related to major sensory events (such as injury, temperature change, and stimulation of erogenous tissue), and may be labeled as neuromodules, which impress subsignatures on the larger neurosignature.

The neurosignature, which is a continuous outflow from the body-self neuromatrix, is projected to areas in the brain – the *sentient neural hub* – in which the stream of nerve impulses (the neurosignature modulated by ongoing inputs) is converted into a continually changing stream of awareness. Furthermore, the neurosignature patterns may also activate a neuromatrix to produce movement. That is, the patterns bifurcate, so that a pattern proceeds to the sentient neural hub (where the pattern is converted into the experience of movement), and a similar pattern proceeds through a neuromatrix that eventually activates spinal cord neurons to produce muscle patterns for complex actions.

The four components of the new conceptual nervous system, then, are: (1) the body-self neuromatrix; (2) cyclical processing and synthesis in which the neurosignature is produced; (3) the sentient neural hub, which converts (transduces) the flow of neurosignatures into the flow of awareness; and (4) activation of an action neuromatrix to provide the *pattern* of movements to bring about the desired goal.

The body-self neuromatrix

The body is felt as a unity, with different qualities at different times. The brain mechanism that underlies the experience also comprises a unified system that acts as a whole and produces a neurosignature pattern of a whole body. The conceptualization of this unified brain mechanism lies at the heart of the theory that Melzack calls the "neuromatrix." "Matrix" has several definitions in Webster's dictionary, and some of them imply precisely the properties of the neuromatrix. First, a matrix is defined as "something within which something else originates, takes form or develops." The neuromatrix (not the stimulus, peripheral nerves, or "brain center") is the origin of the neurosignature; the neurosignature originates and takes form in the neuromatrix. Although the neurosignature may be activated or modulated by input, the input is only a "trigger" and does not produce the neurosignature itself. Matrix is also defined as a "mold" or "die" that leaves an imprint on something else. In this sense, the neuromatrix "casts" its distinctive signature on all inputs (nerve impulse patterns) that flow through it. Finally, matrix is defined as "an array of circuit elements . . . for performing a specific function as interconnected." The array of neurons in a neuromatrix is genetically programmed to perform the specific function of producing the signature pattern. The final, integrated neurosignature pattern for the body-self ultimately produces awareness and action. For these reasons, the term "neuromatrix" seems to be appropriate. The neuromatrix, distributed throughout many areas of the brain, comprises a widespread network of neurons, which generates patterns, processes information that flows through it, and ultimately produces the pattern that is felt as a whole body. The stream of neurosignature output with constantly varying patterns riding on the main signature pattern produces the feelings of the whole body with constantly changing qualities.

Psychological reasons for a neuromatrix

It is incomprehensible how individual bits of information from skin, joints, or muscles can all come together to produce the experience of a coherent, articulated body. At any instant in time, millions of nerve impulses arrive at the brain from all the body's sensory systems, including the proprioceptive and vestibular systems. How can all this be integrated in a constantly changing unity of experience? Where does it all come together?

Melzack proposes a genetically built-in neuromatrix for the whole body, producing a characteristic neurosignature for the body that carries with it patterns for the myriad qualities we feel. The neuromatrix produces a continuous message that represents the whole body, in which details are differentiated within the whole as inputs come into it. We start from the top, with the experience of a unity of the body, and look for differentiation of detail within the whole. The neuromatrix, then, is a template of the whole, which provides the characteristic neural pattern for the whole body (the body's neurosignature), as well as subsets of signature patterns (from neuromodules) that relate to events at (or in) different parts of the body.

These views are in sharp contrast to the classical specificity theory, in which the qualities of experience are presumed to be inherent in peripheral nerve fibers. Pain is not injury; the *quality of pain experiences* must not be confused with the physical event of breaking skin or bone. Warmth and cold are not "out there"; temperature changes occur "out there," but the *qualities of experience* must be generated by structures in the brain. There are no external equivalents to stinging, smarting, tickling, itch; the *qualities* are produced by built-in neuromodules whose neurosignatures innately produce the qualities.

We do not learn to feel qualities of experience: our brains are built to produce them. The inadequacy of the traditional peripheralist view becomes especially evident when we consider paraplegics with high-level complete spinal breaks. In spite of the absence of inputs from the body, virtually every quality of sensation and affect is experienced. It is known that the absence of input produces hyperactivity and abnormal firing patterns in spinal cells above the level of the break (Lenz et al., 1987). However, how, from this jumble of activity, do we get the meaningful experience of movement, the coordination of limbs with other limbs, cramping pain in specific (nonexistent) muscle groups, and so on? This must occur in the brain, in which neurosignatures are produced by neuromatrixes that are triggered by the output of hyperactive cells.

When all sensory systems are intact, inputs modulate the continuous neuromatrix output to produce the wide variety of experiences we feel. We may feel position, warmth, and several kinds of pain and pressure, all at once. It is a single unitary feeling, just as an orchestra produces a single unitary sound at any moment even though the sound comprises violins, cellos, horns, and so forth. Similarly, at a particular moment in time, we feel complex qualities from all of the body. In addition, our experience of the body includes visual images, affect, "knowledge" of the self (vs. not-self), as well as the meaning of body parts in terms of social norms and values. It is hard to imagine all of these bits and pieces coming together to produce a unitary body-self, but we can conceive of a neuromatrix that impresses a characteristic signature on all the inputs that converge on it and thereby produces the never-ending stream of feeling from the body.

The experience of the body-self involves multiple dimensions – sensory, affective, evaluative, postural, and many others (Melzack & Casey, 1968; Melzack & Wall, 1996). The sensory dimensions are subserved, in part at least, by portions of the neuromatrix that lie in the sensory projection areas of the brain; the affective dimensions are subserved by areas in the brainstem and limbic system. Each major psychological dimension (or quality) of experience is subserved by a particular portion of the neuromatrix, which contributes a distinct portion of the total neurosignature. To use a musical analogy once again, it is like the strings, timpani, woodwinds, and brasses of a symphony orchestra that each comprise a part of the whole; each makes its unique contribution, yet is an integral part of a single symphony that varies continually from beginning to end.

The neuromatrix resembles Hebb's "cell assembly" and Bindra's "gnostic organization" by being a widespread network of cells that subserves a particular psychological function. However, Hebb (1949) and Bindra (1976) conceived of the cell assembly and gnostic organization, respectively, as networks developed by gradual sensory learning, whereas, in contrast, the neuromatrix is predominantly determined by genetic factors, although its eventual synaptic architecture is influenced by sensory inputs. This emphasis on the genetic contribution to the brain does not diminish the importance of sensory inputs. The neuromatrix is a psychologically meaningful unit, developed by heredity and shaped by learning, that represents an entire unified entity.

Action patterns: the action-neuromatrix

The output of the body-neuromatrix is directed at three systems: (1) the neuromatrix that produces awareness of the output; (2) a neuromatrix involved in overt action patterns; and (3) the homeostatic system that maintains physiological equilibrium when confronted with stress. Critically, just as there is a steady stream of awareness, there is also a steady output of behavior (including movements during sleep) and homeostatic regulation.

It is important to recognize that behavior occurs only after the input has been at least partially synthesized and recognized. For example, when we respond to the experience of pain or itch, it is evident that the experience has been synthesized by the body-self neuromatrix (or relevant neuromodules) sufficiently for the neuromatrix to have imparted the neurosignature patterns that underlie the quality of experience, affect, and meaning. Apart from a few reflexes (such as withdrawal of a limb, eye-blink, and so on), behavior occurs only after inputs have been analyzed and synthesized sufficiently to produce meaningful experience. When we reach for an apple, the visual input has clearly been synthesized by a neuromatrix, so that it has three-dimensional shape, color, and meaning as an edible, desirable object, all of which are produced by the brain and are not in the object "out there." When we respond to pain (by withdrawal or even by telephoning for an ambulance), we respond to an experience that has sensory qualities, affect, and meaning as a dangerous (or potentially dangerous) event to the body.

After inputs from the body undergo transformation in the body-neuromatrix, the appropriate action patterns are activated concurrently (or nearly so) with the neuromatrix for experience. Thus, in the action-neuromatrix, cyclical processing and synthesis produce activation of several possible patterns and their successive elimination until one particular pattern emerges as the most appropriate for the circumstances at the moment. In this way, input and output are synthesized simultaneously, in parallel, not in series. This permits a smooth, continuous stream of action patterns.

The command, which originates in the brain, to perform a pattern such as running, activates the neuromodule, which then produces firing in sequences of neurons that send precise messages through ventral horn neuron pools to appropriate sets of muscles. At the same time, the output patterns from the body-neuromatrix that engage the neuromodules for particular actions are also projected to the sentient neural hub and produce experience. In this way, the brain commands may produce the experience of movement of phantom limbs, even though there are no limbs to move and no proprioceptive feedback. Indeed, reports by paraplegics of terrible fatigue due to persistent bicycling movements (Conomy, 1973), like the painful fatigue in a tightly clenched phantom fist in an arm amputee (Livingston, 1998), indicate that feelings of effort and fatigue are produced by the signature of a neuromodule rather than particular input patterns from muscles and joints.

Pain and Stress

We are so accustomed to considering pain as a purely sensory phenomenon that we have ignored the obvious fact that injury does not merely produce pain; it also disrupts the brain's homeostatic regulation systems, thereby producing "stress" and initiating complex programs to reinstate homeostasis. By recognizing the role of the stress system in pain processes, we discover that the scope of the puzzle of pain is vastly expanded, and new pieces of the puzzle provide valuable clues in our quest to understand chronic pain (Melzack, 1999).

Hans Selye, who founded the field of stress research, dealt with stress in the biological sense of physical injury, infection, and pathology, and also recognized the importance of psychological stress. In recent years, the latter sense of the word has come to dominate the field. However, it is important for the purpose of understanding pain to keep in mind that stress is a biological system that is activated by physical injury, infection, or any threat to biological homeostasis, as well as by psychological threat and insult of the body-self. Both are correct and important.

The disruption of homeostasis by injury activates programs of neural, hormonal, and behavioral activity aimed at a return to homeostasis. The particular programs that are activated are selected from a genetically determined repertoire of programs, and are influenced by the extent and severity of the injury. When injury occurs, sensory information rapidly alerts the brain and begins the complex sequence of events to reinstate homeostasis. Cytokines are released within seconds after injury. These substances, such as gamma-interferon, interleukins 1 and 6, and tumor necrosis factor, enter the bloodstream within 1–4 minutes and travel to the brain. The cytokines, therefore, are able to activate fibers that send messages to the brain and, concurrently, to breach the blood–brain barrier at specific sites, and have an immediate effect on hypothalamic cells. The cytokines, together with evaluative information from the brain, rapidly begin a sequence of activities aimed at the release and utilization of glucose for necessary actions, such as removal of debris, the repair of tissues, and (sometimes) the induction of fever to destroy bacteria and other foreign substances. At sufficient severity of injury, the noradrenergic system is activated: epinephrine is released into the blood stream, and the powerful locus coeruleus/norepinephrine (LC/NE) system in the brainstem projects information upward throughout the brain and downward through the descending efferent sympathetic nervous system. Thus, the whole sympathetic–adrenal–medullary system is activated to produce readiness of the heart, blood vessels, and other viscera for complex programs to reinstate homeostasis (Chrousos & Gold, 1992; Sapolsky, 1994).

At the same time, the perception of injury activates the hypothalamic–pituitary–adrenal (HPA) system, in which corticotropin-releasing hormone (CRH) produced in the hypothalamus enters the local blood stream, which carries the hormone to the pituitary, causing the release of adrenocorticotropic hormone (ACTH) and other substances. The ACTH then activates the adrenal cortex to release cortisol, which must inevitably play a powerful role in determining chronic pain. Cortisol also acts on the immune system and the endogenous opioid system. Although these opioids are released within minutes, their initial function may be simply to inhibit or modulate the release of cortisol. Experiments with animals suggest that their analgesic effects may not appear until as long as 30 minutes after injury.

Cortisol, together with noradrenergic activation, sets the stage for response to life-threatening emergency. If the output of cortisol is prolonged, or excessive, or of abnormal patterning, it may produce destruction of muscle, bone, and neural tissue and produce the conditions for many kinds of chronic pain.

Cortisol is an essential hormone for survival after injury because it is responsible for producing and maintaining high levels of glucose for rapid response after injury, threat, or other emergency. However, cortisol is potentially a highly destructive substance because, to ensure a high level of glucose, it breaks down the protein in muscle and inhibits the ongoing replacement of calcium in bone. Sustained cortisol release, therefore, can produce myopathy, weakness, fatigue, and decalcification of bone. It can also accelerate neural degeneration of the hippocampus during aging. Furthermore, it suppresses the immune system.

A major clue to the relationships among injury, stress, and pain is that many autoimmune diseases, such as rheumatoid arthritis and scleroderma, are also pain syndromes. Furthermore, more women than men suffer from autoimmune diseases as well as chronic pain syndromes. Among the 5% of adults who suffer from an autoimmune disease, two out of three are women. Pain diseases also show a sex difference, as Berkley and Holdcroft (1999) have argued, with the majority prevalent in women, and a smaller number prevalent in men. Of particular importance is the change in sex ratios concurrently with changes in sex hormone output as a function of age. Estrogen increases the release of peripheral cytokines, such as gamma-interferon, which in turn produce increased cortisol. This may explain why more females than males suffer from most kinds of chronic pain as well as painful autoimmune diseases such as multiple sclerosis and lupus.

Some forms of chronic pain may occur as a result of the cumulative destructive effect of cortisol on muscle, bone, and neural tissue. Furthermore, loss of fibers in the hippocampus due to aging reduces a natural brake on cortisol release that is normally exerted by the hippocampus. As a result, cortisol is released in larger amounts, producing a greater loss of hippocampal fibers and a cascading deleterious effect. This is found in aging primates (Sapolsky, 1994) and presumably also occurs in humans. It could explain the increase of chronic pain problems among older people.

The cortisol output by itself may not be sufficient to cause any of these problems, but rather provides the conditions so that other contributing factors may, all together, produce them. Sex-related hormones, genetic predispositions, psychological stresses derived from social competition, and the hassles of everyday life may act together to influence cortisol release, its amount and pattern, and the effects of the target organs.

These speculations are supported by strong evidence. Chrousos and Gold (1992) have documented the effects of dysregulation of the cortisol system: effects on muscle and bone, to which they attribute fibromyalgia, rheumatoid arthritis, and chronic fatigue syndrome. They propose that they are caused by hypocortisolism, which could be due do depletion of cortisol as a result of prolonged stress. Indeed, Sapolsky (1994) attributes myopathy, bone decalcification, fatigue, and accelerated neural degeneration during aging to prolonged exposure to stress.

Clearly, consideration of the relationship between stress-system effects and chronic pain leads directly to examination of the effects of suppression of the immune system and the development of autoimmune effects. The fact that several autoimmune diseases are also classified as chronic pain syndromes – such as Crohn's disease, multiple sclerosis, rheumatoid arthritis, scleroderma, and lupus – suggests that the study of these syndromes in relation to stress effects and chronic pain could be fruitful. Immune suppression, which involves prolonging the presence of dead tissue, invading bacteria, and viruses, could produce a greater output of cytokines, with a consequent increase in cortisol and its destructive effects. Furthermore, prolonged immune suppression may diminish gradually and give way to a rebound, excessive immune response. The immune system's attack on its own body's tissues may produce autoimmune diseases that are also chronic pain syndromes. Thorough investigation may provide valuable clues for understanding at least some of the terrible chronic pain syndromes that now perplex us and are beyond our control.

In some instances, pain itself may serve as a traumatic stressor. A recent prospective study evaluated the hierarchical factor structure of commonly used pain-related anxiety measures in a large sample of surgical patients; the results suggest that the construct *sensitivity to pain traumatization* (SPT) may be a broad-based vulnerability factor. SPT may also be a maintaining factor for the transition to pain chronicity after surgery (Kleiman, Clarke, & Katz, 2011). SPT was derived from a hierarchical factor analysis of items from several pain-related anxiety measures and describes the propensity to develop anxiety-related, somatic, cognitive, emotional, and behavioral responses to pain that resemble features of a traumatic stress reaction. The results showed that the total SPT score before surgery distinguished between patients with and without chronic postsurgical pain at the 1-year follow up. That is, preoperative SPT scores were significantly higher in patients who went on to report persistent pain compared with those who were pain-free at the 1-year follow-up. SPT may serve as a predisposing factor that triggers specific expressions of pain, such as pain catastrophizing, pain anxiety, and pain avoidance, each of which may have different and unique impacts on the quality of the pain experience as well as on the maintenance of chronic pain. Consistent with the role of stress outlined in the preceding text, once pain is established, it becomes a stressor in itself and may be activated even in the absence of peripheral input not unlike the situation described earlier for phantom limb pain.

The Multiple Determinants of Pain

The neuromatrix theory of pain proposes that the neurosignature for pain experience is determined by the synaptic architecture of the neuromatrix, which is produced by genetic and sensory influences. The neurosignature pattern is also modulated by sensory inputs and by cognitive events, such as psychological stress. It may also occur because stressors, physical as well as psychological, act on stress-regulation systems, which may produce lesions of muscle, bone, and nerve tissue, thereby contributing to the neurosignature patterns that give rise to chronic pain. In short, the neuromatrix, as a result of homeostasis-regulation patterns that have failed, may produce neural "distress" patterns that contribute to the total neuromatrix pattern, and may also produce destruction of tissues that give rise to chronic pains. Each contribution to the neuromatrix output pattern may not by itself produce pain, but both outputs together may do so. The stress-regulation system, with its complex, delicately balanced interactions, is an integral part of the multiple contributions that give rise to chronic pain. The neuromatrix theory guides us away from the Cartesian concept of pain as a sensation produced by injury, inflammation, or other tissue pathology and toward the concept of pain as a multidimensional experience produced by multiple influences. These influences range from the existing synaptic architecture of the neuromatrix – which is determined by genetic and sensory factors – to influences from within the body and from other areas in the brain. Genetic influences on synaptic architecture may determine – or predispose toward – the development of chronic pain syndromes. Figure 35.1 summarizes the factors that contribute to the output pattern from the neuromatrix that produces the sensory, affective, and cognitive dimensions of pain experience and behavior (Melzack, 2001).

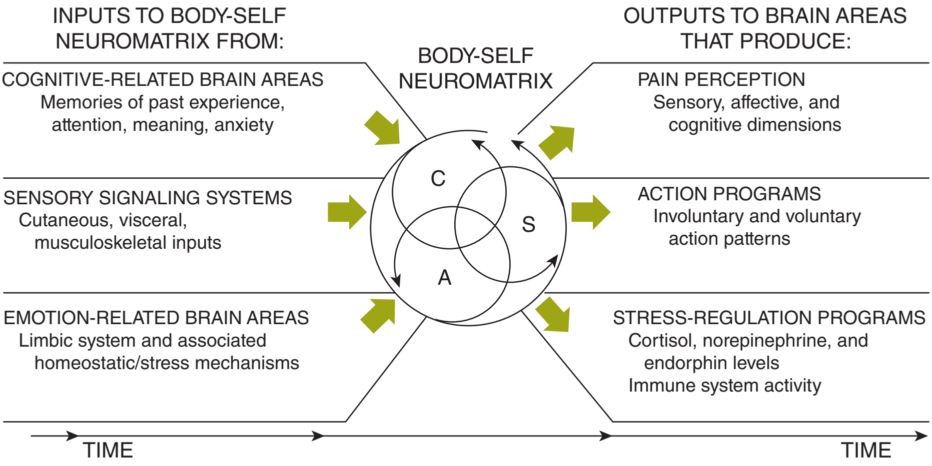

Figure 35.1 Factors that contribute to the patterns of activity generated by the body-self neuromatrix, which is comprised of sensory (S), affective (A), and cognitive (C) neuromodules. The output patterns from the neuromatrix produce the multiple dimensions of pain experience, as well as concurrent homeostatic and behavioral responses. From Melzack (2001), with permission.

Implications of the New Concept

Phantom limb pain

The new theory of brain function, proposed largely on the basis of phantom limb phenomena, provides an explanation for phantom limb pain. Amputees suffer burning, cramping, and other qualities of pain. An excellent study found that 72% of amputees had phantom limb pain a week after amputation, and that 60% had pain 6 months later (Nikolajsen & Jensen, 2003). Even 7 years after amputation, 60% still continued to suffer phantom limb pain, which means that only about 10–12% of amputees obtain pain relief. The pain is remarkably intractable; although many forms of treatment have been tried, none has proved to be particularly efficacious.

The active body-neuromatrix, in the absence of modulating inputs from the limbs or body, produces a neurosignature pattern, including the high-frequency, bursting pattern that typically follows deafferentation, which is transduced in the sentient neural hub into a hot or burning quality. The cramping pain, however, may be due to messages from the action-neuromodule to move muscles in order to produce movement. In the absence of the limbs, the messages to move the muscles become more frequent and "stronger" in the attempt to move the limb. The end result of the *output* message may be felt as cramping muscle pain. Shooting pains may have a similar origin, in which action-neuromodules attempt to move the body and send out abnormal patterns that are felt as shooting pain. The origins of these pains, then, lie in the brain.

Low Back Pain

Low back pain is one of the most common types of pain, yet it is poorly understood. It illustrates the complexity of interactions among different contributing factors and the need for multiple approaches to treat it (Long, 2003).

The only definite causes of low back pain are protruding discs and arthritis of vertebral joints. However, about 60–70% of patients who suffer severe low back pain show no evidence of disc disease, arthritis, or any other symptoms that can be considered the cause of the pain. Even when there are clear-cut physical and neurological signs of disc herniation (in which the disc pushes out of its space and presses against nerve roots), surgery produces complete relief of back pain and related sciatic pain in only about 60% of cases. The rate of success in different reports ranges from 50 to 95%, depending in part on the spatial distribution of the pain. Furthermore, patients with physical signs such as disc herniation in the lower spine are rarely helped by surgical procedures such as fusion of several vertebrae to provide structural support to the back (Long, 2003). A variety of forms of physical therapy are more likely to help low back pain. The most effective is a regimen of exercises that develops the back muscles. Transcutaneous electrical nerve stimulation, ice massage, and acupuncture may also help some patients. Injections of anesthetics into trigger points may be effective as well. Still, despite all of these therapies, many patients continue to suffer severe, unrelenting pain (Lehmann & de Lateur, 2003).

A high proportion of cases of chronic back pain may be due to more subtle causes. The perpetual stresses and strains on the vertebral column (at discs and adjacent structures called facet joints) produce an increase in small blood vessels and fibrous tissue in the area (Jayson, 2003). As a result, there is a release of substances that are known to produce inflammation and pain into local tissues and the blood stream; this whole stress cascade may be triggered repeatedly. The effect of stress-produced substances – such as cortisol and norepinephrine – at sites of minor lesions and inflammation could, if it occurs often and is prolonged, activate a neuromatrix program that anticipates increasingly severe damage and attempts to counteract it. The program to reduce strain and inflammation could include generating the neurosignature for pain – part of a neural program that presumably evolved to induce rest, the repair of injured tissues, and the restoration of homeostasis.

As a result of the persistence of low back pain despite all the available therapies, it is not surprising that psychological therapy, such as relaxation therapy, hypnotic suggestion, and behavior modification, has become an important approach to the problem. However, no one therapy is more effective than the others. In fact, clinics often employ several procedures at the same time to get the best results. One study found that patients with several syndromes, but mostly low back pain, were helped by the use of multiple techniques that converge to relieve the pain – about 80% of patients reported marked-to-moderate improvement after treatment, and 50% claimed they were still improved 3–6 months later. Interestingly, most patients reported that the pain was unchanged but they were able to work, to live with their pain, and to lead more normal lives (Turk & Okifuji, 2003).

Fibromyalgia

Fibromyalgia affects 2% of the population, attacks more females than males (7 : 1), and reflects the complexity of most chronic pain syndromes (Bennett, 2003). The major features of fibromyalgia are multiple tender areas ("trigger points") of the skin and muscles, "aching all over," increased skin sensitivity to almost every kind of stimulation, major sleep disturbances, and several indices of abnormal functioning of the whole stress-regulation system.

An understanding of fibromyalgia has eluded us because we have failed to recognize the role of stress mechanisms in addition to the obvious sensory manifestations that have dominated research and hypotheses about the nature of fibromyalgia. Melzack's interpretation of the available evidence is that the body-self neuromatrix's response to stressful events fails to turn off when the stressor diminishes, so that the neuromatrix maintains a continuous state of alertness to threat. It is possible that this readiness for action produces fatigue in muscles, comparable to the fatigue felt by paraplegics in their phantom legs when they spontaneously make cycling movements (Conomy, 1973). It is also possible that the prolonged tension maintained in particular sets of muscles produces the characteristic pattern of tender spots.

The abnormal neural program of prolonged, centrally maintained alertness may produce a generalized state of perceptual vigilance or "open sensory gates" to receive information for rapid response to threat. The persistent low-level stress (i.e., the failure of the stress response to cease) would produce anomalous alpha waves during deep sleep, greater feelings of fatigue, higher generalized sensitivity to all sensory inputs, and a low-level, sustained output of the stress-regulation system, reflected in a depletion of circulating cortisol.

Goldenberg et al. (1990) described striking similarities between fibromyalgia and chronic fatigue syndrome, and noted that the frequent reports by patients in both groups that the onset of fibromyalgia or chronic fatigue syndrome was preceded by a flu-like or viral illness suggest an immune system abnormality. However, a large proportion of patients (about 45%) do not report a flu-like illness but instead report a preceding accident, surgical operation, or no apparent cause. This suggests that an abnormal, partially genetically determined mechanism fails to turn off the stress response to viral, psychological, or other types of threat to the body-self.

Reflex sympathetic dystrophy

The neuromatrix theory of pain also has implications for understanding reflex sympathetic dystrophy, also known as complex regional pain syndromes (Scadding, 2003), which is characterized by severe, relentless pain and other symptoms after a sprain, fall, or other injury. The pain and symptoms are usually out of proportion to the injury, which is often minor. John Hannington-Kiff (1994) has observed that the early, mainly sympathetic symptoms – such as local changes in skin temperature and blood flow – are usually obvious about 3–6 weeks after the injury. After this time, major dystrophic changes occur in the skin and nails, with muscle and joint stiffness, skin swelling, excessive heat and sweating, abnormal blood flow, skin color and sensitivity, and severe pain. It has long been assumed that reflex sympathetic dystrophy is primarily a disease caused by abnormal activity of the sympathetic nervous system. This may be true initially. However, it is possible that, after a period of time, the pain and destructive signs of the skin are the result of dysregulation of the cortisol system rather than the noradrenergic system. This could explain the observation that anesthetic blocks of the sympathetic system may sometimes stop reflex sympathetic dystrophy if administered early in the disease, but rarely do so if given after the signs are well underway.

At this stage, treatment with sympathetic blocks is rarely effective. The reason may be that the cortisol regulation system may have superseded the sympathetic system and now dominates the stress response to the injury that initiated the cascade of events. For this reason, it is possible that psychological stress also contributes to the sequence of events. This does not mean that reflex sympathetic dystrophy is due to "psychogenic" causes. Rather, it may be a stress-related disease, in which all types of stress contribute to cumulative destructive effects.

These considerations suggest lines of therapy that differ from those now generally in use. Manipulation of the stress system may be more likely to produce pain relief for these people, who suffer so terribly. Kozin and colleagues (1981) have achieved excellent results with many patients by using steroid injection therapy, and Kozin et al. note wistfully that "unlike the interruption of sympathetic pathways, no currently known theoretic mechanisms explain the efficacy of corticosteroids in reflex sympathetic dystrophy." The powerful role of the stress system in chronic pain provides a plausible mechanism.

Recent developments

Iannetti and Mouraux (2010) present a thoughtful, critical review that discusses the neuromatrix theory and a recent, devolutionary offshoot called the *pain matrix*, which is described as a specific, pain-processing network of brain regions that is responsible solely for the perception of pain, not unlike the notion of a pain center. As the authors note, the evidence from studies of brain responses to nociceptive stimuli is not consistent with the concept of a pain matrix, but rather appear to encompass brain activities involved in the processing of salient sensory input – both nociceptive and non-nociceptive. Moreover, the term pain matrix is used in quite a different way than Melzack's original conceptualization of the neuromatrix as reflecting the activity of a multimodal neural network (Melzack, 1989, 1990). The lack of pain specificity, both peripherally and centrally, was the impetus for Melzack to propose a general theory of human behavior, perception, and consciousness, and to propose that pain is but one of the many possible experiences generated by the neuromatrix.

Conclusions

We have traveled a long way from the psychophysical concept that seeks a simple one-to-one relationship between injury and pain. We now have a theoretical framework in which a genetically determined template for the body-self is modulated by the powerful stress system and the cognitive functions of the brain, in addition to the traditional sensory inputs. The neuromatrix theory of pain – which places genetic contributions and the neural–hormonal mechanisms of stress on a level of equal importance with the neural mechanisms of sensory transmission – has important implications for research and therapy. An immediate recommendation is that interdisciplinary pain clinics should expand to include specialists in endocrinology and immunology. Such a collaboration may lead to insights and new research strategies that may reveal the underlying mechanisms of chronic pain and give rise to new therapies to relieve the tragedy of unrelenting suffering associated with needless pain.

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36

Biofeedback as a Treatment for Epilepsy

Yoko Nagai and Michael Trimble

Introduction

The treatment of epilepsy has advanced greatly in the twentieth century due to the development of antiepileptic drugs. However, 30% of patients remain drug resistant and, despite multiple anticonvulsant drugs, their epilepsy still remains refractory. For those patients, behavioral interventions may further facilitate control of their seizures. Biofeedback treatment is generally considered a physiological therapy, rather than a psychological intervention. In the treatment of epilepsy, the overall purpose of biofeedback is to strengthen a patient's ability to control his/her epileptic seizures, and thus understanding precipitating factors is an important step for better control of their seizures. In the first section, we will look into the behavioral aspects of seizure occurrence. Investigations of typical seizure triggers are introduced and discussed. A model will be introduced to reflect the interaction between emotional triggers and seizure occurrence in relation with autonomic regulation.

Biofeedback is a typically non-invasive intervention that can be used to teach patients to control their physiological responses. Biofeedback using electrodermal activity (EDA) is a relatively new approach in epilepsy; however, the preliminary results are encouraging, and the technique is potentially an easy-to-implement and low-cost treatment for seizure control. The clinical results of EDA biofeedback treatment trials will be described alongside findings from EEG and neuroimaging research into the neural mechanisms. Lastly, the potential and the limitations of biofeedback treatment will be discussed.

The Handbook of Behavioral Medicine, First Edition. Edited by David I. Mostofsky.

Behavioral Control of Seizures

Emotional triggers of seizures

Seizure occurrence in patients often appears to take place at random, with no apparent cause. This unpredictability of seizures often makes patients insecure and can markedly limit their general activity and social life. However, a number of studies show that seizure occurrence is often related to ongoing emotional and mental challenges that patients experience in daily life.

According to Antebi and Bird's (1993) questionnaire study on 100 consecutive patients from outpatient lists (seizure type: 51% partial, 20% generalized, 24% partial with secondary generalization, and 56% multiple), negative mental states were potent causes of seizures. In this study, 66% of patients with epilepsy claimed that tension and anxiety increased their seizure frequency, 44% of patients implicated unhappiness and depression, and 38% identified overexcitement as a further underlying enhancer of seizure occurrence. In addition, the study indicated that 92% of patients could recognize states that could either trigger or suppress their seizures.

In earlier study undertaken at the Maudsley Hospital, up to 25% of patients were able to generate seizures voluntarily, and most of them had their own strategy (countermeasures) for inhibiting seizures (Fenwick, 1991). Spector and colleagues (2001) reviewed nine questionnaire studies on seizure precipitants and self-control of seizures in people with epilepsy. Again, stress and anxiety were most commonly reported across the studies. Of 100 outpatients with epilepsy, 86% could describe at least one high-risk situation or state for seizure occurrence. Tension and anxiety were the most commonly reported situations. Conversely, 65% of patients could identify situations in which they had fewer seizures. The most commonly reported low-risk situations or states were: being relaxed, not feeling stressed, feeling restful, not worried (55.4%), mind occupied, concentrating, being busy (29.2%), being happy (18.5%), and when not tired (7.7%).

More recently, Nakken et al. (2005) reported findings from a wider investigation of 1,677 patients with epilepsy. In this study, 53% of patients could identify seizure precipitants. The most common identified precipitants were emotional stress, sleep deprivation, and tiredness. These results were also consistent with a later study of Pinikahana and Dono (2009) with 309 epilepsy patients. Most common triggers were tiredness, stress, and sleep deprivation. In their study, patients (63.6%), but also carers (51.3%), were able to tell when patients′ seizures were likely to occur. Moreover, 26.7% of patients and 15.4% of carers felt that they could stop seizures from occurring.

A more detailed phenomenological investigation was reported by Petitmengin and her colleagues (2006), using structured interviews of patients. They raised the importance of recognizing the prodrome, pre-ictal phenomena, which are not as strong as the aura and may last for a few hours to days. Patients may feel unusual during the prodrome, though the descriptions are typically very individual. In their study, nine patients with drug-resistant partial epilepsy went through an average of one and a half hours interview to describe their pre-ictal experience. All these patients experienced auras and six experienced prodrome. Reported common auras were "vegetative," "dysmnesic," and "psychic." Petitmengin and her colleagues (2006) also pointed out that ictal symptoms can be described as "positive" because they are generally related to motor, sensory, or verbal hyperactivity. On the other hand, symptoms during prodromes are rather negative in a sense that they frequently correspond to decreased energy or lack of concentration. The main symptoms of prodrome reported by patients were feelings of "tiredness," "weakness," "lack of energy," and "fragility." Petitmengin and her colleagues noted that the patients with more frequent auras experienced recognizable prodromes. Associated electroencephalography (EEG) examinations revealed that focal EEG synchronicity decreases during the pre-ictal (prodrome) phase, suggesting regional isolation or loss of connectivity around the epileptic focus during this pre-ictal period.

Behavioral modulation and seizure occurrence

Summarizing the preceding studies, many patients, when asked, are actually able to identify seizure occurrence, and common seizure triggers are stress, tiredness, and sleep deprivation. It is also worth noting that a subset of patients are also able to use countermeasures to prevent seizures from occurring, suggesting that behavioral intervention may be a potent option as a treatment for epilepsy.

There are different behavioral techniques available, and clinical results are mostly encouraging. Nevertheless, a lack of neural mechanisms to account for any effectiveness is often targeted as a criticism. Sham (placebo) effects are also often not accounted for in these studies. Thus, investigations on how the behavioral interreactions interact with an epileptic focus would be essential research.

Behavioral effects on the seizure focus were investigated by Lockard and Wyler (1979), using the alumina-gel model monkey. The experimental study of neural interactions with behavior was previously introduced by Wyler et al. (1975), who had proposed a spectral neural composition surrounding a seizure focus: group 1 neurons, which are highly epileptogenic and not affected by behavioral modulation, and the group 2 neurons, which are constituted of both epileptogenic and normal neurons and which decrease single cell firing with operant conditioning. Experimental disruption of group 2 neurons was associated with decreased ictal events, as this prevented neural recruitment of surrounding normal neurons to ictal events. Wyler and his colleagues also observed that a monkey's seizure activity significantly reduced during feeding time, leading them to conclude that attending to or anticipation of the food was a potent suppressing factor of seizures (Lockard and Wyler, 1979). A similar finding was also reported during visual attention and avoidance conditioning. The suppressing effect was observed to depend on the state of the epileptic focus; suppression was only possible with focus composition of less than

10% of group 1 neurons. When the epileptic focus contained a very high density of group 1 neurons, focused attention tended to cause an ictal event.

It is also important to take into consideration that specific brain regions contribute to seizures in different ways, in relation to site of seizure origin, circuits of spread, and mediation of motor expression (Miller, 1992). While, clinically, a seizure manifestation may not be as simple as the preceding experimental model suggests, it is worth noting that emotional triggers (described earlier) may well interact with epileptic foci along the line of the model proposed by Lockard and Wyler.

Model of emotional trigger and seizure generation

Emotional disturbances are often accompanied by autonomic activation. William James (1983) described it thus: "Without the bodily states following on the perception, the latter would be purely cognitive in form, pale, colourless, destitute of emotional warmth." The model shown in Figure 36.1 illustrates how emotional stimuli may trigger epileptic seizures. Potentially, seizure inducing brain states may be generated from our perception, such as vision and hearing, or through our thoughts. Such information may or may not recruit autonomic activation, according to the degree of stimulus salience. With certain stimuli, some of which may be individual for a patient, the autonomic system is engaged, and it is likely to affect neural excitability around a seizure focus through visceral afferent influences on the structure of the reticular formation and neuromodulatory neurochemical systems. The magnitude of the autonomic response may thus influence the likelihood of seizure generation. The typical emotional triggers of seizures introduced in the

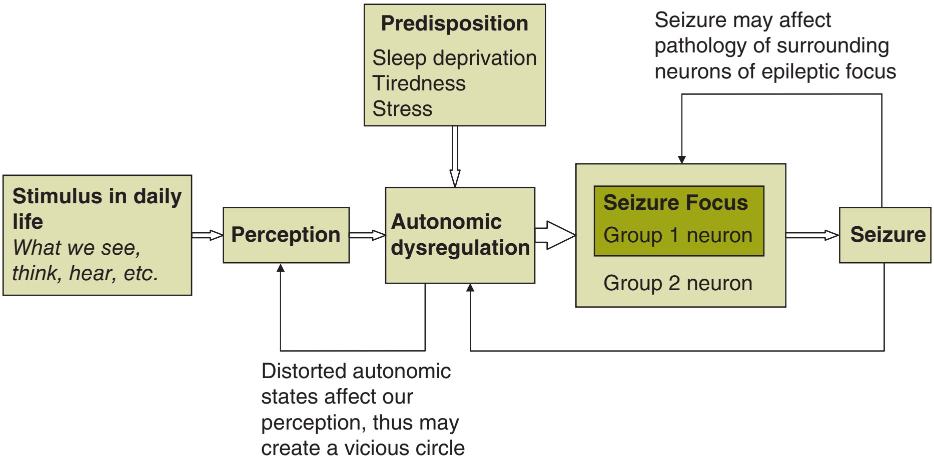

Figure 36.1 Model of behavioral modulation and seizure generation. The model describes psychological and neural interaction influencing seizure generation.

previous section (stress, sleep deprivation, and fatigue) are events likely to disturb autonomic regulation. In cognitive behavioral terms, the disturbed autonomic function in turn affects perceptions and emotional states of individuals, thus creating a vicious cycle.

It is also known that the seizure itself may affect autonomic activity, and postictal autonomic dysregulation may be a potent cause of sudden unexpected death in epilepsy (Poh et al., 2012). It is worth noting that patients with epilepsy may be especially vulnerable to the emotional stimuli, due to the underlying brain pathology (e.g., temporal lobe damage), societal conditioning, and stigma, or even the effects of anti-epileptic drugs. Thus, it is speculated that patients with epilepsy have specific predisposing psychological and neural dynamics interacting, which can lead to seizure generation. Attempting to alter these complex dynamics by modifying physiological and psychological processes can be a valuable treatment option. EDA biofeedback is well positioned to tackle these interactions.

Biofeedback Treatment for Epilepsy

Introduction to biofeedback treatment for epilepsy

Biofeedback is one of a set of behavioral treatments that are widely used to help physical and mental disorders (see Chapter 15 for more details). Biofeedback enables monitoring of physiological signals that are usually not accessible to consciousness, such as heart rate, respiration, cerebral cortical potentials (EEG), muscle tone, and skin conductivity. These signals can be detected and then visually displayed and/or auditory feedback given, so that patients are able to alter the signals by their will and gain control over these physiological events.

There are various physiological measurements that can be used in biofeedback training. As a treatment of epilepsy, the most typical ones are EEG-driven sensory motor rhythms (SMRs) and slow cortical potentials (SCRs). SMR (12–14 Hz over sensory motor area) was initially found in animals (cat) related to motor stillness (Sterman et al., 1972). Sterman and colleagues (1974) subsequently reported that enhancement of this cortical rhythm using biofeedback resulted in reduction of seizure frequencies in patients with epilepsy. While SMR biofeedback modifies specific cortical rhythms, SCP biofeedback modulates DC potential changes: slow cortical potentials (SCPs). The negative shift of the cortical potential is often observed preceding ictal events in humans (Birbaumer, 1990), and successful control of seizures is reported using SCP biofeedback (Rockstroh et al., 1992). SMR and SCP modulate central cortical signals, which are measured by EEG. An alternative approach, described here in more detail, is to use electrodermal activity (EDA), an index of peripheral sympathetic activity. In this chapter, we focus on the peripheral modulation of electrodermal activity using biofeedback as a direct indicator of autonomic arousal (sympathetic activity) in relation to the previous model of seizure generation.

Electrodermal biofeedback

Electrodermal activity (EDA) denotes a small electrical current on the skin surface, which is a measurement of peripheral sympathetic nervous activity, reflecting sweat gland function. In contrast to the other sympathetic innervations, the effecter synapse within the sweat gland is uniquely cholinergic (in contrast with the majority of sympathetic effecter synapses that are adrenergic or noradrenergic). EDA is considered as a sensitive indicator of emotional and physical arousal and widely used as an index of bodily arousal in experimental conditions (Venables & Christie, 1973).

Nagai and colleagues (2004a) investigated the functional relationship between central and peripheral arousal using EEG and EDA, respectively. The central indicator of arousal was slow cortical potentials (SCPs):DC potential changes which are often linked to epileptic activity (Chatrian et al. 1968; Casper & Speckman 1972; Birbaumer, 1989). It is generally agreed that depolarization of apical dendrites in pyramidal cells are responsible for generation of SCPs and thus that this indicates cortical excitation. In this study, SCPs were measured at two different physiological states – relaxation and arousal. These states were induced using EDA biofeedback. Modulation of EDA significantly influenced the amplitude of SCP. An inverse relationship was found, wherein an increase in skin conductance (increased sympathetic arousal) reduced SCP (reduction of cortical arousal).

The results suggested that EDA biofeedback to increase sympathetic arousal may have a therapeutic role in reducing seizures in patients with epilepsy. A clinical trial (RCT) with 18 patients with drug-resistant epilepsy was conducted (Nagai et al., 2004b). Patients were randomly allocated to either active biofeedback or to a sham control group who performed 30-minute biofeedback sessions, three times a week, for 4 weeks. In the biofeedback active session, patients were trained to increase their skin conductance (sympathetic activity) via visual feedback of animation proceeding on the computer screen. In the sham control group, patients' skin conductance change did not reflect any animation changes on the computer screen (Figure 36.2). The results were encouraging. There were significant therapeutic differences between the active biofeedback and the sham control group. Six out of 10 patients receiving biofeedback demonstrated a greater-than-50% seizure reduction after a month of biofeedback treatment (Figure 36.3). Seizure reduction also significantly correlated with behavioral improvement of biofeedback performance. In this study, one patient became seizure free in the active treatment group.

EDA biofeedback mechanisms

The preceding study, taken with the other studies discussed earlier, suggest that biofeedback has an impact on the physiological mechanisms of seizure generation in epilepsy. The neural mechanisms for the positive effect of biofeedback treatments

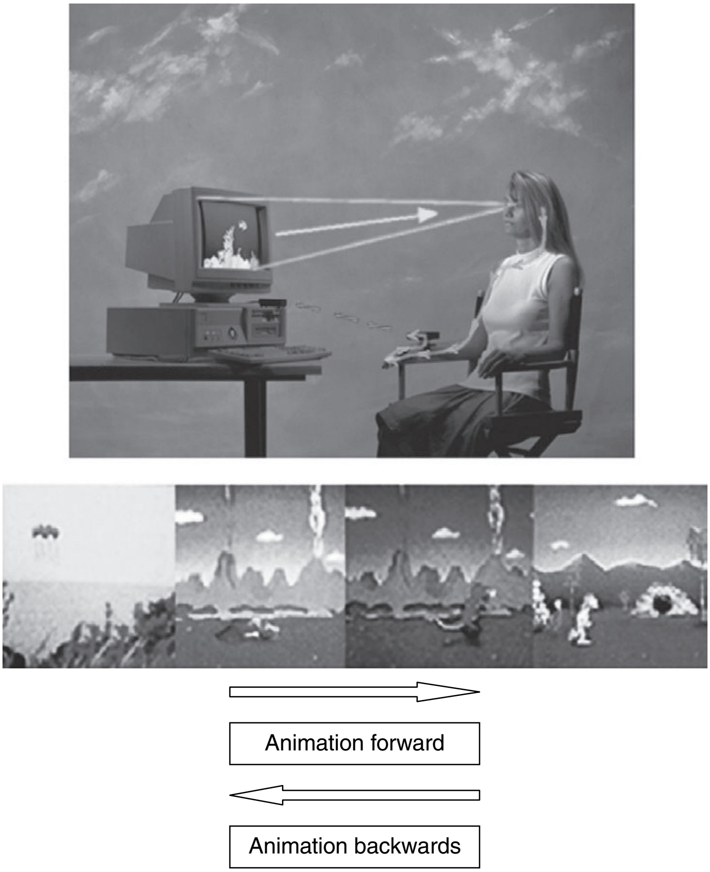

Figure 36.2 Example of biofeedback (using parameter of electrodermal activity). Setting-up of biofeedback and the animation change on the screen. An animation moves forward with decrease in skin resistance and backward with increase in skin resistance. (Nagai et al. *Epilepsy and Behavior*, 2004b. Permission obtained.)

remain unclear, though potentially enhanced thalamocortical regulation is often claimed as a critical contributor. The rationale behind electrodermal biofeedback was founded by the fact that SCPs are linked to epileptic activity, and that electrodermal biofeedback successfully modulated the amplitude of SCP. One mechanism of this modulation could be via regulation of sensory inputs to the cortex via the thalamus. To investigate this, we carried out a neuroimaging study. Neural activity associated with SCPs was investigated using fMRI and EEG simultaneously (Nagai et al., 2004c). SCPs were experimentally induced using a contingent negative variation (CNV) paradigm. In this, a forewarned reaction time task was used, in which subjects are asked to listen to two successive tones, and to respond with a motor reaction to the second "imperative" tone. A slow cortical potential, the CNV, is clearly observed between the two successive tones. Brain activity, measured using

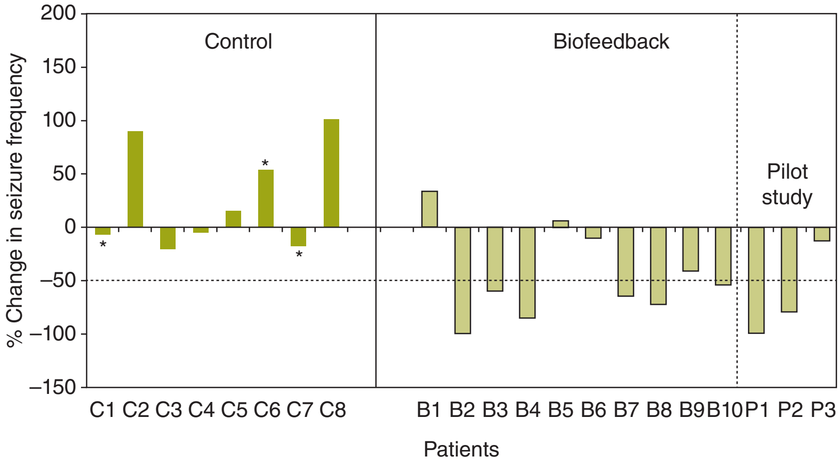

Figure 36.3 Seizure frequency changes using electrodermal biofeedback (% = seizure frequency change after GSR biofeedback treatment in control and biofeedback groups; * = patients who dropped out in the middle of the training). (Nagai et al. *Epilepsy and Behavior*, 2004b. Permission obtained.)

Table 36.1 Regional brain activity associated with the CNV.

Region	*Side*	*Coordinations of peak activity*	*T score*
Cingulate cortex + SMA	L	−2, −6, 50	11.09*
Somatomotor cortex	L	−36, −14, 60	10.71*
Insula	R	42, 6, 0	8.64*
Dorsolateral prefrontal cortex	R	42, 54, 18	7.62*
Cerebellar vermis	–	2, −74, −20	7.58*
Head of caudate	L	−8, 14, −2	7.25*
Insula	L	−40, 2, 8	7.23*
Inferior parietal lobule	R	66, −24, 26	7.12*
Orbitofrontal cortex	R	22, 48, −12	6.55*
Occipitoparietal junction	R	42, 40, 12	6.47*
Thalamus (lateral)	L	−20, −18, 10	6.09**
Thalamus (pulvinar)	R	12, −32, 6	5.43**
Thalamus (pulvinar)	L	−10, −28, 8	5.38**

* $P < 0.05$, corrected for whole brain

** $P < 0.05$, corrected for small volume of region of interest. (Nagai et al. *Neuroimage*, 2004c, Permission obtained.)

fMRI over this CNV period, was found in midcingulate cortex, adjacent supplementary motor cortex (SMA), left somatomotor cortex, right dorsolateral prefrontal, right orbitofrontal cortex, bilateral insula, and dorsal midline cerebellum (Nagai et al., 2004c) (Table 36.1). Furthermore, neural activity reflecting the trial-by-trial magnitude of the CNV was observed in the thalamus, somatomotor cortex, bilateral

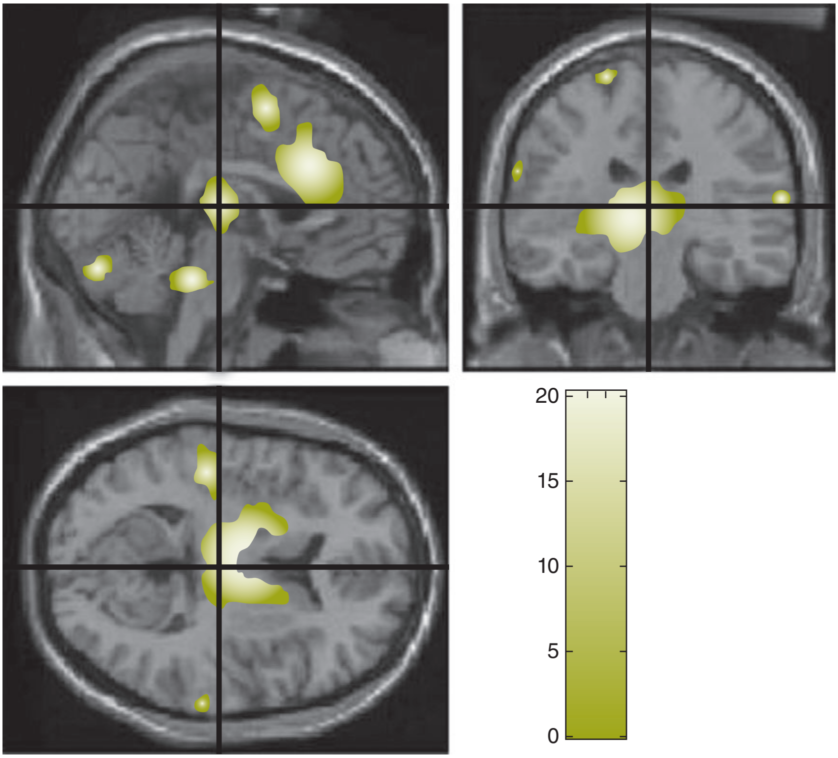

Figure 36.4 Neural activities related to generation of CNV. Neural activities modulated by trial-by-trail-basis CNV amplitudes. The observed regions were in bilateral thalamus, anterior cingulate, SMA, pons, and cerebellum. A fixed-effect analysis was used ($p < 0.05$, corrected). (Nagai et al. *Neuroimage*, 2004c, Permission obtained.)

midcingulate, supplementary motor, and insular cortices, suggesting thalamocortical involvement in the generation of the SCP (Nagai et al., 2004c) (Figure 36.4). Together with our previous study investigating the impact of peripheral electrodermal activity on SCP, it is speculated that biofeedback training may modulate thalamocortical information flow, which influences cortical excitability and seizure threshold.

The neuroimaging study also revealed involvement of ventromedial prefrontal cortex (VMPFC) and orbitofrontal cortex (OFC) during modulation of EDA biofeedback. The tonic skin conductance level was negatively correlated with activity of these areas, and thus increases in sympathetic arousal were associated with decreases in activity of VMPFC and OFC. This broad area of prefrontal cortex, together with medial parietal cortex, is referred to as the default mode network, and activity in this network is prominent in the awake relaxed state and decreases with increased attention and internal and external stimuli (Raichle et al., 2001). These areas of the brain are also affected by loss of consciousness during an epileptic attack

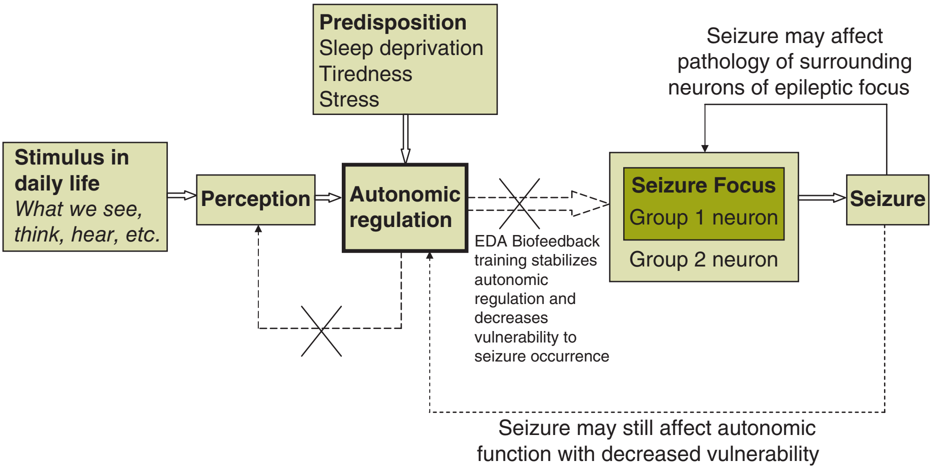

Figure 36.5 Model of biofeedback intervention to behavioral modulation and seizure generation. The model describes biofeedback intervention to alter psychological and neural dynamics influencing seizure generation.

(Cavanna & Monaco, 2009). It is speculated that EDA biofeedback training indirectly affects neural activity within VMPFC and OFC, which are linked to the maintenance of regular brain activity in the awake state, and this decreases vulnerability to internal and external stimulation, which may lead to epileptic seizures.

These observations are supported in the later study. Nagai and colleagues (2009) investigated long-term SCP changes following EDA biofeedback training. In this study, changes of SCP were investigated before and after the biofeedback treatment. SCPs were induced using the CNV paradigm, as was described previously. CNV was measured at the first session and last session of biofeedback. Baseline CNV was significantly reduced after a month of biofeedback training, suggesting that there were enduring changes in neural networks related to generation of SCPs. The effect was also prominent in the early wave, which is linked to orienting responses. The reduction of indices in orienting responses indicates that patients may be less responsive to internal and external stimuli that would trigger seizure occurrence after a month of biofeedback training. A month of EDA biofeedback training may thus stabilize autonomic regulation, and thus decrease the chance of seizure recruitment triggered by stimuli that provoke seizures (Figure 36.5).

Future of biofeedback treatment

Biofeedback treatment is still a second-line option for intervention in the management of epilepsy after pharmacological treatment. However, evidence is accumulating that there are definitely some patients who benefit from biofeedback treatment. Moreover, awareness of the accessibility for such therapy has been increasing in the last decade. This is partly because of recent advances in computer technology that enables the production of more accurate, sophisticated, and low-cost biofeedback machines for consumers. Growing concern about long-term side effects of medication also contributes to an increased interest in behavioral interventions for neurological and psychological conditions.

Biofeedback is currently limited to drug-resistant patients, although it is expected that patients with low drug tolerance, and children, may be good candidates for biofeedback treatment in future trials. However, there are some problems to overcome. As with many other behavioral treatments, duration of biofeedback usually takes from a few weeks to up to 6 months, depending on the type of biofeedback treatment. Patients are often required to visit a hospital or research institution two to three times a week. This demands time and effort for both the patients and for the therapists. Thus, clinical trials are performed with considerably smaller sample sizes compared to pharmaceutical drug trials. The blindness of studies is also often a target of criticism for behavioral treatments, as it is typically difficult to set up strict double-blinded procedures. Providing an independent data assessor separately from the behavioral therapist may solve this problem to a certain extent.

Our data, combined with earlier studies looking at other behavioral techniques for managing seizures (Sterman, 2000; Rockstroh et al., 1993), lead to the conclusion that there is definitely a need for more detailed monitoring and wider clinical trials of biofeedback in the future. This will clarify which types of epilepsy, seizures, and patients groups are more responsive to biofeedback treatment, and will lead to better availability and understanding of biofeedback intervention as a safe adjunctive approach to the management of epilepsy.

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37

Behavioral Treatment of Fecal Incontinence

William E. Whitehead and Olafur S. Palsson

Introduction

Fecal incontinence (FI) is a hidden epidemic (Whitehead et al., 2009). It currently affects 9% of the adult population, and the prevalence increases to 15% in people aged 70 or older. This epidemic remains hidden because over 70% of patients with FI do not discuss it with their physician. When frequent or severe (FI occurs at least weekly in 2.7% of US adults), it can have a devastating impact on social interaction and employment, and may be a risk factor for admission to nursing homes (Grover et al., 2010). Behavioral medicine techniques such as those described in this chapter offer the promise of substantially mitigating this burden. Greater availability of effective treatment may encourage more people with FI to seek treatment at an earlier stage of disease progression, and may also persuade primary care physicians to screen for FI.

Definition

FI is defined in this chapter as the involuntary loss of solid or liquid stool or mucus (Bharucha, Wald, Enck, & Rao, 2006). Some have recommended including involuntary loss of gas in the definition because patients complain that accidental loss of flatus has a negative impact on their lives; when gas is included in the definition, this is referred to as anal incontinence (C. Norton et al., 2002). However, in the National Health and Nutrition Examination Survey (NHANES) for 2005–2006, we showed that involuntary loss of gas is reported by more than 50% of both men and women, and daily involuntary loss of gas is reported by more than 20% (Whitehead

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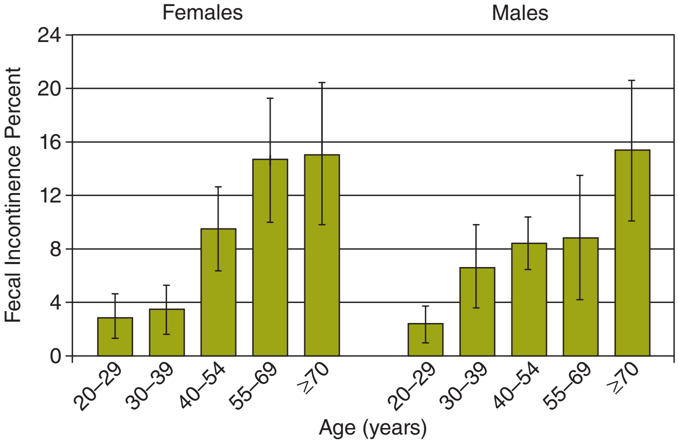

Figure 37.1 Prevalence of solid or liquid stool incontinence in US adults by age and sex (Whitehead et al, 2009, reproduced with permission from Elsevier).

et al., 2009). This suggests that involuntary loss of gas occurs too frequently to be incorporated into a definition of FI.

Prevalence and Incidence of FI

Estimates of the prevalence of FI have varied widely from 2% (Nelson, Norton, Cautley, & Furner, 1995) to 24% (Varma et al., 2006). This variability is believed to be due to the use of differing case definitions, convenience sampling, and restriction of samples to specific age groups (Landefeld et al., 2008). The best estimate of the prevalence of FI in the non-institutionalized adult population of the United States was provided by the NHANES for 2005–2006 (Whitehead et al., 2009), which used a stratified sampling technique to guarantee adequate representation of minorities and the elderly, and then adjusted the sample to the 2000 US census by applying sample weights. The overall prevalence of FI was 8.9% of women and 7.7% of men (8.3% for the combined sample). This corresponds to an estimated 18 million people in the United States. Prevalence of FI was shown to be strongly associated with age and was over 15% in both men and women aged 70 and older (Figure 37.1). In this study, 2.8% of women and 2.6% of men reported experiencing FI at least once a week.

Quality-of-Life Impact

The impact of FI on quality of life, as reported by patients (N. J. Norton, 2004; Rockwood et al., 2000), includes embarrassment, social isolation, and even loss of employment. FI may also increase the risk of referral to a nursing home. The prevalence of FI is 48% in nursing homes (Jones, Dwyer, Bercovitz, & Strahan, 2009) compared to 15% in non-institutionalized elderly adults. Moreover, in both the Program for All-inclusive Care of the Elderly (PACE) (Friedman, Steinwachs, Rathouz, Burton, & Mukamel, 2005) and the Johns Hopkins Elder House-call Program (Tsuji, Whalen, & Finucane, 1995), two demonstration projects that were designed to keep elderly patients out of nursing homes by providing physician-led home healthcare, FI was a strong predictor of which patients were admitted to nursing homes.

We surveyed the physician and nurse practitioner members of the American Geriatrics Society to assess how much FI, alone or in combination with other risk factors such as dementia and mobility impairment, influences the healthcare provider's decision to refer to a nursing home (Grover et al., 2010). Surveys were sent by email or post to 2,181 geriatricians, and 723 completed the survey. Participants were presented with a clinical scenario of a 70-year-old woman ready for discharge from an acute care hospital and asked to rate the likelihood of referral to a nursing home: (a) in the absence of incontinence, (b) with the addition of urinary incontinence alone, and (c) with the addition of FI (which could coexist with urinary incontinence). Subsequent questions modified the clinical situation to include other conditions (e.g., cognitive impairment, mobility restrictions, and multiple comorbidities) and tested the sensitivity to FI severity. The principal findings were these:

1. FI was associated with a relative risk (RR) of referral to a nursing home of 4.71 compared to continence of both bowel and bladder. When the severity of FI was described as at least weekly with occasional large-volume accidents as compared to FI of unspecified severity, the disposition to refer to a nursing home increased from 10.4% to 35.2%.
2. Mobility impairment (RR = 18.58) and cognitive decline (RR = 11.16) were associated with a significantly greater disposition to refer to a nursing home than was FI alone, but in each case, adding FI to the scenario added significantly to the likelihood of referring to a nursing home, increasing the likelihood of referral by approximately 17%.
3. FI was associated with a significantly greater likelihood of nursing home referral compared to urinary incontinence.
4. The likelihood of referring a patient with FI to a nursing home was moderated by the severity of FI and by the availability of family caregivers to help. If FI occurred at least weekly and occasionally consisted of large volumes of stool lost, 35% would refer (RR = 3.5). If there was no family member living nearby to provide assistance, 54% would refer to a nursing home (RR = 5.2), and if family caregivers declared that they were unwilling to assist with toileting, there was an 80% likelihood of referral (RR = 7.7).

Unfortunately, FI does not improve following admission to a nursing home. Nursing homes often do not have the staff to remind patients on a schedule to go to the toilet or to assist them to the toilet, so it is not uncommon for the staff to manage incontinence simply by changing bedding at changes in nursing shifts. A French study (Chassagne et al., 1999) found that 20% of patients who were continent when admitted to nursing homes had FI within 6 months of their admission. This system of care may result in a further loss of quality of life for the incontinent patient and guilt for the caregiver. If an effective behavioral medicine treatment could be made available to patients and their physicians in the community, some nursing home admissions could be avoided with significant benefit to the patient's quality of life, as well as significant savings in healthcare costs.

Impact on Caregivers

The greater burden on family caregivers caused by FI as compared to urinary incontinence (UI) alone is well documented. One study (Noelker, 1987) surveyed 614 households in which a family caregiver provided assistance with one or more activities of daily living (ADLs) to a family member over age 60. The study was based in metropolitan Cleveland. The 299 care recipients who were incontinent included 179 (60%) who had combined fecal and urinary incontinence. The survey showed that caregivers viewed combined incontinence as a more serious problem than isolated UI; it was viewed as more of a burden and was associated with more health deterioration in the caregiver and more negative affect in family relations. Caregivers of patients with combined FI and UI were more likely to say they were considering "other ways their relative could be cared for other than living with them." Another study (Ouslander, Zarit, Orr, & Muira, 1990) of 184 family caregivers of community-dwelling patients with dementia also found that, for those whose dependent family member was institutionalized during follow-up, incontinence (both UI and FI in 74% of cases) played a "very important" (37%) or an "extremely important" (26%) role in the decision. Another group (Finne-Soveri, Sorbye, Jonsson, Carpenter, & Bernabei, 2008) reported a multinational study of 4,010 home care patients from 11 European countries, including 411 patients who had involuntary bowel movements at least once a week. Burden was assessed for three groups of caregivers: visiting nurses, home care aides, and family caregivers. For visiting nurses and home care aides, care time was twice as great for patients with FI, and this difference was significant even after adjusting for dementia and physical impairment. These studies show that FI is associated with greater caregiver burden than UI as measured by hours of care, emotional distress, health deterioration for the caregiver, and willingness to consider admission to a nursing home.

Economic Impact

The lifetime cost of care in women with FI secondary to obstetric injury was estimated to be US$17,166 (Mellgren et al., 1999). However, indirect costs such as work loss, protective pads, and over-the-counter antidiarrheal medications were not included. A Dutch study (Deutekom et al., 2005) estimated total healthcare costs for community-dwelling individuals with FI to be €2,169 per patient per year. This estimate included €714 per year for direct healthcare, €337 for transportation to medical appointments and other out of pocket healthcare costs, and €1,118 for lost work. However, the greatest economic cost of FI is related to the increased risk of nursing home referral. The average cost per patient for nursing homes in the United States ranges from US$3,300 to US$6,000 per month (https://pro.genworth.com/content/etc/medialib/genworth_v2/pdf/Itc_cost_of_care.Par.85518.File.dat/Executive%20Summary_gnw.pdf). Based on the survey of geriatricians, we estimate that 16.5% of admissions are attributable to FI (Grover et al., 2010).

Pathophysiology/Psychophysiology of FI

Continence depends on multiple physiological mechanisms, which are summarized in Figure 37.2. A brief explanation of these physiological mechanisms will facilitate

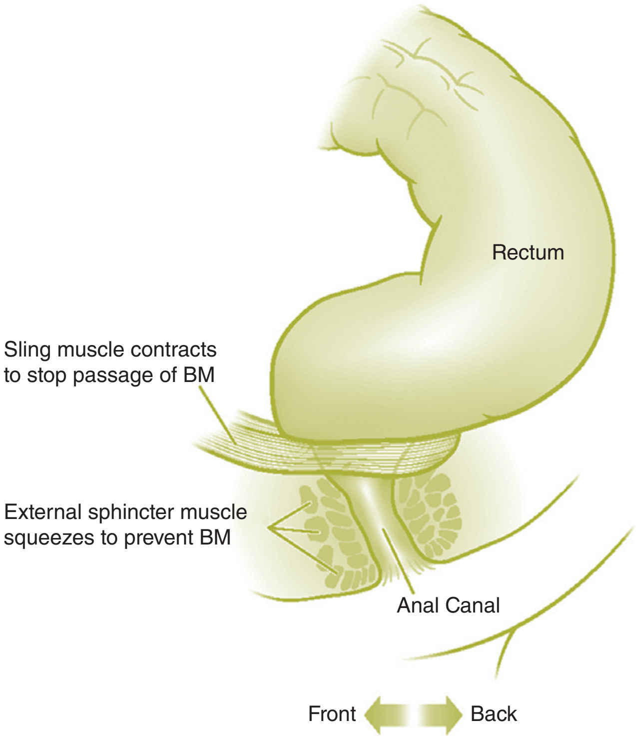

Figure 37.2 Anatomy of the anal canal and rectum showing the mechanisms involved in continence.

understanding the different approaches to treatment, including behavioral medicine techniques.

Diarrhea

Epidemiological studies consistently find that the strongest risk factor for FI is diarrhea (loose or watery stool consistency) (Goode et al., 2005; Whitehead et al., 2009). Liquid or loose stool is more difficult than formed stool to control, and the risk of FI is especially great if diarrhea occurs in a patient who has weak pelvic floor muscles. The two primary physiological mechanisms responsible for diarrhea are the amount of water secreted into the small intestine and the amount of peristaltic motility (contractions of the circular muscles of the colon that move downstream, pushing contents ahead of them). Behavioral interventions do not have a direct impact on these two physiological processes, but behavioral methods may be used to help people prevent or minimize diarrhea by avoiding or minimizing the consumption of foods known to cause diarrhea. This includes foods containing artificial sweeteners, and, in some patients, milk products and wheat.

Urgency due to increased smooth muscle tone

Another strong risk factor for FI identified in epidemiologic studies is the sensation of urgency or needing to rush to the toilet. This sensation often accompanies diarrhea, but it is an independent risk factor for FI. To understand why some patients have a low threshold for experiencing urgency, one needs to begin with an understanding of the normal physiology of the rectum. The rectum is very elastic: it relaxes or stretches as fecal material is added to it without increasing the internal pressure in the rectum until a very large volume is reached. However, the rectum sometimes loses its elasticity either as a result of inflammation that increases the tension in the muscles of the rectal wall, or due to surgical resection of a part of the rectum to treat cancer or inflammatory bowel disease. Stress or anxiety can also transiently increase smooth muscle tone, leading to a less elastic rectum. Some patients may be hypersensitive to rectal distention, independent of smooth muscle tone, which can increase the sensation of urgency. A vicious circle may be set up, in which a sensation of urgency causes the patient to become fearful of incontinence and this fear further reduces the compliance of the rectum, leading to more urgency.

Behavioral interventions, described in the following text, can be helpful for treating urgency as a cause of FI.

(1) Cognitive behavior therapy techniques may be employed to teach the patient relaxation and stress management techniques, and this can be supplemented with specific behavioral strategies. For example, we often teach patients with

urge incontinence that, when they feel an urge to go to the toilet, they should "walk, don't run" to the toilet.

(2) Similarly, we may have them practice a delay strategy when they are at home and not at risk of embarrassing themselves by having an accident; this would take the form of delaying going to the toilet for progressively longer periods beginning with a few seconds and progressing to 30–45 minutes after they feel the first urge.

(3) A type of biofeedback called "urge training" can also be employed, in which a balloon-tipped catheter is inserted into the rectum and is inflated with progressively larger volumes of air to gradually desensitize the patient to the sensation of urgency and teach them to tolerate larger volumes of rectal distention. This would be combined with teaching them relaxation techniques.

Hyposensitivity

The ability to perceive even small distensions of the rectum is important to continence because this is the cue that tells us when to squeeze our pelvic floor muscles to prevent FI. Some patients may lose the ability to detect this sensation. This is usually the result of a neurological disorder such as stroke, spinal cord injury, multiple sclerosis, or diabetic peripheral neuropathy (Wald & Tunuguntla, 1984). This results in passive FI, in which patients are usually unaware of the passage of stool until they discover it in their underclothes. Although patients who have lost all sensation even at high volumes of rectal distention are likely to remain at high risk of FI, many patients have a milder form of sensory loss that can be reversed with sensory discrimination training. This is a type of biofeedback training in which the therapist inflates a balloon in the rectum with enough air for the patient to feel it (typically starting with 50 ml), and gradually decreases the volume of balloon distention until a threshold is reached at which the patient does not sense rectal distention. Then, the therapist distends the balloon with volumes slightly higher than the threshold and slightly below this threshold in a classic discrimination training paradigm. The patients should be encouraged to not just report whether they feel the balloon but to also contract their pelvic floor muscles when they think they feel it. This is done to develop in the patients the habit of responding automatically to any rectal distention by squeezing.

Weak pelvic floor muscles

There are two pelvic floor muscles that are under voluntary control and that are critical to continence: the puborectalis and the external anal sphincter (Figure 37.2). The puborectalis is a sling muscle that loops behind the rectum at the juncture between the rectum and the anal canal and attaches to the symphysis pubis bone in front. It stays partly contracted to prevent formed stool from entering the anal canal, and it can be voluntarily contracted to further pinch off the rectum from the anal canal. The other muscle – the external anal sphincter – is a circular or "purse string" type of muscle that surrounds the anal canal. It can be voluntarily contracted to constrict the diameter of the anal canal and prevent the leakage of gas, liquid, or solid stool from the anal canal. These muscles are frequently found to be weak in patients with FI due either to nerve injuries or to tears in the muscles. A common cause of both types of injuries is childbirth, especially if the child is unusually large or if the delivery is complicated and a forceps must be used to assist delivery. However, other neurological processes such as diabetic peripheral neuropathy and other traumas such as motor vehicle accidents can cause these injuries.

When the structural and/or neurological injuries to the pelvic floor muscles are partial rather than complete, behavioral training techniques may be used to improve the strength of voluntary contractions. The simplest approach is to instruct the patient to practice squeezing these muscles as tightly as possible for 10–20-second periods 50–100 times per day. The goal is to build up the strength of these muscles. Biofeedback may also be used to help patients with very weak muscles learn how to contract them appropriately, and then to augment this biofeedback training with home practice of pelvic floor exercises to build strength. Instrumented biofeedback combined with pelvic floor exercises is superior to pelvic floor exercises alone because the biofeedback instruments ensure that the patient learns to perform the exercises correctly (Heymen et al., 2009).

Internal anal sphincter

The internal anal sphincter (Figure 37.2) is a smooth muscle sphincter that surrounds the anal canal; it lies beneath the external anal sphincter. The internal anal sphincter is an involuntary muscle, and it remains contracted most of the time to help prevent the passive leakage of liquid or gas from the rectum. Injuries to this muscle are associated with passive FI (incontinence without awareness). There are no known behavioral strategies for improving internal anal sphincter tone directly, but it is possible to mitigate this defect by keeping the rectum empty most of the time. A timed toileting schedule consisting of frequent attempts (e.g., every 2–4 hours) to defecate, even if there is no urge present, may be helpful.

Distinction between passive FI and urge FI

It is important to distinguish between patients with passive incontinence for whom FI occurs without warning and often without awareness, vs. urge incontinence in which the bowel accident is preceded by a strong urge and the patient leaks stool while trying to reach the toilet. This distinction helps to identify the likely mechanisms for the patient's FI and to narrow the choice of treatments. Passive FI is usually associated with hyposensitivity of the rectum, injury to the internal anal sphincter, or constipation with retention of a large mass of stool in the rectum, which causes reflex inhibition of the internal anal sphincter. Urge incontinence is often associated with diarrhea, weakness of the external anal sphincter and puborectalis muscle, and/or reduced compliance of the rectum.

Treatment of Fecal Incontinence

Conservative management of FI

Diarrhea is a major risk factor for FI (Whitehead et al., 2009), and medical management is often based on the use of dietary fiber or drugs to control diarrhea. In a small randomized controlled trial (RCT), Bliss and colleagues (2001) showed that increasing dietary fiber significantly reduced the severity of diarrhea-related FI compared to a placebo. Drugs that have been reported to be effective for reducing diarrhea-related FI include loperamide (trade name Imodium) and diphenoxylate combined with atropine (trade name Lomotil) (Read, Read, Barber, & Duthie, 1982). The published trials supporting the efficacy of these compounds are small, and some of the trials were uncontrolled. Nevertheless, these treatments are available to physicians, and some of them are available to patients without medical supervision. However, because only a small fraction of patients with FI report this condition to their physicians, physicians rarely prescribe these treatments to patients with FI, and therefore do not provide the medical supervision that is necessary to optimize their benefit.

Conservative treatment protocols for the management of FI often incorporate the use of fiber or antidiarrheal medications along with pelvic floor exercises or other behavioral strategies to treat FI. This is appropriate because (1) fiber supplements and over-the-counter medications for diarrhea are safe, and (2) this combined treatment acknowledges that diarrhea is a major risk factor for FI, which interacts with pelvic floor muscle weakness and other risk factors that are targeted by behavioral strategies such as pelvic floor exercises and biofeedback. The basic strategy for incorporating medication or fiber use into a conservative treatment regimen is outlined in the following text:

1. Begin with fiber supplementation and advance to loperamide only if fiber is insufficient.
2. Start low and go slow. Most commercially available fiber supplements provide 3–4 grams of fiber per unit dose. Begin with one dose per day and increase up to three doses per day if tolerated by the patient. It may be helpful to mix different types of fiber supplements to improve the tolerability of fiber supplements.
3. Have the patient keep a symptom diary in which they record stool consistency using the Bristol Stool Scale (Lewis & Heaton, 1997). This scale consists of seven

standard pictures and verbal descriptions of different stool consistencies ranging from constipated hard or lumpy stools (types 1 and 2) to diarrhea (types 6 and 7), that is, loose or watery stools. Patients match their own stools to these pictures and are able to report changes in their stool consistency with reasonable accuracy. Fiber should be added to the diet until stool consistency is in the normal range – Bristol types 3–5.

4. When adding loperamide, begin with one 2-mg tablet per day, and monitor changes in stool consistency on the diary. Be aware of the risk of overshooting the mark and causing constipation. If the lowest dose of loperamide in pill form (the 2 mg tablet) is too much, one can switch to the liquid preparation to provide a lower dose, or have them take the 2 mg tablet on alternate days. Do not exceed four tablets (8 mg) per day. If this dose does not control diarrhea, ask the patient to see his or her physician.

Our research team (Heymen et al., 2009) tested this conservative medical management approach during a 1-month run-in that preceded an RCT of biofeedback. The purpose of the run-in was to identify patients who did not require biofeedback and to exclude them from the RCT. Out of 168 patients with severe, treatment-resistant FI (average of three physician visits for FI in the last 6 months), 21% reported adequate relief of FI at the end of the 1-month run-in, and there was a 60% decrease in the number of FI episodes (41% decrease in the number of days with any FI) for the whole sample of 168 patients who participated in the run-in. Patients who reported adequate relief of FI at the end of the run-in were followed for up to 12 months, and 71% continued to report adequate relief (Heymen, Scarlett, & Whitehead, 2008).

Pelvic floor exercises

The primary goal of pelvic floor exercises is to increase the strength of the pelvic floor muscles through daily repetition. For best results, the patient should be carefully instructed on how to isolate the pelvic floor muscles when they squeeze, and in particular to avoid contracting their abdominal wall muscles and lowering their diaphragm when squeezing. These instructions are usually delivered verbally or in writing, and experience suggests that many patients do not perform the exercises appropriately. The most likely reason that instrumented biofeedback is superior to pelvic floor exercises alone is that the feedback can be used to teach patients how to isolate the pelvic floor muscles appropriately. However, an alternative and very effective method of training is to perform a digital rectal examination while instructing the patient on how to squeeze. The examiner can press on the pelvic floor muscles to draw the patient's attention to which muscles to squeeze and can provide verbal feedback on whether they are squeezing appropriately. By holding a hand on the patient's abdomen while having them squeeze, it is also possible to teach them to avoid inappropriate contractions of the abdominal wall muscles. This is the preferred technique for nurses and physicians to teach patients how to perform pelvic floor exercises, but psychologists may be reluctant to teach the exercises in this way. Instrumented biofeedback training may be preferable for these providers.

However the exercises are taught, it is important to have the patient perform 50–100 squeezes per day. Each squeeze should last 10 seconds, and the patient should rest for at least 10 seconds between squeezes. To avoid fatigue, have the patient perform 15–20 squeezes at a time several times a day and record in a diary when they do the exercises. Initially, they should do the exercises in a distraction-free environment and should keep their hand on their abdomen to detect any inappropriate abdominal wall contractions. As their strength improves, they should be encouraged to begin to also do the pelvic floor exercises in everyday situations such as at work or while watching television. As already described, we have shown that pelvic floor exercises alone, taught with verbal instructions, significantly reduce the frequency of FI in patients who have not shown an adequate response to conservative treatment (Heymen et al., 2009). However, in that study, the majority of patients who failed to benefit from pelvic floor exercises did show significant improvement from instrumented biofeedback, indicating that biofeedback offers significant added benefit for many patients.

Biofeedback strength training

Biofeedback is defined by the use of an electronic or mechanical instrument to provide feedback information to the patient and/or therapist, and this feedback is used in real time as an aid to teaching the patient how to alter physiological responses. Three distinct biofeedback protocols are used in the treatment of FI: strength training, sensory discrimination training, and urge training (a form of desensitization). These protocols may be used selectively, based on the physiological deficits responsible for the patient's FI, or they may be combined if the patient has multiple deficits. Strength training is appropriate when the patient has an impaired ability to contract the pelvic floor muscles as a result of nerve injury or altered morphology.

The key concept that guides this type of biofeedback is shaping, which is accomplished by the differential reinforcement of successively closer approximations to the desired response. The practical steps are as follows:

1. *Education:* Explain in simple terms what the physiological responses are that protect against FI. Using the feedback display, patients are shown what their responses are like currently, and the desired response is described.
2. *Set goals or targets that are within the patient's reach:* They should be able to achieve the target response about half the time, and the goals are adjusted continuously by making the task more challenging as they improve. Conversely, the level of difficulty should be reduced if performance deteriorates due to

fatigue, because patients who fail to meet the goal repeatedly may become frustrated and give up.

3. *Praise and encouragement:* Use praise and verbal encouragement liberally, and leverage the positive interpersonal therapist–patient relationship to maintain their motivation.
4. *Eliminating inappropriate responses:* Use the same shaping approach to teach the patient to eliminate inappropriate responses such as abdominal wall contractions. The goal is to isolate the pelvic floor muscle contraction.
5. *Prescribing home exercises (see preceding instructions):* It should be explained to the patient that the purpose of biofeedback training is to teach them how to squeeze correctly, but that improved strength will only come from daily practice.
6. *Behavioral strategies to prevent bowel accidents:* In conjunction with biofeedback and pelvic floor exercise training, specific behaviors that patients can use on their own for reducing the risk of bowel accidents can help reduced incontinence. For example, patients should be taught that, when they experience an urge to defecate, they should calmly walk to the toilet rather than rushing: tell them "walk; don't run." It should be explained that, if they are rushing, it will be more difficult for them to use accessory gluteal muscles to augment their pelvic floor muscle contraction. If they feel they are losing the ability to keep their pelvic floor muscles tightly contracted on the way to the toilet, they should stop and concentrate on squeezing rather than rushing.

Different types of biofeedback instruments are available; the two most common devices provide feedback on the (1) electromyographic (EMG) activity of the pelvic floor, and (2) pressures in the anal canal and the rectum (manometric feedback). EMG biofeedback trainers are often available as inexpensive, portable, battery-operated devices, and the transducer is typically an acrylic plug with stainless steel plates on its sides, which is easily inserted into the anal canal to pick up the EMG activity of the pelvic floor muscles. Manometric feedback training requires a larger physiological recorder, and the transducer is a narrow plastic tube with small balloons attached to its sides to detect pressure changes in the anal canal and rectum; alternatively, solid-state pressure transducers may be attached to the tube to record anal canal and rectal pressures. For strength training, EMG devices are all that are needed. Manometric devices can also be used for strength training, but the real advantage of manometric biofeedback instruments is their ability to support sensory training and urge training (see the following text).

Sensory biofeedback training

This type of training is appropriate when the patient is hyposensitive to rectal distention, that is, does not recognize the need to contract pelvic floor muscles to prevent stool passage. The key concept is discrimination training, in which the patient is repeatedly exposed to distensions slightly above and then slightly below their sensory threshold, and verbal feedback is used to focus their attention on any weak sensations associated with the distention. We and others have repeatedly shown that this process results in improved continence by lowering the threshold for perception of rectal distention (Chiarioni, Bassotti, Stegagnini, Vantini, & Whitehead, 2002). In theory, sensory discrimination training could be done without a biofeedback instrument; it should only require a balloon-tipped catheter, which can be inserted into the rectum and inflated/deflated with a handheld syringe. In practice, however, the most effective training is done with a manometric biofeedback device because (1) hyposensitivity to rectal distention is often combined with weakness of pelvic floor muscles, which may benefit from strength training, and (2) it is helpful to instruct the patient to respond immediately to the sensation of rectal distention by squeezing their pelvic floor muscles rather than simply reporting verbally whether they perceived the rectal distention. This process, often referred to as "coordination training," teaches the patient the habit of responding to faint distensions by squeezing without stopping to analyze the sensation. The steps in coordination training are as follows:

1. Education – explain to the patients that the sensation of rectal distension is the cue that tells them when to squeeze to avoid incontinence. They may not be aware of noticing rectal distension throughout the day because the stimulus–response relationship is an over-learned habit that can occur without conscious awareness. However, studies show that the ability to consciously detect weak distensions is essential to continence (Chiarioni et al., 2002).
2. Instruct the patient to respond to any sensation of rectal distention by contracting immediately, even if they are not sure that they are feeling distention. There is no penalty for squeezing unnecessarily, but there is a high cost to missing this cue.
3. Beginning with a volume of air that patients can easily feel (one usually starts with 50 ml), the balloon is rapidly distended and then immediately deflated. If the patients respond, they are given verbal feedback to acknowledge that they responded appropriately. If the pelvic floor muscle contraction in response to the reported sensation was not immediate but was delayed by several seconds, patients are encouraged to squeeze immediately because a delayed response may be too late (Buser & Miner, 1986).
4. The volume of distention is gradually decreased on successive trials until a threshold is found below which the patients fail to respond (and fail to report any sensation). Then distensions above this threshold are presented, alternating (in an unpredictable sequence) with distensions slightly below the threshold. The patients are encouraged to attend to the sensations. Successful responses that are below the initial sensory threshold are praised, and these successes in improved sensitivity are pointed out to the patients.
5. An alternative way of teaching the patients to focus on faint sensations is to use a forced-choice procedure. Here, the therapist instructs patients that he/she will

put the air into the balloon in one of two intervals. On each trial, the therapist asks, "Did I put the air in now . . . or now?" The patients are instructed to guess if they are not sure. Usually, patients will perform at better than chance levels in the forced-choice trials, and this provides an opportunity to teach them to recognize subtle cues they have not consciously perceived.

6. There are no exercises to do at home to build on sensory discrimination training. However, it is helpful to instruct patients to try to become more aware – "hyper-vigilant" – to any sensations and to squeeze even if they are not certain. Tell them, "It never hurts to squeeze extra."

Urge biofeedback training

Urge training is appropriate for patients who experience a very strong sensation of urgency to defecate, accompanied by a panic-like fear of incontinence. This sensation may have a physiological basis or a psychological basis, and these often interact. The key concept in urge training is systematic desensitization, which is modeled on the treatment for phobias by (1) teaching relaxation as a coping response (which tends to inhibit panic), and then (2) progressively distending the rectal balloon with progressively larger volumes of air. The steps are as follows:

1. Education – explain that the urge sensation results from a combination of physical factors that reduce the size of the rectum and psychological factors that further decrease the compliance of the rectum. The treatment is designed to maximize the compliance of the rectum by reducing the psychological component. Explain how the training is expected to work: you will start out by having them relax, then progressively distend the rectum several times to try to improve the amount of rectal distention they can tolerate.
2. Teach a stress-management technique that can be used as a coping strategy to counteract the panic response to rectal sensations. There are many possibilities here including progressive muscle relaxation training, autogenic training, self-hypnosis, or mindfulness training.
3. In each biofeedback training session, the therapist first helps the patient invoke a relaxed state and then begins to progressively distend the rectum. Air is slowly added to the balloon with a handheld syringe, and the patient is repeatedly told what the cumulative volume of air in the balloon is. The patient is encouraged during the trial to use the previously practiced relaxation coping strategy to control the sensation of urgency and the associated emotional discomfort. When a volume is reached that the patient cannot tolerate and before a volume that elicits frank panic, the balloon is deflated and patient given feedback on any progress made.
4. Home practice – the patient is encouraged to use the "delay strategy," that is, to practice holding back bowel movement for a short, pre-determined length of time after the first feeling of urgency, when at home in a safe environment (i.e.,

where there is low risk of embarrassment from FI). Initially, the target delay time should be short, but it should be gradually increased as the patient gains confidence in coping with the urge sensation.

Many studies have been published supporting the effectiveness of biofeedback training for improving continence, and these have been summarized in several systematic reviews and meta-analyses (Enck, van der Voort, & Klosterhalfen, 2009; Heymen, Jones, Ringel, Scarlett, & Whitehead, 2001; Palsson & Whitehead, 2012). A limitation of these studies is that most of them pool all patients with FI regardless of the physiological deficits that cause their leakage, and these studies do not attempt to distinguish between the effects of strength training, sensory training, or urge training protocols. The findings of these studies can be summarized as follows: (1) biofeedback produces significant reductions in the frequency and severity of FI for 70–85% of patients with idiopathic FI; (2) frequency and volume of FI are reduced by approximately 55% (C. Norton, Chelvanayagam, Wilson-Barnett, Redfern, & Kamm, 2003) to 76% (Heymen et al., 2009), but complete continence is achieved by only 5% (C. Norton et al., 2003) to 44% (Heymen et al., 2009) of treated patients; (3) there is controversy regarding whether pelvic floor exercises taught through verbal guidance during ongoing digital examination may be as effective as biofeedback provided with electronic instruments (Heymen et al., 2009; C. Norton et al., 2003; Solomon, Pager, Rex, Roberts, & Manning, 2003); (4) the improvements in continence seen immediately following biofeedback training are well maintained for at least 3.5 years (Lacima, Pera, Amador, Escaramis, & Pique, 2010; Pager, Solomon, Rex, & Roberts, 2002); and (5) predictors of a good clinical outcome include a motivated patient, an experienced biofeedback therapist, and milder severity of FI prior to treatment (Byrne, Solomon, Young, Rex, & Merlino, 2007).

The guidelines of most GI and colorectal surgery societies recommend biofeedback as the first-line treatment following an unsuccessful trial of medical management, but biofeedback has significant practical limitations. There are few well-trained therapists available to meet the need identified in epidemiological studies, which show that 2.7% of US adults have FI at least once a week. In addition, biofeedback is costly, because it involves several hours of provider time, and it is not covered by many insurance companies.

Comparison to surgery

The most commonly employed surgical procedure for FI is sphincteroplasty, in which the separated ends of a damaged sphincter are approximated or overlapped and sutured together. The principal indication for this operation is obstetrical injury, but it may also be employed for patients with sphincter injuries due to other types of trauma. The short-term outcomes of sphincteroplasty are good, with approximately two-thirds reporting continence or satisfactory improvement

(Madoff, 2004), although objective outcomes do not match subjective ones: 40–85% show persistent defects when examined by ultrasound (Weber, 2004). Moreover, 75% or more of patients experience recurrences of FI within 5 years of sphincteroplasty (Madoff, 2004). Bulking procedures have also been described in which silicone or inert beads are injected into the space surrounding the anal canal to increase resting pressure in the anal canal (Schwandner, Brunner, & Dietl, 2011; Tjandra, Lim, Hiscock, & Rajendra, 2004). Clinical benefits of this procedure are modest, but the procedure is simple and adverse events are rare. Artificial sphincters controlled by pumps and valves implanted beneath the skin have also been advocated, but they are rarely used because of complications related to device erosion and device failure (Madoff, 2004). Colostomy or ileostomy may be performed when the patient's quality of life is severely affected and other options have failed or been ruled out. Ostomies prevent FI for most patients who have them, but this operation is rarely elected by patients or surgeons because there is evidence that quality of life is significantly impaired (Krouse et al., 2007).

The newest surgical treatment for FI is sacral nerve stimulation, which is also called neuromodulation. This involves implanting fine wire electrodes into sacral nerve roots and connecting them to an electrical stimulator that is also implanted beneath the skin. It is possible to connect the electrodes to a temporary stimulator worn outside the body for a 2-week trial before permanently implanting the stimulator to ensure that the device is likely to improve continence. RCTs (Leroi et al., 2005; Tjandra, Chan, Yeh, & Murray-Green, 2008) suggest that about 80% of patients with idiopathic FI report a satisfactory response to sacral nerve stimulation, although the mechanism by which this treatment works remains unclear. The disadvantages of this, as of other surgical implants, are relatively high costs, occasional device failure, and limited availability. Sacral nerve stimulation is approved by the FDA for treatment of FI. There have been no studies to date that directly compare sacral nerve stimulation to biofeedback.

Implications for Practice

Fecal incontinence represents a major opportunity for behavioral medicine. It is a highly prevalent but greatly under-treated condition, and behavioral interventions have been the most effective treatments to date. This is also a condition for which physicians feel they have little to offer and they are more than willing to refer these patients to behavioral medicine practitioners, where a behavioral intervention can substantially improve patients' well-being and life functioning (Palsson & Whitehead, 2012).

Many psychologists will find it challenging to provide biofeedback for fecal incontinence because it requires performing a limited physical examination and placing probes into the anal canal and rectum. Most psychologists are trained in a psychotherapy paradigm in which there are strong taboos against touching patients.

However, psychologists have a unique background in learning theory and the shaping of behavior that may make them more effective than other practitioners if they are able to overcome their discomfort with physical examination.

We recommend that behavioral medicine practitioners who intend to make this a part of their practice develop a close professional affiliation with one or more gastroenterologists, colorectal surgeons, or urogynecologists, and that they insist that patients who are seeking treatment of FI be examined by these or other physicians prior to treatment. A prior relationship with a physician will ensure quick access to answers or guidance if patients develop a medical problem that is outside the behavioral medicine therapist's scope of practice. Physicians are also more likely to refer patients to behavioral medicine treatment if they have an established working relationship with, and good knowledge of the nature of the services of, the behavioral medicine practitioner.

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38

Task-oriented Biofeedback in Neurorehabilitation

Johanna Jonsdottir and Davide Cattaneo

This chapter will focus principally on biofeedback used in rehabilitation of mobility and balance in persons with neurological disorders, starting with a general discussion of what have been the uses of biofeedback in neurorehabilitation, and how the use of biofeedback can be optimized for motor learning. Following that, we will go more into details on how biofeedback has been combined with task-oriented practice in rehabilitation of persons with neurological disorders, in particular, to improve gait and balance.

Biofeedback refers to the retro-information relative to a function and/or biological structures (Basaglia, 1992; Basmajian, 1983). In the 1960s and the 1970s, biofeedback was viewed as the body-and-mind medicine. However, the use of biofeedback has since evolved to be an accepted methodology in the treatment of various disorders, including neurological disorders. It is recognized that people can be taught to control physiological processes if made aware of them. Feedback is thus a method of controlling a system indirectly by reinserting into it the results of concurrent or past performance. When applied to persons with neurological disorders, feedback enables the individual to determine the activity levels of a particular physiological process and find ways of manipulating the same process by internalized mechanisms for the purpose of improving health and performance. Over time, these changes can endure without continued use of an instrument if the biofeedback is applied in a manner concordant with motor learning theories (Bradley et al., 1998; Huang, Wolf, & He, 2006; van Dijk, Jannink & Hermens, 2005, Jonsdottir et al., 2010).

Biofeedback is thus a process of changing information from physiological processes into an immediately meaningful feedback form to the user. Among the most commonly used forms of biofeedback therapy in neurorehabilitation are:

The Handbook of Behavioral Medicine, First Edition. Edited by David I. Mostofsky.

- Electromyography (EMG), which measures muscle tension
- Feedback of center of pressure (force feedback)
- Neurofeedback or electroencephalography (EEG), which measures brain wave activity

A biofeedback device or computer receives biological signals that in turn can be used to modulate an output of movement. The information is most often fed back to the user as auditory, visual, or vibratory information of the activity level of the physiological process.

Augmented feedback of various types is much used to improve motor learning in rehabilitation of persons with neurologic disorders. There are indications that application of augmented feedback in a task-oriented paradigm may help recovery of sensorimotor functions and lead to adaptive plasticity in cortical and subcortical brain tissue (Huang et al., 2006). Theoretically, the use of feedback during the execution of the movement or the function helps the acquiring of a motor ability, in that the controlling process changes gradually from a closed-loop system to an open-loop system using explicit or implicit learning (Winstein, 1991).

Data from fMRI indicate that explicit learning systems are mostly distributed over the medial temporal lobe and the dorsolateral prefrontal cortex, while implicit learning and memory systems engage also the cerebellum, basal ganglia, and the sensorimotor cortex, This wide distribution makes the capacity to learn implicitly more resistant to neural system damages, such as those inflicted by stroke or multiple sclerosis (MS). Motor learning occurs via functional reorganization in relevant cortical areas, probably in response to movement-related afferent processing in response to repeated practice (Subramanian, Massie, Malcolm, & Levin, 2010; Nudo, Plautz, & Frost, 2001). More specifically, it has been suggested that feedback allows spinal neural circuitries to interpret task-specific sensory input and use this information in a feedforward manner to produce appropriate motor responses. This potentially makes the biofeedback approach to rehabilitation particularly appropriate for sensorimotor dysfunctions. It is an approach that could be particularly valid for augmenting activity and learning dependent neuroplasticity. Given during activities (rehabilitation), biofeedback can attribute to the promotion in the sensorimotor pathways. Biofeedback in that context enables motor control during activities and thus mediates use-dependent plasticity in the trained neuromotor systems.

Motivation and Cognition

Motivation and cognition are important elements in goal achieving. A key ingredient promoting motor recovery is the active engagement of the persons throughout the rehabilitation process. High motivation and active participation in the rehabilitation process from the patients' part during a difficult but feasible task can enhance motor learning and thus further augment the rehabilitation outcome (Huang et al., 2006). Learning of motor skills may be affected by patients' attentional focus.

Directing the attention to the effects of their movements can be more functional than directing their attention to the details of their own actions (McNevin, Wulf, & Carlson, 2000). Using biofeedback in rehabilitation is thus a way of making the patients active in their rehabilitation. Providing external feedback can also be useful, in that it helps the person with neurological problems to reduce his or her reliance on the therapist and become more reliant on their own performance. It is a common problem in neurorehabilitation that the performance of tasks practiced in the rehabilitation setting with constant input from the therapist may improve momentarily, but once the patient exits the clinical setting performance goes back the to the level it was before. The performance risks being therapist-dependent rather than in response to problem-solving of the patient itself. The biofeedback draws their attention to sensory cues associated with the movement to be trained consequently promoting improvement of motor control without depending on the therapist.

Feedback in a Task-oriented Approach

One of the purposes of using biofeedback is to promote neuromotor learning of a meaningful task/function and its permanent change. However, few studies have explicitly included motor learning concepts in the study design. Winstein (1991) used continuous concurrent feedback during a partial weight-bearing task with good results, and the weight bearing symmetry got better following treatment. This improvement was not maintained in time, and the authors attributed this degradation to the removal of the feedback, emphasizing the need for gradual fadeout of feedback deliverance. In fact, motor learning principles suggest that the type of feedback deliverance is very important for motor learning to occur (Schmidt, 1988).

Reports on the effectiveness of biofeedback are varied. Those different findings may stem from the situation and the type of information to which participants are instructed to attend. Early biofeedback studies used "static" biofeedback where participants were required to control a specific parameter through a quantified cue, or the movement being performed was unrelated to activities of daily living. Most results from studies using static biofeedback did not demonstrate significant improvements in motor function recovery. However, studies that used functional task-specific "dynamic" biofeedback have yielded more promising results (Huang et al., 2006). Task-oriented biofeedback allows for better interaction between the neuromuscular system and the environment by allowing patients to explore the environment and solve movement problems online. In order for task-oriented biofeedback to be effective, feedback should reflect the physiological processes that will be informative without overwhelming the patient's perceptive and cognitive ability.

In the following section, we will briefly overview the literature for efficacious application of feedback.

Biofeedback is the process of changing physiological processes into a meaningful form to the individual user; however, the characteristics of biofeedback vary by the type of physiological signals provided, as well as by how meaningful these signals are to the user. EMG, joint angle, position, and pressure or ground reaction force are some of the signals that can be used to augment feedback during training through visual display, auditory pitch or volume, or mechanical tactile stimulation (Huang et al., 2006).

The frequency of feedback delivery is important for motor learning. There is limited evidence for how feedback should be scheduled for optimal results in persons with neurological disorders. It has been suggested that delivering biofeedback in a fading frequency paradigm in accordance with motor learning theories may be more beneficial for learning new behaviors than continuous feedback (Schmidt, 1988; Winstein, 1991; Whitall, 2004; Jonsdottir et al., 2007, 2010). Thus, at the beginning of learning the target motor behavior, especially in the case of a complex motor behavior, the feedback is given frequently, and then gradually reduced toward the end. This serves to guide learners into the right "ballpark" early in practice while later in practice it is important that the learner become independent of the feedback and be able to apply the learned behavior over a variety of tasks and environments (Schmidt, 1988; Winstein, 1991; McNevin et al., 2000). Variable task practice is another important learning paradigm that has been used to promote learning of new motor skills in healthy persons and persons with neurological disorders, and which may be helpful in developing retention of effective strategies for motor control using feedback (Lai, Shea, Wulf, & Wright, 2000). It is likely that the combination of these approaches may help in the long-term learning of new complex motor behaviors (Winstein, 1991; Jonsdottir et al., 2010).

Biofeedback is a restorative approach to rehabilitation, in that the aim is to restore an impairment affecting function, but the effect appears task-specific – that is, the biofeedback should be provided during the functional activity that needs restoring (Huang et al., 2006; Jonsdottir et al., 2010; Winstein, 1991;). Providing persons with neurological disorders with biofeedback during tasks to be practiced is also a way of engaging them in the rehabilitation process. There is strong evidence that EMG biofeedback training in a task-oriented protocol improves gait (Level 1a, Teasell et al., 2012) after stroke, whereas the evidence for standing balance is less conclusive, but there are indications that standing balance is improved with the use of force platform feedback and with accelerometer feedback (Badke, 2011; Cattaneo, Jonsdottir, Zocchi, & Regola, 2007). In the following discussion, the focus will be on the use of biofeedback for gait and standing balance when applied in a task-oriented paradigm for persons with neurological disorders and, in particular, for persons with stroke and MS.

Gait and Biofeedback

The techniques of biofeedback have been used extensively in various areas of rehabilitation for adults with neural lesions. Many random controlled studies on the use of biofeedback in rehabilitation of gait were concluded in the 1980s and 1990s. From the beginning of use of biofeedback in rehabilitation of persons with neurological disorders, various types of sensory feedbacks have been used to improve various aspects of the gait, but one of the more common feedback approaches used was the EMG feedback. The patient is provided with simple and objective information as to the level of muscular contraction. Surface electrodes are used to detect the action potentials from underlying target muscles. The information is gathered in a feedback device and the signal changed to a signal meaningful to the user (Basmajian, 1983). With EMG biofeedback, the objective is the acquisition or improvement of voluntary control of the muscles.

EMG biofeedback has been used with auditory or visual feedback to increase voluntary activation of paretic or weak muscles, or to induce relaxing of spastic muscles (Colborne, Olney, & Griffin, 1993; Colborne, Wright, & Naumann, 1994). Biofeedback used in gait was mostly focused on increasing dorsiflexion during swing phase, whether by augmenting recruitment of tibialis anterior or to inhibit gastrocnemius or perineus longus muscle activity with ambiguous results (Basmajian, 1983; Wissel, Ebersbach, Gutjahr, & Dahlke, 1989; Montoya, Dupui, Pages, & Bessou, 1994). Others have used electrogoniometric biofeedback to correct genu recurvato (Olney, Colborne, & Martin, 1989; Morris, Matyas, Bach, & Goldie, 1992) or to improve the weight bearing on the hemiplegic leg (Shumway-Cook, Anson, & Haller, 1988). In general, the use of biofeedback tended to give positive results, although many of the studies were not rigorous enough, and so it was difficult to draw conclusion as to the effectiveness of the biofeedback. In a comprehensive analysis of the quality of studies on the use of biofeedback in rehabilitation, Miller and Haynes (2003) found that only 19 of the 179 studies published were of a standard rigorous enough to conclude anything from them. Schleenbaker and Mainous (1993), using meta-analysis on a series of studies on the therapeutic effect of EMG biofeedback in persons with hemiparesis, demonstrated an effect size of 0.81, which indicated that EMG biofeedback was a valid, efficient method in rehabilitation of persons with hemiparesis. Later reviews, however, showed more ambiguous results of the use of biofeedback in mobility rehabilitation of neurological patients.

Various small studies have used study designs with biofeedback combined or confronted with more traditional rehabilitation methods to improve various parameters of gait and increase gait speed. Colborne and colleagues (1993) used a crossover design with eight subjects with hemiparesis (more than 7 months post stroke), with one group receiving electrogoniometric biofeedback (EG biofeedback) on the ankle angle, another received EMG-biofeedback on the muscle activity of the soleus muscle, while a third group was treated with traditional rehabilitation methods with focus on gait. Using quantitative analysis of gait pre- and post-treatments, they demonstrated that all three groups improved, but they found the biggest improvement in the EMG biofeedback group, followed by the EG biofeedback group. A particular effect of the EMG biofeedback was the increase in push-off impulse of the triceps surae of the hemiplegic side. Another study by Cozean and colleagues (1988) with 36 patients with stroke demonstrated that the effect of a treatment with a combination of functional electrical stimulation with biofeedback can improve the flexion of the knee, the step length, and the timing of the gait cycle. A third single case study by Olney and colleagues (1989) demonstrated an improvement in knee flexion during swing phase, increased gait velocity and an increase in step length, as well as a more efficient transfer of kinetic to potential energy.

A Cochrane review that assessed EMG biofeedback for the recovery of motor function after stroke was published in 2007 (Woodford & Price, 2007). It included 13 randomized or quasi-randomized studies with a total of 269 patients. All of the trials compared EMG biofeedback plus standard physiotherapy to standard physiotherapy. In addition to standard physiotherapy, several studies also included a sham biofeedback group. The studies tended to be small and poorly designed. The authors did not find support for EMG biofeedback to improve motor power, functional recovery, or gait quality when compared to physiotherapy alone.

Another systematic review by Zijlstra, Mancini, Chiari, and Zijlstra (2010), searched for studies evaluating biofeedback-based training to improve mobility and balance in adults older than 60 years of age. Although the review was not limited to studies on motor function after stroke, more than half of the studies included older adults post-stroke. For inclusion in this review, studies needed to include a control group of patients who did not receive biofeedback and to assess at least one objective outcome measure. Nine of the 13 included studies found a significantly greater benefit with interventions that used biofeedback compared to control interventions. However, the outcomes assessed were generally not clinical outcomes but laboratory-based measures related to executing a task, for example, moving from sitting to standing in a laboratory setting and platform-based measures of postural sway, and the effects of biofeedback were difficult to separate from other components of treatment. In the review by Zijlstra and colleagues, only three studies reported long-term outcomes, and none of these reported a significant effect of biofeedback.

A review by Stanton and colleagues (2011), included 22 controlled studies providing feedback during practice of whole activities, and among the feedback types there was also EMG-BFB. The pooled results indicated a positive result of the use of feedback with task-oriented activities. A study by Jonsdottir and colleagues (2010), included in the review, found a strong effect of task-oriented EMG biofeedback from the triceps surae muscle on the affected side when used in conjunction with gait activities and confronted with a standard rehabilitation of the same duration This study and another case study preceding it (Jonsdottir et al., 2007) will be described more in detail in the text that follows.

Meaningful variables are variables that are helpful in understanding the nature of the problem. Most interesting among those are the modifiable variables that, once modified, effect a change in the status of a patient or a group of patients (Olney, Griffin, & McBride, 1994). One of the most relevant variables in gait is the energy production. Triceps surae produces 83% of the total energy. It is known that hemiplegic patients tend to have a reduction of ankle power in the final stance phase of gait; moreover, residual power production is delayed in the gait cycle. This causes a slow, often inefficient gait that also has effect on participation and quality of life of the individual. Giving feedback of the muscle activity of the triceps surae muscle of the affected side in order to increase its force production during gait activities, respects many of the prerequisites for a successful outcome of a treatment using biofeedback for promoting motor learning. Motor learning principles required for CNS-activity-dependent plasticity, in fact, include task-oriented movements, muscle activation driving practice of movement, focused attention, repetition of desired movements, and training specificity (Lai et al., 2000; Nudo et al., 2001; Subramanian et al., 2010). When learning a complex skill, the efficient use of feedback and gradual introduction of task complexities is important. In a single case study (Jonsdottir et al., 2007) preceding the random controlled study by Jonsdottir and colleagues (2010), the longitudinal changes in response to an EMG biofeedback applied to the triceps surae during functional gait activities in a person with chronic hemiparesis following stroke had been studied. The task-oriented biofeedback was applied according to theories of motor learning to maximize the efficacy of the treatment protocol. The task-oriented approach meant the feedback was given during gait activities that were progressively more varied and complex, while the motor learning approach meant that feedback was reduced progressively with no feedback given toward the end of the rehabilitation period. Results were interesting, because the subject increased gait velocity in a functionally significant manner, and many other variables of his gait improved following treatment. Further, the changes seen in the laboratory appeared incorporated into the subject's daily living activities, suggesting that the protocol was effective in promoting learning and transfer (see Figures 38.1 and 38.2).

Figure 38.1 depicts velocity changes as longitudinal measurements of gait velocity of this single subject with chronic stroke. The first five data points were baseline measures taken over 2 weeks, while the remaining data points depicted show the changes in gait velocity with task-oriented biofeedback during the 20 rehabilitation sessions, with the last data point taken 6 weeks after the end of the protocol (Follow up) (Jonsdottir et al., 2007). The significant increase in velocity is evident from the first treatment session. What is interesting to see is that the increase in gait velocity with the first five sessions of continuous biofeedback training during normal walking is immediate and then remains constant until a variation of gait activities is introduced into the rehabilitation protocol at the sixth session, indicating the importance of increasing variety and decreasing feedback during the treatment protocol (see Jonsdottir et al., 2007). The follow-up data point demonstrates the maintenance of improvement in gait velocity, further validating the protocol. Figure 38.2 instead depicts concomitant data points from step length and stride length that show the underlying changes of these variables embedded in the resultant gait velocity. The random controlled study (Jonsdottir et al., 2010) was based on the same protocol and resulted in similar changes in gait variables

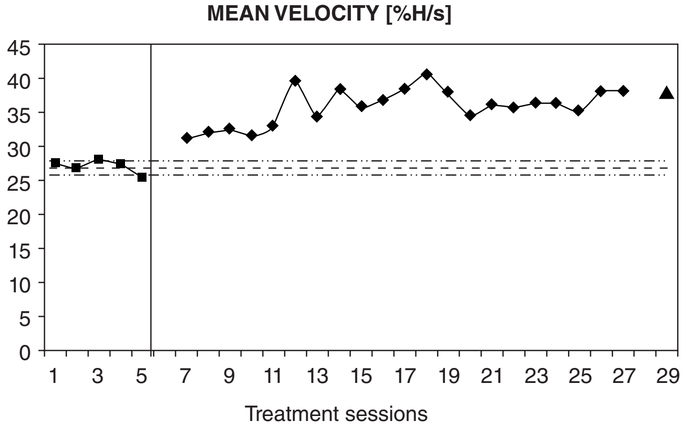

Figure 38.1 Mean gait velocity during baseline, across treatment sessions, and at follow-up.
Note: The vertical lines divide the baseline and treatment phases. The dotted horizontal line represents the mean values of baseline; the other two horizontal lines represent the two standard deviation bands of baseline data points. ■: baseline; ♦: treatment sessions; ▲: follow-up.

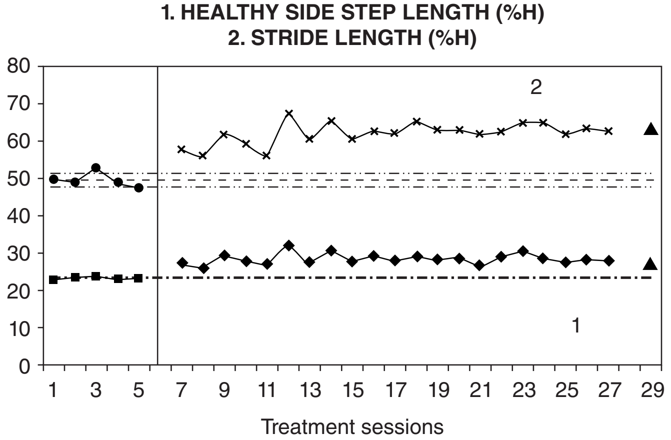

Figure 38.2 Step length and stride length across treatment sessions and at follow-up.
Note: The vertical lines divide the baseline and treatment phases; the dotted horizontal line represents the mean values of baseline; the other two horizontal lines represent the two standard deviation bands of baseline data points ■: baseline healthy side step length; ●: baseline stride length; ♦: treatment sessions healthy side step length; *: treatment sessions stride length; ▲: follow-up.

measured. The control group had the same number and intensity of treatment as did the task-oriented biofeedback group, but rehabilitation was standard usual care, including also gait activities, but they did not show any improvement in the measured activities.

Figure 38.3 depicts the mean changes of both groups from before treatment to after and to follow-up. The analyses found statistically significant effects of the biofeedback intervention on the outcome variables ankle plantarflexor peak power, velocity, and stride length from baseline evaluation to the final follow-up.

The mean increase of velocity in the biofeedback group was of about 38% of the original velocity. As pointed out earlier, the work of the plantarflexors (triceps surae) is a major contributor to forward motion during gait. In persons with stroke, the peak of plantarflexors during push-off tends not to increase with increased gait speed such as it does in healthy persons. They tend to increase gait velocity by increasing cadence and hip positive work. In this study using biofeedback, the plantarflexor muscle activation increased in response to biofeedback from before to after treatment, and also, during sessions, all participants were able to meet the goal production (auditory signal at preset muscle activation goal) during gait activities. The improvement persisted to follow up 6 weeks later, again indicating that the learned motor behavior was incorporated into daily life activities of the participants. This highlights the importance of developing treatment approaches that are effective in maximizing underlying impaired mechanisms responsible for neurological and adaptive recovery in individuals after stroke, even in the chronic state. The application of biofeedback to the calf muscles in the treatment of gait in persons with stroke may be particularly appropriate to achieve a change in gait velocity by ways physiologically more similar to healthy persons.

Balance and Biofeedback

Upright balance deficits are common in subjects with neurological disorders. Stabilometric force platforms have been used to measure and improve static balance. The movement of the center of pressure on the platform can be used to provide patients with feedback related to the position of the center pressure (CoP), that is related to the position of the center of mass, while balance activities are performed. The use of biofeedback with the force plate in stroke subjects has been reviewed by Barclay-Goddard, Stevenson, Poluha, Moffatt, and Taback (2004). The results of the review showed that force platform feedback was not useful for improving balance in activity-related tasks as measured by clinical scale, but that it was useful for improving stance symmetry.

A few studies have applied feedback of center of gravity/pressure to standing balance training with ambiguous results. One of the first studies (Shumway-Cook et al., 1988) used visual force biofeedback of center of pressure on a platform during quiet standing but the results were inconclusive. Similarly, Sackley and Lincoln (1997) applied visual feedback to balance training with ambiguous results. The

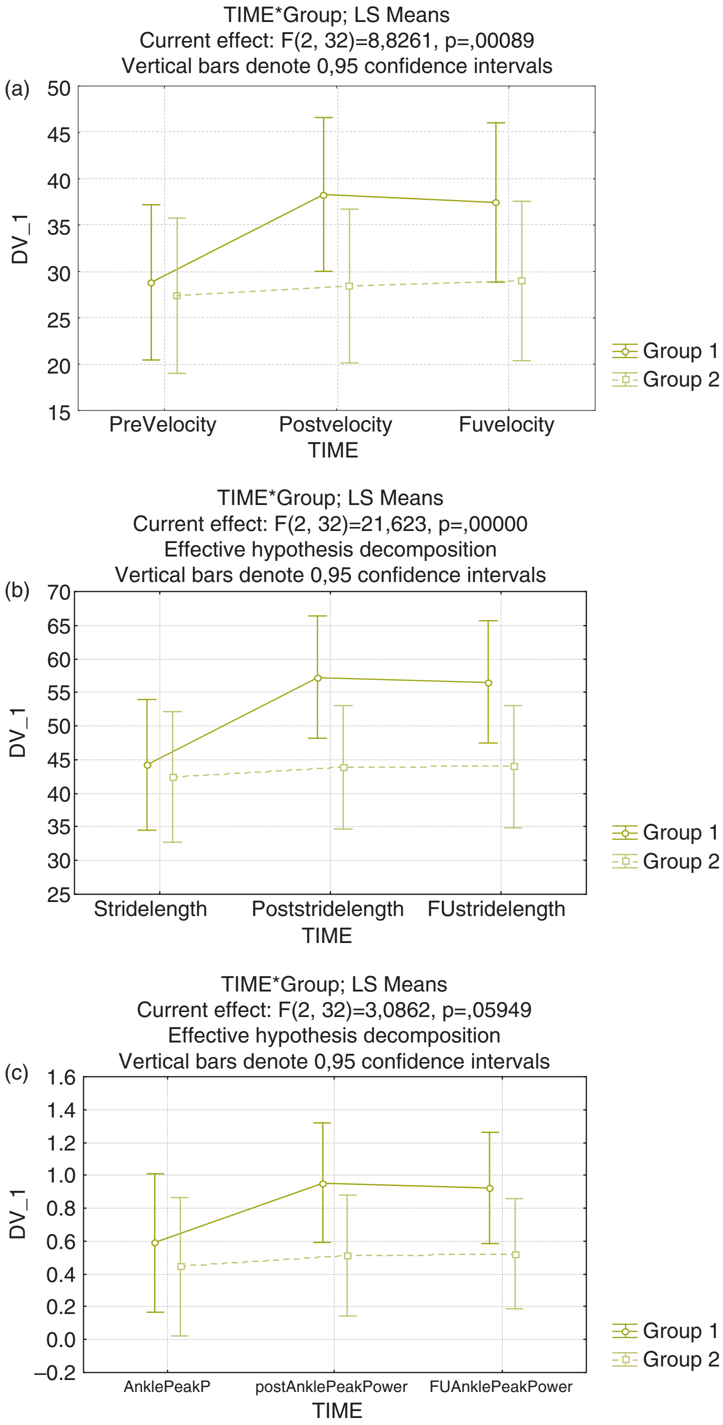

Figure 38.3 Velocity A, stride length B, and ankle power C at pre, post, and follow-up in the experimental and control groups.

Note: Velocity (%H/sec); stride length (m/h); ankle peak power (W/kg); Group 1: experimental group; Group 2: control group.

reason for these inconclusive results are not clear, although it is possible that the measures were not appropriate to the treatment or that feedback in standing does not result in improvement in more dynamic outcome measures.

Other applications of biofeedback in rehabilitation of balance disorders include tongue-based biofeedback applied by Badke, Sherman, Boyne, Page, and Dunning (2011) to a group of persons with chronic stroke. They assessed both balance and quality of life following 7 weeks of home exercises using a tongue-based biofeedback balance device. The subjects were provided with a specific set of exercises to complete, they trained with their eyes closed, and exercises were progressed from sitting to challenging standing. The subjects trained two times per day for 8 weeks and after that were evaluated with clinical scales assessing balance and balance perception and the Stroke Impact Scale for quality of life. The use of biofeedback during exercises was found to improve all aspects of balance in a clinically significant manner, and an impact on quality of life was found in balance-related activities. The feedback in the preceding study was applied in a constant manner throughout the training session and consisted in a vibratory feedback to the tongue in response to changes in head position of the subject.

In another ongoing study, Cattaneo and colleagues used stabilometric force platform to improve static balance in subjects with MS. It was expected that subjects repeatedly treated in a challenging sensory condition would show an improvement in stability with respect to a control group. Forty subjects with MS were assessed by clinical scales and stabilometric platform and randomly assigned to two groups. The group treated for sensory impairments and balance received balance rehabilitation aimed at improving motor strategies and sensory strategies including the use of a stabilometric platform to provide a feedback of the subject's Center of Pressure (CoP) position. The control group received rehabilitation treatment, which did not include training of sensory strategies and biofeedback devices. A stabilometric assessment of sway in quiet standing was performed before and after rehabilitation. The results showed statistically significant improvement in condition with eyes open on compliant surface, and near statistically significant improvement was observed for condition with eyes closed on compliant surface (see Figure 38.4). The results were encouraging, suggesting the possibility of using physiotherapy and biofeedback together to improve central nervous system recovery after neurological lesions.

Srivastava, Taly, Gupta, Kumar, and Murali (2009) investigated the effect of balance training on a force platform with visual feedback for improving balance and functional outcome in chronic stroke survivors. The 40 subjects who completed 20 daily sessions on the force platform improved on all outcome measures, and in the 34 subjects available for follow-up, the improvement in balance function was maintained. The preceding studies demonstrated a positive effect of feedback on balance. Also, a recent review of the effectiveness of biofeedback training for balance control concluded that the adjunct of BFB during balance training among the frail elderly and post-stroke persons was effective in improving balance in persons recovering from stroke (Zijlstra et al., 2010).

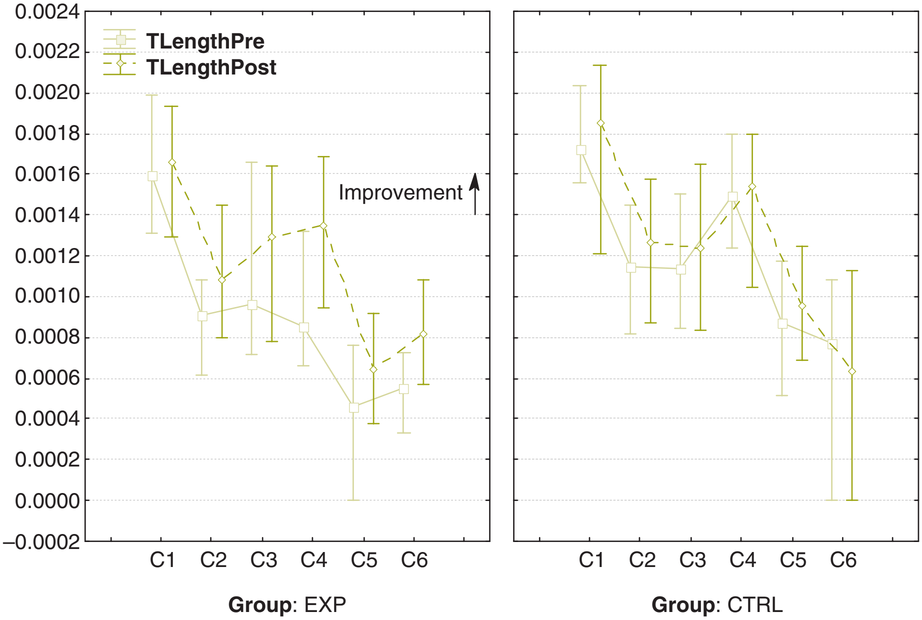

Figure 38.4 Pre- and post-median and range values for experimental and control group across the six sensory conditions.
Note: Tlength (mm^{-1}): Length − 1 of the CoP trajectory; EXP: Group 1, CTRL: Group2; C1: eyes open; C2: eyes closed; C3: sway reference visual enclosure; C4–C6 were similar to C1–C3, but a foam pad was placed under subject's feet.

The following is an overview of the use in practice of a force platform for providing feedback on movement of center of pressure in order to improve balance. Stabilometric force platforms can provide reliable information related to the position of the center of pressure. As stated previously, the position of the center of mass is thought to be a relevant variable for CNS because it can be used to control static and dynamic balance.

It is also important to note that there is no specific sensory system devoted to sensing the position of the center of mass so its position has to be estimated from other sensory information. A stabilometric force platform can be used to provide relevant information on balance control that cannot easily be collected by the CNS (Fitzpatrick & McCloskey, 1994), and the information may be even more difficult to gather and process in case of impairment of sensory systems.

The kind of feedback provided during the exercises has a primary role in fostering motor relearning. With respect to force platform, the feedback can be provided in a two-dimensional space. For example, while standing on the platform, the instant position of the CoP can be provided to the person with balance problems: the person may be asked to reduce as much as possible the dimension of the sway area, using the information provided of the CoP trajectory on a screen in front of him, or he may be asked to exaggerate the body sway within set parameters by the platform program. These exercises can help persons with balance problems in reducing body sway and/or increasing their safe area of sway, thus reducing risk of falls.

A variety of feedback can be provided to persons to improve balance in standing. One type is "band feedback" (Schmidt, 1988) in which the persons with balance problems are required to keep the CoP position within the boundaries: the feedback will be provided only when CoP exceeds this limit.

The dimension and geometry of the circumference is set following some empirical rules:

1. It can be as large as that of healthy subjects. The inside of the circle represents normal swaying in quiet standing, while abnormally increased swaying would be outside the circle.
2. It can represent an area containing a certain percentage of CoP points. For example, if during assessment a patient has a mean body sway of 6.4 mm ± 0.92 and 1.8 mm ± 0.71, respectively, in the antero-posterior or medio-lateral axis, from these data it is possible to calculate and draw an ellipsis containing the 68% or 95% of CoP position.

Another possibility used in the clinical field is the provision of feedback on a single axis with specific boundaries defined as given in the preceding text. The CoP trajectory projected on the screen then reports the position of the center of platform on the anteroposterior axis, with two vertical lines forming the upper and lower boundaries. This can be particularly useful for persons with hemiparesis, where the weight distribution tends to be unequal. Alternatively, the lines can be vertical, thus giving feedback when frontal sway exceeds the limits set. This would be appropriate when the specific balance problem is more in the in the sagittal plane such as might be the case in persons with weakness in plantarflexors.

One of the primary aims of the treatment is to reduce body sway, keeping the center of mass close to the middle of the base of support, as in the examples provided earlier. Sometimes, the person is requested to keep the body stable when the position of the CoP is in a specific zone of the base of support. For example, when treating persons who have had stroke resulting in hemiparesis, the treatment solution could be asking him to control body sway when the CoP is located close to the non-affected side. As the patient improves, the circumference can be shifted toward the middle of the base of support and then toward the paretic side, requiring the patient to control body sway predominantly with the paretic lower limb.

The exercise can be static or more task-oriented – for example, the person in rehabilitation can be asked to control the CoP position (primary aim) while, for example, controlling the position of a ball on the tray (secondary aim).

Table 38.1 Different techniques to provide feedback during a stabilometric treatment training.

Type of feedback	*Description*
Quantitative FB	The performance is scored with measuring a physical variable (e.g., CoP velocity) and is provided as an intervallar measure.
Qualitative FB	The performance is scored as a category (e.g., a integer number ranging from 0 to 10) or as a graphical representation
Concurrent FB	FB available continuously during the execution of the trial
Terminal FB	FB only available after the execution of the trial
Band FB	FB provided if the monitored variable exceeds preset limits

In general, a visual or acoustic feedback is provided when using the stabilometric platform for rehabilitation of balance. Acoustic feedback can be useful because it allows the person to perform exercises without constantly looking at the screen, and the feedback can be given in eyes-closed condition. A number of rich and sophisticated acoustic signals are now available (Mirelma et al., 2011).

The task difficulty has to be increased or decreased to find the proper challenging point (Bayona, Bitensky, Salter, & Teasell, 2005). Besides increasing or decreasing the dimension of the base of support, several other empirical procedures can take place. For example:

- Reduction of the dimension of the base of support (feet together)
- A different geometry of the base of support (feet in tandem position)
- Number of reliable sensory systems (eyes closed and/or foam pad under the feet)
- Static or dynamic exercises (standing balance vs. weight shifting)
- Single or dual tasks (counting backward or controlling a ball on a tray)
- Predictable or unpredictable external perturbation (random nudge on patient's back)

In all of these examples, the feedback can be given when the person exceeds the limits, or even as a positive feedback if the person succeeds in not exceeding the limits stabilized.

Conclusions and Limitations

The techniques of BFB offer the possibility of giving immediate, consistent, and continuous information of specific motor actions in an objective way. It is, however, important that the learned behavior get incorporated into repetitive functional activities, such as gait or reaching or activities during quiet standing. For this purpose, learning techniques are needed that allow the maintaining, as well as the generalization, of the immediate results. The principles of motor learning are an area of study focusing on the acquisition of skilled movement as a result of practice (Schmidt, 1988) that, when applied to a rehabilitation protocol, appears to help for movement relearning.

Several methodological difficulties exist in assessing the efficacy of biofeedback for improving neuromotor performance. It is often difficult to isolate the effect of the biofeedback itself independently of the task-oriented approach or the activity that is trained. Most interventions that include biofeedback are multimodal and include behavioral instructions from, among others, the therapist doing the rehabilitation, which may have effects separate from those that may occur due to biofeedback. Similarly, the repeated practice can have an effect independent of the feedback. The specific contribution of biofeedback to the overall treatment effect is in fact impossible to understand without appropriate control conditions. Moreover, many studies do not provide follow-up measures that are of particular importance since the purpose of using biofeedback in rehabilitation is to change the motor behavior permanently. It is also very important that the measures used to assess the effect be appropriate to the changes expected, and that quantitative and functional changes be related among them and to changes in activities of daily living. In conclusion, if the intent is to improve disease-related health outcomes, as opposed to potentially affecting only physiologic, intermediate outcomes, it is important that the effects be tested beyond the initial, short-term biofeedback training period, and where the effects are expected. Another specific limitation in evaluating the efficacy of biofeedback is the small sample size of most studies.

More research is needed to clarify the relationship between motor learning and feedback types or type of physiological parameters used for the feedback that gives the best learning and the best generalization. Furthermore, there is some evidence that efficacy of biofeedback in promoting recovery and motor learning depend on cognitive functioning and impairment (Subramanian et al., 2010). These issues need to be examined in more detail.

There is, however, much promising evidence that provision of feedback in general may be important for implicit motor learning and for improving motor recovery in persons with neurological disorders (Teasell et al., 2012; Subramanian et al., 2010; Jonsdottir et al., 2007, 2010; Cattaneo et al., 2007; Stanton et al., 2011), which makes more rigorous studies essential. An issue in finding beneficial effect in rehabilitation is its mode of application. While the importance of task-oriented activities within neurorehabilitation is widely recognized, biofeedback has often been applied in static postures and not as part of functional movement activities. To maximize the effect of biofeedback, it may be important to apply it within repeated task-oriented practice and with a feedback mode that facilitates motor learning (Newell, 1991; Schmidt, 1988). The following table lists some of the factors that may be important for the good outcome of biofeedback applied to protocols in neurorehabilitation.

Table 38.2 Main principles in application of biofeedback in a task-oriented protocol designed for recovery of neuromotor function.

- Comprehensive and accurate assessment of the individual functional skills with sensitive measurement instruments appropriate to the target activity
- Realistic short-term and long-term goal setting, in accordance with the needs of the patient and with the goal of impacting on quality of life. Biofeedback should be part of the short-term goal-setting, with an impact on long-term goal
- Select a variety of training options that target the individual's areas of dysfunction and take into account the individual's strength and interests. The application of biofeedback should be appropriate to the task and with the goal of improving an aspect of it – for example, explicit recovery of an impairment hindering a good execution of the activity. Choice of best type of feedback for the individual (acoustic, visual, etc.)
- Select the appropriate level at which to train the activity in order to challenge the ability of the individual and progressively increase the complexity of demands in order to continuously challenge the individual:
  - Increase the complexity of the demands, progressing to more dynamic tasks, dual tasks
  - Increase the variability of practice in functional tasks
  - Practice in increasingly varied contexts to facilitate transfer to outside activities
- Progressively decrease the frequency of feedback in order to make the activity under training independent of feedback
- Regularly reassess skills to provide feedback to the patient and health professionals and, accordingly, reset goals of training, including the level and type of biofeedback
- Give strategies to the patient to maximize both supervised and unsupervised training opportunities, with and without the feedback

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Part II

Social Work, Medical Sociology, and Psychosocial Aspects

39

Behavioral Determinants of Employment Status in Cancer Patients

Saskia Duijts, Evelien Spelten, and Jos Verbeek

Introduction: Work and Cancer – Is There a Problem?

The very first study on the return to work of cancer patients was conducted by McKenna in 1973 (McKenna, 1973). In this study, issues surrounding cancer and work were addressed, pointing, among others, to job discrimination and insurance problems. Indirectly, McKenna's work brought two other issues to our attention: cancer was not just a disease for older (and hence retired) people, and cancer could be cured to such a level that resumption of societal activities became a relevant issue. Some 40 years later, we are still studying the relation between cancer, work, and the patient. And whereas the first studies focused on more material and evident problems of job discrimination and insurance issues, we now include psychosocial functioning, behavioral issues, and the meaning of work in our studies (Banning, 2011; Barofsky, 1989; Verbeek & Spelten, 2007). The broadening of attention in research can be regarded in terms of Maslow's pyramid (see Figure 39.1) (Maslow, 1943; Maslow, 1970).

Research started at the very bottom of the pyramid, looking at physiological and safety needs (e.g., insurance, job discrimination), and is now dealing with love and belonging (e.g., support at the workplace, depression, cognitive problems, and fatigue), only to progress toward issues around self-esteem and self-actualization (e.g., the relation of an individual to work and to illness).

Medical developments in early diagnosis and more effective treatments have had an impact on the widening of the research scope. They have resulted in better and longer survival, drawing attention to more long-term issues in research around

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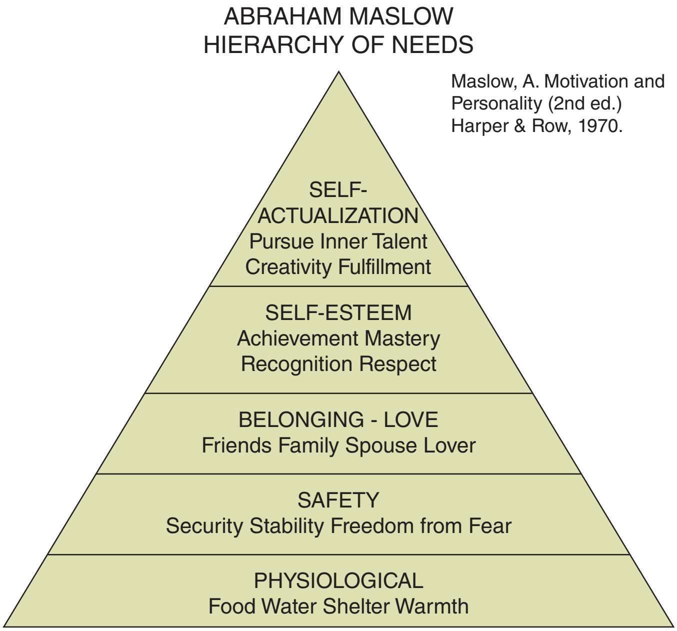

Figure 39.1 Maslow's pyramid of needs. (Maslow, 1943; Maslow, 1970)

survivorship (Feuerstein, 2007). In addition, the broadening of the research scope is also the result of dissemination of research results. Increased awareness of, for example, insurance problems has been an incentive for change – that is, in many countries, laws were changed to alleviate this situation. Subsequent research found that this did not solve all problems for cancer patients returning to work. In line with Maslow's thinking, one could say that when the more imminent problems were being dealt with, others became apparent.

It is recognized that the impact of cancer does not end after treatment, and that current approaches fail to address the full range of physical, psychological, social, spiritual, and financial needs that cancer survivors may have after treatment (Brearley et al., 2011). The focus in research has shifted and now looks beyond survival alone. More complex issues such as how to stay employed, following return to work, are increasingly becoming relevant.

This does not indicate that the very basic problems are no longer an issue. Job discrimination can still be found despite increased awareness. In their meta-analysis, de Boer et al. compared cancer survivors to people who had not had cancer and found that cancer survivors are 1.37 times (95% CI; 1.21–1.55) more likely to be unemployed than those without cancer (de Boer et al., 2009). Among the many reasons for this difference, (overt) job discrimination in any form is expected to be one.

Figure 39.2 Return-to-work triangle.

Cancer, work, and the person: What do we know?

Research into cancer and work involves three parties: work, cancer, and the person (see Figure 39.2).

In this first section, a summary is given of what we do know with respect to these three parties. We move from what we *do* know to what we *do not* know. We look at variation in return-to-work percentages and factors relevant to return to work. We address the question whether the situation of cancer patients and survivors is unique by looking at two other health conditions, and by a comparison with the general population. And, we end with indicating what we think is not highlighted enough until now – thus, what we *do not* know.

In the second section, the focus shifts to the party, we argue to have received little attention in this respect, that is, to the person, and specifically to behavioral determinants: can psychological and/or behavioral theories be applied to the problem of cancer and return to work or functioning at work?

In the final section, we will consider interventions: how is the research knowledge translated to the practice level, how well do current interventions address the behavioral component, and what we know about the effectiveness of these interventions?

Variation in return to work and job loss in cancer survivors

Several studies have documented the impact of cancer on employment, and on return to work. Studies show that approximately 60% (ranging 30–93%) of the cancer patients re-enters the workplace within 1–2 years after diagnosis (de Boer et al., 2011; Earle et al., 2010; Mehnert, 2011; Spelten et al., 2003; Taskila et al., 2007). There are important societal and cultural factors that play a role here. For example, there are clear financial incentives to do so (de Jong & Rijken, 2005), and the impact of social security measures varies across cultures.

The cancer survivors who return to work at some point in their recovery process experience at least temporary changes in work schedules, work hours, wages, and a decline in work ability compared to non-cancer groups (Earle et al., 2010; Mehnert, 2011; Spelten et al., 2003). In terms of job loss and regaining employment, Mehnert (2011) found that between 26% and 53% of cancer survivors lost their jobs or quit working over a 72-month period post-diagnosis (Mehnert, 2011). Between 23% and 75% of patients who lost their jobs were re-employed. Moreover, cancer survivors had a significantly increased risk for unemployment, early retirement, and were less likely to be re-employed (de Boer et al., 2009; Mehnert, 2011). Earle and colleagues (2010) concluded that, although most patients did return to work, labor force departures attributable to cancer occurred in 17% of those employed at baseline, particularly those with worse prognoses or lower socioeconomic status.

Factors relevant to return to work

Studies into return to work of cancer patients invariably involve heterogeneous groups: there are differences in diagnosis, differences in treatment, and differences in work and work environment, not to mention differences in patients. All these differences are relevant to explaining variation in return to work. And their impact can often work two ways: sometimes they hinder return to work, but they may also make it easier to return to work. The different factors can be summarized in terms of the triangle described earlier:

- Work: For example, type of job, possibilities to vary work hours, employer support, attitudes of co-workers
- Illness and treatment: Type of cancer, type of treatment, consequences of treatment and illness. Of the consequences of cancer and its treatment, fatigue is the most well-known, the most persistent, and the most prominent (Spelten et al., 2003)
- Personal factors, such as sociodemographics (e.g., age, education, financial situation), psychosocial and physical well-being

With respect to personal factors, we found that very little attention is paid in research to behavioral determinants of return to work of cancer patients and survivors. This will be considered in more detail in the second section.

Comparison with other health problems and the general population

Sickness absence from work is not only dependant on the person, but also subject to cultural influences – for example, financial impact, job security, and social security measures. In addition, the work conditions and work culture of a particular employer will affect sickness absence rates: absence levels can be seen as a reflection of company policies toward their employers.

Seen in the light of the severe impact a cancer diagnosis has, an average rate of return to work of 60% sounds quite positive and seems to confirm the importance of work in the recovery process. However, how do these rates compare to other health problems? And, are factors influencing return to work comparable? Studies into heart disease, into depression, and of the general population were used as references.

Hallberg and colleagues found that almost half of the patients were working 1 year after coronary artery bypass surgery (Hallberg, Palomaki, Kataja, & Tarkka, 2009). Five years postoperatively, 85% of patients were still working. In all, patients' staying at work was comparable with that in the general population. The best predictors for return to work were younger age and preoperative employment. Recovery expectations at baseline were positively associated with long-term survival and functioning (Barefoot et al., 2011).

Depressive complaints are highly prevalent in the general as well as the working population, and are associated with long-term sickness absence. Studies show that return to work of patients with depression seems as difficult, if not more, when compared to cancer patients: work rehabilitation was found to be very difficult, and symptom reduction did not necessarily lead to work resumption. Unfortunately, in both studies, no percentages were quoted (Lexis et al., 2011; Myette, 2008; Lexis et al., 2011; Myette, 2008).

With regard to the general population, a Dutch report (de Jong & Rijken, 2005) on cancer and work stated that less than half of the people who have ever had cancer in the ages between 18 and 64 have paid employment. This compares unfavorable to the healthy population, where two-thirds have paid employment. In addition, the financial situation of cancer survivors is comparable to that of the chronically ill: they have several hundred euros per month less as compared to the general population, and 90% have medical costs in addition to health insurance coverage. In a study into behavior and sickness absence in the general population (Brouwer et al., 2009), multivariate analysis identified three potential prognostic factors that were significantly associated with the time to return to work: work attitude, social support, and willingness to expend effort in completing the behavior. Information about the influence of behavioral determinants associated with return to work in cancer patients and survivors could not be found.

To summarize, return to work for cancer patients seems worse when compared to the general population, may well be comparable to other physical health conditions and looks favorable compared to patients with depression.

Conclusion

More than 40 years of research has given us a lot of insight into the relation between cancer and work. Looking at the results, it can be said that we *do* know a lot about factors affecting the return to work of cancer patients:

- Attention for return to work of cancer patients has increased substantially.
- A large proportion of cancer patients return to work.
- Possibly because of the importance attached to work (e.g., financial, societal), very few studies have looked at patients *not* returning to work.
- Problems experienced by cancer patients are, to a degree, similar to those faced by patients with other chronic conditions.
- Factors that affect return to work are related to work, cancer and its treatment, and to the person. Attention toward the impact on the person seems to have been limited.

When looking at the presented triangle – work, cancer, and the person – behavioral determinants of return to work seem remarkably under-researched: do these behavioral aspects have an impact on return to work, or staying at work, and how? For example, why does patient X return to work in 6 months, whereas patient Y, whose work conditions, diagnosis, and treatment are comparable, is still at home, 2 years after the end of treatment? In the next section, attention turns to these behavioral determinants.

Employment Status in Cancer Patients: A Behavioral Perspective

Elaborating on the concepts that have been introduced in the first section, attention will now be turned to the aspect we argued to have received little attention – that is, the person, and more specifically, behavioral determinants. We will describe this "personal domain" within the framework of the International Classification of Functioning, Disability and Health, and subsequently link this to different behavioral determinants that might be of influence. However, this section will start with two concepts that cannot be ignored when focusing on the person in relation to cancer and work, namely, the meaning of work, and illness perception.

Meaning of work

Anyone who has ever held a job is more or less aware of the major role it plays in daily life. Work may occupy your thoughts, even beyond the hours of your attendance, it determines the schedule for the day, contributes to social identity and self-esteem, and may even, in certain cases, determine whether or not to have a family (Martel & Dupuis, 2006). From a positive organizational perspective, work fulfillment leads to higher subjective well-being (Feldt et al., 2000; Wiener et al., 1992), and it undeniably influences quality of life and health (Stansfeld et al., 1998). It allows individuals to provide for one's own (Ferrell et al., 1997), to achieve personal satisfaction through social interactions and social integration (Clark & Landis, 1989; Kagawa-Singer, 1993), to express and realize core values, such as creating new knowledge, but also to identify themselves with a profession, which is an important component of having a social role (Peteet, 2000). Such positive consequences of work may affect behavioral concepts such as self-efficacy, but also, for example, perceptions of control over the environment and everyday life.

However, research has also shown that unfavorable characteristics of work, for example, too many unchallenging tasks, or unpleasant events at work, for example, conflicts with colleagues, may enhance future sickness absence (Duijts et al., 2006), and may decrease quality of life. From a negative organizational perspective, work may continuously occupy your thoughts, beyond the hours of your attendance, and may adversely influence important choices in life, because of excessive responsibilities and obligations. On the long term, harmful effects of work may potentially lead to severe morbidity, such as coronary heart disease, depression, or even death. Specifically, research has shown that high demands may relate to poorer health (Roelen et al., 2008), and that the prevalence of psychiatric morbidity is greater in high-job-strain than low-job-strain individuals (Cropley et al., 1999). Also, employees with high psychological and physical job demands, and low job control, report elevated risks of emotional exhaustion, and psychosomatic and physical health complaints.

In everyday life, working is not questioned. It is perceived as something expected and natural (Schultz, 2005). Work has moral connotations for a large part of the population and is considered a duty of the individual to society and to others (Weber, 1995). It is only when the individual is unable to work that the meaning of work becomes visible. The order of everyday life is suddenly broken (Bech-Jorgensen, 1994).

Work, in general, has meaning when it contributes to creating the individual as someone who has social relations with others. Work should enable the person to use skills, to apply problem-solving techniques, and to have a voice with regard to decisions. When the job is performed in a stimulating environment, it could support the development of interesting contacts and the ability to yield influence in the field (Morin, 2004). Work thus becomes an important part of the individual's identity (Rasmussen & Elverdam, 2008).

When it comes to cancer and work, as already described in the first section, survivors see being able to work as an important phase in the recovery process (Holland, 1986; Mellette, 1985), but also as a measure of control over illness, and as a positive step toward the future (Maunsell et al., 1999). Despite all known advantages, some cancer survivors may be required to stop working, reduce their work hours, or change the content of their jobs because of physical or cognitive problems, or psychological concerns arising from their diagnosis or treatment. Others may change their work voluntarily as a result of a re-evaluation of their life priorities, realizing that trying to achieve a level of productivity similar to healthy counterparts may reduce their well-being (Antoni et al., 2001).

Regardless of the fact that, as survival rates increase, and more patients with cancer return to the workplace (Rothstein et al., 1995), cancer remains a life-threatening illness that encourages individuals to rediscover their identity.

Disability may not only undermine unique aspects of the identity, but it also represents a distressing loss of normalcy, intactness, or control (Muzzin et al., 1994). Moreover, cancer may affect not only one's identity, when re-arranging personal and work-related priorities, but, regarding the latter, also one's relationships with supervisors, clients, colleagues, and/or institutions. Consequently, a diagnosis of cancer often stimulates individuals to ask ultimate questions, such as: "What is the most important thing in life?", "What or whom can be counted upon?", but also: "What does work mean to me, and how important is this for me at present?"

Recognizing work-related sources of distress and taking into account the impact of cancer on work performance and employability may improve quality of life of cancer patients. However, reflecting the *meaning* that work has for patients may define the most significant concerns for patients dealing with their work lives throughout the course of illness (Peteet, 2000).

Illness perception

Looking at the triangle of cancer, work, and the person, illness perception is an important concept next to the meaning of work, as described earlier. How our ideas about illness influence our way of coping with disease has been elaborated by Leventhal in the "model of illness representations." The model states that, if the patient considers the disease as a narrowly defined medical disorder, the duration as long, and the consequences as serious, the functional outcome will be worse, irrespective of the objective medical seriousness of the illness (Leventhal & Crouch, 1997). Because this mechanism works over a range of diseases, this strongly suggests that the ideas a patient has about the disabilities that result from the illness are important in encouraging or hindering return to work (Verbeek, 2006).

Leventhal and colleagues (1980) defined illness beliefs as a patient's own implicit, commonsense beliefs about his or her illness. However, even between patients with the same medical condition, these illness beliefs may vary strongly. Leventhal states with his self-regulatory model that individuals, to understand and cope with their illness, form a mental representation of their illness, which has both cognitive and emotional content.

Five cognitive dimensions of illness beliefs have been described, as listed in the following text:

1. *Identity*, which refers to the label the individual has given to the illness (the medical diagnosis of cancer in this context) and the associated symptoms (e.g., fatigue, pain, menopausal symptoms).
2. *Perceived cause* of the illness, which reflects the factors the individual believes caused the illness. This may be biological (e.g., a gene) or a health behavior, such as smoking. Patients may also hold representations of illness that reflect a variety of different causal models, for example: "the tumor I was diagnosed with

has a genetic origin" versus "the tumor I was diagnosed with is due to my own lifestyle."

3. *Time line*, which refers to beliefs about how long an illness will last, whether it is acute (i.e., short term) or chronic (i.e., long term), for example: "Next year, when all treatments will be finished, I hope to be back at work again."
4. *Consequences*, which refer to the patient's perceptions of the possible effects of the illness on his or her life. These may be physical (e.g., pain, lack of mobility), emotional (e.g., loss of social contact, loneliness), or a combination of factors. For example, "being diagnosed with cancer will hinder me doing my job, which makes it difficult for me to see my colleagues."
5. *Curability* and *controllability*, which refer to the patient's beliefs about whether the illness can be treated and cured, and the extent to which its outcome is controllable (either by themselves or by others). For example, "If I follow the planned treatment, the tumor will probably decrease." The emotional component of the model reflects a person's evaluation of the potential emotional impact of the illness or condition (Moss-Morris et al., 2002).

The self-regulatory model states that there is a direct relationship between illness representations and coping behavior. It is based on problem-solving and suggests that we deal with illness and symptoms in the same way as we deal with other problems. The assumption is that, given a problem or a change in the status quo, an individual will be motivated to solve the problem and re-establish his state of "normality." In terms of employment status, if working is your normal state, then you will interpret sickness absence as a problem, and you will be motivated to re-establish your state of going to work (Ogden, 2005).

This problem-solving process traditionally follows three stages: (1) interpretation: making sense of the problem – for example: "I am on sick leave because of cancer, but I am planning to return to work as soon as possible," or "I am on sick leave because of cancer and I want to figure out how important work is for me, and if I want to return to this specific job or even work at all"; (2) coping: dealing with the problem in order to regain a state of equilibrium. Two broad categories have been defined: approach coping (e.g., taking pills, going to the doctor, resting, talking to friends about emotions) and avoidance coping (e.g., denial, wishful thinking). Approach coping is, for example: "I am working during treatment, but fatigue is preventing me from performing my regular tasks. So, I have discussed this with my supervisor and we have made some adjustments to enable me to continue working, which is what I prefer to do"; and (3) appraisal: assessing how successful the coping stage has been – for example: "Not having to think about work during treatment was something I really needed back then."

These three stages are said to continue until the coping strategies are deemed to be successful and a state of equilibrium has been attained. This process is regarded as self-regulatory because the three components interrelate, in an ongoing and dynamic fashion, in order to maintain the status quo. In other words, they regulate the self (Ogden, 2005).

Against the background of both the *meaning of work* and *illness perception*, we will focus on the "personal domain" within the framework of the International Classification of Functioning, Disability and Health, and question if this might be the missing link when assessing employability in cancer survivors. Are personal factors, and more specifically behavioral determinants, of significant influence when it comes to employment status in cancer survivors?

International classification of functioning, disability and health

As we have seen in Leventhal's description of illness perception, there is a wide range of disability among patients, even when they have had the same disease with equal severity (Verbeek, 2006). At the end of the first section, we already questioned why patient X returns to work in 6 months, whereas patient Y, whose work conditions, diagnosis, and treatment are comparable, is still at home, 2 years after the end of treatment.

Research has shown that, among patients who have survived breast cancer after surgery and chemotherapy, sickness absence is on average about a year. Nevertheless, the large variation that is present diverges from a couple of days to a couple of years. Among patients with testicular cancer who have undergone surgery, there is a variation of several weeks in the duration of sick leave (Spelten et al., 2003). Even when diagnosis, treatment, and side effects are taken into account, variations still exist.

A basic framework that could help in understanding the problem of return to work is provided by the World Health Organization (WHO). The WHO explains in its International Classification of Functioning, Disability and Health how disease and disability are related (see Figure 39.3).

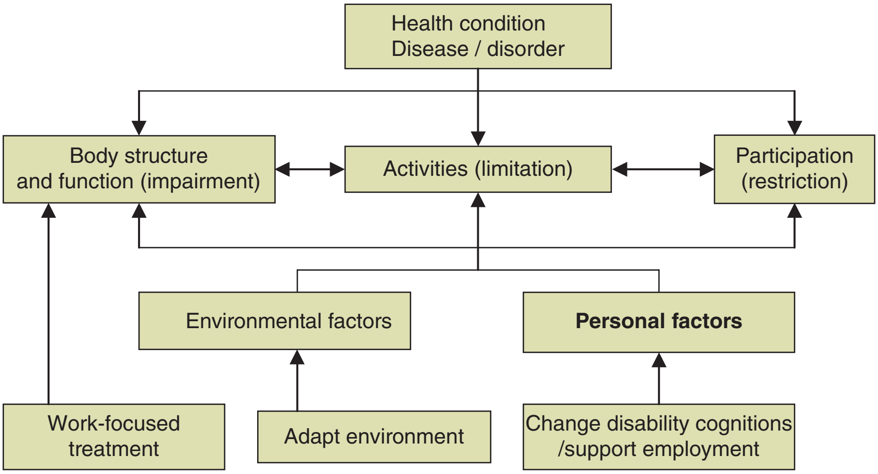

Figure 39.3 The WHO model of functioning, disability, and health (ICF-model).

The model considers the influence of disease on an individual's participation in society. Diseases or disorders affect the triad of "body structure and function," "activities," and "participation," which lead to either disability or no disability. It depends on important conditional factors of both environmental origin, such as heavy physical work, and personal origin, such as personal ideas about disability (World Health Organization, 2001). Regarding the former, a person can be affected by the environment, or actively change the environment. For example, job discrimination is not unlikely for a cancer patient or survivor to experience when applying for a job. This makes it more difficult to change jobs or start a new job after a period of not working. With regard to personal factors, mentioned in the WHO International Classification of Functioning model, these factors may be an important domain in predicting return to work. Their potential influence is already described by Mechanic in the "theory of illness behavior," which states that people interpret bodily symptoms differently and, as a consequence, will *behave* differently (Mechanic, 1995). For example, a woman who is undergoing hormonal treatment for breast cancer may experience hot flushes as extremely disruptive, and causing her to be absent from work, while another woman may cope with them by means of relaxation practices, during the day and at work.

Both the *meaning of work* and *illness perception* may influence the person here and affect subsequent behavior.

Return to work as a health behavior

As already indicated, behavior in general plays an increasingly important role in health and illness (Ogden, 2005). It has been suggested that 50% of mortality from the 10 leading causes of death is due to behavior. For example, Doll et al. estimated that tobacco consumption accounts for 30% of all cancer deaths, alcohol 3%, diet 35%, and reproductive and sexual behavior 7% (Doll & Peto, 1981). Moreover, approximately 75% of all deaths due to cancer may be associated with behavior. It has been calculated that 90% of all lung cancer mortality is attributable to smoking, which is also linked to other illnesses, such as cancers of the bladder, pancreas, mouth, larynx, and esophagus, and to coronary heart disease. Also, bowel cancer, which accounts for 11% of all cancer deaths in men and 14% in women, appears to be linked to diets high in total fat, high in meat, and low in fiber. As health behavior seems to be important in predicting mortality and longevity (Ogden, 2005), an attempt could be made to increase our understanding of behavior in the triangle of work, cancer, and the person.

Promoting healthy behaviors among cancer patients and survivors receives significant attention. Various interventions have been offered to help them to stop smoking, eat healthy, exercise regularly, and reduce alcohol intake (Pinto & Floyd, 2008). Correspondingly, return to work or staying at work could be conceptualized as a complex human behavior. That is, an employee takes the final decision to actually return to or stay at work or not (Brouwer et al., 2009).

When trying to influence health-related behavior, it is important to understand why people behave as they do. Gaining insight in determinants of behavior, even when it comes to employability in cancer survivors, is significant if behavioral change is desirable. It should be noted that identifying behavioral determinants of employment status is not an isolated process – that is, diagnosis and treatment- and work-related factors cannot be disregarded. However, in this chapter, the person and, specifically, his or her behavior are explored, since the eventual return to work or staying at work is something you do or you do not (Meertens et al., 2000).

One could question what has priority, in identifying behavior. Is it searching for determinants of desired behavior (e.g., returning to work), for determinants of undesired behavior (e.g., not returning to work), or for determinants of behavioral change (e.g., why do cancer survivors chose (not) to return to work?)? Moreover, one could ask oneself, in the context of cancer survivorship, what can be indicated as *desirable*, since deciding that other aspects of life deserve more priority than work may be the most advantageous decision at a certain point in life.

Taking all known determinants for return to work in cancer survivors into account, it is interesting to understand why the final decision to return or stay at work differs between people. Here, psychological and/or behavioral theories and models can significantly contribute to our knowledge base (Pinto & Floyd, 2008).

Behavioral theories applied to cancer and return to work

One of the most influential behavioral change models that can be applied here is the theory of planned behavior (TBP) (Ajzen, 1991; Fishbein & Ajzen, 1975). This TPB model (see Figure 39.4) states that people's behavior is best predicted by basically asking people about their intention to display a specific behavior. When it is simply not possible to show that specific behavior, or when unexpected barriers appear, the intention will not result in the desired outcome. However, when an intention is not hindered by, for example, lack of skills or environmental barriers, a shift toward explaining the intention can be observed.

Intention is influenced by three determinants: (1) attitudes: the positive and negative evaluation of the expected outcome of a certain behavior (e.g., "by returning to

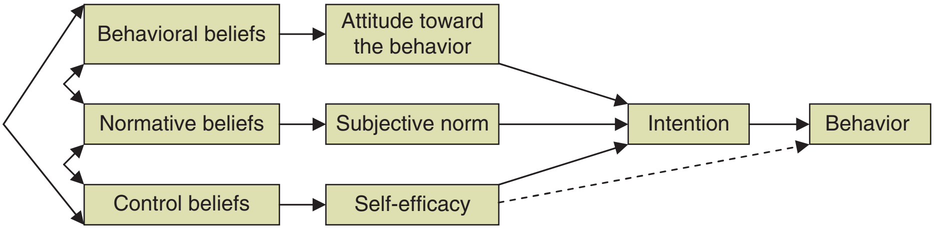

Figure 39.4 Theory of planned behavior model.

work, I will regain a sense of normalcy"); (2) subjective norms: the belief about what others think of the behavior, as derived from the behavior and/or direct feedback of significant others (e.g., "my occupational physician told me to report sick after receiving my diagnosis"); and (3) perceived behavioral control or self-efficacy: the degree to which an individual believes that the behavior is under his or her control (e.g., "I am not able to perform my tasks at work at this moment"). Behavioral intention is considered as a mediating factor in the association between attitude, subjective norm, and perceived behavioral control on the one hand, and behavior on the other (Bandura, 1977). Regarding return to work, self-efficacy has been highlighted as playing an important role in the process (Labriola et al., 2007; Shaw & Huang, 2005). That is, believing in one's own capability of returning to work half determines the actual return to work. However, employability is something that not only involves the cancer patient or survivor, but also requires commitment and efforts from employers; occupational, general, and insurance physicians; and social security organizations.

The TPB has been extensively applied to all kinds of health-related problems, such as smoking prevention, reduction of alcohol consumption, and breast and testicle self-examination (Ajzen & Madden, 1986; Armitage & Conner, 2001; Godin & Kok, 1996; Sutton, 1998). Meta-analytic reviews of studies using the TPB have supported its ability to predict these behaviors (Armitage & Conner, 2001). Still, the application of the TPB to employment issues is limited. In the work context, a few studies have been found using the TPB model in developing preventive interventions to reduce occupational injuries and health problems (Colemont & van den Broucke, 2008; Heymans et al., 2006; van Oostrom et al., 2007). Furthermore, several studies showed that a positive attitude to return to work (Arnetz et al., 2003; Krause et al., 2001; Young et al., 2005), high social support (Krause et al., 2001; Nielsen et al., 2006), and a high level of self-efficacy (Faucett, Blanc, & Yelin, 2000; Labriola et al., 2007) are all positively associated with return to work (Brouwer et al., 2009). Such findings suggest that using the TPB model may be a promising approach to better understanding the duration of sickness absence and factors influencing returning to or staying at work. Moreover, it could be a promising approach when exploring employment status in cancer patients and survivors.

Another applicable model concerns the social cognitive theory, based on the learning theory of Bandura (Bandura, 1977). It states that people's health-related behavior is best predicted by the expectations they have about certain behavior – that is: (1) expectations about consequences of certain actions in the environment, so-called "situation-outcome expectancies"; (2) expectations about consequences of personal actions, so-called "action-outcome expectancies"; and (3) expectations about if one is capable to perform a certain action, the earlier described "self-efficacy." Within this model, behavior is indicated as a continuous interaction between aspects of the environment, characteristics of the person himself or herself, and the behavior of the person.

All three aspects can influence each other. A person can be affected by the environment or actively change the environment. For example, a cancer survivor who is still confronted with long-term side effects of treatment, such as concentration problems, may implement some adjustments to the tasks at work, after returning, corresponding to his or her abilities at that time. Also, personal characteristics may influence behavior – for example, a cancer survivor at higher age may decide not to return to work anymore, but instead spend more quality time with family and friends.

Regarding cancer patients and survivors, the social cognitive theory may provide a framework to evaluate outcomes, such as return to work, through interventions. The components of self-efficacy, outcome expectations, and self-regulations may be used to evaluate the mechanism of change (Graves, 2003).

Bandura states that people do not only learn from their own experiences when performing certain behavior, for example, positive remarks about being back at work again by colleagues, but also by observing others, for example, learning from experiences of others who already returned to work during or after treatment (Bandura, 1977). When positive expectations are present regarding returning to work or staying at work, the most important step toward employability is established (Meertens et al., 2000).

As most behaviors are acquired, and in essence are a reaction to a specific stimulus, it is plausible to assume that these behaviors can be changed. Not returning to work, as attained behavior, because of disappointing experiences and lacking support from employer and/or occupational physician, may change the work-related attitude from positive to negative, and thereby become crucial in the decision of staying sick-listed. Arranging additional support at work, for example, by employing a coach with whom problems at work can be discussed on a weekly or monthly basis, may affect self-efficacy, lead to better functioning at work, and may even prevent sickness absence in future.

Conclusion

Having described the meaning of work, illness perception, the personal domain, and specifically behavioral determinants in relation to employment status of cancer patients and survivors, one could ask how these concepts could contribute to return to work or staying at work. Should they be taken into account, next to diagnosis and treatment-related factors? Or is it still a wait-and-see approach, since work is not as important in Maslow's pyramid as physiological and safety needs? Maybe we should realize that work, as a result of a re-evaluation of life priorities, is not nearly as important as we all might believe. Whether cancer patients and survivors return or not return to work, whether they function well at work or not, may have to do with the search for meaning, with gaining a sense of mastery, and the process of self-actualization, after being confronted with a life-threatening event such as cancer.

If and how these concepts have been applied within the field of cancer and employment will be addressed in the final section.

How Well Are Behavioral Determinants Addressed in Interventions to Help Cancer Patients Return to Work?

Feuerstein et al. proposed a model of return to work in cancer survivors with the explicit aim to guide the evaluation, prevention, and management of survivors who experience problems returning to and/or remaining at work (Feuerstein et al., 2010). They consider return to work as the outcome of an interaction between health, symptoms, functioning, work demands, and work environment. Behavioral symptoms are considered a part of health and seem to play only a minor role in the model. Thus, the model does not give much guidance as to how to address behavioral determinants in interventions to help cancer patients or survivors to return to work.

Recently, the contents and effectiveness of interventions to help cancer patients return to work have been extensively summarized (de Boer et al., 2011; Tamminga et al., 2010). From these reviews, we can learn how well behavioral determinants are addressed in current intervention strategies and where we could still improve.

Tamminga et al. found 23 studies describing 19 interventions that aimed at helping cancer patients to return to work regardless of whether the studies evaluated the effectiveness of the intervention (Tamminga et al., 2010). Based on the ICF model, the interventions were divided into person-directed and environment-directed interventions. Most studies (16/19) used person-directed interventions to achieve, among others, a goal of return to work. Table 39.1 gives an overview of the person-directed interventions and their content.

Over time, there is a trend from simple interventions that encourage patients to resume work and counteract discrimination, to more complex interventions such as self-management and self-actualization that are supported by behavioral theories. This is in line with a change in perceptions of the problems of cancer survivors, as described in the introduction section of this chapter. However, most interventions that were reviewed formed a minor part of the whole intervention, aimed to support survivors in coping with a variety of problems such as fatigue and pain. Only two interventions were directly focused on return to work and not on other aspects of cancer survivorship, but neither are based on behavioral theories, even though one uses goal setting, which is important to increase self-efficacy (Clark & Landis, 1989; Nieuwenhuijsen et al., 2006). Two other interventions used self-management as the intervention to increase quality of life (Cimprich et al., 2005; Korstjens et al., 2008; van Weert et al., 2008). Even though there is no generally accepted definition, self-management has been defined as a systematic intervention that is targeted toward patients with chronic disease and which should help them actively participate in either or both of the following: self-monitoring (of symptoms or of physiologic processes) or decision-making (managing the disease or its impact through self-monitoring). Self-management approaches that are based on psychological theory are shown to be more effective in a meta-analysis (Chodosh et al., 2005). Another meta-analysis of interventions that contained various numbers of components of self-management showed that more components were associated with greater effects on quality of life

Table 39.1 Overview of interventions and their content related to behavioral determinants, based on Tamminga et al. (2010).

Study	*Year*	*Providing information*	*Behavioral components*			
		Educational session	Information	Counseling	Group discussion	Problem solving
Capone	1980			Early RTW		
Maguire	1983			RTW		
Clark	1989			Satisfaction of and desire to work		Myths
Leitsmann	1991				Work among others	
Zampini	1993	Workshops legal rights				
Berglund	1993					Coping role playing; problems at work
Rinehart	1994		Tips how to handle issues			
Fismen	2000				Relation with colleagues	
van Weert	2005		Information about work to reduce uncertainty			
Cimprich	2005				Challenges and strategies	
Heim	2006	Training course				
Korstjens	2006			RTW		
Nieuwenhuijsen	2006		Educational leaflet			
Meneses	2007	Education				
Hoybye	2008				Working life	
Korstjens	2008					Self-management goal also work

(Graves, 2003). Self-management is usually realized through some kind of educational program in which groups of participants are involved. Self-efficacy and illness perceptions are important aspects of behavioral determinants that are addressed in self-management programs (van Weert 2008). However, neither of the included self-management programs was evaluated against their effect on return to work.

This review of the contents of interventions aimed at enhancing return to work shows that interventions are mostly based on simple concepts of providing information, encouraging or supporting cancer patients, but that they hardly use behavioral theories. When interventions are based on such theories, such as social cognitive theory and self-efficacy, they are part of more expanded self-management programs.

Another recent Cochrane review looked in a different way at interventions to enhance return to work. The review included any type of intervention that had been evaluated by its effect on return to work in cancer patients, whether or not the intervention itself was directly aimed at enhancing return to work (de Boer et al., 2011). Of the 14 included studies, six evaluated psychological interventions, which were defined in a broad sense varying from education to problem-solving therapy. Three of these interventions had the specific aim of helping patients to return to work in addition to other objectives (Berglund et al., 1994; Capone et al., 1980; Maguire et al., 1983), and were also included in the review by Tamminga et al. The other three interventions had more general aims, such as to increase well-being or to reduce stress, and apparently hoped that this would also increase return to work (Gordon et al., 1980; Lepore et al., 2003).

The interventions consisted either of patient education in combination with other rehabilitation components (Berglund et al., 1994; Lepore et al., 2003) or of counseling in combination with other components (Capone et al., 1980; Gordon et al., 1980). Patient education involved providing information about the medical system and the patient's own condition, while counseling was mostly aimed at coping. None of the studies used explicit behavioral theory, even though most of the approaches could be labeled as to improve self-management through increasing self-efficacy and changing illness perceptions. The studies could not be pooled in one meta-analysis but, overall, showed results favorable for psychological or educational interventions, especially in non-randomized studies.

From these reviews, we can conclude that there is a lack of interventions that are based on behavioral theory that can help in reducing variation in return-to-work rates. Even though the effects of psychological interventions are promising, there is no conclusive evidence that interventions that address behavioral determinants of return to work are more effective than those interventions that do not contain such elements.

Conclusion

Work resumption is a problem in a substantial part of cancer patients. It is especially important because it can have serious consequences such as loss of employment.

Personal factors are one of the determinants of return to work in cancer survivors that can explain variation in return-to-work rates beyond disease- and work-related factors.

Behavioral theories have been used successfully to underpin interventions in cancer patients for other health-related behavior, such as regular physical exercise and self-management, generally aimed at improving quality of life. Many of these interventions include a work component, but there is no convincing evidence that this increases return to work due to several problems. One of the problems is that there is no universal nomenclature for interventions, and that the description of the interventions, especially in evaluation studies, is usually rather scant. It is therefore difficult to determine which behavioral elements an intervention encompasses.

To better elucidate the importance of behavioral determinants of return to work and our ability to influence these, it would be helpful to develop interventions that specifically aim to enhance return to work by addressing behavioral determinants. Such an intervention could be constructed along the same lines as a self-management program and should address behavioral concepts, for example, illness perceptions and self-efficacy. Correcting misconceptions about work, disability, and cancer might be difficult to realize in practice because such attempts to redress misconceptions can be easily interpreted as putting pressure on a patient to return to work. This, in turn, could be interpreted as lack of consideration toward a patient with a life-threatening disease, and could evoke anger in the patients and their relatives or co-workers. Therefore, it is important to develop a communication model that takes these problems into account. The target population for such an intervention would be cancer patients or survivors who are screened for illness perceptions that prevent return to work and who lack self-efficacy in resuming work. If such an intervention has a positive effect on return to work in a randomized controlled trial, it can be included in clinical interventions that aim to enhance the quality of life in cancer patients.

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Psychosocial Factors in Low Back Pain Management

James E. Moore and Sean J. Tollison

Low back pain (LBP) is a common and costly healthcare problem. Most individuals experience back pain at some point in their lives (Frymoyer & Cats-Baril, 1991; Andersson, 1999). It is the most common cause of disability in working-age adults and one of the most common reasons for seeking healthcare (Hart, Deyo & Cherkin, 1995; Deyo, Mirza & Martin, 2006). It is costly, not only in terms of medical care expenses, but also in lost productivity, disability payments, and human suffering (Dagenais, Caro, & Haldeman, 2008; Manchikanti, Singh, & Datta, Cohen, & Hirsch, 2009; Rizzo, Abbott, & Berger, 1998). Despite the absence of convincing evidence of efficacy, healthcare expenditures for diagnostic imaging, spinal injections, spinal surgeries, and prescription opioids have continued to rise (Deyo, Mirza, Turner, & Martin, 2009). This trend has contributed to the growth of direct healthcare expenditures for LBP in the United States to US$90.7 billion in 1998 (Luo, Pietrobon, Sun, Liu, & Hey, 2004). Disability benefits and lost productivity add billions more to the total cost. Although 80–90% of LBP episodes resolve within 12 weeks, a substantial minority of individuals continue to experience chronic or recurrent back pain and significant disability (Carey, Garrett, Jackman, & Hadler, 1999; Von Korff, Deyo, Cherkin, & Barlow, 1993; Von Korff & Saunders, 1996). Those off work for more than 4 weeks have a 20% risk of chronic disability (Waddell, 1998). After 2 years of low-back-pain-related disability, return-to-work probability drops to almost zero (Spitzer et al., 1987).

Despite the high prevalence of back pain, and the enormous personal and societal costs, the healthcare system response has been unsatisfactory, especially the traditional biomedical approach to back pain. There is poor correlation between complaints of pain or disability and results of diagnostic studies (Boos et al., 2000; Carragee, Alamin, Miller, & Carragee, 2005). Many biomedical treatments in

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common practice today are not supported by improved outcomes (Chou et al., 2009; Deyo et al., 2009), and despite advances in medical technology, back pain disability has continued to increase (Fordyce, 1995).

The failure of the biomedical model to yield improved outcomes for chronic low back pain (CLBP) prompted the adoption of a biopsychosocial model recognizing the reciprocal influences of cognitive, emotional, behavioral, and social/environmental factors and how they interact with the biomedical factors of injury, nociception, and pain perception (Engel, 1977). The adoption of the biopsychosocial model to the treatment of pain conditions was influenced by Melzack and Wall (1965) and their classic article on gate control theory in which they suggest that pain experiences are influenced by cognitive and emotional factors, including past learning experiences. Also highly influential was a behavioral model for the treatment of chronic pain developed by Fordyce (1976). His application of the principles of operant conditioning to the treatment of chronic pain paved the way for the current cognitive behavioral and interdisciplinary pain rehabilitation approaches. Turk, Meichenbaum, and Genest (1983) subsequently expanded the behavioral approach to a cognitive behavioral approach, in which dysfunctional thought processes also became a target of treatment. In the last 40 years, there has been continued growth in the research and application of biopsychosocial concepts in the field of chronic pain. Pain and the sequelae of pain are now known to be influenced by a complex interplay among biomedical factors, nociception, cognitive processes, emotions, the behavioral response to pain, the ways in which behaviors influence pain, and the social and environmental contingencies of pain behavior.

This chapter will review common psychosocial issues related to CLBP, including factors that influence the onset of pain, the transition from acute to chronic pain, responsiveness to treatment, and the maintenance of chronic pain and disability. The research on CLBP strongly suggests that psychosocial factors are at least as important in predicting and influencing the course of pain as are biomedical factors (Boos et al. 2000; Carragee et al., 2005; Chou & Huffman, 2007). Unfortunately, it is still unclear which specific psychosocial factors have the greatest influence on LBP. There is inconsistency among studies due to the employment of widely differing measures, settings, and subject populations. In addition, many psychosocial constructs and measures share common variance, thus creating significant measurement redundancy. Depending on the number, selection, and order of variables entered into multivariate analyses, the results can yield contradictory conclusions regarding the specific psychosocial factors that impact LBP.

Behavioral Factors

Fordyce (1976), in his classic text *Behavioral Methods for Chronic Pain and Illness*, described a new approach to the management of chronic pain based on principles of learning. It is likely that he implemented the first treatment of chronic pain based on operant principles (Fordyce, Fowler, & DeLateur, 1968; Fordyce, Fowler, Lehmann, & Delateur, 1968). His work truly revolutionized the way in which chronic pain was viewed and the treatment approaches that were employed. Consequently, it was widely adopted around the world. Rather than focusing entirely on finding and repairing the pain generator, his approach focused on the amelioration of dysfunctional observable pain behaviors associated with excessive disability. He described how pain behaviors developed and were maintained by operant reinforcement processes. According to operant theory, behavior that produces positive consequences for the individual will likely increase in frequency, whereas behavior that is punished or ignored is likely to decrease in frequency or extinguish. The goal of this behavioral approach was to reinforce healthy and productive behaviors while extinguishing or punishing dysfunctional pain behaviors.

Following an acute injury, pain behaviors such as limping, guarding, bracing, or not moving are reinforced by the reduction or avoidance of pain. If these avoidance behaviors persist beyond healing time or represent excessive avoidance of healthy activities, the result will be deconditioning and likely a worsening of the pain problem. It is not uncommon for secondary pain problems to result from the deconditioning, and the abnormal postures and movement patterns that are part of the avoidance behaviors that are exhibited in response to LBP.

Fordyce also emphasized how environmental contingencies such as financial compensation, attention, sympathy, assistance from others, and avoidance of aversive situations could reinforce pain behavior and excessive disability. The behavioral approach, although focusing strictly on altering observable pain behaviors, does not imply that noxious stimulation and nociception are not present, or that cognitive processes are not important. It is simply an approach to diminish behaviors that retard recovery or create excessive disability (Fordyce, Roberts, & Sternbach, 1985). As part of an interdisciplinary approach, a behavioral analysis can be completed during a psychological evaluation to determine the reinforcing contingencies that are maintaining pain behaviors and to explore ways that healthy and productive behavior can be reinforced. Virtually all interdisciplinary pain rehabilitation programs continue to apply these behavioral concepts with positive outcomes (van Tulder et al., 2000).

Financial reinforcement of pain behavior may be a factor when pain has resulted from an industrial injury, motor vehicle accident, or when there may otherwise be disability payments or a pending future financial settlement. Evidence suggests that disability is prolonged in compensable versus non-compensable back injuries (Greenough, 1993; Greenough & Fraser, 1989; Sander & Meyers, 1986). If someone is receiving disability income while off work that closely approximates what they would be earning if on the job, and especially if the individual was dissatisfied with his employment, then pain behavior might be reinforced by the combination of financial compensation and avoidance of an aversive work environment. Patients with limited formal education who were earning a high income performing skilled heavy labor may receive more disability income than they can expect to receive if they return to work at a lighter duty job. Anema and colleagues (2009) demonstrated that compensation policies in different countries can influence sustainable return-to-work rates for injured workers with LBP by creating differing incentives for returning to work.

Attention, rest, increased affection from family and friends, or offers of assistance are potential reinforcers of pain behaviors. Pain behaviors can also be negatively reinforced or strengthened by avoidance or escape from a negative environment or dreaded responsibility. Examples might include avoidance of a work environment that is unpleasant, hostile, or unsupportive; time out from the demands of a stressful and overly demanding workplace or home environment; avoidance of social obligations that create anxiety or are aversive; or the avoidance of pain and pain-related fear resulting from not performing activities expected to increase pain. Attention and concern from caring medical professionals can be a particularly powerful source of reinforcement for pain behavior for many individuals. If the provider encourages excessive avoidance of physical activity, extended time off work, ongoing use of opioid medication, and suspension of normal household responsibilities, the provider may be reinforcing pain behavior and disability. For anxious individuals who repeatedly seek medical care with worries and complaints of pain, even reassuring comments from the provider might paradoxically reinforce catastrophic pain cognitions and pain complaints by temporarily reducing the patient's anxiety.

Patients' beliefs and pain cognitions are also susceptible to operant and respondent conditioning. Kirsch, Lynn, Vigorito, and Miller (2004) reviewed data from various sources demonstrating how expectations are learned via observations and verbally provided information. Observing someone with back pain respond with pain behavior in a particular situation, for example, while lifting groceries, can reinforce the expectation that lifting things is dangerous or painful. Dysfunctional pain cognitions, such as the belief in the need for passive treatments, the thought that movement is dangerous, or the expectation that pain will cause long-term disability, can also be influenced by verbally provided information. Medical providers can also play a strong role in reinforcing these expectations by cautioning that lifting should be avoided while experiencing back pain. A physician ordering unnecessary tests or referring the patient for another opinion may reinforce the belief that some serious pathology might have been missed. Cautioning a patient to rest, "take it easy," or "listen to your body" might reinforce the belief that it is dangerous to be physically active, or that pain is a sign of injury. Fordyce, Brockway, Bergman, and Spengler (1986) demonstrated that telling patients with acute LBP to "let pain be your guide" regarding exercise, return to work, or use of pain medications produced worse outcomes than just prescribing increased activities or discontinuation of pain medications.

Cognitive Factors

Shortly following the emphasis on observable pain behaviors, and a behavior modification approach to pain management initiated by Fordyce, was the rising interest in cognitive variables, and the rapid growth of cognitive behavioral therapy for treatment of pain conditions (Turk et al., 1983). When humans experience pain, they cognitively appraise the meaning of the pain, including whether it represents a serious or dangerous condition, whether it is safe to be physically active, whether it will resolve quickly or last forever, and whether it will get progressively worse and disabling. How someone appraises his or her pain greatly influences the experience of pain, the emotional and behavioral responses to the pain, and the recovery process.

More than any other cognitive variable influencing LBP, fear-avoidance beliefs appear to have the greatest impact on the course of pain. Fear avoidance refers to the extent to which an individual is fearful and avoidant of activity when pain is present versus a tendency to confront pain by remaining active (Lethem, Slade, Troup, & Bentley, 1983). There is evidence that fear-avoidance beliefs, or related concepts of pain catastrophizing and pain-related fear, can actually influence the onset of LBP. That is, individuals who believe that physical or work activities are dangerous, and should be avoided when one is in pain, have an increased probability of developing LBP in the future (Jensen, Albertsen, Borg, & Nabe-Nielsen, 2009; Linton, 2005; Linton, Buer, Vlaeyen, & Hellsing, 1999; Van Nieuwenhuyse et al., 2004, 2006). Leeuw and colleagues (2007) suggested that pain-free individuals with high fear-avoidance beliefs may be particularly vulnerable to the development of new LBP, possibly by influencing how they interpret ambiguous physical sensations.

These pain-related cognitions and beliefs have demonstrated an association with development of chronic pain (Foster, Thomas, Bishop, Dunn, & Main, 2010; Grotle, Vollestad, & Brox, 2006; Iles, Davidson, & Taylor, 2008; Iles, Davidson, Taylor, & O'Halloran, 2009; Linton, 2000; Schultz et al., 2002, 2004; Turner et al., 2006). For example, Turner and colleagues (2006) found that injured workers with LBP were 4.6 times more likely to remain on work disability at 6 months if they had high scores on work fear avoidance. Patients with low expectations of returning to work were also less likely to be working at 6 months. Similarly, in a review of outcome predictors in a primary care population, Ramond and colleagues (2011) noted that recovery expectations and fear-avoidance beliefs were often predictive of outcome, but, like others, they also noted that the outcome literature is not entirely consistent regarding psychosocial predictors of outcome.

Catastrophic pain cognitions, negative recovery expectations, or strong fear-avoidance beliefs can be acquired through direct experiences such as experiencing pain or injury as a result of physical activity or failed attempts at recovery. Vicarious experiences and acquiring information verbally or from print or digital media can additionally influence pain cognitions. Consistent avoidance of activities thought to cause pain or injury can prevent extinction of these dysfunctional beliefs. Healthcare providers acquire fear-avoidance beliefs via the same mechanisms. Providers with high levels of fear-avoidance beliefs are more likely to advise patients to avoid painful movements and take more time off work, and less likely to encourage patients to remain as physically active as possible (Linton, Vlaeyen, & Ostelo, 2002; Coudeyre et al., 2006).

Emotional Distress and LBP

Depression

Although depression, anger, and anxiety all can coexist with LBP, depression has received the greatest attention (Bair, Robinson, Katon, & Kroenke, 2003; Banks & Kerns, 1996; Romano & Turner, 1985). Depression is at least twice as common in those with CLBP versus those without pain, but can affect the majority of the most seriously disabled patients, such as those treated in pain clinics (Demyttenaere et al., 2007). In most cases, depression is a consequence of CLBP, often beginning when it becomes apparent that pain has become a chronic condition (Fishbain, Cutler, Rosomoff, & Rosomoff, 1997). However, only a minority of those with CLBP develops significant depression. It may be that most individuals have reasonably good cognitive coping skills and supportive social relationships that insulate them from depression (Banks and Kerns, 1996).

There may be a minority of cases of coexisting pain and depression where depression is a precursor of pain. Those individuals with preexisting depression, when they experience the onset of LBP, may have more negative cognitive schemas, a more passive style of coping, and fewer cognitive and social resources to cope with pain, and are therefore more likely to develop chronic pain and disability (Carroll, Cassidy, & Cote, 2004; Fishbain et al., 1997).

Depression has been identified as a risk factor for the transition to persistent LBP and disability (Pincus, Burton, Vogel, & Field, 2002). Bair and colleagues (2003) reviewed the literature on coexisting pain and depression and concluded that depression is associated with poor outcomes in the treatment of LBP. Depressed patients continued to have more severe pain complaints, a greater number of pain complaints, more future complaints of pain, higher utilization of healthcare, more work-related disability, and more functional limitations. In a review by Iles and colleagues (2008), additional evidence suggests that depression, although contributing to the development of chronic pain, may not always be a predictor of ongoing work disability.

Anger

Anger is a common emotional correlate of CLBP, although the relationship and significance for recovery are still not fully understood (Fernandez & Turk, 1995; Greenwood, Thurston, Rumble, Waters, & Keefe, 2003). In a sample of mostly CLBP patients, 69% reported anger at someone; most commonly, the anger was directed at self or healthcare providers (Okifuji, Turk, & Curran, 1999). In patients participating in a comprehensive multidisciplinary pain management program, men scoring high on anger expression showed less improvement in physical capacities. Men scoring high on anger suppression showed less improvement in depression and general activities. Greenwood and colleagues (2003) reviewed the literature on anger and persistent pain and concluded that persons who report high levels of anger experience higher levels of pain. Men who score high on anger expression are more likely to have higher levels of pain-related disability, greater paraspinal muscle tension, greater difficulties establishing therapeutic relationships, and poorer functional outcomes. There is evidence to suggest that anger expression in CLBP patients suppresses increases in plasma beta-endorphin, and leads to higher levels of pain (Bruehl, Chung, Burns, & Diedrich, 2007). In another study, Bruehl, Liu, Burns, Chont, and Jamison (2012) found that CLBP patients showed higher daily levels of anger expression than controls. They also found that this higher level of anger expression lead to a subsequent increase in CLBP intensity.

Trost, Vangronsveld, Linton, Quartana, and Sullivan (2012) attempted to identify some of the cognitive dimensions of anger in patients with chronic pain. They suggest that anger results from *goal frustration* – the inability to attain important goals in life, including complete resolution of pain; *external attribution* – the tendency to blame others for causing the injury or failing to provide adequate medical care, compensation, or emotional support; or *perceived injustice* – the sense of being wronged or victimized. They suggest that treatment of patients can be undermined by anger, which disrupts engagement in treatment, impairs development of a therapeutic alliance, and intensifies a preoccupation with pain.

Pain-related fear and anxiety

There is limited research on the relationship between general anxiety and LBP. There are associations reported between trait anxiety and level of disability (Moix, Kovacs, Martin, Plana, & Royuela, 2011), and between a pre-pain lifetime diagnosis of generalized anxiety and subsequent development of chronic pain and disability. Gerhardt and colleagues (2011), using diagnostic interviews, found a diagnosis of anxiety disorder (panic disorders, agoraphobia, social and specific phobias) in 20.9% of subjects with CLBP, suggesting that anxiety disorders should be a focus of providers treating patients with pain. Most of the research on anxiety and LBP has been specific to pain-related fear or pain catastrophizing.

There is now an extensive literature supporting the concepts of pain-related fear and fear-avoidance beliefs (Leeuw et al., 2007; Vlaeyen, Kole-Snijders, Boeren, & van Eek, 1995; Vlaeyen & Linton, 2000, 2012). The model suggests that the experience of pain is cognitively appraised by the individual as either benign or worrisome. Catastrophic pain cognitions will lead to pain-related fear, then to avoidance behaviors and hyper-vigilance to pain, and gradually to disuse, deconditioning, depression, and disability. As we discussed earlier, avoidance of activity can be operantly reinforced by the reduced anxiety resulting from the avoidance. Vlaeyen and colleagues (Meulders & Vlaeyen, 2012; Vlaeyen & Linton, 2012) have also discussed the fear-avoidance model from a classical conditioning framework.

In a laboratory setting, they were able to demonstrate the conditioning of pain-related fear, followed by extinction of the fear via an exposure treatment.

Workplace Factors

Unhappy workers are more likely than satisfied workers to develop new episodes of LBP. Those who were dissatisfied with their work status, felt their income was inadequate, or who were performing unskilled or manual tasks were more likely to seek medical care for LBP (Papageorgiou et al., 1997; Papageorgiou, Croft, Thomas, Silman, & Macfarlane, 1998). Similarly, those who evaluated supervisors or coworkers as lacking in social support were more likely to report future episodes of LBP (Clays et al., 2007; Eriksen, Bruusgaard, & Knardahl, 2004; Hoogendoorn et al., 2001; Hoogendoorn et al., 2002; Hoogendoorn, van Poppel, Bongers, Koes, & Bouter, 2000; Linton, 2001; Van Nieuwenhuyse et al., 2004). Workers with low job satisfaction (Hoogendoorn et al., 2000; 2002), limited control over their work (Clays et al., 2007), or an excessive workload (Bigos et al., 1991) have increased risk of future back pain.

Cognitive Behavioral Treatment of LBP

Psychosocial interventions for LBP are largely cognitive behavioral interventions. That is, the goal is typically to help the individual alter cognitive processes and behaviors. This in turn can bring about improvements in function, pain, emotional status, employability, and health. Cognitive behavioral therapy assumes a complex reciprocal interaction among cognitions, behaviors, emotions, and biomedical factors, and that there is further interaction involving the behavior exhibited by the individual and the response of the social environment. Cognitive behavioral therapy with LBP patients includes teaching them to identify, challenge, and replace dysfunctional pain beliefs; helping them confront and overcome excessive fears and avoidance behaviors via graded exposure to feared activities; teaching them to employ self-regulatory strategies such as relaxation, meditation, hypnosis, and mindfulness; and helping to change the contingencies for pain behavior versus healthy function. Cognitive behavioral therapy approaches have strong empirical support for the treatment of patients with LBP (Chou & Huffman, 2007; Hoffman, Papas, Chatkoff, & Kerns, 2007; Kerns, Sellinger, & Goodin, 2011; Roditi & Robinson, 2011).

Cognitive restructuring

Cognitive restructuring helps patients to identify and challenge their beliefs and assumptions about pain and many other events in their lives as a way of developing more objective and rational interpretations of situations, and to respond in more productive ways. Common dysfunctional beliefs include thoughts that something is seriously wrong, that activity is dangerous, and that it is safest to avoid movement to prevent further injury (Von Korff & Moore, 2001). They also may think that they are not fulfilling the expectations of others and that they have lost self-worth, that they are a victim of injustice, or that they are helpless to control their fate (Trost et al., 2012). Cognitive restructuring helps patients revise irrational and dysfunctional thoughts to ones that are more objective and logical, and which leads to more appropriate coping responses. If patients start to question their belief that movement is dangerous, they are more likely to participate in an exercise program and learn that movement is safe. If they question their belief that providers do not care about them, they might develop a better therapeutic alliance with the provider and participate more actively in recommended treatment.

Exposure therapy

The most effective way to overcome an irrational fear is to confront it. In addition to helping patients challenge their beliefs by exploring the evidence and alternative cognitions, they can be assisted in performing behavioral experiments to gather evidence to support or disconfirm their beliefs. For example, patients who are excessively fearful of a particular activity considered medically to be safe can be encouraged to perform that activity repeatedly. If that happens without injury or severe pain, the individual is likely to overcome pain-related fear and avoidance of that particular activity (de Jong et al., 2005; Vlaeyen, de Jong, & Geilen, 2001; Vlaeyen, de Jong, Geilen, Heuts, & van Breukelen 2002). If this process is viewed within a classical conditioning model in which a feared stimulus (physical activity) is repeatedly paired with a benign response (absence of injury or pain), the fear response should gradually extinguish. This theory was supported in a laboratory setting by Meulders and Vlaeyen (2012).

Exposure therapy is likely the treatment of choice for individuals with high fear-avoidance beliefs. Patients with high levels of pain-related fear over-predict how painful an activity will be, have greater amounts of disability, and report more functional limitations (Crombez, Vlaeyen, Heuts & Lysens, 1999). Pain-related fear was a better predictor of performance than was pain. After exposure to a feared activity, predictions of pain resulting from the activity are more accurate, but since this more accurate prediction does not generalize to novel activities, it may be important to arrange or encourage exposure in vivo to a wide variety of activities to extinguish a range of pain-related fears and avoidance behaviors (Crombez et al., 2002).

Vlaeyen and colleagues (2001, 2002) found that when comparing graded in vivo exposure to graded exercise, only the graded exposure reduced pain-related fear. However, others have not found graded exposure superior, and this question remains unresolved (Macedo, Smeets, Maher, Latimer & McAuley, 2010). In part, graded activity or exercise programs may be a reasonably satisfactory way to accomplish exposure since performing a variety of physical activities likely approximates many of the movements of which patients are fearful.

Motivational interviewing

Patients with LBP are often ambivalent about changing their activity patterns. Motivational interviewing (MI) is a therapeutic style to help patients resolve ambivalence (Miller & Rollnick, 2002). MI is "a collaborative, person-centered form of guiding to elicit and strengthen motivation for change" (Miller & Rollnick, 2009, p. 137). It is guided by multiple principles and interviewing strategies to help the patient talk more about and commit to behavior change. MI has been adapted to the treatment of chronic pain (Jensen, 1996; 2002; Turk et al., 2008). MI can be used to increase patient positive expectancies to engage in physical activities, meet the patient where he or she is at in terms of readiness to change, and encourage engagement in more proactive pain-coping skills to facilitate self-management of chronic pain (Jensen, Nielson, & Kerns, 2003). The clinician uses interviewing strategies such as asking open-ended questions and using reflective listening to evoke patient responses that increase problem recognition about the pain condition, develop discrepancy between the patient's current and desired levels of functioning, and reinforce the patient's statements and sentiments for change.

The MI therapy style is an empathic approach in which reflective listening is used to convey understanding and affirm the patient in his or her experience. The person-centered nature of MI makes it an effective approach for handling patient resistance (e.g., patient arguing, interrupting, challenging) often encountered in patients with chronic pain. To reduce resistance, MI can be used to reflect patient perspectives without arguing for another point, shift focus, and simply affirm the patient in his or her view by emphasizing patient autonomy (Jensen, 1996). Therefore, the clinician avoids having the patient argue against change and can maintain therapeutic alliance. Once the patient is willing to take action, MI can be used to collaborate with the patient to develop a change plan and strengthen commitment to change.

Little research has been conducted to investigate if MI is an effective treatment for chronic pain. Brief motivational interventions incorporating elements of MI have been shown to increase engagement in pain management workshops (Habib, Morrissey, & Helmes, 2005) and improve some elements of pain coping (Rau, Ehlebracht-Konig, & Petermann, 2008). Specific to CLBP, MI can be taught to and effectively used by physical therapists to improve working alliance, treatment expectancy, physical capacities, and compliance with home exercise programs compared to therapists who do not use MI (Vong et al., 2011). In a study using similar motivational strategies, patients who participated in treatment for LBP with physical therapists who were instructed in a motivation program to increase compliance showed a higher rate of attendance in PT sessions, reduced disability, and reduced pain levels than those in a control group (Friedrich, Gittler, Halberstadt, Cermak, & Heiller, 1998). Contrary to these positive findings, another study demonstrated that a motivational intervention was not superior to a placebo control group in elderly patients experiencing CLBP (Basler, Bertalanffy, Quint, Wilke, & Wolf, 2007).

Mind–body approaches

In addition to traditional CBT, other "mind–body" approaches such as meditation and acceptance, relaxation, and hypnosis are potentially effective in the treatment of chronic pain (Astin, 2004). What is less clear is their effectiveness in the treatment, specifically of CLBP.

Meditation and acceptance Meditation and acceptance-based approaches involve being present with, finding meaning in, and increasing objectivity toward chronic pain to reduce suffering from chronic pain. Types of meditation used for chronic pain include transcendental, mindfulness, and loving kindness meditation. Acceptance and Commitment Therapy (ACT: Hayes, Strosahl, & Wilson, 1999) utilizes mindfulness as one element of its approach but also aims to reduce engagement in ineffective control strategies to escape or avoid aversive experiences in an effort to commit to valued action. In a systematic review and meta-analysis, Veehoff, Oskam, Schreurs, and Bohlmeijer (2010) found that the effect size for mindfulness-based therapies and ACT on chronic pain was 0.37, and on depression was 0.32. However, only one study they examined focused specifically on CLBP (Morone, Greco, & Weiner, 2008). This RCT found that, compared to controls, individuals who participated in a mindfulness meditation program displayed significant improvement in measures of chronic pain acceptance, engagement in activities, and physical function, but not in measures of pain and perceived disability. Teixeira (2008) reviewed meditation treatments for chronic pain and found that most studies demonstrated reductions in pain and improvements on other psychological variables, but this review was solely a qualitative analysis. Again, only one study focused specifically on LBP (Carson et al., 2005). This RCT demonstrated that those who participated in a loving kindness meditation program showed improvements in pain, anger, and psychological well-being, with no change in the control group. Effect size was 0.42 for physical variables and 0.50 for psychological variables. Another non-experimental study described in this review that had patients primarily suffering from CLBP showed significant improvements in pain and psychological variables such as depression and anxiety (Kabat-Zinn, Lipworth, & Burey, 1985). Two other studies using a mindfulness-based treatment that were not included in any of these reviews demonstrated improved coping and decreased pain intensity in patients with failed back surgery syndrome (Esmer, Blum, Rulf, & Pier, 2010) and CLBP (Berman & Singh, 1997), though the latter also incorporated relaxation and Qi Gong movement therapy.

Relaxation Relaxation has been applied to the treatment of chronic pain to help reduce physiological arousal, which can exacerbate pain symptoms. Types of relaxation include progressive muscle relaxation, passive relaxation, autogenic training, biofeedback, and guided imagery. Carroll and Seers (1998) reviewed nine studies showing some benefit of relaxation on the treatment of chronic pain, though they concluded that there was insufficient evidence to support that relaxation can reduce pain. In this review, only one study was specific to patients with CLBP and found that relaxation did not improve pain outcomes (Donaldson, Romney, Donaldson, & Skubick, 1994). They also reviewed a number of other studies investigating the effects of relaxation on CLBP, in which three out of five had non-significant results. These studies were not included in their final review because of low numbers in the treatment groups. In another review by Kwekkeboom and Gretarsdottir (2006), one study found progressive muscle relaxation to reduce pain sensation in CLBP (Hernandez-Reif, Field, Krasnegor, & Theakston, 2001), but no changes in pain in another study (Field, Hernandez-Reif, Hart, Theakston, Schanberg, & Kuhn C, 1999). Overall, the evidence that relaxation approaches are effective for the treatment of chronic pain in general is not strong (Dunford & Thompson, 2010).

Hypnosis Hypnosis has often been used in the treatment of pain and has been shown to provide significantly more analgesic response compared to standard care or no treatment (Montgomery, DuHamel, & Redd, 2000). Hypnosis for the treatment of chronic pain involves hypnotic induction with suggestions for relaxation and comfort, post-hypnotic suggestion to easily induce a cued state of comfort, and providing patients with recordings of hypnosis sessions to practice self-hypnosis at home (Elkins, Jensen, & Patterson, 2007). There are a number of studies that demonstrate the potential efficacy of self-hypnosis for patients with CLBP to reduce pain, improve activity, and improve mood (Elkins et al., 2007; Tan, Fukui, Jensen, Thornby, &Waldman, 2010). However, there is a dearth of research in this area.

Interdisciplinary Treatment of CLBP

When LBP is accompanied by work disability that extends beyond 12 weeks, an interdisciplinary pain rehabilitation program may be necessary to restore normal function. As discussed earlier, most individuals with LBP recover quickly, with little if any disability. When recovery is prolonged without medical explanation, it is likely that cognitive, emotional, and behavioral factors as well as environmental contingencies reinforcing pain and disability behavior are retarding recovery. Waiting longer to implement comprehensive treatment may make recovery less likely as the person settles into the disability role, and returning to the job at which they were injured is no longer an option.

An interdisciplinary pain rehabilitation program is typically a cognitive behaviorally oriented intensive and coordinated program consisting of daily treatment over the course of several weeks. Treatment includes active physical and/or occupational therapy designed to improve function via training in safe and efficient movement patterns combined with a graded exercise program to improve strength, endurance, and flexibility. Treatment also includes in vivo exposure to activities or simulated activities the patient needs to perform at work or home in order to extinguish pain-related fears and avoidance behaviors. Most programs include cognitive behavioral therapy to help patients with strategies for managing pain and the emotional, behavioral, and social sequelae of chronic pain. When work disability is an issue, vocational rehabilitation counseling helps return the patient to productive employment. Physicians manage medications, typically reducing dependency on opioid and sedative medications. They also provide medical education and reassurance to patients that movement is safe and beneficial. Interdisciplinary pain rehabilitation programs provide education on numerous topics designed to foster the ability for patients to independently manage pain problems in the future.

Numerous reviews have confirmed the efficacy of comprehensive pain rehabilitation programs (Chou & Huffman, 2007; Chou et al., 2007; 2009; Flor, Fydrich & Turk, 1992; Guzman et al., 2001; Turk, 2002; Turk & Burwinkle, 2005). Recent evidenced-based guidelines from the American Pain Society and the American College of Physicians have strongly recommended intensive interdisciplinary rehabilitation for subacute and chronic LBP (Chou et al., 2009, Chou & Huffman, 2007). Interdisciplinary pain rehabilitation for non-radicular LBP has outcomes at least as good as more invasive interventions such as injections or surgery but without the greater risk of iatrogenic consequences and greater cost (Chou et al., 2009, Turk & Burwinkle, 2005).

Haldorsen and colleagues (2002) assigned work-disabled patients with differing prognoses for recovery to different levels of treatment intensity. Patients who were less complex physically and psychologically did well with less intensive treatments, but complex patients with poor prognoses did best in a comprehensive interdisciplinary pain rehabilitation program. Similarly, Guzman and colleagues (2001) noted that, in CLBP patients off work for more than 3 months, only intensive multidisciplinary biopsychosocial rehabilitation improved pain and function; less intensive treatments were not effective. In summary, medically and psychologically complex patients with continuing disability greater than 3 months likely require an interdisciplinary pain rehabilitation program to return to work and a functional lifestyle. Less intensive single-modality treatments are unlikely to be effective.

Summary

Psychosocial factors are likely more important than biomedical ones in influencing the onset, maintenance, and responsiveness to treatment of LBP and disability. When recovery is delayed beyond a few weeks, and especially if pain, medication use, or functional limitations are not showing signs of improvement, providers should start considering cognitive, emotional, behavioral, or environmental issues that may be contributing to this delayed recovery. Cognitive behavioral therapy, more intensive active rehabilitation, or an interdisciplinary pain rehabilitation program may be indicated. Cognitive behavioral therapy can address dysfunctional pain cognitions, avoidance behaviors, negative emotions, and the environmental contingences maintaining pain and disability. When psychosocial issues are severe and recovery is significantly delayed without medical explanation, an intensive interdisciplinary pain rehabilitation approach may be indicated.

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41

Behavioral Self-management of End-stage Renal Disease

Implications for Social Work Practice

Joseph R. Merighi

Introduction

Chronic kidney disease (CKD) is a serious public health concern in the United States and around the world (Hamer & El Nahas, 2006; Saran et al., 2010). Behavioral medicine research on CKD, and end-stage renal disease (ESRD) in particular, has begun to identify interventions that can strengthen adherence to complex treatment regimens and improve the health outcomes of people with impaired renal functioning (Christensen & Ehlers, 2002; Christensen & Raichle, 2002). Kaptein and colleagues (2010) identified seven stages of behavioral research in the field of ESRD from 1960 to the present. Viewed from a chronological perspective, the dominant theoretical approaches to behavioral research started with psychosomatics in the 1960s–1970s and subsequently included neuropsychology, quality of life, patient education, coping and illness, self-management, and disease management over the course of 50 years. Although these approaches overlap and share key constructs, the current focus on self-management and disease management points to an increasing emphasis on the primacy of people with kidney disease becoming active participants in their healthcare treatment (Kaptein et al., 2010). One striking finding in the literature on CKD and ESRD is the paucity of research on strictly behavioral approaches that are used to address the biopsychosocial consequences of these chronic conditions. Mostofsky (2012) reports that “the emblematic and characteristic applications from behavioral medicine rest largely on the use of behavior therapy, biofeedback, relaxation, and hypnosis that are uniquely behavioral in nature” (p. 315). Treatment modalities of this sort are used infrequently in nephrology settings, but there exists some research that points to improved treatment

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adherence with regard to fluid and dietary intake, sleep disorders, and respiratory capacity when employing behavioral techniques.

This chapter has a three-part framework that explores issues related to behavioral self-management of people with kidney disease. The first part outlines chronic kidney and end-stage renal disease, with a focus on epidemiological trends in the United States. It continues with a discussion of patient self-management and highlights the primacy of predialysis education as an essential part of the self-management process. Finally, it concludes with a brief discussion of self-determination theory and its application to managing the complex nature of kidney disease treatment and health-related behaviors. The second part summarizes the limited research on behavioral approaches that have been utilized to improve patient self-management and health outcomes, with a particular focus on fluid restriction and interdialytic weight gain, sleep disorders, and biofeedback for respiratory muscle strengthening. The third part will elucidate how social workers can support people with kidney disease by promoting self-management and taking part in behaviorally focused interventions that can enhance patient well-being and quality of life.

Chronic Kidney Disease (CKD)

According to the Kidney Disease Outcomes Quality Initiative (K/DOQI), a diagnosis of CKD is made when a person has an estimated glomerular filtration rate (eGFR) of $<60\,\mathrm{mL/min/1.73\,m^2}$ and/or sustained structural or functional kidney abnormalities (e.g., microalbuminuria/proteinuria, hematuria, histologic or imaging abnormalities) for 3 months or more (National Kidney Foundation, 2002). Table 41.1 shows CKD stages based on eGFR. When kidneys are unable to filter blood effectively, waste products and toxins build up and result in health conditions such as cardiovascular disease, bone disease, and anemia (Centers for Disease Control and Prevention [CDC], 2010). If left untreated, CKD can progress to kidney failure and increase the likelihood of cardiovascular events, hospitalizations, and mortality (Go, Chertow, Fan, McCulloch, & Hsu, 2004).

Table 41.1 Stages of CKD.

Stage	*Description*	*eGFR (mL/min/1.73 m^2)*
1	Kidney damage with normal or ↑ GFR	≥90
2	Kidney damage with mild ↓ GFR	60–89
3	Moderate ↓ GFR	30–59
4	Severe ↓ GFR	15–29
5	Kidney failure	<15 (or dialysis)

Adapted from: National Kidney Foundation (2002).

A comparison of National Health and Nutrition Examination Survey (NHANES) data between 1988–1994 and 1999–2004 found that the prevalence rate of CKD in the United States had increased by 30% (Coresh et al., 2007). Recently, 2005–2010 NHANES findings reported that 6.7% of all participants age 20 years and older had an eGFR of $<60\,\mathrm{mL/min/1.73\,m^2}$. This represents a 37% increase in the prevalence of CKD between 1988–1994 and 2005–2010 (United States Renal Data System [USRDS], 2012). It is important to note that the prevalence of CKD varies depending on the estimating equations that are used (Zhang & Rothenbacher, 2008). Despite the variability that can result from using alternate equations to calculate CKD prevalence, it is estimated that more than 20 million adults aged 20 and older in the United States have CKD (CDC, 2010). This high prevalence in the general population necessitates actions to prevent disease progression by offering structured behavioral and psychosocial interventions to reduce morbidity and improve quality of life.

End-Stage Renal Disease

End-stage renal disease (ESRD) is the most severe and final stage of CKD (Stage 5). For people with ESRD, two types of interventions are available to sustain life: kidney transplantation or dialysis. The number of people diagnosed with ESRD is increasing steadily in the US population. In 2010, there were 594,374 diagnosed cases of ESRD (i.e., people on dialysis or living with a transplant) in the United States (USRDS, 2012). This compares to 571,414 in 2009, 547,982 in 2008, and 527,283 in 2007 (USRDS, 2009, 2010, 2011). Overall, the prevalent population of people with ESRD increased by approximately 4% each year between 2007 and 2010. It has been predicted that the number of ESRD patients in the United States will increase to more than 700,000 by 2015 (Gilbertson et al., 2005). Of the total ESRD patients reported in the preceding text, 179,361 (30%) were living with a kidney transplant in 2010.

Two dialysis treatment options are available for ESRD patients: hemodialysis (HD) and peritoneal dialysis (PD). The most recent analysis of 2010 ESRD surveillance data reports a prevalence rate of 383,992 patients on HD, 29,733 on PD, and 1,288 with an unknown treatment modality (USRDS, 2012). HD involves being connected to a hemodialysis machine either by a catheter in a patient's chest or needles that are inserted into a vascular access, that is, arteriovenous fistula or arteriovenous graft. In hemodialysis, blood travels through tubes to a filter, called a dialyzer, that removes wastes and extra fluid. The cleaned blood then flows through another set of tubes back into the body. Most hemodialysis treatments are performed at in-center facilities in the United States (USRDS, 2012). Typically, patients in these settings dialyze three times per week for 3–4 hours at a time. Alternatively, hemodialysis can be performed in a community setting, such as the patient's home, with a back-up facility for emergencies and periodic clinical assessment. Home-based treatments can be shorter in duration and more frequent.

In peritoneal dialysis, a dialysate fluid is drained from a plastic container into the abdomen using a surgically implanted catheter. Fluids and wastes flow through the lining of the cavity and remain "trapped" in the dialysate solution. The solution is then drained from the abdomen, removing the extra fluids and wastes from the body. There are two main types of peritoneal dialysis. The most common type is continuous ambulatory peritoneal dialysis, which does not require a machine. The dialysis solution passes from a plastic container into the abdomen through a catheter. After several hours, the patient drains the solution into a disposable plastic container and refills the abdomen with fresh solution through the same catheter. Continuous cycling peritoneal dialysis (CCPD) uses a machine that automatically fills and drains the dialysis solution from the abdomen. A typical CCPD schedule involves several exchanges during the night while the person sleeps and one daytime exchange that lasts the entire day. Peritoneal dialysis is typically performed at home or work, although one form of peritoneal dialysis (intermittent PD) is usually provided in a hospital.

Transplantation is the best form of renal replacement therapy; however, the number of donors does not meet the pressing need. The average wait time for a kidney transplant in the United States is 1.7 years (USRDS, 2012). Although kidney transplant recipients are classified as having ESRD, only research on ESRD patients on dialysis will be reported in this chapter.

Self-Management and Kidney Disease

The 2008 Medicare Conditions for Coverage (CfC) for End Stage Renal Disease Facilities are federal regulations that ensure the health and safety of people who require dialysis or a kidney transplant as a life-saving intervention. These regulations stipulate that patients are collaborative members of their interdisciplinary care team. Patient participation in the interdisciplinary team represents a substantive reframing in healthcare arena from patient *compliance* or *adherence* to patient *self-management* (Alt & Schatell, 2009; Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Glasgow, Jeon, Kraus, & Pearce-Brown, 2008; Lindberg & Lindberg, 2008; Wagner, 1998). Self-management is defined as:

> . . . the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioral, and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established (Barlow et al., 2002, p. 178).

Successful self-management involves increasing the knowledge and skills of hemodialysis patients, thereby promoting collaborative partnerships with their healthcare partners, self-care activity, self-care self-efficacy, clear and effective communication, and adherence to treatment regimens (Schatell & Burrows-Hudson, 2005). Patient self-management is important to promote in dialysis units because it involves patients in the assessment, care planning, and management of their kidney disease as well as treatment regimens (Browne & Merighi, 2010). In addition, enhancing patient self-management may decrease the high cost associated with poor medication adherence, estimated to be US$290 billion per year, or 13% of total healthcare expenditures in the United States (New England Healthcare Institute, 2009).

Self-Management and Predialysis Education

To create the best possible environment for people with kidney disease to manage their chronic illness, education and treatment options need to be provided so that patients can be key decision-makers and active participants in their care. Not only is this approach in keeping with new CfC regulations, but it increases the likelihood that patients will engage in health-related behaviors that will yield positive health outcomes and improve quality of life. Studies from around the world have consistently found that when patients receive predialysis education about dialysis options, 45–60% will choose a home-based treatment such as PD (Gomez et al., 1999; Goovaerts, Jadoul, & Goffin, 2005; Manns et al., 2005; Mehrotra, Marsh, Vonesh, Peters, & Nissenson, 2005; Prichard, 1996; Marrón et al. 2006; Schreiber et al., 2000; Wuerth et al., 2002). Two different research groups have found that patient education is more effective than early nephrologist referral for slowing the progression of CKD (Devins, Mendelssohn, Barre, & Binik, 2003), ensuring a planned rather than emergent dialysis initiation (Malberti & Ravani, 2003), and even improving survival (Devins, Mendelssohn, Barre, Taub, & Binik, 2005; Ravani, Marinangeli, Tancredi, & Malberti, 2003). A study in Belgium found that 55% of ESRD patients who completed a predialysis education program chose a self-care dialysis modality (i.e., PD, self-care HD in a satellite clinic, or home HD) over conventional in-center HD (Goovaerts et al., 2005). Unfortunately, the current distribution of dialysis treatment in the United States suggests that patients are not receiving adequate education about treatment modalities because more than 90% of patients with ESRD use in-center HD (USRDS, 2012).

Studies have documented the advantages of home-based dialysis treatments such as PD over in-center HD – for example, enhanced quality of life and increased autonomy and control (Curtin, Johnson, & Schatell, 2004; Juergensen et al., 2006; Oberley & Schatell, 1995, 1996; Wuerth et al., 2002); potential alleviation of depressive symptoms (Lew & Piraino, 2005); and more positive ratings of dialysis care (Rubin et al., 2004). Research examining the influence of dialysis modality on the survival of people with ESRD has been shown to vary by country (Heaf, 2004; Heaf, Lokkegaard, & Madsen, 2002; Schaubel, Morrison, & Fenton, 1998; Vonesh, Snyder, Foley, & Collins, 2004). For example, PD patients in Canada (Schaubel et al., 1998) and Denmark (Heaf et al., 2002) have a lower rate of mortality than HD patients in those countries. In the United States, PD and HD patient outcomes are mixed: some reports show improved survival on PD vs. HD (Collins et al., 1999; Xue et al., 2002), some show better outcomes for HD (Bloembergen, Port, Mauger, & Wolfe, 1995; Ganesh et al., 2003), and others show little or no difference (Vonesh et al., 2004; Vonesh & Moran, 1999). Proper education during the early stages of disease progression, for example, during CKD Stages 3 or 4 if the patient is willing to explore treatment options, can help empower patients and promote active involvement in their care.

Self-Determination Theory

Self-determination theory (SDT; Ryan & Deci, 2002; Ryan, & Deci, 2000) provides a useful framework for promoting behavioral self-management in people with kidney disease. SDT examines the dialectic between people and their social contexts to determine factors that either support or hamper mastery of experiences or conditions. According to Ryan and Deci (2002), "the concept of basic psychological needs for competence, autonomy, and relatedness serves to define those contextual factors that tend to support versus undermine motivation, performance, and well-being" (p. 27). Two key concepts are associated with SDT: autonomous motivation and perceived competence. Autonomous motivation involves a sense of personal endorsement, volition, and self-initiation when interacting with others (Williams et al., 2006). For example, patients on dialysis are autonomously motivated when they can actively participate in decisions about their treatment and are personally committed to improving their health. In turn, this sense of autonomous motivation can be buttressed when patients experience *autonomy support* from their dialysis team, that is, the team refrains from controlling the patient's behavior or decisions (Williams et al., 2006). Research by Williams and colleagues (Williams, Cox, Kouides, & Deci, 1999; Williams, Rodin, Ryan, Grolnick, & Deci, 1998) has demonstrated that autonomy support mediates health behaviors. Perceived competence, which is similar to Bandura's concept of self-efficacy (Bandura, 1997), is experienced when a person feels able to achieve key health and social outcomes. For example, a dialysis patient will feel competent when he or she has a favorable lab or interdialytic weight gain report after purposefully monitoring daily fluid intake. In general, people report greater competence when they feel more autonomously motivated, and autonomy support from others improves one's perceived competence and autonomous motivation (Williams & Deci, 1996). In accord with the tenets of self-determination theory, high levels of autonomy support and perceived competence are associated with a greater level of adherence to prescribed treatment regimens. Self-determination theory helps researchers and clinicians alike understand how patients develop the necessary motivation to initiate health-specific behaviors and maintain them over time (Ryan, Patrick, Deci, & Williams, 2008; Sheldon, Williams, & Joiner, 2003).

Behavioral Interventions to Improve Kidney Disease Outcomes

Health-related quality of life (HRQOL) has been shown to be a strong predictor of mortality and hospitalization in ESRD patients (Mapes et al., 2003). HRQOL takes into account physical (e.g., work capacity), psychological (e.g., anxiety, depression), and social domains (e.g., familial and social interactions). For patients with renal failure, HRQOL is influenced by factors such as the disease process, the dialysis treatment modality (HD vs. PD), comorbid illnesses, anemia, and age (Valderrábano, Jofre, & López-Gómez, 2001). Behavioral interventions can enhance a renal patient's quality of life by helping them manage complex treatment regimens, reduce negative symptoms associated with the disease process, maintain energy levels that allow for active participation in daily activities, and achieve therapeutic goals set by their healthcare providers. CKD and ESRD can cause a range of health problems that impact quality of life and limit one's sense of autonomy. This section will highlight behavioral research that has been undertaken to help patients with ERSD, specifically in the areas of fluid restriction and interdialytic weight gain, fatigue and sleep disorders, and respiratory muscle functioning. In addition, it will conclude with a description of a holistic breathing intervention that focuses on improving dialysis patients' subjective well-being, energy levels, and other key health-related domains.

Fluid restriction and interdialytic weight gain

People on hemodialysis are required to limit fluid intake as part of their treatment regimen. The general recommendation for this patient group is to restrict their fluid intake to 1–1.5 liters per day (Welch & Thomas-Hawkins, 2005), and sometimes to as little at 0.5 liters daily, depending on their residual urine production (Denhaerynck et al., 2007). Poor fluid management in hemodialysis patients is associated with a range of health problems such as muscle cramping, dizziness, pulmonary edema, and hypertension (Denhaerynck et al., 2007; Leggat et al., 1998; Welch & Thomas-Hawkins, 2005). The consequences of consuming too much fluid between dialysis treatments and gaining weight as a result (called "interdialytic weight gain" or IDWG) underscore the importance of adhering to fluid restrictions to avoid a high IDWG and subsequent adverse health outcomes. Research indicates that non-adherence to fluid restrictions range from 30% to 74% based on patient self-report and 10% to 60% based on calculating IDWG (Denhaerynck et al., 2007). The reason for these high rates of suboptimal adherence among hemodialysis patients is multidimensional (Kaveh & Kimmel, 2001), and this serious problem requires innovative approaches to be addressed.

To date, a variety of interventions that employ the tenets of behavioral theory have been used to help hemodialysis patients restrict fluid intake and reduce IDWG.

Studies have investigated the use of personal digital assistants (Welch, Dowell, & Johnson, 2007), behavioral self-regulation interventions (Christensen et al., 2002), behavior modifications (Cummings, Becker, Kirscht, & Levin, 1981; Hart, 1979; Tucker, 1989), and cognitive behavioral treatments (Lindberg, Wikström, & Lindberg, 2011; Sagawa, Oka, & Chaboyer, 2003; Sharp, Wild, Gumley, & Deighan, 2005) to help patients self-manage effectively. In general, many of the aforementioned studies supplemented behavioral interventions with other approaches (e.g., psychoeducational), which makes it impossible to assess the independent effect of a strictly behavioral strategy. Welch and Thomas-Hawkins (2005) reported that positive reinforcement and behavioral contracting have been shown to be unsuccessful in reducing IDWG; however, behavioral self-monitoring interventions (often performed in combination with other treatments) held the most promise in helping hemodialysis patients manage their fluid intake. Some of the challenges associated with evaluating the extant research on reducing interdialytic weight gain is the lack of long-term follow-up in many studies, differences in the way interdialytic weight gain is operationalized, and the use of multiple treatment interventions in one study.

Despite these challenges, there are some notable research studies that have incorporated behavioral techniques to reduce IDWG. Sharp et al. (2005) conducted a randomized controlled trial to reduce IDWG using a cognitive behavioral group intervention. Although behavioral techniques (e.g., controlling the environment, goal setting, and self-regulation) constituted one part of the larger intervention, study findings showed a statistically significant decrease in IDWG (measures in kilograms) between baseline (3.56 ± 0.91) and 10-week follow-up assessment (2.96 ± 1.09). A similar improvement in fluid self-management at follow-up was found in Christensen et al.'s (2002) study using a behavioral self-regulation intervention. In this study, the difference in IDWG values at 8-week post-intervention between the intervention (2.88 kg) and control (3.48 kg) groups was significant ($p < .001$), but due, in part, to the intervention group's improved self-management and the control group's worsening self-management. The findings reported by Sharp et al. (2005) and Christensen et al. (2002) point to the potential role that behavioral interventions can play in helping hemodialysis patients manage strict fluid consumption guidelines while on hemodialysis. However, given the complex nature of thirst (Welch, 2002) and the multiple cues to consume liquids in social settings, helping hemodialysis patients with their IDWG will require interventions that address the cognitive, behavioral, and environmental aspects of fluid restriction.

Fatigue and sleep disorders

People with CKD and end-stage renal disease are very likely to experience a high level of fatigue and a variety of sleep disorders (Casey, 2010; Bossola, Vulpio, & Tazza, 2011; Gusbeth-Tatomir, Boisteanu, Seica, Buga, & Covic, 2007). Three common sleep disorders among people with ESRD include: insomnia (Novak, Shapiro, Mendelssohn, & Mucsi, 2006), sleep apnea (Sim, Rasgon, & Derose, 2010), and restless leg syndrome (Merlino et al., 2006). Insomnia is defined as experiencing difficulty falling asleep, difficulty staying asleep (frequent awakenings), and/or early-morning awakening (Merlino et al., 2006; Novak et al., 2006). Sleep apnea is classified as either obstructive (i.e., partial or total obstruction of the upper airways) or central (i.e., cessation of voluntary respiratory drive from the hypothalamus) (Chakravorty, Shastry, & Farrington, 2007). Restless leg syndrome consists of having an urge to frequently move one's legs to alleviate discomfort that results from sensations such as tingling, aching, itching, and cramping (Gul, Aoun, & Trayner, 2006). Sleep disorders such as the ones outlined in the preceding text have been shown to reduce quality of life, increase morbidity and mortality, impair daytime functioning, and increase fatigue (Novak et al., 2006).

Murtagh, Addington-Hall, and Higginson (2007), in their review of the literature on the prevalence of sleep problems in ESRD patients, reported that 12–97% (weighted mean = 71%) of ESRD patients experienced fatigue or tiredness, 20–83% (weighted mean = 44%) indicated that they had sleep disturbances, and 8–52% (weighted mean = 30%) had restless leg syndrome. This wide variation is due, in part, to differences in how researchers measured fatigue and sleep disturbance in their studies. However, these findings highlight that a large percentage of people with ESRD have trouble sleeping. With regard to dialysis modality, Bossola et al. reported that 45–85% of hemodialysis patients and 30–70% of peritoneal dialysis patients experience fatigue. Interestingly, sleep apnea has been shown to improve when patients are treated with nocturnal PD or nocturnal HD as compared to conventional in-center hemodialysis (Hanly, 2009). Much less is known about sleep disorders among patients with CKD who are not on dialysis. Novak and colleagues (2006) found that 26% of non-dialysis CKD patients experienced insomnia, and the presence of insomnia was significantly associated with serum albumin level and psychological distress.

Despite the abundance of research that has been done to identify and quantify sleep disorders in people with kidney disease (mainly ESRD patients on dialysis), few rigorous intervention studies have been performed with the CKD or ESRD population. One recent exception is a randomized controlled cognitive behavioral intervention conducted by Chen and colleagues (2011). Findings indicated that a 6-week CTB treatment was effective in correcting sleep disturbances and reducing inflammation and oxidative stress in HD patients. Previous research has shown that sleep deprivation is associated with an enhanced inflammatory response (Meier-Ewert et al., 2004). Novak and colleagues (2006) recommend that treatment approaches for people with ESRD include behavioral interventions (e.g., sleep hygiene, relaxation, biofeedback) combined with a prudent use of pharmacologic agents (hypnotics). For example, they propose a series of sleep hygiene tips (Table 41.2) to help patients follow a consistent sleeping routine to reduce the occurrence of insomnia. These sleep hygiene tips offer a simple and practical approach to getting CKD and ESRD patients to practice sleep-related behaviors that can reduce the occurrence of insomnia, which in turn will improve their health outcomes and quality of life.

Table 41.2 Sleep hygiene tips.

- Sleep only when sleepy. If you cannot fall asleep within 20 min, get up and do something boring until you feel sleepy.
- Do not take naps, unless your doctor advises so.
- Regular sleep–wake schedule is important. Get up and go to bed at the same time every day, even on weekends.
- Regular exercise improves sleep, but most people should refrain from exercise at least 4 hours before bedtime.
- Develop sleep rituals (listening to music, etc.). It is important to give your body cues that it is time to slow down and sleep.
- Only use your bed for sleeping and intimacy. Refrain from using your bed to watch TV or work.
- Stay away from caffeine-containing beverages, foods, and medications, nicotine, and alcohol for at least 4–6 hours before bedtime.
- Have a light snack before bed with a glass of milk, which contains sleep-promoting tryptophan.
- Take a hot bath 90 min before bedtime. A hot bath will raise your body temperature, but it is the drop in body temperature that may leave you feeling sleepy.
- Make sure your bed and bedroom are quiet and comfortable.
- Use appropriate curtains, earplugs, or a white noise machine if necessary. A cooler room is recommended. Use a humidifier if the air is too dry.

Source: Novak, M., Shapiro, C. M., Mendelssohn, D., & Mucsi, I. (2006). Diagnosis and management of insomnia in dialysis patients. *Seminars in Dialysis*, *29*(1), 25–31.

Biofeedback to strengthen respiratory muscles

Biofeedback has been used for many years in clinical and research settings to improve patient outcomes for health conditions such as stress, anxiety, asthma, hypertension, and cardiovascular disease (Calderon & Thompson, 2004). According to Calderon and Thompson, biofeedback teaches people to "control their physiological processes through various feedback signals. Biofeedback is based on operant conditioning, whereby individuals learn from reinforcement (in this case, biological feedback) of the performed behavior (in most cases, relaxation or even increased concentration)" (p. 187). People with chronic renal failure can experience a variety of pulmonary complications (e.g., pulmonary edema, pleural effusion, pulmonary calcification, pulmonary embolism, and dialysis-associated hypoxemia) as a result of being on hemodialysis (Turcios, 2012). Also, Johansen and colleagues (2003) reported that dialysis patients' ankle dorsiflexor muscles were weaker and that their contractile cross-sectional area was significantly smaller than control subjects without kidney disease. Given these findings, respiratory muscle strengthening using biofeedback offers an important opportunity to improve pulmonary functioning in renal patients.

Little systematic research using biofeedback has been done with CKD or ESRD patients. Recently, however, researchers in Brazil tested the effect of biofeedback on respiratory muscle strengthening in ESRD patients on hemodialysis (Figueiredo et al., 2012). In this study, the researchers assigned hemodialysis patients into three groups: (1) control, $n = 10$; (2) respiratory muscle training using a device that measures pressurized linear load of 40% of maximal inspiratory pressure (Threshold method), $n = 16$; and (3) respiratory biofeedback, $n = 15$. The respiratory biofeedback training consists of having:

> . . . a belt placed in the patient's abdominal region connected to a manometer which converts the abdominal displacement (in cm) into pressure (in cmH_2O). This system produces a sonorous beep during the inspiratory phase that shows when the diaphragmatic muscular activity occurs. It also has a visual display for the inspiratory and expiratory phases that ranges from -40 to $+40\,cmH_2O$. The biofeedback display was placed in front of the patients so that they could observe the thoraco-abdominal movement associated with the muscular effort within each respiration. Patients were familiarized with the equipment before beginning the programme and were encouraged not to change their pattern of muscular activity during the study. The system was calibrated before training for each patient sitting and resting for five minutes. During training, patients were instructed to visualize the biofeedback display in order to control the diaphragmatic inspiratory and expiratory efforts to achieve a $+30\,cmH_2O$ pressure which corresponded to approximately 40% of the maximal inspiratory pressure (Figueiredo et al., p. 726).

Both treatment groups (Threshold and biofeedback) took part in 20-minute respiratory muscle trainings at each dialysis treatment (×3 per week) over a 6-week period (18 training sessions). Findings indicated that forced vital capacity (FVC), forced expiratory volume in the first second (FEV_1), maximal voluntary ventilation (MVV), and maximal expiratory pressure (MEP) improved for both treatment groups. However, there was no significant difference in FVC, FEV_1, MVV, or MEP between Threshold and biofeedback. Figueiredo and colleagues (2012) stated that achieving increases in respiratory muscle strengthening using the "gold standard" Threshold method and respiratory biofeedback is noteworthy because it offers hemodialysis patients options for improving their lung functioning.

Holistic breathing to improve overall well-being

Stanley, Leither, and Sindelir (2011) assessed the effect of a self-directed holistic breathing intervention with 94 dialysis patients. Instructions for the breathing exercise are outlined in Table 41.3. A holistic specialist provided patients and staff with instructions on a card so that patients could refer to it after their training was completed. During the training session, an emWave® device was used to monitor heart rate variability (HRV) and confirm HRV improvement with the holistic breathing exercise during training. Studies indicate that HRV is reduced in ESRD patients (Ranpuria, Hall, Chan, & Unruh, 2008) and a low HRV is associated with poor health outcomes in both acute and chronic illnesses (Lehrer, 2007). After the

Table 41.3 Holistic breathing technique instructions.

- Whether sitting, standing, or lying down, keep your spine as straight as possible to allow your lungs to get plenty of air.
- Position your head so that if you hum, you feel it in your chest.
- Place your tongue behind your front teeth and flat against the roof of your mouth.
- Breathe in normally and breathe out very slowly and evenly. It should take you about two times longer to breathe out. Count if you need to in the beginning, but your body will automatically slow your breathing after the first three or four breaths.
- Focus on simply moving air slowly and evenly rather than the amount of air you are breathing in and out. Your lungs are getting plenty of air, and the oxygen is exchanging better in your lungs as you breathe more slowly.
- Take a breath when you feel you need it, just like when you are talking with someone. Do not hold your breath in between breaths, and do not wait until you have fully exhaled to take your next breath. Also, there is no need to push or force air out of your lungs. Just simply breathe normally, only slower.
- Practice this breathing anytime before, during, or after dialysis. It is especially helpful if you can remember to practice this breathing technique when you get home on your dialysis days.

Source: Stanley, Leither, and Sindelir (2011). Reprinted from the *Nephrology Nursing Journal*, 2011, Volume 38, Number 2, pp. 149–152. Reprinted with permission of the American Nephrology Nurses' Association, East Holly Avenue/Box 56, Pitman, NJ 08071-0056; (856) 256-2300; FAX (856) 589-7463; Web site: www.anna.org; For a sample copy of the journal, please contact the publisher.

training was completed, patients were instructed to implement the breathing techniques on their own, without the emWave® device, within 12 hours of being dialyzed. Also, staff promoted patients to do so while in the dialysis clinic.

Data from this descriptive pilot study were obtained 6–8 weeks after training. Approximately one-half ($n = 49$, 52%) of patients continued to use the breathing technique; they reported feeling more relaxed (53%), having more energy than prior to using the breathing technique (27%), sleeping better (12%), and experiencing reduced pain (8%). Patients who discontinued using the breathing exercise did so because of lack of interest (47%), lack of perceived benefit (26%), and failing to remember (27%). Although these findings are modest, they point to the potential benefit of teaching dialysis patients breathing techniques that can improve feelings of relaxation, especially in a patient population that endures frequent needle sticks and blood pressure monitoring during treatment.

There were two notable elements in the delivery of this intervention: (1) inclusion of the dialysis unit social worker in the implementation of the breathing intervention, and (2) training staff as well as patients. Given the nature of dialysis care, patients and staff interact frequently (typically three times per week) for a total of 9–12 hours per week. Involving dialysis unit staff can be very beneficial to patients because the staff can help motivate patients to engage in this behavioral intervention and offer support and coaching as needed. In fact, Stanley and colleagues (2011) reported higher patient participation rates in dialysis units where staff reminded patients to utilize the breathing exercise as compared to units where staff did not do so. Further, staff reported a calmer clinic environment as a result of patients engaging in the breathing exercise. This low-cost and easy-to-implement breathing exercise can potentially help hemodialysis patients improve their health outcomes, especially for patients who shorten their dialysis treatment to less than the required 3–4 hours because of experiencing anxiety or feeling restless.

Implications for social work practice

The profession of social work can make important contributions to the treatment and prevention of chronic illness through behavioral health interventions (Lawrence, Zittel-Palamara, Wodarski, & Wodarski, 2003). Nephrology social workers in particular provide important services and psychosocial interventions to patients with ESRD as mandated by Medicare's CfC (Federal Register, 2008). Patients with ESRD often face difficulties such as managing intensive treatment regimens and coping with the social, vocational, and mental health challenges that result from being on a renal replacement therapy. Social workers in dialysis facilities are specifically trained to provide a variety of supports to help patients manage the treatment process and improve their quality of life (Browne, 2012). Some of the primary interventions offered by social workers include patient and family education, supportive counseling, crisis intervention, provision of information and community referrals, interdisciplinary care planning and collaboration, and patient advocacy (Browne, 2012; Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2001; McKinley & Callahan, 1998; McKinley, Schrag, & Dobrof, 2000; Merighi & Ehlebracht, 2004a, 2004b, 2004c; Russo, 2002; Wolfe, 2011). These interventions help renal patients to cope with the health and mental health consequences that are often associated with a diagnosis of ESRD (Browne, 2012; Cukor, Peterson, Cohen, & Kimmel, 2006), and can help promote treatment adherence and self-management (Browne & Merighi, 2010; Cukor, Rosenthal, Jindal, Brown, & Kimmel, 2009; Kammerer, Garry, Hartigan, Carter, & Erlich, 2007). Studies have documented the positive effect that social work interventions have on ESRD patients' well-being and quality of life (Beder, 1999; Dobrof et al., 2001; McCool et al., 2011; Sledge et al., 2011).

Counseling and psychosocial assessment were maintained as key social work activities in the 2008 Conditions for Coverage. However, the CfC final rule now requires a "psychosocial status" component in a patient's Plan of Care. This component outlines how professional social work services are provided to ESRD patients and how standard mental and physical health assessments, for example, the Kidney Disease Quality of Life-36 (KDQOL-36) survey, are used to evaluate their functioning and inform follow-up interventions (Federal Register, 2008). A plan of care needs to be developed within 30 days of a patient's admission to a dialysis facility (or within 13 dialysis sessions) and updated regularly in accord with CfC guidelines. In addition, social workers are key members of an interdisciplinary team, which is comprised of at least an ESRD physician, registered nurse, social worker, dietician, and patient (if feasible). A social worker's involvement in an interdisciplinary team and role in care planning provide outstanding opportunities to introduce the implementation of behavioral therapeutic strategies to improve patient self-management.

The extant research on behavioral self-management in CKD provides helpful suggestions for nephrology professionals, especially with regard to interdialytic weight gain and sleep disorders. Although social workers are trained in psychosocial treatment and counseling, behavioral self-management efforts need the support of the interdisciplinary care team in order for them to be implemented in an effective manner. A social worker's engagement in behavioral therapies will involve, in most cases, additional study and training in order to master the skills and knowledge needed to implement interventions such as biofeedback and relaxation techniques. In addition, dialysis providers (for-profit, non-profit, and independently owned) will need to provide social workers with ample resources (e.g., training opportunities) in order for them to integrate behavioral techniques into their practice. Rigorous training that utilizes evidenced-based research is essential in behavioral interventions, so that social work practitioners can implement best practices that will promote self-management, improve health outcomes, and enhance quality of life.

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Behavioral Health and Childhood Obesity

Implications for Social Work Practice

Shawn A. Lawrence and Eileen Mazur Abel

Introduction

Despite the fact that high-risk behaviors and lifestyle choices have a clear impact on client morbidity, behavioral health interventions, including therapy and counseling, have played a minor role in the response from the medical community (Whitlock, Orleans, Oender, & Allan, 2002). Within the last decade, however, the healthcare field has seen a marked increase in the role of behavioral health (Glanz & Bishop, 2010). The staggering rise in disorders and diseases such as diabetes, heart disease, stroke, and cancers, which are often a direct result of diet and life style, has resulted in the development of a wide range of behavioral approaches aimed at preventing and treating these concerns (Lawrence, Zittel-Palamara, Wodarski, & Wodarski, 2003).

Obesity is a serious health problem in the United States, with almost 41 million women and more than 37 million men aged 20 meeting the criteria for obesity in 2009–2010 (Ogden, Carroll, Kit, & Flegal, 2012). The prevention and treatment of childhood obesity has become a critical focus of national health efforts (Dehghan, Akhtar-Danesh, & Merchant, 2005). Prior to 1980, only 6.5% of children aged 6–11 and 5% of children aged 12–19 were overweight or obese (Eliadis, 2006). By 2008, the percentage of overweight children had increased to 19.6% of children aged 6–11 and 18.1% of children aged 12–19 (Ogden & Carroll, 2010). In 2009–2010, approximately 12.5 million children and adolescents in the United States were reported as being obese (Ogden, Carroll, Kit, & Flegal, 2012).

Obesity has become far and away the most prevalent chronic childhood issue of the modern era (Nemet, Barkan, Epstein, Friedland, Kowen, & Eliakim, 2005). While improving health behaviors is important for all children, it is especially

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important as a means of addressing health disparities. Economically disadvantaged adults and children are especially at risk for poor nutrition, obesity, and related physical diseases (Trust for America's Health & Robert Wood Johnson Foundation, 2012).

We have come to realize that, if we are to decrease the prevalence of behavior-linked chronic illnesses such as those caused by obesity, the diet and behaviors of American children must be significantly modified. Toward this end, it is important for social workers to have baseline information regarding the need for, development of, and effectiveness of behavioral healthcare treatments aimed at preventing and reducing childhood obesity. The field of social work is characterized by interdisciplinary research, scholarship, and practice. It includes a wide array of prevention, treatment, and intervention approaches on the micro, mezzo, and macro levels, including education, advocacy, counseling, therapy, nutritional guidance, exercise, and pharmacology. This chapter provides background information about the incidence and prevalence of obesity and childhood obesity. Next, the authors offer an overview of the current social work approaches for preventing and treating obesity as a systemic issue. Emphasis is given to describing treatments for obese children and youth. Information about the roles for social work on all three levels, including evidence-based practices (EBPs) based on scientific research, will be highlighted in light of their effectiveness for treating and preventing childhood obesity. Finally, the authors draw implications for future social work practice and research.

Obesity

Obesity is most often defined in terms of body mass index (BMI). BMI is calculated by dividing weight (in kilograms) by height (in meters) squared. Recent clinical guidelines developed by the National Heart, Lung, and Blood Institute (NHLBI) identify "overweight" adult individuals as those having a BMI of 25–29.9 kg/m^2 and "obesity" as a BMI of 30 kg/m^2 and greater (NIH, NHLBI, 1998). A BMI index of 30 or higher kg/m^2 is classified as obesity in adults (NIH, NHLBI, 1998). For example, for an adult individual who is 5'4", this translates to a weight of 174 pounds or more (Ogden et al., 2012). The definition of obesity for children is different. Obesity in children is defined as a BMI greater than or equal to the age- and sex-specific 95th percentile of the 2000 CDC growth charts (Ogden & Flegal, 2010, as cited in Ogden et al., 2012). The greater the BMI, the greater the risk for developing chronic illnesses such as hypertension, diabetes, osteoarthritis, coronary heart disease (CHD), sleep apnea, gallbladder disease, and some cancers (National Institutes of Health & National Heart Lung and Blood Institute, 1998).

In the United States, over one-third of adults are considered to be obese (Flegler, Carol, Ogden, & Curtin, 2010). The economic impact of obesity is considerable, an estimated US$147 billion in 2008. For an individual, obesity is associated not only with increased healthcare expenditures (US$1,429 more for those who are obese) (Finkelstein, Trogdon, Cohen, & Dietz, 2009), but also with decreased educational opportunities and reduced job earnings (Lawrence, Hazlett, & Hightower, 2010). According to the Trust for America's Health in collaboration with the Robert Wood Johnson Foundation (2012), estimates suggest that if current trends continue, the cost of obesity by the year 2030 will increase by US$48–66 billion (Trust for America's Health & Robert Wood Johnson Foundation, 2012).

Childhood obesity

Alarmingly, 17% of children aged 2–19 in the United States are classified as being obese (Ogden, Carroll, Curtin, Lamb, & Flegal, 2010). An additional 31% of children under the age of 18 are believed to be at risk of being overweight (Hedley et al., 2004). Clearly, childhood obesity is a serious problem that, if left unchecked, could reach epidemic proportions. Obesity is not an American issue, however. Worldwide, obesity has been increasing, not only in adults but also in children. Childhood obesity has become a global issue irrespective of socioeconomic status, ethnicity, and gender (Raj & Kumar, 2010). In 2010, it was estimated that, globally, 43 million children under the age of 5 were overweight, with 35 million of these children living in developing countries (Rossouw, Grant, & Viljoen, 2012). The fastest obesity growth rates have been found in Africa, with the rates of childhood obesity doubling since 1990. In Europe, it is estimated that one in five children is overweight, with the rates increasing by 400,000 every year (International Obesity Task Force, 2005, as cited in Evans, Glacken, & Goggin, 2011), 10 times higher than in 1970 (Branca, Nikogosian, & Lobstein, 2007).

Childhood obesity is of great concern because excess weight in childhood can adversely affect health in adulthood (Ogden, Carroll, Kit, & Flegal, 2012). Risk factors for CHD are already identifiable in overweight children (Freedman, Khan, Dietz, Srinivasan, & Berenson, 2001). It has been noted that 70% of obese youth have on additional risk for cardiovascular disease (Freedman et al., 2004). Children who are obese are 6–50% more likely to be obese adults than non-obese children. In addition, one study found that 80% of "tweens" and teens were obese at age 25 (Whitaker, Wright, Pepe, Seidel, & Dietz, 1997). If the trend of obesity is not reversed, the current generation of children could be the first in history to die younger than their parents' generation (Trust for America's Health & Robert Wood Johnson Foundation, 2012).

Many factors have contributed to the rise in obesity among school-age children (CDC, 2008). These include heredity, parental life style, lack of exercise, reliance on fast food, and increased sedentary activity (i.e., video games, tablets, cell phones, computers, etc.). While it is true that children who have two parents who are obese or overweight may have a genetic predisposition to being overweight (Francis, Ventura, Marini, & Birch, 2007), environmental factors appear to be a leading contributor to childhood obesity (CDC, 2008). Further, behavioral factors such as diet and exercise (Arluk, Branch, Swain, & Dowling, 2003) often appear to be more important than heredity in contributing to childhood obesity. Obesity has both physical and behavioral health implications (Bosch, Stradmeijer, & Seidell, 2004). Overweight and obese children and adolescents suffer psychosocial consequences associated with social and peer stigma in the form of bullying, depression, and diminished self-esteem and self-worth (Lawrence, Hazlett, & Abel, 2011).

Consequences of Obesity

Bullying

Being a victim of bullying involves a child being repeatedly exposed to peers who have the intention to hurt and or humiliate him or her (Due et al., 2005). Bullying involves, among other things, a power imbalance. This imbalance may be real or perceived, and may be physical, verbal, and/or relational (e.g., social exclusion) (Wang, Iannotti, & Nansel, 2009). Bullying behaviors in general, as well as those related to obesity, have become a growing social concern (Ross & Horner, 2009). Stigma, bullying, and name-calling inflicted at an early age are known to negatively impact the self-esteem and psychosocial functioning of children (Schwartz & Puhl, 2003; Sjoberg, Nilsson, & Leppert, 2005). Research indicates that overweight and obese youths are victims of bias and stereotyping by peers (Kraig & Keel, 2001; Latner & Stunkard, 2003), teachers (Bauer, Yang, & Austin, 2004), and even parents (Davison & Birch, 2004). Bias against overweight and obese children increases the likelihood that this group will become involved, either as perpetrator or victim, in bullying behaviors (Griffin & Gross, 2004).

According to data from the World Health Organization's Bullying survey (Nansal et al., 2001), 53% of boys and 37% of the girls surveyed report having participated in bullying on a weekly basis. Nansel and colleagues reported that 47% of boys and 36% of girls have been bullied, with 11% of boys and 6% of the girls reporting being bullied weekly. Children who are obese report being teased three times more often than average-weight children (Neumark-Sztainer et al., 2002; Warschburger, 2005). This teasing likely acts as a mediating variable between obesity and the psychological consequences of stigmatization. Interestingly, recent evidence also suggests that overweight and obese adolescent boys are more likely to be perpetrators of bullying than their non-obese peers (Griffiths, Wolke, Page, & Horwood, 2006).

Stigma

Given the increase in childhood obesity, one would think that the stigmatization of children who are overweight or obese would decrease. The stigmatization against obese and overweight children has actually grown stronger (Lawrence, 2010). For girls, appearance alone may be problematic. In a society where thin is the standard for young girls, those who are overweight may suffer from social isolation or avoidance of activities (Puhl & Luedicke, 2012) because of stigmatization. In 1961, Richardson, Goodman, Hastorf, and Dronbusch conducted a (now classic) study on obesity stigmatization. The researchers found that when adolescent children were asked to rank pictures of children (four with disabilities, one "average" and one overweight) they would most like to be friends with, the overweight child was ranked as the most unlikeable. This study was replicated in 2003 by Latner and Stunkard, and the findings were very similar. The overweight child was ranked as the least likeable; however, the distance between the average rankings of the highest- and lowest-ranked pictures increased by over 40%. This stigmatization may expose the children to more victimization. Further, the negative impact of lowered self-esteem, bullying, and isolation may lead to a variety of other difficulties and life-stage disadvantages such as getting into college, renting a residence, and getting married. Conversely, factors such as self-esteem, perception of ability (self-efficacy), and self-confidence have been shown to reduce obesity (Marquez, McAuley, & Overman, 2004) and, hence, increase opportunities.

Self-esteem

While research surrounding the relationship between self-esteem and obesity is weak in the immediate sense, prospective studies examining the development of low self-esteem typically show that being overweight in childhood predicts future low self-esteem (Hesketh, Wake, & Waters, 2004; Tiggeman, 2005). As mentioned earlier, it is likely that stigma-related variables such as weight-based teasing and criticism from parents (Davison, Markey, & Birch, 2003) mediate the relationship between obesity and self-esteem. Similar to the relationship between obesity and self-esteem, research indicates that weight-based teasing may mediate the relationship between depression and obesity in adolescents (Eisenberg et al., 2003; Keery, Boutelle, van den Berg, & Thompson, 2005). The same was found regarding the relationship between body dissatisfaction; actual body weight does not affect one's body image; the effect is moderated by teasing (Keery et al., 2005).

Depression

The research surrounding the relationship between obesity and depression is conflicting. Sjöberg, Nilsson, and Leppert (2005) investigated the association between adolescent obesity and depression in a nonclinical population ($n = 4703$). Specifically, they examined whether or not there was a relationship between self-reported BMI and depression. Control factors included gender, shame, parental employment, parental separation, and economy. The authors found that among the 15–17-year-olds in the study, obesity was significantly related to depression, shame, and depressive symptoms. Conversely, some studies have found that obesity did not predict depression; however, depression in childhood predicted a higher BMI in adulthood (Anderson, Cohen, Naumova, & Must, 2006; Goodman & Whitaker, 2002). Further findings indicated that adolescents reporting the highest incidents of shame were at increased risk for depression (Sjöberg et al., 2005). Their results suggest that the behavioral health of children and adolescents dealing with obesity go beyond diet and exercise. Treatment may also need to focus on coping with issues of shame and social isolation.

Investigators have noted high prevalence for depression and other psychiatric disorders among obese youth. Britz and colleagues (2000), for instance, reported that, from a clinical group of 47 extremely obese adolescents, 70% met the criteria for at least one DSM-IV diagnosis. In a review aimed at determining the validity of the Diagnostic Statistical Manual IV diagnosis of *binge-eating disorder*, Wonderlich, Gordon, Mitchell, Crosby, and Engel (2009) found that there is "reasonable evidence that BED can be differentiated from other existing eating disorders and is associated with significant impairment. . ." (p. 687). Consequently, one of the new revisions for the new Diagnostic Statistical Manual Fifth Edition (DSM 5) (American Psychiatric Association, 2013), is the inclusion of *binge-eating disorder* as a diagnosis. This disorder is characterized by eating a large amount of food in a short period of time and having a sense of loss of control during the eating period. Other criteria include: embarrassment, eating very quickly, feeling uncomfortably full, feelings of disgust or depression, and eating when not hungry. Unlike bulimia nervosa, binge-eating disorder does not include purging behaviors (American Psychiatric Association, 2013).

Theory and Practice for Behavioral Interventions Targeting Childhood Obesity

Because our clients are affected by and in constant interaction with systems, the profession of social work seeks to engage in effective collaborative prevention interventions at three levels: micro, mezzo, and macro. A micro-level intervention focuses on individual needs and strengths, while mezzo-level interventions focus on small-group or family needs and strengths. A macro level intervention will focus on the community and sociopolitical environment (Zastro & Kirst-Ashman, 2010).

Micro-level practice

Several theoretical frameworks have been used successfully in helping us to explain and predict the most effective means for addressing obesity. These include: (1) the health belief model (Hochbaum, 1958); (2) social cognitive theory (Bandura, 1986); and (3) the transtheoretical model/readiness-for-change framework (Prochaska, Norcross, & DiClemente 1994).

The health belief model (HBM) The HBM was initially employed to explain the patterns of preventative care such as vaccines, mammograms (Rosenstock, 1990), etc., emerging in various population groups. Developed in the 1950s, this perspective has more recently been used to explain newer health phenomenon such as high-risk sexual behaviors, illicit drug use, and high-risk behaviors. The HBM posits that the likelihood of an individual sustaining proactive preventive healthcare is a function of the degree of threat perceived by the individual. According to the model, patients comply with treatments when they believe that the illness (or prospective illness) will result in serious harm, or if the recommended therapy reduces a perceived imminent health problem. In other words, the expected vulnerability to the disease or condition is recognized by patients who knowledgeably weigh the cost of complying (i.e., money, time, discomfort, inconvenience, etc.) against the potential cost of continuing to take health risks, or because they chose not to be adherent to medical recommendations (Berman, Epstein, & Lydick, 1997).

In this model, the probability of an individual following advice (diet, exercise) both in terms of prevention and treatment of disease is a function of the patient's perceptions of his or her susceptibility to the disease (family history of disease caused by obesity, current weight, current health issues), the likely severity of the disease if contracted (will the disease caused by obesity kill me?), and the benefits (decreased weight, more energy, better physical appearance, better overall health) and barriers (lack of physical energy, lack of funds to purchase healthy food items, lack of family support) likely to be derived and encountered as a result of the recommended action.

Social cognitive theory Social cognitive theory explains health behaviors differently. The theory puts forth the belief that behavior is learned in response to the interaction of personal characteristics, environment, rewards, and sanctions (Bandura, 1986). Antecedents to behaviors are assessed as well as consequences that result from carrying out actions. Behavioral treatment is based primarily on principles gleaned from both of these frameworks (Thyer, 2011). The process of behavioral treatment helps clients identify cues that trigger inappropriate eating. Treatment focuses on offering reinforcement to clients as a means of rewarding positive eating/exercise behaviors.

Cognitive theory is often incorporated into the behavioral treatment of obesity, resulting in an overall approach known as cognitive behavioral therapy (CBT). The underlying assumption of CBT is that client thoughts directly affect feelings and behaviors (Thomilson & Thomilson, 2011). With CBT, the focus is on helping clients understand both the antecedents and consequences of their behaviors while, at the same time, enhancing client awareness of thought distortions that may contribute to unhealthy behaviors. Within the context of CBT, clients learn to set realistic goals for weight and behavior change and to realistically modify their thought and behaviors related to eating and exercise. The social workers also guide the clients to evaluate their progress in modifying eating and activity habits and reward themselves appropriately.

A large number of clinical studies has been conducted for examining the effects of CBT on the treatment on weight loss. Wing (2002) reviewed behavioral weight loss studies from 1996 to 1999, which resulted in a mean short-term weight loss of 10.6% (9.6 kg) during the treatment phase (21 weeks) and 8.6% (6 kg) at follow-up (18 months).

Transtheoretical model Trans-theoretical readiness-for-change perspectives have been increasingly used to help us understand differences in behavior changes among clients dealing with obesity (Logue, Sutton, Jarjoura, & Smucker, 2000). The readiness-for-change perspective puts forth the belief that the timing and client readiness for change may be the most important predictor of actual behavior change. Developed by Prochaska and DiClemente (1992), this transtheoretical model identifies a sequence of stages through which individuals move through in the process of achieving changes in their lives. Per the model, in the beginning of a change process, an individual will begin in the *precontemplation stage*. In this stage, the individual has recognized that he or she is overweight but is not actively trying to change. The person will then move from a *precontemplation* stage, to a *contemplation stage*, where they begin weighing the pros and cons of changing. In this stage, the individual is likely going to weigh the benefits of exercise and healthy diet (weight loss) against the cons (time, money, support). Next, the individual will reach a *determination phase* where he or she actually decides whether or not to pursue change, such as to begin the diet and exercise, or accept being overweight. If change is selected, the next phase is *preparation* for change. In the preparation stage, the individual may consult a doctor or nutritionist regarding a diet, join a weight loss program, and/or begin exercising. The model would then have the individual take action. Once change has been accomplished, the *maintenance phase* follows. The stages may end here, or in the case of relapse, begin again with *precontemplation* (Miller & Tonigan, 1996).

Solution-focused behavioral therapy Newer short-term behavioral treatments, such as solution-focused brief therapy (SFBT) (Gingerich & Eisengart, 2000) and motivational interviewing (Burke, Arkowitz, & Menchola, 2003; Miller & Rollnick, 1991) reflect the readiness-for-change perspective. These treatments have also been found to have utility for working with youth dealing with weight problems.

Solution-focused behavioral therapy developed as an outcome of social work practice (de Shazer, 1982). Social workers adhering to this framework hold the belief that clients want to change and will make changes as they are ready to do so (Weiner-Davis, de Shazer, & Gingerich, 1987). Key elements of SFBT include helping the client focus on: (1) what works; (2) exceptions to the problem; (3) the "miracle question"; and (4) scaling questions. Solution-focused behavioral therapy has been used successfully with children and adolescents for a wide range of behavioral concerns (Franklin & Gerlach, 2007). It has also been used to promote parenting skills.

Both CBT and short-term therapies have been found to be effective in normalizing eating and reducing distress in obese patients with binge-eating disorder, although neither intervention is associated with significant weight loss (McCallum et al. 2006). Short-term, client-centered approaches, such as solution-focused therapy or motivational interviewing, may be instrumental in helping the client develop greater self-acceptance and overall self-esteem (Robinson & Sirard, 2005). These techniques are discussed further in the next section of this chapter.

Behavioral treatments for childhood obesity The consequences of childhood overweight and obesity affect individuals at the micro, mezzo, and macro levels. Therefore, interventions need to focus on individual children, families, communities, and the public. Historically, we believed that obesity developed from poor eating and exercise habits, which could be corrected by the individual himself or herself. Today, we realize that dealing with obesity requires a more systematic approach that includes not only medical professionals but also social workers.

The United States Preventative Services Task Force (Pignone, 2003) notes that effective interventions to target obesity "combine nutrition education with behaviorally oriented counseling" (p. 94). In regard to childhood obesity, behavioral interventions may include individual weight counseling, therapy, family counseling, exercise programs, school-based programs, and/or community-based interventions.

Behavioral intervention is goal-oriented, process-specific, and collaborative (Lawrence et al., 2003). Behavioral treatment to target obesity focuses on helping individuals to develop skills to change their actions in order to achieve a healthier weight (Foster, Makris, & Bailer, 2005). Toward this end, the social worker will guide the client to identify unhealthy "triggers" of inappropriate eating (Brownwell, 2000) and then assist him or her to develop new responses to being "triggered." The social worker will also offer positive reinforcement of appropriate eating and exercise behaviors of the client. Several approaches have been identified as offering effective strategies for preventing and reducing childhood obesity. These strategies include: individual counseling (micro level), nutritional information and support programs (micro, mezzo, and macro levels), exercise programs (micro and mezzo levels), family counseling (mezzo level), school-based programs (mezzo or macro level), and community-based programs (macro level).

While physical health is certainly impacted by obesity, the challenge to social work professionals is considerable. When working with young clients with obesity, social workers must strive to build self-esteem among their clients, regardless of the child's weight and of whether they actually succeed in efforts at weight control. The core conditions of empathy, respect, and warmth are key elements in producing successful client outcomes (Coady & Lehmann, 2008).

Though counseling alone is not the primary treatment for obesity, it has a critical role in addressing childhood obesity. One of the greatest challenges for the social worker working with obese and overweight children and adolescents may be in addressing the significant disparity between actual and expected weight losses.

Although professionals generally accept a 10% weight loss as successful, teens, in particular, may have "magical thinking" about outcomes. These unrealistic outcomes are often fueled by media (Gortmaker et al., 1999). Encouraging clients to discuss what they hope to change besides their weight will help identify any unrealistic expectations or “magical thinking” regarding weight loss.

Body image therapy programs have been developed to help obese individuals alter the way they perceive and evaluate their bodies (Smolak, 2004). These interventions are particularly crucial for children and adolescents, because appearance is such a major component of self-esteem for children and especially teens.

Contrary to what many believe, clients who are overweight and/or obese are painfully aware of what they “should” eat. Thus, providing nutritional guidelines and information becomes a minimal role for the social worker. Instead, the social worker needs to focus on helping the client understand and avoid environmental situations (“triggers’) that contribute to their weight problems. Helping the client to identify, anticipate, and clarify barriers to their success may be more useful than spending time trying to “fix” the problem. As a rough indicator, the more a clinician speaks during the session, the less effective the session will be for the client. If the clinician is talking for 50% of the session, it may be that the social worker is providing too much “advice giving” and not allowing sufficient time for the client to consider and create his or her own solutions.

When counseling clients, it is important to describe expected behavior modifications in concrete/measurable terms (i.e., limit between meal snacks to 200 calories between dinner and bedtime; walk for 20 min after dinner daily), rather than more generally. Client strengths should be overtly acknowledged by the social worker (Saleeby, 1997).

When working with youth, it is especially important to have clients feel as if they are empowered by the helping process. The client, per solution-focused therapy, is the “local expert” regarding the problem (Turner, 2011). The social worker is the guide and facilitator. The social worker can learn with the client in a variety of ways. For example, asking the client to provide a written record of the plan, a journal or diary, and/or a list of key steps for implementation may enhance the overall adherence to the treatment plan. Clients are likely to benefit more from examining “what worked” rather than focusing on why things did not go as planned.

Recognizing that weight loss and weight management are difficult, clients/patients need to know that their social worker will not give up on them if they have setbacks. The social worker must keep in mind that criticizing clients can undermine their motivation. Unconditional positive regard (Rogers, 1995) is essential to the therapeutic relationship.

Further, the social worker can assist clients in recognizing patterns of non-adherence. Identifying behaviors that need special attention also empowers the client. Another means of client empowerment comes from the social worker’s attitude; it is the social workers responsibility to bring hope to the therapeutic relationship. Working closely with clients to help them think through barriers and obstacles to behavior change can serve to increase self-efficacy and give clients hope in both themselves and in the therapeutic process.

Interventions to increase exercise The relationship between activity level and obesity is well researched (Strauss, Rodzlisky, Burack, & Colin, 2001). People who are obese exercise less than individuals who are lean. Exercise is known to play a critical role in both the prevention and treatment of obesity among children and adolescents. In addition to increasing weight loss and improving mood and appearance, exercise lowers blood pressure, reduces risk of coronary artery disease and hypertension, and lowers depression and anxiety (Strauss et al., 2001).

Davis, Tomporowski, McDowell, Austin, Miller, Yanasak, and Naglieri (2011) conducted a randomized controlled experiment to investigate the impact of exercise on brain activation in overweight children. The study employed a sample of 171 sedentary, overweight children (7–11 years of age). The children were randomly assigned to one of three conditions: (1) a low-dosage exercise group (that consisted of 20 minutes of vigorous types of daily exercise followed by 20 minutes of a sedentary activity); (2) a high-dosage exercise group (consisting of 40 minutes of vigorous daily exercise); or (3) a no-exercise control group. Brain functions were measured with a standardized battery of neurocognitive tests. Findings indicated that children in the high-dosage group had significantly better neurocognitive test performance scores than the children in the low- or no-exercise groups. Further, children assigned to one of the exercise interventions exhibited significant changes in cerebral blood flow in the regions of the brain associated with executive function and attention, while children in the no-exercise group showed no blood flow changes. The authors concluded that participation in regular vigorous exercise may lead to better academic performance, and increases in individual self-control.

Mezzo-level practice

Family counseling If a child has risk factors for being overweight and/or obese, social workers can provide guidance to his or her parents on how to help their child make healthful choices. Social workers working with families of obese children need to emphasize the critical role of parents in helping the child develop new eating habits. By creating a structured environment that supports healthy eating and exercise, parents may be able to help their children to regulating their eating and exercise behaviors outside of the home (Friedlander, Highlen, & Lassiter, 1985). Research also suggests that parents should be discouraged from trying to prescribe or enforce strict diets (Schwartz & Puhl, 2003). This restrictive behavior may only serve to create conflict between parent and child. The literature indicates that parental attempts to control the food intake of children tend to work best when "bad" foods are not brought into the home (Birch & Fisher, 2000). Moreover, social workers may need to provide education to parents regarding healthy eating and exercise patterns. This education is particularly important if weight is an issue for the family as a whole. Strategies for reducing household intake of unhealthy foods such as sweets and fats need to be offered (Lawrence et al., 2003).

Goldfield, Epstein, Kilanowski, Paluch, and Kogut-Bossler (2001) suggest that family-based behavioral treatment can be effective in managing pediatric obesity. These authors compared the cost-effectiveness of two protocols for the delivery of family-based behavioral treatment. Employing a sample of 31 families with obese children, they used random assignment to two treatment groups. The first group offered group and individualized treatment. The second treatment offered only group intervention. Cost-effectiveness of treatment was defined as the magnitude of results for the 24 families with complete data. Results indicated that the group alone intervention was significantly more cost-effective than the mixed treatment.

Macro-level practice

School-based programs Much of the prevention efforts aimed at combatting childhood obesity have occurred within the school setting (Austin, Kim, Troped, Feldman, & Peterson, 2007). Schools have been a preferred setting for obesity prevention programs aimed at children and adolescents as they are systems that serve a continuous presence in children's lives and offer a structure in which children function (Brown & Summerbell, 2008). As of 2005, at least 21 US states have enacted legislation aimed at improving the nutritional health of children. Kropski, Keckley, and Jensen (2008) conducted an evidence-based review of 14 school-based programs that focused on reducing obesity. The bulk of these programs combine nutritional guidance with exercise (Bradshaw, Koth, Bevans, Ialongo, & Leaf, 2008). While these authors did raise concerns about the strength of some of the evaluation procedures used, they generally concluded that 12 of the 14 programs found significant changes in "at least one measure of dietary intake, physical activity, and/or sedentary behavior" (p. 1009).

A nationwide survey found that parents cited schools, more often than even healthcare providers, as a key element in reducing childhood obesity (Perry & Associates, 2003). In 2004, the National Institute for Health and Clinical Excellence (NICE) sponsored a team to review current practices aimed at children struggling with weight and obesity. The resultant NICE Obesity Guidance (Centre for Public Health Excellence, 2006) has provided a foundation for what is known about school-based weight control programs.

Brown and Summerbell (2008) conducted a systematic review of school-based interventions targeting overweight and obese children. Thirty-eight studies were included in their sample. Findings from the existing research was inconsistent. However, overall, the authors concluded that school-based programs that combine diet and exercise may help children reduce the risk of becoming overweight and/or obese.

Kropski, Keckley, and Jensen (2008) also conducted a systematic review of school-based prevention programs in order to assess their effectiveness for reducing childhood overweight or obesity. Again, though results were sometimes based on what the authors called "methodological concerns," the overall findings supported school-based behavioral interventions as a useful method of addressing the obesity issue in this population.

Bullying victimization frequently occurs in school settings (Black, 2007). School-based bullying is associated with increased anxiety, depressive feelings, loneliness, lowered self-esteem, and behavior problems for the victim (Burgess, Garbarino, & Carlson, 2006).

While interventions aimed at reducing bullying have been developed, evaluations of these programs have been mixed (Merrell, Gueldner, Ross, & Isava, 2008). In fact, though participant gains such as improved self-esteem and self-efficacy are often reported, none of the 16 anti-bullying programs assessed by Merrell et al. (2008) demonstrated any reduction in reported incidents of bullying. One key exception appears to be the Olweus Bullying Prevention Program (BPP). The Olweus BPP is an internationally recognized school-based project. Of the 29 best practices in youth violence prevention identified by the US Surgeon General's Office, the Olweus BPP was the only one to be designated as a "best practice" (Ross & Horner, 2009).

The Olweus BPP, developed in Norway, aims to target and change social norms that accept bullying behaviors (Olweus, 1993). It is a behaviorally based intervention delivered to students in group settings. The program utilizes a curriculum stressing consistent rules, positive incentives, pro-social values, and careful monitoring of progress. While highly effective when implemented in Norway, it has been somewhat less effective in the United States due to cultural differences and owing to issues related to fidelity of dosage (Black, 2007).

Community-based programs Community programs such as Boys and Girls Clubs are frequently selected as settings for after-school life-skills education and sport-related activities. These centers often offer opportunities for physical activities, and educational workshops (for parents and the children) related to healthy food choices and family-based physical activities. While these programs show promise, it is essential that parents and other key adults reinforce the message of healthy eating and exercise (Bauer, Yang, & Austin, 2004).

With regard to community-based interventions, the American Academy of Pediatrics, Council on School Health, has developed recommendations for schools inviting the formation of school wellness teams comprising doctors, nurses, dieticians, parents, and other community members (Spear et al., 2007). McCallum and colleagues (2007) conducted a randomized control experiment employing a sample of children visiting 29 community-based general practices in Melbourne, Australia ($n = 2112$). They found that this type of physician-led community-based intervention provided an improvement in nutrition scores. They also found some improvement in exercise and physical activity, but it was weaker.

It is important to recognize that, as with intervention implementation, research on policy interventions for obesity prevention has been hampered by the importance of individual responsibility and choice (Huang & Glass, 2008) and the lack of an environmental perspective.

Social workers need to participate in local planning and partnership efforts to implement needs assessments and provide appropriate solutions, such as increasing opportunities for physical activity within communities, particularly with high-risk populations and in areas that lack safe and accessible opportunities (Lawrence et al., 2010).

Implications for Research and Practice

Despite the serious concerns regarding childhood obesity, there is a paucity of research on evidence-based practice with this population. Eden, Orleans, Mulrow, Pender, and Teutsch (2002), using a database from the Cochrane Collaboration, concluded that, to date, evidence on behavioral intervention in the primary care setting effecting increases in physical activity has been mixed. Similarly, Whitlock et al. (2002), in their systematic review of the literature, found no empirically validated behavioral interventions for obesity. These latter authors, however, did strongly recommended the "Five A's" (assess, advise, agree, assist, and arrange) model. This model has been adapted from the model that was successfully used to help clients stop smoking (Fiorre et al., 2000).

SAMHSA's National Registry of Evidence-based Programs and Practices (2012) lists only one program on this site related to childhood obesity. The program *ParentCorps* is a culturally informed, family-focused prevention program targeting children aged 3–6 years of age. *ParentCorps* has both a parent education component and a child education component. The program's goals are related to the areas of parenting practices, child behavior, child academic achievement, and BMI. The target population that the intervention was tested with comprises low-income, culturally diverse families. In terms of childhood obesity, 10 public elementary school (including public pre-K) students and their families were randomly assigned to receive either the intervention or the control condition. All members of the study sample were drawn from economically disadvantaged geographic areas. At follow-up, those children who received the intervention had significantly lower BMI scores than those in the control group ($p = .006$). The BMI component of the *ParentCorps* program received an overall rating of 3.2 (on a 4.0 scale) from SAMHSA.

In sum, there is little research regarding the effectiveness of interventions for preventing and/or reducing childhood obesity. Systematic reviews of the literature have produced mixed results. Only one program has been identified by SAMHSA as an evidence-based practice. Clearly, more research is needed in this area.

If we are to reverse the trend of increasing childhood obesity, existing programs need to be more systematically evaluated, so that best practices and EBPs can be identified. In addition, behavioral healthcare professionals concerned about the negative consequences of obesity must join together to establish formal lines of communication that will allow for enhanced communication across disciplines. Social work interventions are needed at the micro, mezzo, and macro levels. Preventative efforts must begin before the elementary years. This will require the help of primary care providers and pre-school educators. Once children are enrolled in the K-12 school system, they need to be exposed to nutrition education, dietary monitoring, and exercise. Social workers are a critical element of all of these efforts. One of the roles of social work is to address barriers to and within individual interventions, community engagement, and research efforts (Eliadis, 2006). The current disagreement over whether childhood obesity is a personal or social problem serves to potentially limit progress (Stroup, Johnson, Proctor & Hahn, 2009). This barrier is one of problem definition. Social workers function with the understanding that the origin of the problem is multisystemic, and thus the definition must incorporate the micro, mezzo, and macro interactions within a child's environment (Lawrence et al., 2010). Social workers heeding the call to action should work to help stakeholders redefine this problem from a systems perspective in which the problem is systemic and not individual.

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Caring for the Family Caregiver

Jane R. Schubart

Introduction

A growing number of individuals take care of family members over an increasingly greater part of the life cycle. Adults live longer with conditions that use to be life threatening, such as diabetes, heart disease, and cancer, and children now live with illnesses that used to be fatal or required institutional care. This extension of life has increased the need for families to provide care. As Rolland points out, the psychosocial strains on a person caring for a family member with a chronic or life-threatening condition can rival the physical strains on the patient, yet the challenges of these family caregivers are often hidden from the medical community (Rolland, 1994). This chapter provides an overview of the issues facing family caregivers and a limited survey of research and applications in behavioral medicine.

Who Is the Family Caregiver?

A national profile of family caregivers is provided from a series of studies conducted in 1997, 2004, and most recently in 2009, by the National Alliance for Caregiving and AARP. Caregivers are broadly defined as those who provide unpaid care to an adult or a child with special needs, whether or not the person lives with the caregiver. Unpaid care is described as helping with personal needs or household chores, and includes managing the person's finances, arranging for outside assistive services, or visiting regularly. The 2009 survey results, based on a random sample of 1,480 telephone interviews with family caregivers aged 18 or older, estimated that nearly

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66 million people in the United States had served as unpaid family caregivers in the previous 12 months. These caregivers were predominantly female (66%), average age of 48 years, and a third of them were taking care of two or more people, usually relatives (86%). The caregivers reported being in their role for an average of 4.6 years, with 30% for 5 years or more. Advanced age (12%) and Alzheimer's or dementia (10%) comprised the top two reasons for individuals needing care. Other frequent problems included mental/emotional illness (7%), cancer (7%), heart disease (5%), and stroke (5%). It was reported by 30% that their care recipient had an emotional or mental health problem (32%), and in the majority of these cases (78%) a physical condition was also present. On average, caregivers reported spending more than 20 hours per week providing care.

How Caregiver Time Is Spent?

It was reported by 56% of caregivers that they helped their relatives with one or more activity of daily living (ADL). Common tasks included helping the care recipient get in and out of beds/chairs (40%) and personal care tasks such as helping their care recipient get dressed (32%), bathing or showering (26%), getting to and from the toilet (26%), and helping to deal with incontinence (18%). One in five helped feed their care recipient (19%). In addition, caregivers of adults helped on average with four out of seven instrumental activities of daily living (IADLs), including transportation (83%), housework (75%), grocery shopping (75%), meal preparation (65%), managing finances (64%), and arranging or supervising outside help. These caregiving activities resulted in a burden of care that was high for 32% of caregivers, moderate for 19%, and relatively low for 46%. Half of the caregivers reported that their care recipient lived in his or her own home (51%), and 29% lived together with their care recipient. The caregivers reported that 4% of their care recipients lived in nursing homes, and 4% lived in assisted living facilities. When asked about their own health, most caregivers reported that their health was excellent or very good (57%), while 17% said it was fair or poor; however, of those who had been providing care for 5 years or more, 23% reported their health to be fair or poor. By comparison, 13% of the general adult population described their health as fair or poor.

Impact of Caregiving on the Caregiver

The US healthcare system is expensive and fragmented, and focuses on the patient with little to offer the family. Family caregivers are viewed as co-providers of care. Their own needs as care recipients tend to be overlooked, and they are not considered to need help (Hecht et al., 2003; Pagnini et al., 2010). In instances where there is recognition of informal caregivers as co-recipients of care in the literature, strategies to enhance supportive care have not been well articulated (Penrod, Hupcey, Shipley, Loeb, & Baney, 2012). One reason for this may be that efforts to extend psychosocial care to family caregivers are thwarted by the caregivers' tendency to focus on the needs of the patient over their own needs. Often, caregivers do not see themselves as recipients of care, and this perception is re-enforced in their ongoing interactions with formal care providers (Penrod et al., 2012; Stajduhar, 2003). Yet, caregiver roles are profoundly affected by a patient's prognosis and the goals of care. Family caregivers experience their own responses to their family members' diagnoses, and they may need emotional support separate from the support offered to patients (Given, B. A., Given, C. W., & Kozachik, 2001). Elderly family caregivers are at greater risk. In fact, studies have demonstrated an increase in caregivers' risk of mortality after hospitalization of a spouse (Adamson, Price, Breeze, Bulpitt, & Fletcher, 2005; Pitceathly & Maguire, 2003). Christakis and Allison (2006) were involved in a large study of over 500,000 couples enrolled in Medicare in 1993, using Cox regression analysis and fixed-effects (case-time-control) methods to assess hospitalizations and deaths during 9 years of follow-up. The study results show that the risk of death for elderly men associated with hospitalization of a spouse was 22% of that associated with a spouse's death (95% confidence interval, 17–27%); and for women, the risk was 16% of that associated with a spouse's death (95% CI, 8–24%) (Christakis & Allison).

Caregiver burden has been defined as a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual. Caregiver burden threatens the physical, psychological, emotional, and functional health of caregivers (Carretero, Garces, Rodenas, & Sanjose, 2009; Etters, Goodall, & Harrison, 2008; Parks & Novielli, 2000; Zarit, Reever, & Bach-Peterson, 1980). Negative emotional states such as depression in older adults and caregivers has been associated with increased mortality, strokes, high blood pressure, and other negative health outcomes in a number of studies (Adamson et al., 2005; Krishnan, Mast, Ficker, Lawhorne, & Lichtenberg, 2005; Schulz et al., 1997).

The burden of caregiving differs between acute and chronic conditions. As Rolland (1994) points out, in acute health crises that are resolved within days, weeks, or even months, the focus is on good biomedical care. While the psychosocial demand on the family may be intense, it is time-limited and predictable, which helps the family maintain a positive outlook. In contrast, there are uncertainties in the case of a chronic illness that often extend into the distant future, frequently with the expectation that the patient's illness will worsen and eventually result in death (Rolland, 1994, p. 2). For example, it is widely reported that cancer and cancer treatment impact the well-being (emotional, social, and physical) of family caregivers (Kim & Given, 2008), with caregivers often experiencing levels of emotional distress (anxiety, depression) as high as patients, especially in the late stages of cancer illness (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Given et al., 1993). The challenges faced by family caregivers of cancer patients are well described by Northouse and colleagues (Northouse, Katapodi, Song, Zhang, & Mood, 2010) in their meta-analysis review. They note that the physical well-being of caregivers is at greater risk because they have little time to rest, engage in fewer self-care behaviors, and do not seek medical care for themselves when sick. Added to this, family caregivers of cancer patients often have chronic health problems of their own that can be exacerbated by the stress of caregiving such as heart disease, hypertension, and arthritis.

Quality of life (QOL) in families of cancer patients has not been studied in depth, despite results that show a significant impact on the cancer patient's own survival (Gotay & Muraoka, 1998). The interaction between patient and family QOL is likely to be complicated. Raveis and colleagues showed that increasing caregiver burden resulted in increased depressive symptomatology on the part of the caregivers of cancer patients (Raveis, Karus, & Siegel, 1998). Also, a correlation has been demonstrated between increased caregiver burden and a decrease in the care provided for the cancer patient by the family caregiver (Schott-Baer, Fisher, & Gregory, 1995; Siegel, Raveis, Houts, & Mor, 1991).

Caregiving and dementia

The needs of caregivers of demented individuals differ substantially from the needs of many other caregivers. Although many of the hardships encountered by Alzheimer's caregivers are shared with those caring for individuals with any chronic illness, caring for an individual with Alzheimer's can be especially challenging. The functional impairments that are a fundamental part of dementia are accompanied by behavioral symptoms that add to the challenges and stressors related to providing care to someone with dementia. Psychological distress and increased risk for depression are consistently associated with caregiving for individuals with dementia (Haley, Levine, Brown, & Bartolucci, 1987; Hooker et al., 2002; Levine, 2003; Schulz, Visintainer, & Williamson, 1990).

Caregiving and brain tumor patients

The experiences and needs of family caregivers of specific populations are often unique. For example, family caregivers of brain tumor patients experience a burden posed by the rapid onset and progression of a brain tumor, cognitive and behavioral changes, and uncertainty surrounding prognosis. Recent studies show that they live with a clinically significant reduction in overall quality of life as compared with the general population (Janda et al., 2007). Family caregivers must take on more responsibility for monitoring the illness, arranging treatments, communicating with healthcare professionals, and providing physical, emotional, and social support to the patient. They are challenged to make decisions as care needs change, yet often feel untrained and unprepared as they adjust to new roles and responsibilities. They may have difficulty understanding complicated medical directions, be unskilled in performing medical duties, and may find this type of care too emotionally difficult (Nezu, Nezu, Friedman, Faddis, & Houts, 1998). Family caregivers of brain tumor patients report high levels of stress and poor physical and emotional health, as well as career sacrifices, monetary losses, and workplace discrimination. Because the focus is on the patient, the needs of the caregivers are often neglected. Schubart, Kinzie, and Farace (2008) found that the quality of life of family caregivers of brain tumor patients directly relates to the patients' neuropsychological and behavioral impairment, particularly with changes in language ability and executive function. Sherwood and colleagues also reported that caregiver stress was significantly increased when the patients exhibit neuropsychiatric behaviors (e.g., agitation or hallucinations) (P. Sherwood et al., 2004). It is clear from the dementia literature that cognitive decline in patients has a negative effect on family caregivers over and above the stress from a family member having a serious illness (George & Gwyther, 1986), and recent studies have examined factors that contribute to caregiver strain for caregivers of persons with both oncological and neurological symptoms (Janda, Eakin, Bailey, Walker, & Troy, 2006; Schubart et al., 2008; Sherwood, Given, B. A., Doorenbos, & Given, C. W., 2004). A significant correlation between depression and QOL in caregivers of brain tumor patients has also been shown (Grov, Fossa, Tonnessen, & Dahl, 2006; Janda et al., 2006).

Studies examining the needs of brain tumor family caregivers show that their needs differ from those of other cancer patient family caregivers and often are unmet by existing resources. Fox and Lantz (1998) conducted a QOL study using individual and support group interviews. Their findings were organized around conceptual themes that included the stigma of a mind–body illness and a brain tumor as a family disease. Leavitt, Lamb, and Voss (1996) analyzed themes from brain tumor support groups and reported themes that include changes in family life, managing unexpected problems and complications, need for resources, provider burnout, and balancing hope with realistic expectations. Information-seeking emerged as a distinct theme. Sherwood and colleagues (2004) built on earlier theories of stress and coping to describe a conceptual model of providing care for someone with a primary malignant brain tumor that suggests an ongoing feedback loop as family caregivers appraise care demands and resources. Schubart and colleagues (2008) conducted interviews with the family caregivers of 20 brain tumor patients. These caregivers reported feeling overwhelmed and isolated, and struggled with a sense of denial and feelings of resentment, anger, and depression. Fang, Manne, and Pape (2001), in their study of marital quality and patient psychological distress, reported that spouse distress was directly related to patient distress and indirectly related to patient functional impairment.

Caregiving and the ALS patient

For some caregivers, the burden of care is both intense and lengthy. Caregivers of patients with amyotrophic lateral sclerosis (ALS), a neurodegenerative disease, provide an example. ALS patients need increasing assistance with all activities of daily living as the disease progresses. For patients <65 years of age at onset, 50% will survive 3 years; 20% live >5 years; and 10% live >10 years. As the patient's ability to speak or write diminishes, the physical demands of care become increasingly difficult (Coyne, 2010; Fukui, Ogawa, Ohtsuka, & Fukui, 2008; Garofalo, Choppala, Hamann, & Gjerde, 2009; Griggs et al., 2007). It has been estimated that ALS caregivers spend 10–15 hours/day caregiving even with paid home care assistance, and the caregiving burden is even higher when the patients are placed on ventilators (Hegel et al., 2006; Kenefick, 2006; Knobf, 2007). The psychological well-being of most ALS caregivers worsens over the course of caregiving (Lauver, Connolly-Nelson, & Vang, 2007; Leak, Hu, & King, 2008), and the home care services received by ALS patients are often too little and too late to relieve the care burden.

Family caregivers and the hospitalized patient

The challenges of caregiving are not limited to the home setting. When the patient is admitted to the hospital, the family caregiver is often present. Although no longer needed for the direct medical caregiving tasks that may have occurred in the home setting, family caregivers may feel they need to be present as an advocate for the patient, to communicate special needs or concerns to the nursing staff, and to be alert for medical errors or care that is not sensitive to their family member. These issues may be heightened if the patient or family has had a negative experience previously. Family caregivers are concerned about undertreatment, overtreatment, and medical mistakes. They are suspicious of the cost-cutting financial environment in healthcare today. With the increase in medical "teams," families are not always sure who is in charge. For example, in the hospitalist structure, the patient's primary care doctor (who knows the family and patient best) is not the physician providing hospital care (Levine & Zuckerman, 1999). Families bring a number of important issues to the table, along with their own frustrations and stress. Unfortunately, physicians are generally not well trained in dealing with family dynamics. The formal medical school curriculum does not prepare them to work well with families, and the informal curriculum of residency training may actually model and teach the wrong lessons. Consequently, physicians often turn to nurses and social workers to interface with the family, but their roles and availability are often limited or not well defined.

Family caregivers play different roles, and the perception of these roles can be a source of tension with the health provider. While some family caregivers may be present simply as trusted companions, others serve as advocates or even as surrogate decision-makers. And while surrogates ideally will know the patient's wishes and act in the patient's best interest, studies show that family members do not always know the precise wishes of the patient (although, arguably, they come the closest). Families who serve as surrogate decision-makers may be unclear about the precise wishes of their relative, about the real choices available, and about how to meaningfully participate in decision-making (Emanuel, Danis, Pearlman, & Singer, 1995; Fagerlin & Schneider, 2004; McAuley, Buchanan, Travis, Wang, & Kim, 2006).

Instead of rational decision-making, in reality, decision-making is encumbered with many extraneous issues that include culture, personal history, beliefs, and other family members.

Family caregivers and the health system

The relationship of the family caregiver to the health system is complex and evolving. In the United States, there has been an underlying assumption that families *ought to* provide care, and that government or insurance companies should only step in when there is no family, or when families do not provide the needed care (Levine & Murray, 2004, p. xxxiv). In fact, Medicare rules and regulations (and, by extension, most of the third-party payer policies regarding home care) are based on the assumption that the individual, not the family, is the sole beneficiary. That is to say, family caregivers are not entitled to any benefits. In this context, it is not surprising that so little attention has been given to assessing caregiving competence and confidence in performing specific day-today caregiving tasks, or determining what support a caregiver might need.

The societal context of caregiving is evolving, perhaps as the impact of caregiving on the caregivers' own health is being recognized as a public health concern (Talley & Crews, 2007). Caregivers report having one or more chronic conditions at nearly twice the rate of non-caregivers (National Alliance for Caregiving, 2006; Schulz & Beach, 1999). Caregiving has significant monetary costs, including greater out-of-pocket health costs, which are much higher for people who have a relative with a disability (Altman, Cooper, & Cunningham, 1999). As pointed out by Levine and Murray, "A health care system built on a culture that equally values technical skill and compassionate care must rethink the current ways it treats family caregivers. It is no longer justifiable to dismiss family caregivers as troublesome extensions of the patient or to exploit them as 'free labor' " (Levine & Murray, 2004, pp. xxv–xxvi).

Assessing Caregiver Burden

Assessment of family caregivers has been done since the 1960s. The early focus was on the "burden" experienced by family members, with a broad meaning that reflected the impact that caregiving has on the caregiver's mental, physical, and social well-being, as well as employment and financial problems (Feinberg, 2002). The concept was refined in the mid-1980s to enable comparison of family caregivers to other groups of people (George & Gwyther, 1986), and to expand assessment to include the consequences of caregiving beyond the single dimension of "burden." Multiple dimensions of the impact of caregiving emerged in research studies (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989) and were grounded in theoretical or conceptual models. For example, many studies of caregivers of persons with dementia focused on the stress process models (Folkman, 1997) of caregiving and were grounded in the sociological theory (Feinberg).

Many instruments have been developed to measure various family caregiver outcomes. Examples include the caregiver burden inventory (CBI) (Novak & Guest, 1989), which measures caregiver response to the demands of caregiving. This is a validated instrument with 24 items and five subscales (time-dependence, developmental, physical, social, and emotional). The Quality of Life in Life Threatening Illness – Family Carer Version (QOLLTI-F) (Cohen et al., 2006) measures caregiver quality of life. This validated instrument includes 16 items that cover carer's own state, relationships, carer's outlook, quality of care, patient condition, finances, and environment. Other measures have been developed to measure caregiver self-efficacy as a mediator of caregiver coping. For example, Zeiss and colleagues developed an assessment that measures self-care self-efficacy and caregiver problem-solving self-efficacy (Zeiss, Gallagher-Thompson, Lovett, Rose, & McKibbin, 1999).

The distress experienced by families of intensive care unit (ICU) patients has sparked interest in family-centered care (Azoulay et al., 2001; Heyland et al., 2002). Studies have been conducted both to assess the health impact of the ICU experience on family members (Kentish-Barnes, Lemiale, Chaize, Pochard, & Azoulay, 2009), and, in some settings, families are recipients of specific interventions aimed at lessening the burden placed on them during and after the ICU stay (Molter, 1994). The quality of end-of-life care has received increasing attention among healthcare providers, researchers, policy-makers, and consumers of healthcare. Increasingly, the family's perspective is regarded as important. For example, Curtis and colleagues developed and validated the Quality of Dying and Death Questionnaire (QODD) (Downey, Curtis, Lafferty, Herting, & Engelberg, 2010) to assess aspects of the end-of-life care and the dying experience that are important to patients and their families. The researchers recommend that family burden be evaluated at three time points: (1) shortly after ICU admission to assess comprehension, satisfaction, and symptoms of anxiety and depression and to understand the family's specific needs; (2) after the third day, in a routine formal family meeting, to determine a communication strategy that fits the family's needs; and (3) when there is a shift from curative care to comfort care.

Numerous measures of informal caregiving in community settings have been identified (Lawton et al., 1989). Yet, in actual practice, caregiver assessments typically comprise a section of the assessment of the home or community-based care delivered to the care recipient. This section typically addresses questions about the type of care provided, frequency/duration, and willingness of the family caregiver to continue in the caregiving role. The focus is on the needs of the care recipient, and less about the caregiver. Although less commonly used, there are assessment instruments that focus exclusively or primarily on the family caregiver's needs. Caregiver assessment tools tend to differ by program, caregiver population, how care is administered, and how the data is used. Even questions in specific areas often vary widely in wording and perspective. Whereas some instruments are very brief screening tools with single-item questions that ask about overall burden, others are domain-specific tools that may contain multiple questions about specific aspects of caregiving. Some instruments assess the caregiver's information needs about specific caregiving tasks (e.g., medication management), financial/insurance/legal information, and knowledge and use of advance directives and other advance care planning tools. Others contain questions about the home environment. Many of the measures used in caregiver assessments were originally developed for research studies, usually with small, predominantly white, middle-class samples, but are now being used in various forms and formats by a range of different types of practitioners to assess family caregiver needs (Feinberg, 2002).

Interventions for Family Caregivers

Although many programs and interventions have been developed to help caregivers cope with the demands of caregiving and reduce their burden and stress, there exists limited research regarding the effectiveness of these programs and interventions to improve caregiver (and care recipient) outcomes.

A starting point in reviewing what is known about caregiver programs and interventions are the service areas described by the National Family Caregiver Support Program (Older Americans Act Amendment of 2000, Title III-E). Interventions generally include *providing information* to family caregivers about services that are available, and then *providing assistance to access* those services. Other services include individual counseling and support groups. Training is often provided to help caregivers in performing caregiving tasks and responsibilities, making decisions, and solving problems. Respite care services provide family caregivers some temporary relief from their caregiving responsibilities and/or provide supplemental services to complement the care that they provide to their family member (Whittier, Coon, & Aaker, 2001).

In evaluating these kinds of services, program leaders and policy-makers usually assess service utilization. This typically covers availability and accessibility, whether acceptable and affordable to the caregiver and whether appropriate for diverse cultures. One of the greatest challenges in evaluation is the diverseness of the services offered. For example, counseling services offered to caregivers may include individual psychotherapy, couples counseling, group counseling, and family treatment. Regardless of delivery format, counseling typically aims to reduce caregiver emotional distress, as well as address pre-existing issues that might complicate caregiving, such as family conflict. Many studies have examined the effectiveness of various types of counseling services, with generally positive outcomes reported.

Examination of links between chronic illness and family relationships have led to psychosocial interventions targeted at the patient's closest family members or both patient and family members. Results of a meta-analysis of 70 randomized studies comparing these interventions with usual medical care found positive effects for caregiving burden, depression, and anxiety; these effects were strongest for non-dementing illnesses and for interventions that targeted only the family member, and which addressed relationship issues (Martire, Lustig, Schulz, Miller, & Helgeson, 2004). More recently, studies have examined the positive aspects of caregiving and have included measures of the extent to which caregiving has made the caregiver feel more useful, learn new skills, and find more meaning in life (Cohen, Colantonio, & Vernich, 2002; Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Lawton et al., 1989; Pearlin, Mullan, Semple, & Skaff, 1990).

A number of interventions have been implemented aimed at the family caregivers of hospitalized elderly with the goal of having family caregivers participate in the patient's care to reduce the dysfunctional outcomes experienced by elderly patients (confusion, fall, pressure ulcers, nutritional deficiency). In their review, Li, Melnyk, and McCann (2004) found 20 intervention studies, including unpublished doctoral dissertations published between 1983 and 2003 on the topic of family care for hospitalized patients, of which nine involved family caregivers in the hospital care for patients aged 60 years or older. Among the nine reviewed studies, five involved interventions for family care in the transition from hospital to home, such as discharge planning, one intervention addressed family care in the rehabilitation period, and three interventions involved family caregivers in caring for elderly patients during the hospital stay. All nine studies used paper-based handouts, audiotapes, and/or counseling sessions to teach knowledge and skills to the family caregivers. Outcomes measured included patient outcomes (emotional responses, physical and cognitive outcomes, utilization and cost, preparedness, and/or satisfaction), and family outcomes (emotional responses such as anxiety or mood, care provided, burden, satisfaction and cost, family functioning). The authors noted a number of weaknesses, including: lack of measures of family involvement; conducting studies at one hospital site or one transition period; lack of a theoretical framework and mediating variables to explain the process that produced positive outcomes; and lack of a comparison intervention group.

Harding and Higginson (2003) reviewed the literature of interventions for caregivers of cancer patients and found few targeted interventions. Twenty-two interventions were identified that included only three problem-solving and education interventions (Ferrell, Grant, Chan, Ahn, & Ferrell, 1995; Goldberg & Wool, 1985; Toseland, Blanchard, & McCallion, 1995). Ferrell and colleagues (1995) conducted a single-group prospective study in 50 elderly caregivers that included three 1-hour pain education session delivered in the home. They reported improvement in all scores, including caregiver burden. In another study of problem-solving interventions, Toseland and colleagues (1995) evaluated a problem-solving intervention that consisted of six 1-hour sessions and reported improvement that was statistically significant for a distressed/burdened subsample. Several other studies of problem-solving skills in cancer patients have shown that participant's outcomes (depression, stress, physical symptoms, and problem-solving ability) are improved with a problem-solving skill intervention. The basic mechanism is thought to be that problem-solving moderates the normal stress sustained by cancer patients (Nezu & Nezu, 1989). In another study, Schulz and colleagues reported that caregivers of dementia patients benefited from knowledge about the disease, the caregiving role, and available resources, and after their information needs were met, they benefited from additional training in general problem-solving skills (Schulz et al., 2002).

More recently, Northouse and colleagues (2010) reviewed RCTs of interventions targeting family caregivers of cancer patients published between 1983 and March 2009. The authors noted that, while previous systematic reviews had described interventions conducted with family caregivers of cancer patients, they did not evaluate the efficacy of these interventions on multiple caregiver outcomes. Their meta-analysis was based on data extracted from 29 studies that assessed interventions that were psychosocially, cognitively, or behaviorally oriented and included family caregivers of cancer patients (Badger, Segrin, Dorros, Meek, & Lopez, 2007; Baucom et al., 2009; Budin et al., 2008; Bultz, Speca, Brasher, Geggie, & Page, 2000; Campbell et al., 2007; Carter, 2006; Christensen, 1983; Derdiarian, 1989; Giarelli, McCorkle, & Monturo, 2003; Given et al., 2006; Goldberg & Wool, 1985; Heinrich & Schag, 1985; Hudson, Aranda, & Hayman-White, 2005; Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999; Keefe et al., 2005; Kissane et al., 2006; Kozachik et al., 2001; Kuijer, Buunk, De Jong, Ybema, & Sanderman, 2004; Kurtz, M. E., Kurtz, J. C., Given, C. W., & Given, B., 2005; Manne, Babb, Pinover, Horwitz, & Ebbert, 2004; McCorkle, Robinson, Nuamah, Lev, & Benoliel, 1998; McCorkle, Siefert, Dowd, Robinson, & Pickett, 2007; McMillan et al., 2006; Mokuau, Braun, Wong, Higuchi, & Gotay, 2008; L. Northouse, Kershaw, Mood, & Schafenacker, 2005; Northouse et al., 2007; Scott, Halford, & Ward, 2004; Toseland et al., 1995; Walsh et al., 2007). The types of interventions delivered to caregivers were psycho-educational, skills training, and/or therapeutic counseling. The authors note that many of the interventions reviewed were designed mainly to address the patient's care, with caregiver self-care being a secondary focus or an afterthought in some patient-focused interventions. Only nine of the 29 studies focused solely on the caregiver. The effects reported were small to moderate in size; however, there was evidence that interventions can significantly reduce caregiver burden, improve coping ability, and increase confidence in the caregiver role, reduce anxiety, and improve family relationships. These findings were consistent with reports of interventions targeting caregivers of chronically ill patients with dementia.

Implications

Because caregivers typically experience multiple problems, interventions that are flexible and address multiple aspects of caregiving are likely to be most successful. Also, interventions should be designed to fit the specific needs of specific caregiver populations. For example, the needs of family caregivers caring for a person with dementia will be different from the needs of a person caring for a child with a disability. Caregivers are likely to differ in terms of stressors and perceived stress, and also in terms of the type of support services needed. Interventions should be based on solid theoretical frameworks to guide measurement of mediating variables. Family caregiver beliefs, emotions, and behaviors should be considered as outcomes or mediating variables to improve care recipient outcomes. In addition, measures over time are important to evaluate both short-term (e.g., during hospitalization) and long-term outcomes for family caregivers to determine whether interventions have lasting effects (Li et al., 2004). Also, future studies need to have more racial, cultural, and socioeconomic diversity. There is a need for multisite studies to obtain larger samples of patients and caregivers in order to generalize findings.

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Part III

Education and Health: New Roles for both Teacher and Physician

44

Chronic Health Conditions in Schools

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Of the 63.2 million students and youth aged 0–17 in the United States, it is estimated that approximately 11.2 million have a medical condition that could be considered a chronic health condition (CHC) (Data Resource Center for Child and Adolescent Health, 2012). The Council for Children and Adolescents with Chronic Health Conditions (2012) defines CHCs in terms of the duration of the illness and the functional limitations they pose for students. Specifically, they define a CHC as one that: (1) is biologically based, (2) has persisted for at least 3 months, (3) has significantly impacted the student or family's day-to-day functioning, and (4) requires medical intervention and ongoing maintenance that exceeds what is typical offered by pediatricians and family physicians. This chapter addresses CHCs that meet these criteria and impact, or potentially impact, school performance.

While many students are diagnosed with a CHC before starting school, onset can occur in childhood or go undetected; thus, symptoms may present for the first time in the school setting (Flores, 2010; Kenney, Ruhter, & Selden, 2009). This chapter describes the role of teachers, school nurses, and other specialized instructional support personnel (SISP) in identifying and working with students who have CHCs in schools. SISPs include school social workers, school psychologists, and school counselors, whose role in identifying and working with students with CHCs are often interchangeable. Specifically, we will address: (1) the prevalence of CHCs in US schools, and symptoms of CHCs related to student performance, (2) suggested best practices for identifying and working with CHCs in schools, and (3) specific legislation, policies, and practices related to working with students who have CHCs in schools. The chapter concludes with a case example that demonstrates the application of the ideas presented.

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The Prevalence and Characteristics of CHCs in Schools

Table 44.1 presents the National Survey of Children with Special Health Needs (2009–2010), describing the prevalence of CHCs among US youth by race/ethnicity, gender, and socioeconomic status (Data Resource Center for Child and Adolescent Health, 2012). As can be seen in the table, environmental allergies are the most common CHC, affecting 49% of the student population. Asthma and attention deficit disorder (ADD)/attention deficit hyperactivity disorder (ADHD) are the next most common problem, inflicting 35% and 30% of the population, respectively. Also noteworthy is the elevated prevalence rate for males across all CHC categories. Brain injury/concussion, developmental delays, seizure disorders, and arthritis/joint problems appear to have the strongest associations with socioeconomic status (SES), while environmental allergies, asthma, and brain injury/concussion have the strongest associations with race. Further analyses of this data, as well as the National Longitudinal Survey of Youth and the National Health Interview Survey, indicate that CHCs such as asthma, obesity, and ADD/ADHD are increasing (Boyle et al., 2011; Van Cleave, Gortmaker, & Perrin, 2010).

Table 44.2 provides a list of symptoms that may present in schools and possible effects on school performance for the most educationally relevant CHCs. As with the definition of CHC given in the preceding text, it is important to note that, even though a CHC such as asthma or food allergies can produce acute health events and symptomatology may ebb and flow, what makes them CHCs of interest to school personnel are the functional challenges they pose with regard to school performance, particularly with regard to academic and social engagement (Forrest, Bevans, Riley, Crespo, & Louis, 2011). As can be seen in Table 44.2, the symptoms of some CHCs, such as ADHD and autism, have a direct effect on school performance (McCoy & Banks, 2012). The symptoms of other CHCs, such as food allergies, may have only an indirect relationship to school performance, but are still relevant to school personnel, as they often require teacher awareness and possible accommodations within the school environment (Lacina, 2010).

Identifying and Working with Students Who Have CHCs

Most schools are not equipped with medical diagnostic and treatment technology, and thus it may seem uncomfortable to even discuss schools as places where student's CHCs are identified. However, student health researchers have long acknowledged that many CHCs go undiagnosed, and school personnel are uniquely positioned to observe the symptoms and effects of CHCs summarized in Table 44.2 (Basch, 2010; Flores, 2010; Kenney, Ruhter, & Selden, 2009). We advocate for the adoption of a coordinated school health framework to identify students who have CHCs and/or increase parents' knowledge regarding the

Table 44.1 Prevalence of chronic health conditions among US youth by race/ethnicity, gender, and socioeconomic status.

Chronic Health Condition	*Prevalence (Population Estimate of US Youth Population, n = 11,203,616)*	*Prevalence Estimates by Race*	*Prevalence Estimates by Gender*	*Prevalence Estimates by SES (below FPL = Family Poverty Line)*
Arthritis/joint problems	326,000 (2.9% of National Sample)	64% White 17% African-American 13% Hispanic 6% Other	54% Female 46% Male	29% below FPL
Asthma	3,904,000 (35%)	49% White 23% African-American 19% Hispanic 9% Other	60% Male 40% Female	27% below FPL
Attention deficit disorder/ ADHD	3,200,000 (30%)	65% White 14.5% African-American 13.5% Hispanic 7% Other	68% Male 32% Female	24% below FPL
Autism or autistic spectrum disorders	839,000 (8%)	62% White 10% African-American 16% Hispanic 12% Other	81% Male 19% Female	19% below FPL
Brain injury/ concussion	159,000 (1.4%)	51% White 24% Hispanic 14% African-American 11% Other	61% Male 39% Female	33% below the FPL
Developmental delays	1,900,000 (17.6%)	54% White 18% Hispanic 16% African-American 12% Other	66% Male 34% Female	28% below the FPL
Diabetes (type 1)	189,000 (1.7%)	58% White 18% African-American 17% Hispanic 7% Other	52% Female 48% Male	18% below FPL

(*Continued*)

Table 44.1 (*Continued*)

Chronic Health Condition	*Prevalence (Population Estimate of US Youth Population, n = 11,203,616)*	*Prevalence Estimates by Race*	*Prevalence Estimates by Gender*	*Prevalence Estimates by SES (below FPL = Family Poverty Line)*
Epilepsy/ seizure disorder	345,000 (3.1%)	54% White 19% African-American 17% Hispanic 10% Other	58% Male 42% Female	29% Below FPL
Environmental allergies	5, 374,000 (49%)	58% White 17.5% African-American 15.5% Hispanic 9% Other	50% Male 50% Female	21% below FPL
Food allergies	1,300,000 (12%)	54% White 19.5% African-American 15.5% Hispanic 11% Other	58% Male 42% Female	17% below FPL
Heart problems or heart disease	335,000 (3%)	60% White 19% Hispanic 13% African-American 8%Other	54% Male 46% Female	Other 26% below FPL

Data source: Data Resource Center for Child and Adolescent Health, 2012.
Note: The NSCHSHCN survey referenced here is sponsored by the Department of Health and Human Services and the Center for Disease Control, and has been conducted in 2000–2001, 2005–2006, as well as the present survey noted here, 2009–2010.

symptoms associated with those CHCs that are most likely to impact school performance. Schools nurses are uniquely positioned to assist teachers and school administrators in doing initial assessments of student health problems (Baisch, Lundeen, & Murphy, 2011). A small but growing population of school-based health centers where physicians, nurses, and other primary care health professionals work within the school building increases the likelihood that teachers may be able to quickly get a student's potential CHC assessed and treated (Brown & Bolen, 2008; Strolin-Goltzman, 2010).

Admittedly, identifying and working with students who have CHCs in schools can be challenging without clear protocols and trained school personnel. We were unable to locate any protocols to conduct universal screening of CHCs in schools. Typically, in our experience, CHCs are identified in schools by a variety of

Table 44.2 Common CHCs that interfere with school performance.

Chronic Health Condition	*Symptoms that May be Seen at School*	*Domains of School Performance Impacted*
Attention deficit disorder/ADHD	1) Limited attention span 2) Elevated activity level 3) (In some students) Social and emotional deficits related to problems functioning in regular classroom setting with peers and teachers	1) Academic engagement (i.e., work completion) 2) Following directions 3) Organizational skills 4) Social engagement (i.e., establishing and maintaining relationships with peers and teachers)
Asthma	1) Difficulty breathing in class or other school activities 2) Chronic persistent coughing 3) Tendency to have asthma attacks after overexertion (usually exercise) at school	1) Academic engagement (e.g., frequent trips to nurse's office) 2) Social engagement (i.e., participation in school activities such as, play, PE, field trips. 3) Attendance
Autism or autistic spectrum disorders	1) Difficulty reading social cues and dealing with peers 2) Challenges in coping with transitions and changes to school routine	1) Social engagement (e.g., difficulties with peers that can produce behavior referrals and/or student-isolating behavior) 2) Organizational skills
Food allergies	1) Significant and adverse reaction to specific foods and food ingredients 2) Food allergy reactions that require immediate medical intervention at school and/or hospitalization	1) Academic engagement (e.g., restriction of student activities such as lunchtime, snack time, field trips; need for emergency medical) 2) I would think we would want to add a social engagement piece as children have to disclose allergies or may have limitations, e.g., separate lunch table

Data sources: American Academy of Pediatrics, 2004; Clay, 2004; Special Education Branch of British Columbia, 1995; Roberts & Steele, 2010.

professionals observing student symptoms, contacting parents for more information, and doing some basic screening and observation of the student at school. Our suggestions for those schools interested in creating a universal screening system include reviewing existing data and conducting a literature campaign to promote awareness of the symptomatology of common CHCs.

Table 44.3 School personnel typically involved with identifying and working with students with CHCs.

School Personnel	*Roles*	
School nurse	Examining students, completing initial screening, contacting parents, referring for additional evaluation	Providing psychoeducation to parents, students, and faculty; and assisting with medication management and counseling for students
Other SISP (school social worker, school psychologist, school counselor)	Observing classroom behavior, interviewing students, contacting parents, working with school nurse and outside health professionals to coordinate additional evaluation	Providing counseling to students to help them manage their CHC at school; assisting in providing psychoeducation on the CHC to faculty and staff; and advocating for the creation of a formal plan (e.g., IEP or 504 plan)
Classroom teachers	Observing students in classroom, referring to school nurse and/or SISP for further assessment	Following through with the school plan (IEP, 504, or other school plan) as related to the students' CHCs
School principal	Observing students in classroom and other school settings, refer to school nurse and/or SISP for further follow-up and assessment	Assisting school team, parents, and students in developing effective plans to help students with their CHCs
School secretary	Observing students in school office, referring to school nurse and/or SISP for further follow-up and assessment	(In some schools) Assisting school nurse with dispensing medication for students
Teacher's aide/ paraprofessional	Observing students in classroom and other school settings, referring to school nurse and/or SISP for further follow-up and assessment	For students on their caseload, assisting with implementation of the health plan (IEP, 504, or other school plan) for the students' CHCs

Table 44.3 lists a range of school personnel who are typically involved in the identification of students with CHCs. Schools typically have unique configurations of SISPs. Obviously, when there is a nurse in the school, he/she is a logical candidate to screen for students who have CHCs. When there is not a school nurse available, another SISP may serve as the de facto screener of CHCs, but must remain cognizant

of their limitations in this role since they do not have medical expertise. Principals, school secretaries, and teachers are also often key participants in this process, though without a school nurse and/or other SISPs this can present a challenge to effective identification, case management, and treatment of CHCs in the school setting.

Frequently, schools or districts collect health information from parents, whereby they are asked to identify CHCs for which the student has already been diagnosed. We recommend someone in the school, typically as SISP or secretary, keep a master list of all the students in the school with an educationally relevant CHC. Additionally, schools can publish newsletter articles, particularly early in the year, emphasizing the importance of communicating any known CHCs to the office staff, and creating articles or links to resources emphasizing early identification of common CHCs.

Intentionally, we are not advocating teachers identifying students who may have a CHC. Indeed, we believe that such a position is both unfair to teachers, given their workload demands, and potentially harmful to students and their families, as teachers are not trained healthcare professionals. Outside of some highly specialized educational environments that are beyond the scope of this chapter, teachers are not expected to be diagnosticians or medical professionals, but rather are educators who are likely to welcome consultation and training on CHCs to increase their knowledge without increasing their workload. Moreover, they need to be supported by non-teaching personnel who help families access health professionals in the school and community to assist them in addressing the health needs of their children.

Working with CHCs: Specific Federal Policies and Suggested Strategies

There are a variety of strategies that school personnel can engage in to improve the academic and social functioning of students with CHCs. Since many of these options occur within a broader service delivery context, policies governing this work are reviewed, followed by specific suggestions for working with students, parents, and teachers.

Policies related to working with students who have CHCs

There are many federal, state, and local policy initiatives that have direct implications for students with CHCs and the public schools they attend. In the following text, we have described three federal policy areas that have far-reaching impact for those working with students with CHCs.

In 1975, Congress passed the Education for All Handicapped Children Act (EHA), or PL-94–142, which altered education opportunities for students with disabilities. EHA provided for screening and identification for students with a wide range of disabilities and required schools to offer a variety of services for students based on an individualized education plan developed by a multidisciplinary team. The EHA contained four components: (1) screening and identification of students with disabilities; (2) intervention services for students with disabilities; (3) inclusion of students with non-disabled students to the greatest extent possible; and (4) discipline provisions for students with disabilities.

A 1990 reauthorization of EHA, the Individuals with Disabilities in Education Act (IDEA), was the first in a series of policy efforts to ensure students with disabilities were exposed to positive and proactive interventions. The Individuals with Disabilities Education Improvement Act of 2004 (IDEIA), a reauthorization of IDEA (PL 94-142), continued to promote the adoption of interventions known to be effective and placed a premium on primary prevention by altering the screening and identification procedures for students with disabilities (Klotz & Nealis, 2005). Students with CHCs who also qualify for special education services have an additional layer of services, which frequently include the provision of services by an SISP.

Students with CHCs who do not qualify for special education services most likely qualify for services through Section 504 of the Rehabilitation Act, which specifies that no one with a disability can be excluded from participating in federally funded programs or activities. “Disability” is defined as a physical or mental impairment that substantially limits one or more major life activities. Since learning is one of life’s major activities, student who meet the criteria defined earlier are likely to qualify for services under this provision. A 504 plan articulates the accommodations needed for students to have an opportunity to perform at the same level as their peers (US Department of Education, 2010).

As the Patient Protection and Affordable Care Act of 2010 (P.L. 111-148) (ACA) made drastic changes to the nation’s healthcare system, it also provided critical support to school-based health that will impact students who have CHCs. Capital grants totaling US$200 million were included in ACA to support the building, renovation, and equipment for school-based health centers. The ACA also provides authorization to Congress to appropriate funds to operate school-based health centers. While the funds have not yet been appropriated by Congress, the ACA has opened the door for federal funding. The ACA focused heavily on enhancing the role of primary care, which has clear implications for students with CHCs and for school health.

Working with students, families, and teachers

Health policy advocates and researchers agree that there is much work to do to secure support for public school students with CHCs. Whether via an IEP, 504 plan, or other official school document, a plan that documents the CHC and its potential impact on the student's learning needs to be established in writing. This plan may not be necessary for all students with CHCs, but if one is written, it should stipulate a structure to review the plan annually or in the event of changes to the student's or teacher's status, and thus should also provide an extra layer of protection for students and families if they change schools or districts. These plans will also guarantee that specific accommodations are provided to the student related to their CHC. The plan should address the following factors:

1. The provision of educationally relevant resources to parents and teachers that are CHC specific.
2. CHC-specific teacher training and support, often including classroom management strategies, home–school communication systems, direct teaching of social skills, and self-regulation skills to the entire class.
3. Direct services (as needed) related to the symptoms of the CHC, including individual behavior plans, case management, crisis intervention, and small group work (National Asthma Education and Prevention Program–School Subcommittee, 2003).

Additionally, there are interventions on the macro-level that educators and parents can work toward. SISPs can advocate for coordinated school health to become the norm in their school district to better facilitate prevention work as well as the more intensive efforts often needed for students with CHCs (Centers for Disease Control & Prevention, 2011; National Asthma Education and Prevention Program – School Subcommittee, 2003). The ACA and other state-level initiatives are renewing the focus on building more school-based and community-based health centers that have the potential to increase the access to quality healthcare for students with CHCs (National Assembly on School-Based Health Care, 2012). And the increased recognition of the need for coordinated school health frameworks will help to provide the social/emotional support for some of these students, and reinforce the idea that a student's health is inseparable from their ability to learn (Trust for America's Health, 2012).

Services to support teachers

While it is crucial to not overstate the role that teachers should play in diagnosing and "treating" students with CHCs, it is equally important to not neglect the crucial role they do play in making the day-to-day management of a student's CHC successful (Nabors, Little, Akin-Little, & Iobst, 2008). Teachers have the most frequent contact with students, and they are uniquely poised to notice any significant difficulties students might be having with their academic and social functioning (Grier & Bradley-Klug, 2011). Making teachers a focal part of the process, however, is not a given, as many teachers are unsure how much to do (or not do) to assist students with their CHC. An effective plan to support teachers working with students with CHCs should include:

1. Initial training for all teachers in basic information about CHCs (as well as providing access to some of the online databases and fact sheets cited in this chapter).
2. Support for helping a student with a specific CHC in his or her classroom, including detailed and timely sharing of information with the teacher about the student's CHC and what he or she can do as a teacher to help the student.
3. Clear protocols for students with severe CHC issues on how the teacher is expected to handle any emergencies that may arise related to the student's CHC, and details about specific SISPs in the school who can help the teacher and the student (National Asthma Education and Prevention Program–School Subcommittee, 2003).

Services to support families

As we will see in our case example in the following text, families sometimes need help in recognizing their child's CHC and accessing health services to address the specific health concerns that have been noted at school. Certainly, schools that have school-based health centers can help engage families in getting the right care for their child's CHC; however, most schools do not have healthcare providers on site, and the challenge for the school becomes how best they can help families find the resources and supports they need. We know that interventions that originate from IEP and 504 plans can be excellent school-based solutions for helping a student who has already been identified with a CHC; but what about a student who has no diagnosis yet, or who has parents who are unsure of what to do about their student's healthcare situation? While the ACA does allow for more support to families exploring whether their child has a specific CHC, there is more work to do to figure out how schools can best mobilize those resources and direct parents to them in a timely manner (National Center for School-Based Health Centers, 2010; Basch, 2010).

In the meantime, parents who have worked to identify and treat their child's CHC can enhance their child's success at school by considering these best practices:

1. Ensure that the school is fully aware of their children's CHC and any related medication that their children may need to have at school to help them manage their CHC.
2. Provide written authorization and documentation for any CHC-related interventions and accommodations recommended by the family's physician (this can again involve a 504 plan or a request for a case-study special education evaluation to determine eligibility for an IEP).

3. Convene a meeting with school personnel to review the CHC information and to develop a plan to address any issues that may develop.
4. Work closely with their children (at an age-appropriate level) to educate them about their CHC and to gradually increase their capacity to practice self-care and manage their own CHC over time (National Asthma Education and Prevention Program–School Subcommittee, 2003).

Case Example: Bobby and His "Damn Asthma Thing"

We conclude our chapter with a case example demonstrating how a student's CHC (asthma) might be successfully managed with the collaboration of the student (in this example, Bobby, a seventh grader), his teachers, and SISP personnel.

Bobby Anderson is a seventh-grade Caucasian male attending Manual Middle School in a suburban Chicago school district. The Carlson family moved into the district from California shortly after the school year started, and by late September there were still no records from Bobby's past school in California on file. Bobby Anderson had been diagnosed with asthma in second grade. He had excessive absences in third and fourth grade, but his CHC did not affect his ability to benefit from school at all over the past 2 years. His parents did not report his condition to the school.

Like many new students, Bobby was a bit slow to adjust; he was referred to the school social worker as part of a "new student" welcoming group orientation. The interactions between Bobby and the school social worker, Mr. Raines, were brief, largely because Bobby reported not needing any help. However, the new student protocol at Manual required Mr. Raines to inquire about CHCs; he did, and Bobby reluctantly disclosed his asthma diagnosis. Mr. Raines wanted to convene a meeting with him, his parents, the school nurse (Ms. Dupper), his teacher, and the PE teacher (Ms. Thompson). Bobby reluctantly agreed – with the understanding his CHC would not be disclosed to other students. Bobby had been stigmatized at his previous school, and was not at all excited his health status was revealing itself in Chicago.

The next week, Mr. Raines convened the meeting. Ms. Anderson shared some history about the diagnosis, including the fact that it had affected attendance in third and fourth grade, and that it had, at times, been an issue during PE and recess (in elementary school). Bobby shared his concerns with being stigmatized, and Ms. Dupper assured him that a well-thought-out plan and good communication should reduce, not increase, the likelihood that other students learn of his asthma. Mr. Raines provided Ms. Anderson some current information on the educational affects of asthma, and were reassured the family had made the necessary medical connections since moving to Illinois. The meeting lasted 40 minutes, and provided enough information for Ms. Dupper to write up a plan of action, should Bobby's asthma surface. The plan involved sending him to the office without bringing unnecessary attention to his condition.

One day in late September, during his physical education class, Bobby took himself out of the kickball game the class was playing, saying he was “tired.” Ms. Thompson monitored Bobby to make sure he was paying attention and not bothering other students, and noticed that Bobby looked pale and very sweaty. She asked Bobby if he was okay, and he told her he was “fine.” Ms. Thompson winked at him, normalized his behavior by stating it happens all the time, and suggested he take a trip to the office to make sure he was not coming down with something. Bobby was fine, but obviously the family needed to consult their physician and report the symptoms, which had not been present in over 2 years.

The team reconvened the next week. Bobby was back at school, and Ms. Anderson brought an inhaler for him to put in Ms. Dupper’s office. She also said that Bobby would now have an inhaler with him to use before gym class each afternoon.

This scenario demonstrates clearly the power of a formal, yet not-very-sophisticated universal screening protocol (i.e., asking about CHCs to students being interviewed because they are new) and a little advance planning.

Conclusion

CHCs are prevalent among school-aged students, and affect several domains of school performance, such as academic engagement, social engagement, and attendance. Little has been written on the role of school personnel to identify CHCs, and work with student, families, and teachers to manage the potential effects they can have on academic achievement. In this chapter, we have provided a framework for schools to identify and work with CHCs to maximize students’ school experiences. We have emphasized the importance of developing a coordinated universal identification system and formalizing necessary accommodations through a written plan of action, and emphasized the importance of advocating for students with CHCs at the school, district, and state policy levels. Finally, we have used a case example to demonstrate how this framework may effectively be used in a school setting.

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45

Behavioral Medicine for the Classroom Teacher

Sally Bittinger and David I. Mostofsky

Case Study of Ashley, Age 16

Ashley was diagnosed with type 1 diabetes at 16. When she returned to school, her parents spoke with the school nurse about concerns over her unstable blood sugar. Per the school nurse's suggestion, Ashley's doctor wrote letters to school personnel confirming her diabetes diagnosis, the problems with stabilizing her blood sugar levels, and ordered the school to make snacks available to her during the day and provide glucose tablets in each of her classrooms (snacks and tablets provided by the parents). . . . One day Ashley had a substitute teacher. About halfway through class, Ashley began to experience low blood sugar symptoms. The substitute asked her why she was not paying attention. Ashley told the teacher that she was diabetic and needed the sugar pills in her bag. The teacher became angry and took Ashley's bag from her and stated she could have it after class. About 10 minutes later, Ashley got up in class and stated she needed to see the nurse. The teacher told her to sit down and "shut up." Ashley sat down, but according to her classmates she was visibly shaking. A short time later, Ashley left the classroom stating she was going to the nurse's office. . . . Ashley was found, very confused, in a remote corner of the school. An ambulance was called and the emergency medical technicians recorded Ashley's blood glucose as 17 mg/dL (the goal is to keep plasma blood glucose between 90 and 130 mg/dL for adolescents and young adults). Ashley's endocrinologist told her parents that a blood glucose reading that low was potentially fatal.

(*Continued*)

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> Before Ashley returned to school, her parents met with the school's administrators, the district high school coordinator, and the school nurse. In that meeting, the administrators acknowledged that this had been a serious situation, but stated that they were not responsible for informing all their substitute or regular teachers of children's health concerns. . . . Because of the unwillingness of the administrators to address prevention possibilities, Ashley's parents hired a lawyer to address any violates of the ADA (Americans with Disabilities Act). . . . The school district and the parents reached a settlement that mandated yearly in-service training for all regular teachers and substitutes, and who are to be given a class roster with an asterisk denoting students with health concerns (this is per the parent's written permission to identify these students). Modifications to the school's teacher manual state that students who ask to go to the school nurse should not be barred from leaving the classroom. (Case Report from Mandali & Gordon, 2009)

There is general acceptance that the school (including the teachers, support staff, and administrators) is expected to proactively engage public health concerns including, but not limited to obesity, drug use, alcohol, teenage pregnancy, nutritional health, physical exercise, and more. There is considerably less of a consensus on how to meet whatever local goals have been established by regulatory agencies for these public health concerns and for other chronic health conditions. This case report is admittedly an extreme instance that exposes the dangerous gaps in current school health policy and services, but an example that ought to provide a wake-up call for chronically ill children in the classroom at large. The *Journal of School Health* is but one of the many journals – and it does not begin to reflect the immense collection of monograph volumes and books – that deal with health issues that have brought attention to the role that the school must play in its relationship to health management. There is a vast literature dealing with specific concerns such as "who is responsible for the administration of medicines in school" (Bannon and Ross, 1998), or "teaching teachers about school health emergencies" (Barrett, 2001), to name but a few. The important take-away message is that there are many prominent *non-mental-health* chronic disorders of childhood that do not constitute requiring "special need" classrooms or instruction, and yet the educational ramifications of a child with chronic disorder can constitute conditions in a classroom that may negatively affect the teacher or the unaffected other students in the class who are often overlooked. In most instances, the teacher is ill equipped to intervene or to provide constructive intervention to deal with a disruptive (let alone health-alarming) situation. In addition to diabetes, disorders such as asthma (which accounts for serious absenteeism), migraine headache (which is too often viewed as a manipulative complaint when reported by the student), Tourette syndrome (which may appear unreal or even a sign of madness), epilepsy (which may go undiagnosed until it is brought to the attention of the school nurse or social worker that the child repeatedly does not always pay attention, and persists in staring at the ceiling), rheumatic pain, chronic abdominal pain, chronic fatigue syndrome, and the list goes on. In the United States, up to 54 million children attend almost 129,000 schools for an average of 6 hours of class time daily for 13 years (Snyder & Hoffman, 2002). Since the school is the only institution that can reach almost all youth, it is also an invaluable delivery site to address health challenges, and thereby to positively impact educational outcomes. Although federal and school-level policies are in place to ensure support and assistance during school for children suffering from chronic diseases, they are often inconsistent and not enforced by administrators. Unfortunately, schools are often unable to adequately address these growing health and social issues on their own due to financial and personnel constraints. Behavioral medicine, an area often misunderstood by the public and health professionals, provides an invaluable resource to educate, train, and develop school personnel who will be able to assist children such as Ashley and their parents so that these children will no longer risk the denial of daily support and care in the classroom.

To attempt a concise cookbook or menu of options for the teacher in the application of behavioral medicine is beyond the scope of this chapter, but the interested reader can benefit much from other chapters in this handbook and from the numerous publications that are available which deal specifically with children with chronic disorders and their management in the classroom. This chapter explores the academic and social effects of chronic illness on students and on the role of the classroom teacher in assisting and supporting these children. We will also consider important implications for establishing structured methods of documentation that are needed for the school, parents, and treating medical team to ensure the students' success in the face of chronic illness. When information is shared effectively, students with chronic disease will no longer be victims of unprepared, overwhelmed, or uninformed support systems. We will argue for the cost-effective remediation provided by instituting workshops for teachers in particular, and the need to establish more efficient methods of communication to ensure that children with chronic illness do not escape the attention of trained personnel.

Relevance for the Classroom Teacher

If an otherwise normal child suffers from a chronic physical disorder, including but not limited to, pain, diabetes, epilepsy, or asthma, and attends a school for normal children in a normal classroom, that child's mere attendance presents a number of different challenges, namely: (a) a challenge to the teacher to ensure that the child's academic performance is optimized and developed to the limits of his/her aptitude and capability in the face of the chronic disorder; (b) a challenge to the teacher to educate the others in the class who do not suffer any serious health conditions and whose performance should not suffer from the presence of the affected youngster; (c) a challenge to the remaining students in the class to get on with their responsibilities in the class without distraction from the presence of their suffering classmate; (d) a challenge to the teacher to be aware of potentially disturbing chronic and non-mental-health disorders, and their inevitable consequences in jeopardizing academic performance (Jimerson et al., 2007; Gunnar, 1998). Inattention, missed school hours or days, and stressful intrusion of symptoms and reaction to biological manifestation are but some of the impairments in the student's quality of life and school performance (not to mention the biological side effects of medications). A corollary of the teacher's challenge is the need to maintain awareness of lurking chronic health disorders. This refers to both the situation where the medical diagnosis has been obtained and relayed to the teacher, as well as when symptom detection is done by the teacher for those students who are yet to receive proper medical review, thus engaging the teacher to bring the child's condition to the attention of the school nurse and social worker, and ultimately to the appropriate medical specialist(s). These challenges can exist both in school settings where the children are from affluent and financially comfortable homes and supportive families and inner-city school settings populated by the financially poor and where children lack healthy family environments, routine medical and dental care, and where medical conditions are all too often first discovered in the classroom. It seems fair to suggest that, at this time, these challenges are not being adequately met.

Regrettably, a number of premises underlie the current unacceptable status quo. The barriers to a more efficient program to address and rehabilitate these problems can, in part, be traced to several underlying premises that have: (a) characterized the culture of the present public school and the teacher training programs that prepare personnel for frontline classroom teaching, and (b) withheld the opportunity to benefit the school and the child. Historically, teachers and school administrators have regarded their professional domain as being peripheral to issues of chronic physical health disorders that may surface in their school or classroom. Similarly, state and federal agencies that are generally concerned with pediatric chronic disorders have largely remained distant from the needs of the public school teacher, classroom, or afflicted student. Furthermore, the teacher, school nurse, school social worker, and principal are generally uninformed of the contribution that theory and technology from behavioral medicine and/or health psychology might provide via a mechanism of instructive workshops to enable a teacher (and others) to recognize potentially serious sickness symptoms and to appreciate how they can learn to best provide optimal educational services for a child with a chronic disorder in a classroom with unaffected children. A priority message of the current chapter is that the long-standing neglect, whereby school personnel remain uninformed, is no longer tenable. Teachers and their colleagues in K-12 public schools should no longer have the option to deny their involvement with student health, because: (a) the school is ever-increasingly becoming the site of discovering (diagnosing) chronic health problems, often disguised as inattention (e.g., absence seizures, sleep disorders, ADHD), personality and behavior deviance (e.g., as a consequence of side effects of headache, abdominal pain, tinnitus), or hyper-arousal and respiratory discomfort (e.g., as often experienced following stress in asthma, or in medication abuse and non-compliance).

Chronic health problems and the traditional pharmaco-therapeutic attempts at their resolution often produce side effects that seriously interfere with learning and deportment, and with the efficiency of the teacher's role in the classroom. The rationale for imposing a pharmacological and chemical response with all its attending side effects has been seriously tarnished by controlled studies and numerous respectable reports by expert researchers and clinicians who have demonstrated that it is not a violation of science to expect behavioral-based treatments and interventions to be effective in moderating or modulating an underlying physiologically based mechanism. (After all, Pavlov's historically classical demonstration of producing salivation following behavioral conditioning is a well-accepted example.) Fortunately, the modification of symptoms and their underlying physiological substrates can often be understood, and implemented, by applying established principles from the world of learning and behavior change. The classroom teacher, de facto, dispenses "rewards" and "punishers" by attending or not attending to health symptoms (the only possibilities available). Chronic conditions and their symptoms can be unwittingly strengthened, or can be strategically and intentionally modified by the teacher's routine interactions with the student, whether by offering succor and comfort, providing appropriate coping tasks and instructions, or adopting a course of attentional neglect. The skills and techniques required for the involvement of the teacher or social worker in meeting such challenges can be acquired with modest investment of time and effort.

To optimize the mission of the school and to provide the climate for more effective learning, in-service continuing education in health psychology/behavioral medicine can be valuable. Teachers, in particular, would benefit from a better appreciation of how their behavior- and teaching-related activities involve the interaction of many social science, psychological, and psychobiological variables that are relevant to health crises, including, but not limited to, rewards, conditioning effects, personality style, anxiety and stress management, nutrition, sport/exercise, menstrual variables, and gender (sex) vulnerabilities. Among the objectives of a model workshop in behavioral medicine for the teacher would be an examination of the benefits of introducing changes in the status quo that includes teacher preparation, administrative priorities, and teacher-training curricula. Such an effort might result in the design of promising models for the *implementation* of programs, development of workshops, preparation of special educational materials, and development of uncomplicated systems for assessment and updating, and also provide the basis for a practical framework to collect local health census data and for the interaction with agencies statewide and replications on a national multi-site level. A thoughtful example of successful organizational efforts dealing with schools and the comprehensive interaction with others in the life space of the student is represented by the *Good Practice Manual*, published by various councils in the United Kingdom. An Internet search for "supporting pupils with medical needs at school" should generate a healthy list from which to select information and guidance manuals, along with sample forms for collecting relevant data. It may be of interest to note a disclaimer that appears in many of these manuals: "Note that teachers are not required to administer medication or to support pupils with medical needs as part of their employment contract but they may volunteer to do so." It should also be noted that there are municipalities where teachers receive special training, and are then legally permitted to dispense medical services.

The message of behavioral medicine is poorly understood not only by the public at large but also by health professionals. A brief overview of the activities and techniques associated with this interdisciplinary area can be found elsewhere (Mostofsky, 2012). Regrettably, there is a prevailing reluctance to entertain the possibility that chronic non-mental-health conditions and disorders can be managed by non-drug and non-surgical interventions. The contribution of behavioral medicine to treatment may be realized in many ways, not least in reducing the dependence on a "drug/medication" solution, especially when professional medical and support services are in short supply, in the classroom, or in less affluent parts of the world in general, and behavioral treatment protocols can often be taught with relative ease. Larsson, Carlsson, Fichtel, and Melin (2005) reviewed the benefits of applying behavioral interventions in school-based health treatment for recurrent headaches that can offer effective alternative treatments in children and adolescents. Dating back to the 1920s, when Edmund Jacobson developed relaxation training and suggested that teachers might be its administrators who could guide children through treatment in school, a review over 20 years concluded that 282 adolescents (aged 10–18 years) who underwent a program of a non-invasive and time-effective relaxation therapy for their headaches, within regular school settings, showed that relaxation therapy compared favorably as an effective treatment in place of the extensive policy requirements and paperwork. Furthermore, other forms of relaxation methods (such as meditative relaxation, hypnotic suggestions, and guided imagery) have been successfully used in the treatment of other chronic conditions such as asthma, allergies, epilepsy, and anxiety (Larsson, 2002). Behavioral medicine often employs exercise and physical activity as a substitute for traditional medical treatment to alleviate symptoms of chronic health conditions and a number of public health concerns including eating disorders (Basch, 2011a; Barnett, O'Loughlin, Gauvin, Paradis, & Hanley, 2006). Physical activity has an impact on all body systems, with positive influences on the brain and spinal cord, leading to emotional stability, physical health, and the ability to learn, and conversely suggests that a lack of physical activity can have a detrimental impact on academic achievement (Basch, 2011d). Many schools, under increasing pressure to raise standardized test scores of achievement, have reduced the exposure to physical education classes, despite the experimental and cross-sectional studies that have concluded that allocating *more* curricular time to physical activity programs and less time to other academics studies did not bring about negative effects on the academic performance of elementary school students (Trudeau and Shepard, 2008). Increased school-mandated physical activity can be achieved through physical education classes, structured recess and after-school activities, co-curricular physical activity opportunities, and campaigns to increase bicycling and walking to and from school (Basch, 2011c). It is also important to recognize that, although behavioral medicine may be regarded primarily as playing an adjunctive role in medical treatment, in many instances the application of behavioral strategies may constitute the treatment of choice.

There is a long history of keeping the role of the teacher separate from dealing with health issues, which are traditionally considered to be the responsibility of the school nurse and pediatrician. With the ratio of students requiring special healthcare to nurses at over 1,400:1 (over six times the suggestion of 225:1), and the number of school-aged children diagnosed with chronic illnesses increasing each year, this separation can no longer be the acceptable norm. Even among health and education professionals, research and dissemination is limited except for a select number of journals such as the *Journal of School Health*. The status quo appears to be persistent and is supported today at the local, state, and federal agency levels, as well as among the various professional societies and teacher-training programs. The result translates to an undesirable condition that works against more efficient public health goals for policy planning as well as improved service delivery, and efficient use of K-12 class time for both student and teacher. Yet, the National Center for Chronic Disease Prevention and Health Promotion (CDC, 2009) reported that chronic disease is not only the most common and costly health issue in the United States, but it is also the most preventable. Lacking in policy planning and implementation is the interdisciplinary cooperation among the various specialties in school administration and health maintenance. The teacher, social worker, and applied behavior specialist all have much to contribute to health problems that intersect, at least in part, with the interests of the separate disciplines. However, while the National Association for School Nurses (1995) recommends one nurse to every 225 special healthcare needs students, the actual ratio is closer to one nurse to 1,400 students. This results in school nurses often delegating tasks of teaching skill learning for prevention and symptom relief for selected disorders, not to mention the administration of medicine, to unlicensed personnel, potentially placing the chronically ill child in harm's way (Reutzel et al., 2008). In addition, the school nurse may help schools devise individualized care plans for students with special medical needs or train staff members to administer medication and become reasonably proficient to evaluate a school-based medical history. However much the school nurse is likely to be the main contact between the school and primary healthcare provider, the triad of involving the teacher cannot be neglected. The number of school-age children diagnosed with chronic illness has significantly increased (Brown, 1995), leaving their teachers and classroom peers insufficiently prepared to meet their special needs and ill equipped to maintain normal educational standards. For their part, parents and children with chronic illnesses predominantly see school as a "place that can help recovery, make children successful, experience friendship, and free them from diseases" (Mukherjee, Lightfoot, & Sloper, 2002).

Since the early 1970s, school-based health centers (SBHCs) have been implemented in schools to act as a bridge between education and health by addressing the individual health needs of students. SBHCs are usually located in schools or on school property, and staff an interdisciplinary team of professionals to provide accessible, quality, and culturally competent care to students. SBHCs are often the primary healthcare provider for students who are uninsured or who lack access to healthcare services. A health center may staff a combination of a nurse practitioner, physician's assistant, registered nurse, dietician, clinical psychologist, health educator, or social worker. The goal of SBHCs includes: health promotion, disease prevention, diagnosis and treatment of chronic conditions, assessment and reduction of risks, and developing a trusting relationship with students. Ideally, SBHCs will conduct interdisciplinary case reviews to track and monitor high-risk students, as this practice is especially beneficial to youth with complex mental health and health issues. And, ideally, these centers will be properly staffed to educate parents, students, and other specialists about the bio-psychosocial contributions to the development and maintenance of many biologically involved disorders. Although school-based health centers were conceived to be an ideal collaboration between healthcare providers and schools, such a partnership can be challenging. The diverse skills and backgrounds of educational and healthcare staff can have powerful outcomes when successfully paired, but the confusion of priorities between the two institutions and the competition for space, supplies, and resources can cause problems (Webb & Bannor, 2005). There are also numerous issues of professional territoriality and boundaries, aside from budgetary allocations, that have not yet been recognized as requiring revision.

In a study of 15 SBHCs operating in Cook County, Illinois, Webb and Bannor (2005) found that nurse practitioners reported their programs were doing "extremely well" in the following areas: including students, families, and school staff; defining responsibilities between the SBHC and the school; mutual respect and support for each partner's contribution; planning and implementing services and programs to promote the health of the student body; information sharing; and ensuring quality and confidentiality. The one area in which nurse practitioners reported their SBHC programs were consistently falling short was creating a collaborative focus on student academic outcomes. Of the interviewees, 64% reported that focusing on academic outcomes was difficult because academic success was not within the scope of the SBHC. More importantly, at the frontlines where teacher meets student, the uninformed teacher generally resists becoming involved in resolving problems arising from chronic, non-mental-health disorders, and fears of being transformed into a nurse's aid or medical tech. Admittedly, school district personnel face legal, financial, and administrative issues in addressing health issues of students in schools, and there has not been a sense of urgency to lobby for upgrading agency and interagency mandates or to provide for teacher unions to adjust pay scales and related considerations that are needed to meet the realities of the age where teachers must face the added pressures of dealing with frequent and complex health emergencies that can occur with children who face care needs on a daily basis (Barrett 2001). Even a rather uncomplicated answer to a recurrent quandary, concerning allowing students themselves to assume some measure of responsibility to administer their own medicinal or behavioral remedies, has never been resolved with any satisfaction. It has been noted for quite some time that only a minority of schools allow children to be responsible for their own medications for chronic illness, such as asthma inhalers, leaving the responsibility for such a critical element in dealing with a serious health issue in a confused state of finger-pointing (Bannon & Ross, 1998). Additionally, the lack of information and training results in the teacher resisting involvement in the daily care and preventative aspects of chronic illness in the classroom, but most importantly, it leaves them feeling unprepared, outside the loop, and totally unable to assist in an emergency situation. Management of chronic health issues is conceptually the responsibility of parents and health professionals, but classroom teachers report that both employers and parents expect them to manage illnesses and emergencies *in loco parentis* during school hours (Glazer 1999). Repeated surveys indicate that 20% of teachers could not recognize and/or take charge of chronic illness emergencies such as asthma or diabetes (Sexson & Madan-Swain, 1993). How much more inadequate do teachers feel with less threatening, but nonetheless disturbing, health intrusions such as headache, chronic fatigue syndrome, and sleep and eating disorders that invariably change the climate of the classroom and too often bring about non-trivial consequences to the suffering child, consequences that translate into school absences and even hospitalization, which may lead to psychosocial underdevelopment and failure to achieve academic excellence? The inability to deal with a specific medical problem can also cause teachers to become defensive and nervous, thereby isolating the child and causing damage to their self-confidence and peer relationships. Interviews of students with chronic disease or disability report that teachers who were aware of and who understood their disease were able to provide better help (Strong & Sandoval, 1999). One student's comment is particularly expressive of this belief: "The more people know, the less mistakes are made . . . ignorance is the root of all problems I've had; it is people with a lack of knowledge that have made it difficult for me" (Mukherjee et al., 2002, p. 63). In all schools, regardless of socioeconomic status, classrooms are often the first settings where chronic illness can be detected. All too often, the expression of the disorder (or a side effect of medications that have been prescribed) is masked as inattention, lack of motivation, fatigue, or multiple absences, and these symptoms of chronic illness can impede student success if left undiagnosed. Not infrequently, the failure to recognize such symptoms as possible links to a chronic disorder go undiagnosed, and the unfortunate student will suffer academically, psychologically, and physically. Since most children attend school, the school setting is an important location for detection, treatment, support, and assistance to the chronically ill child (Mandali & Gordon, 2009). It is essential that teachers be trained to recognize when urgent medical care is needed, how to access the necessary care, and how to handle emergency situations when they arise; this is even more important in the case of chronically ill students, whose medical treatment may often be complicated (Emergency Medical Services for Children, 2000). Some chronic illnesses are less visible in daily life than others, causing teachers who are unaware of the illness status to distrust the pain of the child and force them to participate in activities that can only aggravate the condition (Mukherjee, Lightfoot, Wright, & Sloper, 2000). We are told that three out of four classroom teachers are unprepared to teach students with chronic diseases, and that teachers express a need for practical information regarding warning signs of illness, information about the impact on development and classroom instruction, and information about incorporating students into the classroom (Duggan, Medway, & Bunke, 2004). The lack of knowledge and feeling of helplessness experienced by untrained teachers when faced with a classroom emergency contributes to heightened anxiety (Stainback & Stainback, 1996).

Many medical issues (e.g., seizures, headaches, pain, etc.) or public health concerns (e.g., obesity) share fuzzy boundaries with education, despite local and national policies intending to take notice of their importance in discussions on student health. The Americans with Disabilities Act (ADA) prevents discrimination on the basis of special needs, and also requires support for the student through individualized management plans (Section 504) for the disease during school enrollment. Regrettably, the efforts to publicize and educate teachers and students about such conditions deserve to be strengthened significantly, along with constructive direction for coping with symptoms when they invade the classroom. Even when instructions from government and health agencies exist, these recommendations do not reliably reach school personnel. For example, at least one study concluded that, in 50% of the schools, less than half the administrative personnel surveyed had read the well-prepared guide *Supporting Pupils with Medical Needs* (published by the Department of Health and Department of Education and Skills in England, 1996), and one-third of the personnel at these schools were unaware that the document even existed (Wong, Awolowo, Gordon, & Mo, 2004). School personnel are not always aware that chronic conditions such as diabetes or asthma are included under the ADA, a gap in knowledge that ultimately leaves teachers to confront crisis situations in chronic health conditions with little or inadequate training. This lack of knowledge and support may have negative consequences, such as for students with poor diabetic control who may be at risk to develop hearing complications, peripheral nerve function loss, and other serious dysfunctions (Mandali & Gordon, 2009). In a study of 161 Australian parents of children with chronic conditions, half of them stated that they did not think teachers had the knowledge or skill to provide adequate care to their children (Notaras et al., 2002).

There is a present need for curriculum reform, especially to bring to the attention of the teacher-training institutions that the school administrator, school nurse, and school social worker need to be better informed about the nature of chronic disorders and about the myths and realities surrounding many of these chronic conditions, and their respective impact on the students. It should be emphasized that, although such conditions of ill health are serious, they do not preclude the assignment of such children to an otherwise “normal” classroom. An effective educational program for staff of all stripes should include: (a) education/information about the myths and realities of the respective disorder, and the prominent manifestations and recognition of the respective symptoms of the disorder; (b) the important distinctions among diseases, illnesses, and predicaments, as summarized in Mostofsky

(1981); (c) the utility of behavioral intervention strategies; (d) the acquisition of basic skill training for the teacher in applications of biofeedback, behavior therapy, relaxation therapy, and hypnosis techniques for providing symptom relief; and (e) familiarity with available local resources for the purposes of gaining more expertise, and for referral to medical service providers.

Education and Public Health: Helping Classroom Teachers Close the Gap

In 2008, Reutzel and colleagues conducted educational programs at 15 schools for all school personnel, addressing depression and/or ADHD in the classroom. Clinical pharmacists and mental health therapists from a local biomedical university developed and presented a 1-hour mini-in-service program using audiovisual media. They first provided background on the disease state of interest, including epidemiological data, diagnostic criteria, symptoms, non-drug treatment options, and potential interventions by school personnel. The clinical pharmacist then described drug therapy options, explaining drug type, duration, food and drug interactions, and potential side effects. Feedback from these sessions found that school personnel requested that the presentations be longer, demonstrating the need and perceived benefit of the program interventions. Additional feedback found that school personnel felt they needed more training on how to deal with these and other health issues that are present in the school setting. Based on cognitive measures, it was found that the program increased knowledge, awareness, and confidence levels about dealing with problems arising from the symptoms of the disorder as well as from the pharmacotherapy used in treatment. Perhaps most important to addressing health in the classroom is that a clear policy understood and accepted by staff, parents, and pupils must be developed to create a sound basis for ensuring that children with medical needs receive proper care and support at school.

The overall goal of a proposed multi-day workshop is to improve the knowledge of teachers, administrators, nurses, and other school staff working with student health issues which impact learning. This should be done by incorporating pediatric physician specialists to share with other non-medically-trained professionals the perspective and priorities of the physician when confronting the particular medical condition, including but not limited to the detection of warning signs, consequences of treatment neglect, and willful, accidental, and psychosocial contributions to non-compliance.

A representative outline for a proposed 4-day program would include instructions for detecting warning signs and to whom to report such information, while the physician's lecture should present an exposition of the fundamental medical problem; the consequences of treatment neglect (whether willful, accidental, or via non-adherence or poverty); and the side effects of traditional medical procedures (iatrogenic factors). Such a presentation would be followed by a discussion of behavior options for treatment, assessment, and prospects for longer-term management, accompanied by examples suited for classroom application as treatment or intervention. The workshop would emphasize how it can offer an organized framework for collecting local census data and suggestions for promoting collaborations within the health and education agencies at local, state, and national levels. Assuming a 4-day workshop, the allocation of subjects to be covered would be designed to track a daily (morning and afternoon) course of topics, such as: [Day 1] migraine; rheumatisms/arthritis; diabetes; recurrent abdominal pain; seizures; [Day 2] chronic fatigue; asthma; Tourette syndrome; obesity; sleep; [Day 3] adherence/compliance (including medications; insulin injection; proper use of inhalants; nutrition; crisis prevention; and avoidance of triggers); [Day 4] available behavioral technologies: behavior modification; biofeedback; hypnosis; CBT with adequate time to integrate psychological aspects of chronic disorders, such as academic performance, cognitive deficits; social skills improvement; stress and coping; dealing with missed school days; ethnic and cultural factors; and interpersonal relations and attitudes, as well as how the teacher needs to communicate with medical specialists and community agencies.

The Importance of the Classroom Setting

The classroom has entered the world of partnership with medicine owing to increases in the number of children lacking consistent, adequate medical care, thereby making the classroom an important source for initiating awareness, proactive intervention, and the road to medical treatment through a school nurse, school administrator, or social worker. A teacher should be able to inform the school personnel of a potential chronic disorder that might otherwise go unreported. The teacher can impact the formulation of local, regional, and wider public health policies and facilitate creating an infrastructure for systematically gathering health census information. Three of the most common school-based medical emergencies are: breathing difficulty (obstructed airway or asthma), choking, and seizures – emergencies about which teachers need to be informed how to promptly and appropriately respond (Knight, Vernon, Fines, & Dean, 1999).

An excellent guide prepared by the Department of Health and Department of Education and Skills in England, *Supporting Pupils with Medical Needs*, provides a superb model for developing print materials for educational settings for teachers with students having medical needs and requiring extra attention, and developing awareness of the cost of academic consequences suffered by a student with a chronic disorder that can impair the motivation and ability to learn, such as sensory perceptions, cognition, connectedness and engagement with school, absenteeism, and dropping out (Basch, 2011b).

Such deficiencies may arise from organic aspects of the disorder, or from secondary effects of the disorder's symptoms or medications affecting attention, cognitive function, sleep deficiency, or pain and discomfort requiring hospitalizations or repeated clinic visits. A summary of the known impacts on learning in a handful of childhood health conditions and their typical treatment trajectories can be found in Figure 45.1 (Thies, 1999). The number of students with chronic illness falling

The Impact on Learning of Selected Childhood Health Conditions

Condition	Disease Process or Treatment	Impact on Learning
Pulmonary conditions (eg. asthma, cystic fibrosis)	oral steroids (eg, Prednisone)	depressed mood, anxiety, difficulty with memory
	long-term use of steroids	impaired sight, cataracts
	aminoglycosides (eg, Streptomycin)	impaired hearing
	theophylline (caffeine-like)	feel “wired,” impaired attention
	poor oxygen perfusion	fatigue, confusion
Diabetes	chronic hypoglycemia (low blood sugar)	impaired planning tasks visual scanning/reading (esp. if diagnosed before age 6) difficulty attending to detail slower response time
	acute hypoglycemia	fatigue, confusion
	chronic hyperglycemia (high blood sugar)	impaired spatial abilities, eye damage
Leukemia	radiation of central nervous system	impaired attention, short-term memory, visuomotor coordination, information processing
Other cancers	chemotherapy	fatigue, risk for infection, school phobia
Arthritis	oral steroids (eg, Prednisone)	depressed mood, anxiety, difficulty with memory
	long-term use of steroids, swollen, stiff joints	impaired sight, cataracts, difficulty with fine motor tasks, eg, writing, hands-on projects, typing, difficulty walking to class, sitting/standing
	pain/pain medications	impaired concentration
Gastro-intestinal illnesses (eg, Chron’s disease, CF)	oral steroids (eg, Prednisone)	depressed mood, anxiety, difficulty with memory
	long-term use of steroids	impaired sight, cataracts
	poor nutritional status, diarrhea	fatigue, impaired concentration
AIDS	opportunistic infections of the central nervous system	impaired short-term memory, loss of previous abilities, eg, reading, dementia
	brain abscesses, focal tumors	depends on area of brain, age of child
Sickle cell anemia	low hemoglobin, poor oxygen diffusion	fatigue, impaired concentration, neuropsych deficits

Note: In general, conditions and treatments that affect the central nervous system and brain may have neurocognitive/neuropsychiatric implications such as impaired visual scanning, spatial abilities, attention, and memory. These impairements in turn have implications for development of many academic skills such as reading, math, and planning/problem-solving tasks. Some impairments may develop over time and are not reversible, eg, damage to sight, hearing, and cognitive processing. Some impairments may be associated with acute exacerbation of disease, eg, feeling “wired” on Prednisone. Fatigue and pain, often major factors in chronic illness, undermine concentration, stamina, and ultimately, motivation.

Figure 45.1 The impact on learning of selected childhood health conditions. Reproduced from Thies (1999) with permission from John Wiley & Sons, Ltd.

behind in their schoolwork, leading them to dislike school, with the inevitable consequences of jeopardizing academic performance or missing a fourth of their total classes, if not more (Gunnar, 1998; Jimmerson et al., 2007; Lynch, Lewis, & Murphy 1993), is hardly insignificant. Factors secondary to the physical disease, such as the parents' education levels, ability to participate in physical activities, and the response of the family and child to disease, are additional complicating factors that must be addressed, often in collaboration with the school social worker (Cook, Schaller, & Krisher, 1985). The separate disorders are commonly associated with their own secondary consequences, such as children under the age of 5 years with diabetes experiencing a heightened difficulty with schoolwork (Brown, 1995); children with cancer having reduced capability of fine motor exercises, eyesight and exercise coordination, and quantitative techniques (Peckham, Meadows, Bartel, & Marrero, 1988); and asthmatic children having decreased studying ability due to complications and problems from illness and treatment (Bender, 1999). On the other hand, Bonner, Gustafson, Schumacher, and Thompson (1999) reported that children adapting well psychologically to school had higher attendance rates than those showing difficulty adapting.

The impact of the presence of such a student on the other students in the class may affect socialization, self-image, and classroom participation, and further complicate the school life of such children by causing long-term absences, diminishing academic performance because of a reduced ability to study or complete assignments, and posing difficulties in relating to peers and teachers (Mukherjee et al., 2000). School-age children recently diagnosed with a chronic disease report discomfort and fear about having to explain their illness to peers and cope with ridicule regarding their change in appearance (Sexson & Madan-Swain, 1993). Not to be lightly disregarded is the social isolation attributable to the chronic disorder and the accompanying excessive curiosity of peers regarding the disease, as well as misunderstandings regarding infectiousness. These factors make it even more difficult for chronically ill children to make new friends; such children are often additionally victimized by receiving more than three times the amount of verbal and physical violence than do children without diseases (Lähteenmäki, Huostila, Hinkka, & Salami, 2002).

Impairment of the Optimal Performance of the Teacher with Such a Student in the Classroom

Special treatment from teachers can cause issues and resentment in peer relationships, as application of different rules can be misconstrued as favoritism (Lightfoot, Wright, & Sloper, 1999). While students with chronic diseases usually have the capacity to be successful in school, assisting these students in learning requires teachers to take on additional responsibilities of disease management, specialized care, and instruction. In fact, Bessel (2001) found that school-age children diagnosed with cancer reported teachers as the most important variable impacting their school experience. Teachers worry that the chronically ill child will affect others, which makes it difficult for the sick child to adjust to school life. This creates confusion about whether the teacher should overprotect the children with low expectations or treat them with indifference, and causes additional worry about not devoting enough time to the other children (Sexson & Madan-Swain, 1993). Duggan, Medway, and Bunke (2004) found that three out of four teachers are unprepared to teach students with chronic diseases, and that teachers express a need for practical information regarding warning signs of illness, information about the impact on development and classroom instruction, and information about incorporating students into the classroom.

Effective educational and public healthcare approaches to chronic illness in the classroom should be tailored to the unique needs of each child and sensitive to condition-specific barriers. In a guide for families, schools, and students, the National Heart, Lung, and Blood Institute suggests that school districts be responsible for developing and implementing district-wide guidelines and protocols for general chronic illness and specific plans for asthma, allergies, diabetes, epilepsy, and other common chronic illnesses. Condition-specific protocols, while ideal, might not be the most realistic next step for the education system in America, given the thousands of different chronic conditions. An alternative approach, proposed by Forrest, Bevans, Riley, Crespo, and Louis, (2011), is to use a non-categorical method of identifying students as having a "special healthcare need" (SHCN) in school-based health policy and programs. Students considered to have SHCN would include those with long-term physical, behavioral, emotional, and developmental disorders that require medication and medical/educational services. According to the 2003 National Survey of Children's Health, up to 20% of children aged 6–17 years are considered to have an SHCN (Bethell, Read, Blumberg, & Newacheck, 2008). Children with SHCN often face significant challenges while attempting to be successful at school. Learning challenges or behaviors can be confusing to classmates and teachers, especially if they require additional instructional or medical support. If such support is lacking, children can feel socially isolated and lose interest in achieving academic success, which over time can increase the risk for skill deficit and student disengagement (Forrest et al., 2011). Project Healthy Pathways, a study of 34 schools in Maryland and West Virginia, explored the association of having an SHCN and school outcomes in fourth-through sixth-grade students (aged 9–11 years). In 34 schools, 33% of fourth-through sixth-grade students screened positive for an SHCN. Students with functional limitations had an increased risk for less engagement with school, more exposure to bullying, more behaviors that threaten social competence, and overall lower academic achievement. Not only is this a threat to their well-being as school-age children, but is also associated with a diminished future flourishing as adults. However, children who had a chronic illness that only required the administration of a prescription medication while at school, obese children, and those with asthma had similar school outcomes to students with a SHCN. Therefore, chronic disorders do not necessarily affect school performance; instead, it seems that students with a functional limitation as a result of a chronic illness are at the highest risk for poor school achievement. An advantage to using a non-categorical approach is its simplicity and practicality, allowing screening to be done in any setting. It also alleviates the reliance on parents to report specific diagnostic labels to school personnel. Parents can be administered the Children With Special Health Care Needs (CSHCN) screener (Figure 45.2), which is a non-categorical measure of long-term health issues that require specialized health services or cause functional limitations (Bethell et al., 2002). Students are considered "positive" for an SHCN if they have a condition lasting at least a year and if they have at least one of the following: a requirement for additional medical, mental health, or educational support than most children of the same age; are currently using medication prescribed by a doctor; are limited in their ability to do things most children of the same age can do; need or receive special therapy; or have any kind of emotional, behavioral, or developmental problem requiring treatment or counseling.

Future Directions

Children with chronic illness face a unique set of difficulties in school due to their medical, psychological, and social impairments. School is a place where chronically ill children can reach academic, psychological, and social success if administrators, social workers, nurses, and most importantly, teachers, are properly trained to deal with these stressors and challenges. However, no matter how prepared teachers and staff are to assist students with health concerns, educational success will be significantly diminished if students are not motivated and able to learn. According to Basch (2011a), health-related problems may play a major role in limiting both motivation and ability to learn in youth, highlighting the need for interventions that address these specific problems.

School is one of the most important environments for promoting the growth and development of a child, and experiences had at school can often be the most meaningful (Davis, 1989). However obvious it may appear, it is well to remember that *healthier students are better learners* (Basch, 2011a). Coordinated, organized school health programs are needed to eliminate the challenges faced by students with health concerns through *disease detection, prevention, and treatment* for school-age children while *optimizing learning and development for all.* Teacher workshops can serve as an effective template for improving educational standards for addressing chronic illness in the classroom if implemented nationally. Bannon and Ross (1998) also suggest that schools should draw up internal policies and protocols to support children with medical needs, including devising individual healthcare plans for chronically ill children; planning the administration and storage of drugs; making all staff aware of the child's medical needs; involving the students, parents, medical caregivers, and teachers in making individual care plans; and encouraging teachers who seek further training in implementing behavioral interventions to volunteer for such continuing education. A sample healthcare plan template is shown in Figures 45.3 and 45.4 (taken from *Supporting Pupils with Medical Needs*).

All 3 Parts of at Least One Screener Question (or, in the case of question 5, the 2 parts) Must Be Answered "Yes" In Order for a Child to Meet CSHCN Screener Criteria for Having a Special Health Care Need.

1. Does your child currently need or use medicine prescribed by a doctor (other than vitamins)?
   - ☐ Yes → Go to Question 1a
   - ☐ No → Go to Question 2

   1a. Is this because of ANY medical, behavioral, or other health condition?
   - ☐ Yes → Go to Question 1b
   - ☐ No → Go to Question 2

   1b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

2. Does your child need or use more medical care, mental health, or educational services than is usual for most children of the same age?
   - ☐ Yes → Go to Question 2a
   - ☐ No → Go to Question 3

   2a. Is this because of ANY medical, behavioral, or other health condition?
   - ☐ Yes → Go to Question 2b
   - ☐ No → Go to Question 3

   2b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

3. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?
   - ☐ Yes → Go to Question 3a
   - ☐ No → Go to Question 4

   3a. Is this because of ANY medical, behavioral, or other health condition?
   - ☐ Yes → Go to Question 3b
   - ☐ No → Go to Question 4

   3b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

4. Does your child need or receive **special therapy**, such as physical, occupational, or speech therapy?
   - ☐ Yes → Go to Question 4a
   - ☐ No → Go to Question 5

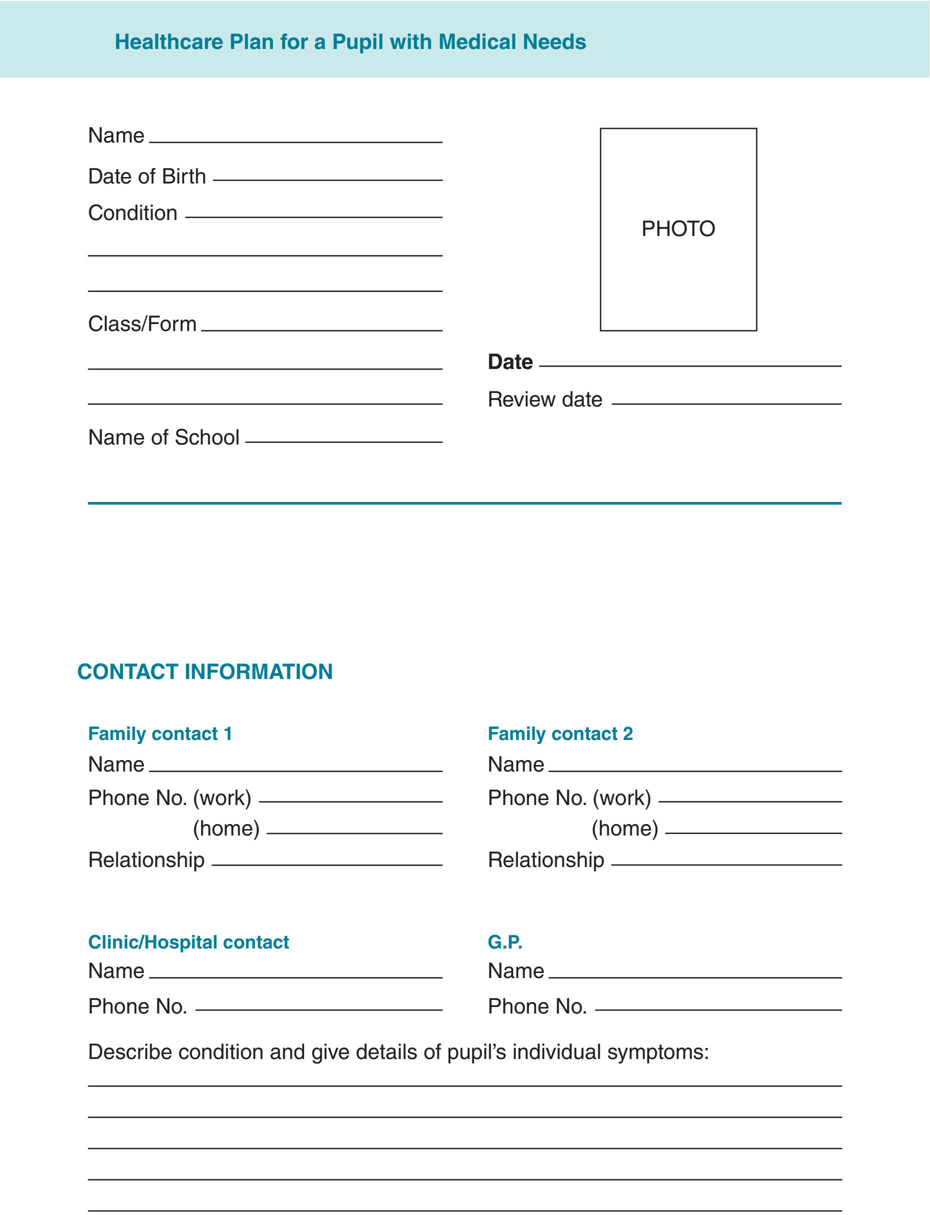
   4a. Is this because of ANY medical, behavioral, or other health condition?
   - ☐ Yes → Go to Question 4b
   - ☐ No → Go to Question 5

   4b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

5. Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or receives **treatment or counseling**?
   - ☐ Yes → Go to Question 5a
   - ☐ No

   5a. Has this problem lasted or is it expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

Figure 45.2 Children with Special Health Care Needs (CSHCN) screener.



Healthcare Plan for a Pupil with Medical Needs

Name ______________________

Date of Birth ______________________

Condition ______________________

____

____

Class/Form ______________________

____

____

Name of School ______________________

PHOTO

Date ______________________

Review date ______________________

CONTACT INFORMATION

Family contact 1

Name ______________________

Phone No. (work) ______________________

(home) ______________________

Relationship ______________________

Family contact 2

Name ______________________

Phone No. (work) ______________________

(home) ______________________

Relationship ______________________

Clinic/Hospital contact

Name ______________________

Phone No. ______________________

G.P.

Name ______________________

Phone No. ______________________

Describe condition and give details of pupil's individual symptoms:

____

____

____

____

____

Figure 45.3 Healthcare plan for a pupil with medical needs.

Daily care requirements: (e.g. before sport/at lunchtime)

Describe what constitutes an emergency for the pupil, and the action to take if this occurs:

Follow up care:

Who is responsible in an Emergency: (state if different on off-site activities)

Form copied to:

Figure 45.4 Healthcare plan for a pupil with medical needs, page 2.

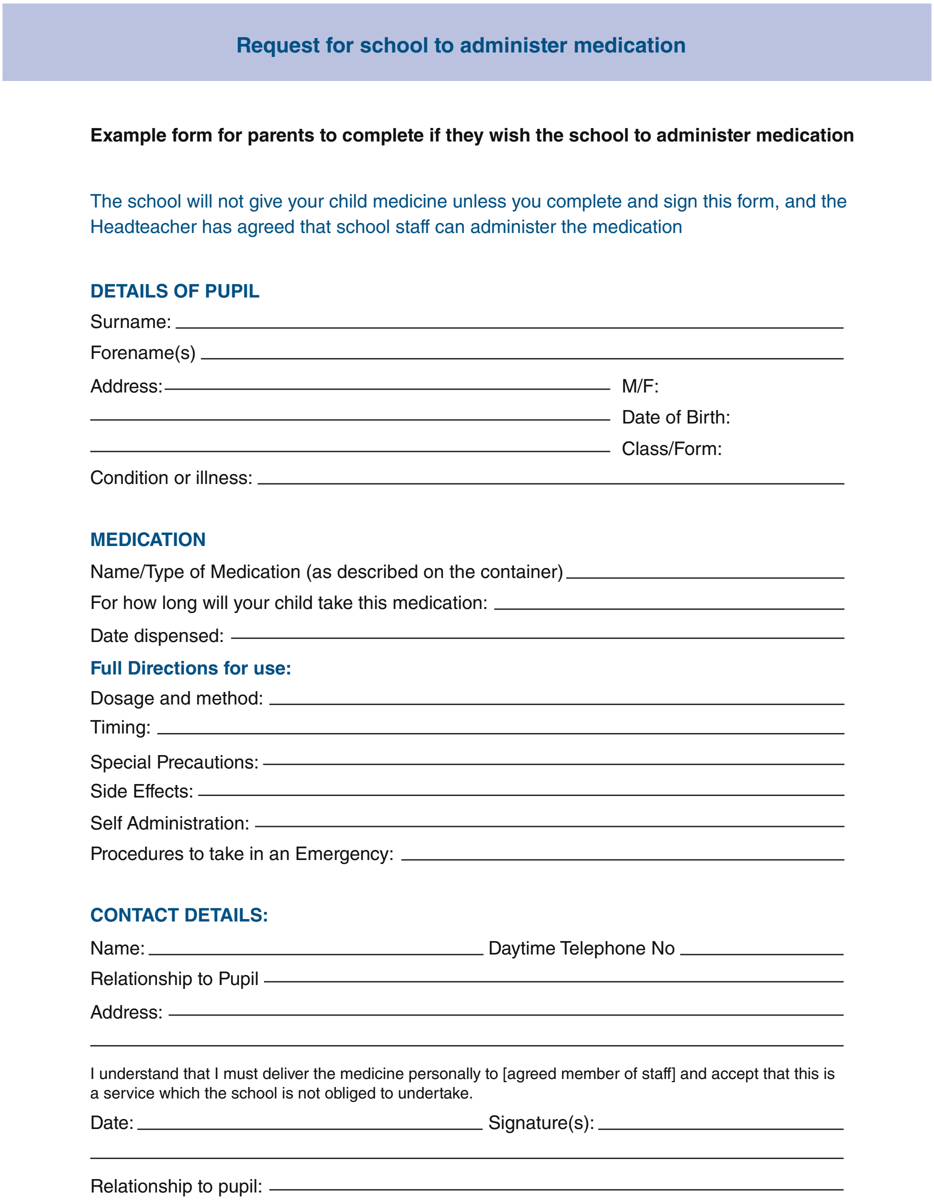
Planning should also allow provision to address the gap between healthcare reform, behavioral medicine, and public school training and the need to focus on the important role of *communication* within the student's medical support system. Barrett (2001) suggests that the anxiety of teachers about dealing with health emergencies can be decreased through collaboration with a multidisciplinary team, including the parents, system consultants, health professionals, specialized equipment technicians, student peers, and the children.

Within the school An effective structured method is needed for documenting symptoms of suspected chronic disorders, medical management in the classroom, psychological triggers and vulnerabilities, and effective reward/punishment. This needs to be accessible to the teacher, social worker, nurse, and appropriate administrators. Frieman and Settel (1994) found that teachers need an in-depth understanding of the disease process, medical management, and classroom integration to assist chronically ill children daily. Students with chronic conditions will often need to take medication at some point during the school day. Schools need an internal system of determining who will administer the medication (the students themselves, the school nurse, a teacher, etc.), and how to track medication history. A possible suggestion, taken from *Supporting Pupils with Medical Needs*, is to have parents and/or the primary healthcare provider submit a written request for the school to administer medication (Figure 45.5).

For the schools records, having a written record of medicine administration is suggested (DfEE, 1996; Figure 45.6).

Parents Parents play one of the most important roles in managing chronic illness. Some parents will know how to treat and assist the already-diagnosed chronically ill student at home to ensure psychological, physical, and academic success, and school officials need to maintain communication with these parents to keep both the school and the parent informed of any changes. Other situations may arise in which the chronic illness is first detected in the classroom, leaving the parents unaware of their child's special needs. In this instance, teachers and other school officials need to act as educators to the parents and direct them toward appropriate community resources to treat the child effectively. Lastly, if the child is without consistent parental support to manage his or her disease, school officials need a method of communication with the appropriate state agencies (Child Welfare or Child Protective Services) for investigation and supervision to ensure the well-being of the chronically ill child.

Medical team With documented HIPAA consent, public schools need to maintain communication with the medical team responsible for a student's care to ensure both parties have the most up-to-date information regarding the physical and psychological status of the student. Without this information, teachers are unable to share their findings and observations with the medical team, and the treating doctor is unable to update the teacher on new symptoms, treatment side effects, or a change



Request for school to administer medication

Example form for parents to complete if they wish the school to administer medication

The school will not give your child medicine unless you complete and sign this form, and the Headteacher has agreed that school staff can administer the medication

DETAILS OF PUPIL

Surname:

Forename(s)

Address:

M/F:

Date of Birth:

Class/Form:

Condition or illness:

MEDICATION

Name/Type of Medication (as described on the container)

For how long will your child take this medication:

Date dispensed:

Full Directions for use:

Dosage and method:

Timing:

Special Precautions:

Side Effects:

Self Administration:

Procedures to take in an Emergency:

CONTACT DETAILS:

Name: Daytime Telephone No

Relationship to Pupil

Address:

I understand that I must deliver the medicine personally to [agreed member of staff] and accept that this is a service which the school is not obliged to undertake.

Date: Signature(s):

Relationship to pupil:

Figure 45.5 Request for school to administer medication.

in illness severity. Ideally, the parents would act as the coordinators in transmitting this information. According to Thies (1999), unlike health records, school health records can be an invaluable source of information regarding not only the specific diagnoses, but also potential effects of medication, treatments, and impacts on academic performance.

Request of medication administered in school

Example form for schools to record details of medication given to pupils

Date	Pupil's Name	Time	Name of Medication	Dose given	Any Reactions	Signature of Staff	Print Name

Figure 45.6 Record of medication administered in school.

Local health department/agency Schools need to report the frequency of newly diagnosed chronic illnesses to their local health agencies. This communication is extremely important, because it informs the local governance of the need for more community resources, jobs, or education initiatives to support their specific needs. In addition, stronger and more thorough school health policies that promote student health and academic achievement are needed at the federal, state, and local levels (Basch, 2011c).

Clearly, a structured method of documentation is needed for the school, parents, and treating medical team to ensure student success in the face of chronic illness. When information is shared effectively, students with chronic diseases are no longer victims of unprepared, overwhelmed, or uninformed support systems. Future workshops and trials are needed to explore and establish the most efficient method of communication to ensure children with chronic illness are no longer overlooked by the education system. Mukherjee and colleagues (2000) identified the two key areas that teachers and parents reported as needing additional support: obtaining health-related information and providing medical care in school. Specifically, teachers explained that they needed professional medical advice about the implications of the condition on school performance, and they preferred to have easier access to both this information and to medical professionals for support. Teachers seem to be unclear on their role in providing medical care and unsure of how to handle medical emergencies that occur in school.

In arguing that "healthier students are better learners," Basch (2011c) emphasizes the importance for federal, state, and local governments to eliminate health-related barriers to school performance by ensuring that schools address health goals in mandated school improvement plans; making schools accountable for their ongoing participation in health policies and programs; facilitating a continual process to create, implement, and sustain an effective, strategically planned, and high-quality school health program by requiring the establishment of school-based health leadership teams; requiring a substantial amount of curricular time to be devoted to health education and promotion, with a specific focus on helping youth learn and implement developmentally appropriate social emotional skills that can reduce the risk of health-compromising behaviors; adopting policies to address educationally relevant health issues (e.g., vision problems, asthma, etc.); and addressing additional critical health needs by promoting health on the school grounds (e.g., prohibiting all tobacco use on school grounds). Although many schools in the United States have attempted to provide some health services and programs, the quality and effectiveness vary greatly. Until school health becomes a central component of the fundamental mission of schools in the United States, the potential for schools to offer effective health-based interventions to promote academic achievement is diminished. According to the National Heart, Lung, and Blood Institute, chronic illnesses affect at least 10–15% of school-age children. In order to effectively respond to the special needs and unique barriers that these children face, a coordinated, systematic, and comprehensive approach is needed. Despite the undeniable evidence presented in this chapter that health and academic achievement are interrelated, the US Department of Education still has not developed a national initiative to reduce health-related road blocks to learning. Fortunately, other leading educational professional organizations such as the National Association of State Boards of Education, National School Boards Associations, Council of Chief State School Officers, American Academy of Pediatrics and National Association of School

Nurses, and the Centers for Disease Control and Prevention have begun proposing policies and guidelines to target health-related concerns in schools (Basch, 2011b). There are sufficient ideas on the table that await translation into action. There is sufficient supportive data to encourage the integration of behavioral medicine in the multidisciplinary approach to control the educational, social, and medical impact that too often accompanies the school-aged youngster with a chronic health disorder.

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46

The Salutogenic Framework for Health Promotion and Disease Prevention

Monica Eriksson

Introduction

"It [salutogenesis] is on the leading edge of a class of academic movements that wish to emphasize human strengths and not just weaknesses, human capacities and not just limits, well-being and not just illness" (Maurice Mittelmark, professor and immediate past president of the International Union for Health Promotion and Education [IUHPE], 2008).

The aim of this chapter is to introduce, update, and provide a deeper understanding of the salutogenic framework for health, including the key concepts of the sense of coherence (SOC) and the generalized resistance resources (GRR). An extensive review is undertaken by the author. The theory explains how people under stress can cope and stay well, which becomes an important contribution to health promotion and public health research. Aaron Antonovsky was professor of medical sociology and chairman of the department of the sociology of health at Ben Gurion University of the Negev, Beersheba, Israel. He studied history and economics, interrupted by service in the US Army during World War II. He was awarded a PhD in sociology in 1955. He was the research director of the New York State Commission Against Discrimination, and served as professor of sociology at the University of Tehran (1959–1960). His research interest initially was on studies of multiple sclerosis and coronary diseases, that is, pathogenesis. Another interest was preventive oral health behaviors. Furthermore, he carried out research into social class and health. Being involved in a large-scale study of ethnic differences in adjusting to problems of menopause, he found out something different: how some people stay well and others do not under the same circumstances. How do we manage to

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stay healthy? More than 30 years have passed since Antonovsky introduced the salutogenic framework for health to the scientific world (Antonovsky, 1979). The origin of salutogenesis derives from interviews of Israeli women with experiences from the concentration camps of World War II who, in spite of this hardship, remained healthy. His fundamental contribution to health research was to raise the philosophical question of what creates health and search for "the origin of health" rather than to look for the causes of disease. According to the original idea, it was more important to focus on people's resources and capacity to create health than the classic focus on risks, ill health, and disease.

Antonovsky clearly stated that salutogenesis was not limited by the disciplinary borders of one profession; rather, it was an interdisciplinary approach that involved bringing an SOC between disciplines and understanding what connects them. Furthermore, it is not only a question of the individual but an interaction between people and the structures of society, that is, the human resources and the conditions under which people live their lives. Over the years, the salutogenic framework has become a relatively well-established concept in public health and health promotion. There are now more than 1,300 articles on the topic available in the established databases of public health (Eriksson, Sagy, & Lindström, 2012). However, there is an apparent need to provide a more comprehensive understanding of this extensive research in areas such as medicine/psychiatry/psychology, public health/health science, sociology, nursing, social work, and education.

Salutogenesis in the Context of Health Promotion

The central document of health promotion, the Ottawa Charter, was the result of discussions held at an international health conference in Ottawa in 1986 (WHO, 1986). At the heart of the Ottawa Charter, health promotion was seen as a process enabling people to develop good health through empowerment, thereby giving them the opportunity to lead a good life. Policies leading to a healthy society became central, thus expanding the focus from individuals and groups to the wider social context. Twenty years after this document, the IUHPE asked some of the key actors involved in the development and implementation of the Ottawa Charter to comment on the development of health promotion over the past 20 years (IUHPE, 2007; Hills & McQueen, 2007).

Is it at all possible to manage the impact of global challenges on our everyday life without stress? This issue can be approached from a philosophical point of view exploring theories enhancing health. The biomedical approach where health is generated through the elimination of risks for diseases is the dominating paradigm at present. The salutogenic approach, however, focuses on resources for health and health-promoting processes. The philosophy behind the salutogenic theory harmonizes well with the essence of the Ottawa Charter.

However, the full potential of the salutogenic theory has not been exploited as much as expected in spite of the theoretical similarities. Health promotion research

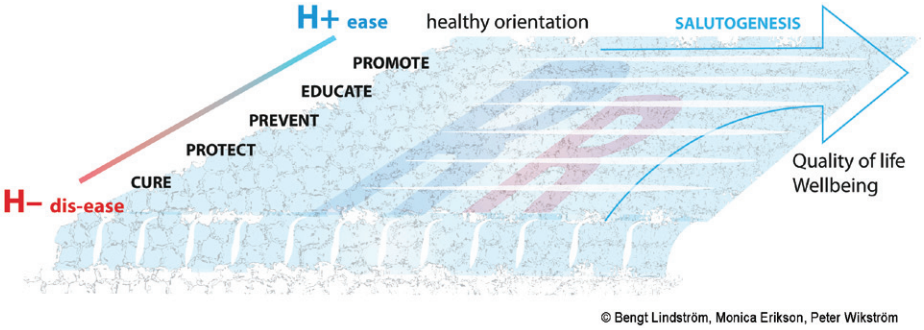

Figure 46.1 Health in the river of life (Lindström & Eriksson, 2010).

is mainly based on theories of organizational behavior, sociology, social psychology, psychology, anthropology, education, economics, and the political sciences. Much of this research has been limited to health-related behavior (Dean, 1996). The diversity of disciplines reflects the fact that health promotion practice is not only concerned with the behavior of individuals but also with the ways in which society is organized and the policies that underpin social organization (Nutbeam & Harris, 2010). Many scientists have used the river as a metaphor for explaining health. In the preface to the Swedish translation of Antonovsky's second book *Unraveling the Mystery of Health*, Professor Lennart Levi expressed that "it is not enough to promote health by avoiding stress or by building bridges so that people do not fall into the river. Instead, people have to learn to swim in the river of life." Salutogenesis in the context of health promotion is here figuratively explained by Figure 46.1.

Health as a Process

According to Antonovsky, health was seen as a movement in a continuum on an axis between total ill health (dis-ease) and total health (ease). It is a continuous movement, meaning that, even if we are affected by diseases, we can, to some extent, still be healthy. Moreover, the health ease/dis-ease continuum challenges the existence of a dichotomy between health and disease.

The ability to comprehend the whole situation and the capacity to use the resources available was called the SOC. This capacity was a combination of people's ability to assess and understand the situation they were in, to find a meaning to move in a health-promoting direction, and also having the capacity to do so – that is, comprehensibility, meaningfulness, and manageability, to use Antonovsky's own terms. Antonovsky distinctly stated that salutogenesis was not limited by the disciplinary borders of one profession but was rather an interdisciplinary approach and a question of bringing coherence between disciplines. Furthermore, it is not only

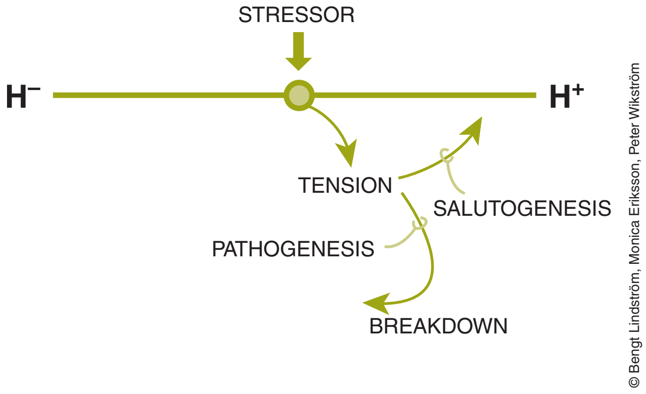

Figure 46.2 The health continuum (the ease/dis-ease continuum), modified after Lindström and Eriksson (2010).

a question of the person but an interaction between people and the structures of society – that is, the human resources and the conditions under which people lead their lives.

Salutogenesis, the origin of health, is a stress-resource-orientated concept that focuses on resources and maintains and improves the movement toward health. It gives the answer why people, despite stressful situations and hardships, generally stay well. The theory can be applied at an individual, a group, and a societal level. It is the opposite of the pathogenic concept where the focus is on the obstacles and deficits. The SOC is a life orientation, a way of viewing the world as comprehensible, manageable, and meaningful (Antonovsky, 1987). It is defined as "a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement" (Antonovsky 1987, p. 19). A crucial element in the salutogenic orientation is to view stimuli as challenges, not as threats leading to breakdown, to view challenges as being a natural part of everyday life (Antonovsky, 1985).

In a review of major worldviews, Koltko-Rivera describes several approaches during the twentieth century, referring to philosophy, anthropology, and subdisciplines of psychology (Koltko-Rivera, 2004). According to Koltko-Rivera, a worldview is defined as ". . . a way of describing the universe and life within it, both in terms of what is and what ought to be. A given worldview is a set of beliefs that includes limiting statements and assumptions regarding what exists and what does not. . . . A worldview defines what can be known or done in the world, and how it can be known or done. . . . What goals can be sought in life . . . defines what goals should be pursued" (Koltko-Rivera, 2004, p. 4). Somewhat surprisingly, bearing in mind this extensive overview of worldviews, Koltko-Rivera has failed to find the life orientation concept, sense of coherence.

The sense of coherence

The SOC reflects a person's view of life and capacity to respond to stressful situations. It is a global orientation that views life as structured, manageable, and meaningful or coherent. It is a personal way of thinking, being, and acting, with an inner trust that leads people to identify, benefit, use, and re-use the resources at their disposal. The SOC consists of three elements, namely, comprehensibility, manageability, and meaningfulness. The original definition by Antonovsky ran thus: "a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement" (Antonovsky, 1979, p. 19).

Comprehensibility refers to the extent to which you perceive the stimuli that confront you, deriving from the internal and external environments, as making cognitive sense as information that is ordered, consistent, structured, and clear. The person scoring high on the sense of comprehensibility expects that stimuli they encounter in the future will be predictable, ordered, and explicit. This is the cognitive component of the SOC.

Manageability is the extent to which a person perceives that resources are at his or her disposal that are adequate to meet the demands posed by the stimuli that bombard them. "At a person's disposal" refers to resources under the person's own control or to resources controlled by legitimate others. This is the instrumental/behavioral component of the SOC. Meaningfulness refers to the extent to which a person feels that life makes sense emotionally, and that problems and demands are worth investing energy in, are worthy of commitment and engagement, and are seen as challenges rather than burdens. This is the motivational component of the SOC.

Generalized resistance resources

The second key factors are the resources available to make such a movement possible. Antonovsky used the term *general resistance resources* (GRRs) for those resources that could be found within people as resources bound to their person and capacity, but also to their immediate and distant environment, as of both material and non-material qualities. The key factor is not what is available but the ability to use and re-use them for the intended purpose. The GRRs provide a person with sets of meaningful and coherent life experiences, thanks to the resources at the person's disposal. The GRRs are of genetic and constitutional character, as well as of psychosocial character such as material, knowledge/intelligence, ego identity, coping strategy (rational, flexible, far-sighted), social support, ties, commitment (continuance, cohesion, control), cultural stability, magic, religion/philosophy/art (a stable set of answers), and a preventive health orientation (Antonovsky, 1979, 1987). It was thought that people develop their SOC through the whole lifespan but mainly in the first decades of life when they learn how to deal with life in general. The beauty of the conceptual world of the salutogenesis is its dynamic and flexible approach and the persistent focus on ability and capacity to manage. In comparison to concepts such as coping or resilience (where the conditions and mechanisms are more rigid and contextual), the salutogenic model has its strength in adaptability and universal use. It is a major life orientation, always focusing on problem-solving.

Measuring SOC

The Orientation to Life questionnaire is originally a 29-item scale for measuring the global life orientation, which reflects a person's ability to perceive life as comprehensible, manageable, and meaningful. A shorter form, of 13 items (abbreviated to SOC-13), was later developed (Antonovsky, 1987). The SOC questionnaire is a seven-point Likert scale compiled into a score ranging from 13 to 91 points (SOC-13) or 29-203 (SOC-29). High scores are analogous with a strong SOC, indicating better coping capacity.

Eleven items measure the comprehensibility dimension (five items in SOC-13), for example: "When you talk to people, do you have the feeling that they don't understand you?" and "Do you have the feeling that you are in an unfamiliar situation and don't know what to do?" The manageability dimension is measured by 10 items (four items in SOC-13), among others by asking "Has it happened that people whom you counted on have disappointed you?" and "Do you have the feeling that you're being treated unfairly?" Eight items measure the meaningfulness component of the SOC (four items in SOC-13), for example: "How often do you have the feeling that there's little meaning in the things you do in your daily life?" and "Until now, has your life had very clear goals and purpose, or no clear goals or purpose at all?"

A detailed description of the questionnaire is found elsewhere (Antonovsky, 1987). Up to 2003, the SOC questionnaire had been used in at least 33 languages in 32 countries (Eriksson & Lindström, 2005). A recent update shows there are additional translations in at least 16 languages: Albanian (Roth & Ekblad, 2006), Croatian (Singer & Brähler, 2007), Brazilian (Bonanato et al., 2009), Hungarian (Biro, Balajti, Adany, & Kosa, 2010), Korean (Han et al., 2007), Lingala (Pham, Vinck, Kinkodi, & Weinstein, 2010), Persian, Swahili (Rohani, Khanjari, Abedi, Oskouie, & Langius-Eklof, 2010), and these local languages in Africa – Afar, Bilein, Hidareb, Kunama, Nara, Saho, Tigre, and Tigrinya (Almedom, Tesfamichael, Saeed Mohammed, Mascie-Taylor, & Alemu, 2007), and in an additional 13 countries: Eritrea (Almedom et al., 2007), Croatia (Pavicic Bosnjak, Rumboldt, Stanojevic, & Lee Dennis, 2012), Hungary (Biro et al., 2010), India (Suraj & Singh, 2011), Iran

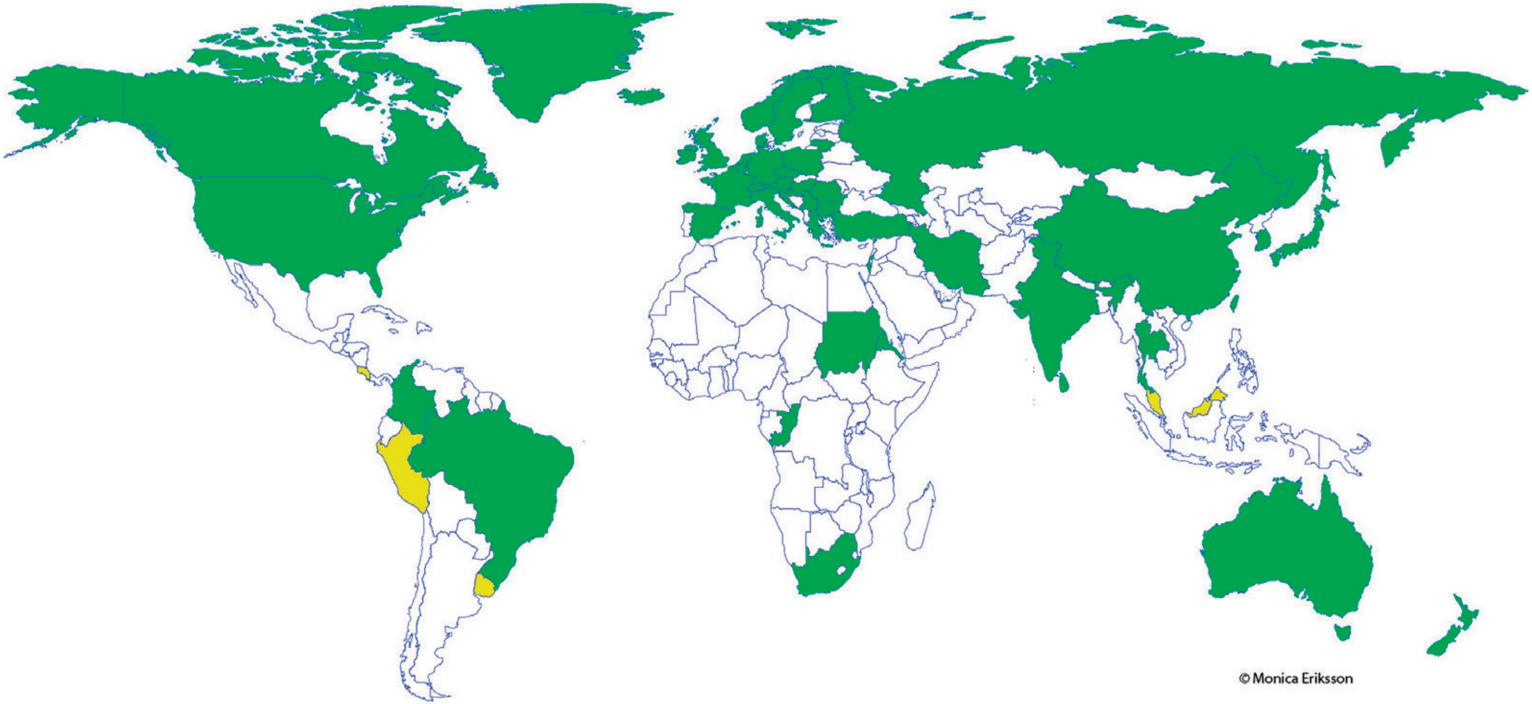

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Figure 46.3 Countries using the SOC questionnaire for measuring health (as per October 2012). Copyright Monica Eriksson.

(Rohani et al., 2010), Italy (Ciairano et al., 2010), Korea (Han et al., 2007), Kosovo, Republic of Congo (Pham et al., 2010), Spain (Virues-Ortega, Martinez-Martin, Del Barrio, Lozano, & Grupo Español, 2007), Sudan (Abdelgadir, Shebeika, Eltom, Berne, & Wikblad, 2009), Taiwan (Tang & Li, 2008), and Turkey (Öztekin & Tezer, 2009). In all, the SOC questionnaire has been used in at least 49 languages in 45 countries all over the world, in all continents, in varying cultures, and on different samples in the form of healthy populations, several groups of patients and disabled people, and among medical professionals.

Most of the studies used one of the original scales, the SOC-29 or the SOC-13. Both questionnaires are associated with copyrights, which remain solely in the hands of the executor of the estate of Aaron Antonovsky. On behalf of Professor Avishai Antonovsky, son of Aaron Antonovsky, permission can be obtained from the author of this chapter (monica.eriksson@hv.se). The opportunity to grant permission for using the SOC scales also provides knowledge about ongoing research that has not yet been published. Research is currently ongoing in Costa Rica, Malaysia, Pakistan, Peru, and Uruguay (Monica Eriksson, personal communication, 2012).

Other Related Concepts Explaining Health

Salutogenesis is more than just the measurement of the SOC; it is a much broader concept focusing on resources, competencies, abilities, and assets on different levels – individual (Eriksson, 2007), group (Antonovsky & Sourani, 1988), organizations (Feldt, 2000; Mayer & Boness, 2011; Graeser, 2011), and societies (Eriksson, Lindström, & Lilja, 2007; Lindström & Eriksson, 2009). Today, we can talk about salutogenesis as an umbrella concept, as visualized in Figure 46.4, which also shows other concepts contributing to the explanation of well-being. We do not claim that SOC covers the entire spectrum of personal resources; instead, we use it to open up a reflection on other resource-oriented constructs than the SOC.

In the following text, a selection of concepts related to salutogenesis is described: resilience, coping, and reasonableness. All of them are important for good functioning and well-being. However, to scrutinize all of them fully is not possible within the space of this chapter. Resilience is illuminated since there is a common misunderstanding that salutogenesis is the same concept as resilience. Personal growth is an interesting concept, responding to the salutogenic question of why some people not only stay well but achieve personal growth when suffering major life events and severe hardships. Many models of coping with stress have been presented down the years. Here, the salutogenic model of coping with stress is related to the theory of coping by Lazarus. Reasonableness is a new conceptual framework in the field of salutogenic research, linking supportive factors in the environment with perceived health and well-being. Flourishing is highlighted because this is a new expression of mental health from a resource-oriented perspective. The concept of *resilience* is a familiar concept related to coping with adversities (Rutter, 1985; Garmetzy &

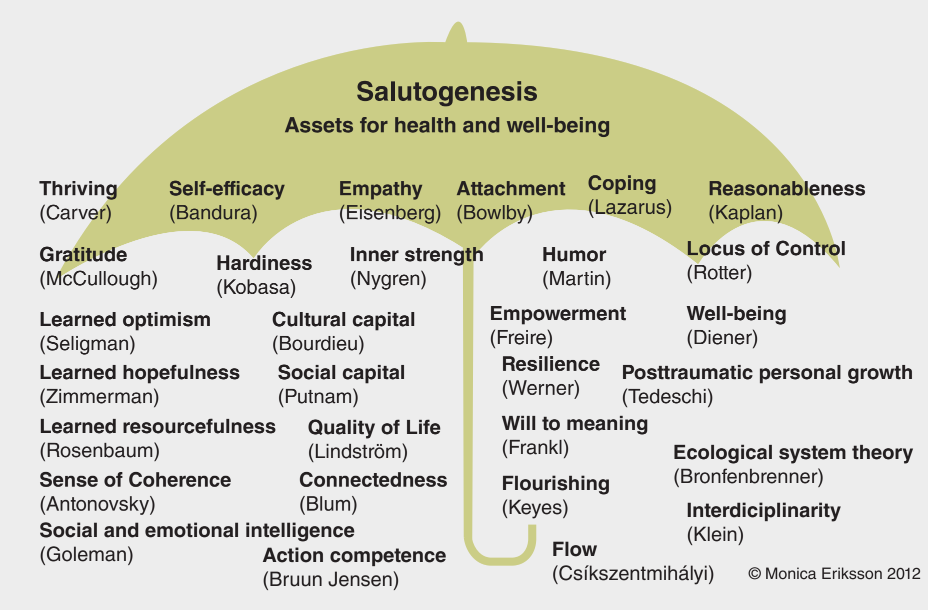

Figure 46.4 The salutogenic umbrella. Copyright Monica Eriksson.

Rutter, 1988; Werner & Smith, 1982, 2001). Do resilience and SOC describe the same thing? The answer is no; however, there are similarities and differences between the two concepts (Eriksson & Lindström, 2011). First, the starting points are different. While Antonovsky refers to a positive outcome independent of stress under certain conditions, research into resilience starts by recognizing the risk for a negative health outcome. Both the concepts are process-oriented (in a continuum), and not part of personal characteristics. Both the SOC concept and resilience can be applied to different levels, the individual, group (families), or society. A further development of resilience research is the concept of posttraumatic personal growth (Calhoun & Tedeschi, 2006; Aspinwall & Tedeschi, 2010).

What makes people not only survive but perceive personal growth after encountering adversity? The resilience to personal growth model has interpreted SOC as the capacity to cope with major life events. Here, a strong SOC is an important factor for developing personal growth. The concept is distinct from an SOC or resilience, which emphasizes how people resist adversity or bounce back from it. PTG (posttraumatic growth) emphasizes a transformation of people in the aftermath of traumatic events that may shatter the assumptive world of those experiencing them, requiring a reconceptualization of fundamental beliefs about self, others, and the future, thereby producing personal growth. This growth may include a greater sense of personal strength, a greater appreciation of life, improved relationships with others, spiritual change and development, and new life opportunities (Aspinwall & Tedeschi, 2010, p. 5).

The term "stress" has been defined in various ways and means different things to different people. It is defined in terms of pressure, tension, unpleasant external pressures, or an emotional response. The response to a stressor such as the feeling of tension may be viewed as stress or distress. Further, the concept of stress can be considered to involve biochemical, physiological, behavioral, and psychological changes. Stress in this chapter will only describe the relational aspect, that is, as a relation between the person and the environment, and coping as a process. Coping as a process means that the relationship between the person and the environment is seen as dynamic and constantly changing, with the person and the environment acting on each other. Besides considering coping as a process, it is also important to distinguish between coping resources, coping strategies, and the meaning of coping. Here, the emphasis is on coping as a resource and the meaning the person gives it. The sense of coherence and social support are examples of coping resources, but they do not refer to a particular coping strategy (Antonovsky, 1993b).

The cognitive theory of stress and coping developed by Lazarus and described by Folkman (1984) is relational and process-oriented. The relational characteristic becomes apparent in the definition of stress as a relationship between the person and the environment that is appraised by the person as exceeding available resources and as endangering his or her well-being (ibid p. 840). The individual meaning a person gives the event also influences the outcome of the coping process. Citing Averill, Folkman states that it is evident that no simple relationship exists between personal control and stress. The only general statement that can be made with confidence is that the stress-inducing or stress-reducing properties of personal control depend on what meaning the individual gives the control response; what gives meaning to the response is largely based on the context in which it is embedded. According to the cognitive theory of stress and coping, the meaning of an event is determined by two major forms of cognitive appraisal process, that is, primary appraisal and secondary appraisal. Primary appraisal means that the person evaluates the specific event with respect to well-being. In the secondary appraisal process, the person evaluates his or her coping resources and options. Both primary and secondary appraisals shape the meaning of the event. However, there is also research into positive psychological states in situations of severe stress (Folkman, 1997). Results from a longitudinal study of the caregiving partners of men with AIDS showed that, along with intense negative psychological states, these men also experienced positive psychological states through caregiving and bereavement. Despite the loss of a relative, the caregiving was meaningful and, in a long-time perspective, gave life meaning (Linn et al., 1993). The co-occurrence of positive and negative psychological states in stressful circumstances has important implications for our understanding of the coping process.

The positive psychological state occurred when the caregivers were able to infuse ordinary events with positive meaning. The social support of the caregivers became a meaningful task for their partners. Antonovsky extensively discussed the theories behind stress and coping. In his second book, a whole chapter dealt with the pathways leading to successful coping and health (Antonovsky, 1987). However, he particularly rejected the thoughts behind Lazarus's cognitive theory on stress and coping and theories in life event research. According to Antonovsky, the assumption behind these theories was a life in balance, that is, homeostatic. A disturbance was assumed to damage the balance and damage health, that is, a pathogenic view of life. Furthermore, the traditional theories on stress and coping are mainly focused on the concept of control. In the salutogenic theory, the emphasis is on the person's ability to use the GRRs, both internal and external, at his or her disposal to manage stressful situations. This is the salutogenic view of stress and coping, that is, to be able to live in chaos.

The reasonable person model (RPM) is a conceptual framework linking supportive factors in the environment with perceived health and well-being (Basu et al., in press; Kaplan, R. & Kaplan, S., 2011; Kaplan, S. & Kaplan, R., 2003). People are more reasonable, cooperative, helpful, and satisfied when the environment supports their basic informational needs (Kaplan, S. & Kaplan, R., 2003, p. 1484). How does one deal with the overwhelming amount of somewhat confusing and even untrustworthy information and maintain civility toward others (Basu, Kaplan, R., & Kaplan, S., Forthcoming)? The model proposes three dimensions essential for developing reasonableness. While the RPM model puts emphasis on exploration and understanding, meaningful action, and restoration, the focus in the salutogenic model of health is on comprehensibility, manageability, and meaningfulness (Antonovsky, 1987). Antonovsky discussed the complexity of communities and social organization using civility as an outcome of coherence (Antonovsky, 1993a). Civility affirms plural commitments and loyalties to oneself and to others. The foundation of civility is that of respect, and finally it presupposes constraints against domination, oppression, and deprivation (ibid, p. 973).

SOC and the evidence for health

An extensive research synthesis is in process to clarify the contribution of the SOC to the development and maintenance of health, partly published and defended as a doctoral thesis in 1992–2003 (Eriksson, 2007), and an ongoing review by the author as a continuation in 2004–2010. The conclusions drawn in this chapter are based on systematic research (Cooper, 1998), and present the state of knowledge on the salutogenic concept of SOC during the period 1992–2010 (Eriksson, 2007). The review is systematic in the sense that all included papers have been critically examined by the author, according to a set of criteria.

The papers were analyzed as follows: (1) the study objective as the exploration of how SOC can affect mental health; (2) how SOC is affected by culture; (3) the distribution of studies on ethnic and linguistic minorities; (4) the study designs and methods for analysis; and (3) conceptual description of mental health. The effect sizes of the correlation applied in the review follow Cohen's recommendation for behavioral sciences (Cohen, 1988). The effect size $r = 0.10$ is considered small,

$r = 0.30$ medium, and $r = 0.50$ large. Furthermore, based on the results from longitudinal studies, the ability of the SOC questionnaire to predict mental health is presented.

Inclusion and exclusion criteria for the review were established. Included were (1) papers dealing with the SOC concept and/or using some of the different versions of the SOC questionnaire published in scientific peer-reviewed journals aiming at exploring the relationship between SOC and health; (2) peer-reviewed papers and doctoral theses; (3) quantitative as well as qualitative studies, and cross-sectional as well as longitudinal study designs with equal weight assigned to the method used; (4) papers in English and the Nordic languages; (5) papers with a careful description of the translation process of the SOC questionnaire to languages other than English; (6) quantitative studies with an acceptable reliability and validity (face, consensual, construct, criterion, predictive, and responsiveness); and (7) publications in the timespan 1992–2010. The following search strategy has been used: (1) electronic search in the databases PubMed (Medline), Bibsys, ISI, Libris, PsycInfo, Cinahl, Social Services Abstracts, and Sociological Abstracts, extended with ProQuest (additional ERIC, PsycArticles, PILOTS) for the search 2004–2010; (2) search on the key words "salutogenesis," "salutogenic," "sense of coherence," and the Nordic translations, (3) reviewing reference lists in the identified papers; and (4) personal communication with authors and colleagues. Cross-sectional and longitudinal studies are analyzed separately, and so are quantitative and qualitative studies. There is a need for longitudinal studies to confirm causality between the SOC and health.

The electronic database search identified 1,332 papers and doctoral theses meeting the inclusion criteria from an ongoing systematic review of the salutogenic research, as measured by Antonovsky's SOC scale 1992–2010. The assessment of the included papers is described in detail elsewhere (Eriksson, 2007; Eriksson & Lindström, 2005).

In general, the results from the review showed that the SOC has an impact on promoting health. However, there seem to be different effects of the SOC on the various dimensions of health. The SOC appears to be strongly associated with perceived good health, especially the mental dimension, at least among persons with a strong SOC. The relationship between SOC and physical health is more complex and seems to be weaker than with mental health. The stability of the SOC has been unclear. Antonovsky assumed the SOC to be in a phase of development until 30 years of age, and then being stable until retirement age, thereafter to decrease. This statement does not find support from empirical studies to date. Contrary to what Antonovsky stated (1987), the SOC improves with age during the whole life cycle (Eriksson & Lindström, 2011; Nilsson et al., 2009). In a random Swedish sample of about 43,000 respondents aged 18–85, Nilsson and colleagues showed a relationship between SOC and age, with stronger SOC in the older age groups. To conclude, the SOC seems to be a health resource promoting resilience and the development of a positive subjective state of health during the life cycle.

This finding opens up for discussion the contribution of the SOC to disease prevention and coping with chronic diseases.

Disease Prevention

One of the major challenges in health promotion and disease prevention is how to deal with the major killers among non-communicable diseases (cardiovascular diseases, diabetes, cancer, and mental illnesses). What is the evidence of the SOC in relation to these diseases? There are some findings available (Poppius, 2007). In the Helsinki Heart Study, a 5-year randomized, double-blind, placebo-controlled primary prevention trial of gemfibrozil, the hypotheses were tested that people with a strong SOC have decreased all-cause mortality and incidence of coronary heart disease, cancer, and injuries. The SOC-29 questionnaire was here used among 5,866 Finns who attended the first screening visit within the Helsinki Heart Study and were monitored after 8 years.

The findings showed that the SOC had an impact on health, but the impact differed depending on occupation. In white-collar work environments, the low SOC tertile had a high CHD (coronary heart disease) incidence of 20.1 per 1,000 person-years, whereas the incidence in the moderate and high SOC tertiles were 10.9 and 12.3, respectively. According to Poppius, the effects of the SOC on CHD vary depending on age, illness, and occupation. A strong SOC protects from CHD only in a white-collar environment. Myocardial infarction has pronounced effects on an individual and challenges daily life routines. Survivors of cardiac arrests describe the life-threatening event as an awakening in perplexity and a memory gap as a loss of coherence (Bremer, Dahlberg, & Sandman, 2009). Survival means a search for coherence with distressing and joyful understanding as well as existential insecurity exposed by feelings of vulnerability.

Much is known about the risk factors (i.e., heredity, hypertension, diabetes, insufficient physical activity) but less about factors promoting health after a cardiac event. One hundred Swedes underwent a follow-up (1 month) after their first myocardial infarction; the aim was to describe their SOC and symptoms of angina attacks (Bergman, Malm, Karlsson, & Berterö, 2009).

The participants were divided into three groups according to their SOC – low (39–61 points), medium (62–79 points), and high (80–91 points). The results showed that the participants in the high-SOC group had better mental health (measured by the Short Form-12 Health Survey Questionnaire, mental component summary), lower angina frequency (OR 1.06), and were more physically active (OR 9.5) than those in the low-SOC group (ibid, p. 135). However, some gender differences were found. The increased physical activity and better mental health in the high-SOC group could not be verified in the male subsample, and might thus be interpreted as a female contribution to the differences between the SOC groups. The low-SOC group was found to be less physically active, to have more frequent attacks of angina, and to be less satisfied with their medical treatment. Support for the findings on the relationship between SOC and physical activity was found in a cohort of Israeli patients ($n = 643$) with incidence of myocardial infarction (Myers, Drory, & Gerber, 2011). The SOC here was consistently associated with engagement in leisure-time physical activity throughout the follow-up period (13 years).

Persons in the lowest-SOC tertile had almost twice the odds (OR 1.99; 95% CI, 1.52–2.60) of decreasing their engagement as those in the highest tertile, even after controlling for disease severity, depression, and sociodemographic and clinical factors. However, contrary findings are also reported. The length of follow-up may be of significance. A similar sample of Norwegian women suffering myocardial infarction was followed up after 10 years, with the aim of determining whether 10-year survival after MI was related to their SOC. Contrary to the findings by Bergman et al. (2009), the SOC did not predict adverse events (Norekvål et al., 2010). Similar results were found among Swedes ($n = 98$) who were treated for myocardial infarction 1 year back (Brink, 2012). The results showed that depression, fatigue, optimism, and SOC variables were all correlated with both the physical and mental dimensions of health-related quality of life (HRQOL), where fatigue was the most significant factor associated with HRQOL. Optimism and SOC did not contribute to significant variations in mental and physical HRQOL (ibid, p. 92).

Coping with chronic diseases

Living with chronic diseases is life challenging in terms of coping with long-term stress. How the SOC as a coping resource might contribute in dealing with these life situations is extensively examined, that is, among patients with Parkinson's disease (Pusswald et al., 2012), strokes (Surtees et al., 2007), mental illnesses (Langeland et al., 2006; Nitsche, Koch, & Kallert, 2010), chronic pain (Lillefjell & Jakobsen, 2007; Schult, Söderback, & Jacobs, 2000), diabetes (Zhang, Vitaliano, Lutgendorf, Scanlan, & Savage, 2001; Ahola et al., 2010; Lundman & Norberg, 1993), chronic heart failure (Nahlen & Saboonchi, 2010), cancer (Poppius, Virkkunen, Hakama, & Tenkanen, 2006), and multiple sclerosis (Pakenham & Cox, 2009). Even more examples of studies exploring the potential contribution of the SOC in coping with chronic illnesses can be found. The EPIC-Norfolk prospective cohort study in the United Kingdom (Surtees et al., 2007; Wainwright et al., 2007) is one of the largest population studies using the SOC concept ($n = 20{,}629$). A subsample of about 400 participants with either a fatal or non-fatal stroke event was examined. A strong SOC was here associated with a 25% reduced rate of stroke incidence (RR 0.76; 95% CI, 0.60–0.96) after adjustment, for example, for age, sex, pre-existing myocardial infarction, hypertension treatment, and diabetes. Those with the strongest SOC had a 40% reduced rate of stroke incidence relative to those who reported the weakest SOC.

Among Norwegian patients with psychiatric illnesses, a randomized control trial was performed that aimed to examine the effect of talk-therapy based on salutogenic treatment principles in coping with mental health problems (Langeland et al., 2006).

The results showed that using talk-therapy based on salutogenic principles significantly improved coping in the experiment group; particularly, the manageability component of the SOC was improved. In other words, the SOC can be improved and strengthened by interventions. As we already know that the SOC improves with age during the whole life cycle, and now also know that it can be strengthened, the usefulness of the SOC concept becomes promising in public health and health promotion practice.

SOC has an impact on health behavior. Health behavior related to SOC is a new area of salutogenic research. Antonovsky used the concept of healthy orientation instead of health behavior. Combined with other GRRs, a healthy orientation serves as a prerequisite for the development of a strong SOC (Antonovsky, 1987). The evidence demonstrates that SOC has an impact on health behavior; in general, the stronger the SOC, the healthier the behavior (Posadzki, Stockl, Musonda, & Tsouroufli, 2010). A person with a strong SOC consumes less alcohol, tobacco, and drugs (Andersen & Berg, 2001; Kuuppelomaki & Utriainen, 2003; Von Ah, Ebert, Ngamvitroj, Park, & Kang, 2005; Bergh, Baigi, Fridlund, & Marklund, 2006), exercises more frequently (Hassmén, Koivula, & Uutela, 2000), chooses healthier food (Lindmark, Stegmayr, Nilsson, Lindahl, & Johansson, 2005), and has better oral-health-related behavior (Bernabé et al., 2009; Bernabe et al., 2010; Ayo-Yusuf, Reddy, & Van Den Borne, 2008; Dorri, Sheiham, Hardy, & Watt, 2010; Savolainen et al., 2009). Further, parents' SOC has an impact on the pattern of food intake of children, and parents' weaker SOC was associated with children's unhealthier eating patterns (Ray, Suominen, & Roos, 2009). In addition, among adolescents, a strong SOC was related to a lower consumption of medicine for headache (Koushede & Holstein, 2009).

Independently of social class and the level of education, there are individual differences in healthy lifestyles associated with SOC (Wainwright et al., 2007). This result is based on the EPIC-Norfolk study on the adult population in the UK ($n = 18287$). Persons with the strongest SOC were 28% less likely to smoke at present (OR 0.72, 95% CI, 0.58–0.89), 36% less likely to be physically inactive (OR 0.64, 95% CI, 0.55–0.75), and consumed on average more fruits, vegetables, and fiber per day than those with the weakest SOC. Further, the focus of most health promotion programs has been on the prevention of smoking and alcohol use, all based on what parents worry about. The efforts to change health behavior among adolescents is an important health promotion intervention; however, there is a need for a broader approach, shifting focus toward the conceptual world of the adolescents. Olsson and colleagues found that Swedish schoolchildren worried about their social situation and personal relationships, while the parents more often worried about destructive health behaviors (early onset of smoking and drug use) (Olsson, Fahlén, & Janson, 2008). What can we learn from such research? As a minimum, there is a need to more actively listen to the adolescents and to actively engage them in the development of health promotion programs.

Conclusions

The aim of this chapter was primarily to describe salutogenesis and the two key concepts – the SOC and the GRRs – and, then, to show some evidence of the SOC on health promotion and disease prevention, and, finally, to give some directions for future research. After 30 years of research, there is comprehensive evidence of the salutogenic model of health. The theory has been extensively examined, the SOC questionnaire has been tested on different samples all over the world, and there is an extensive research synthesis available, showing its potential for health promotion and disease prevention. What is most important now is to implement salutogenic principles in practice as a way of treating people under the care of health services, those in contact with social services, and in all activities aimed at supporting people. Finally, I wish to emphasize that there is no conflict between a salutogenic and a pathogenic approach to treating people; both are needed for promoting health and preventing diseases.

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The Impact of Pediatric Illnesses on Students

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Introduction

From age approximately 5 to 18 years, most US children are engaged in the process of schooling. This means they spend innumerable hours in a succession of classrooms and learning environments that require them to pay attention, socialize, as well as learn, understand, retain, and apply facts and knowledge. In large part, school is responsible for transforming young, dependent, illiterate children into independent, literate young adults able to join the workforce or pursue higher education. This means the stakes for education are high. School failure of any type may include objective lifelong implications, and it is often accompanied by subjective distress for the student and his or her immediate family.

Although school failure is abundant in contemporary society, it is a particularly distinct risk for students with pediatric illnesses. Unfortunately, there are many medically impacted students subject to this risk. It is estimated, for example, that up to 15% of students will encounter a significant illness before high school graduation (Thies & McAllister, 2001). Furthermore, as many as 40% of these students confront an illness-related educational problem. This chapter provides readers with an overview of issues related to the education of students with chronic illnesses. It does so by explaining the multiple, school-specific risks that are connected to chronic pediatric illnesses, and by providing a list of things that might be done to minimize, or at least limit the severity of, school problems. To the extent possible, the chapter relies on empirical studies to buttress its points.

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How to Characterize the Educational Consequences of Chronic Pediatric Illnesses

It is fortunate that healthcare providers, social scientists, educators, and discerning parents are afforded an extensive and rich literature regarding the psychological consequences of chronic pediatric illnesses. At the scholarly level, much of this is appears in excellent publications, such as the *Journal of Pediatric Psychology* and *Journal of Behavioral and Developmental Pediatrics*. It is unfortunate, however, that this literature is relatively sparse and poor regarding the educational consequences of such illnesses. The school aspects of illnesses simply appear to be overlooked. For example, Brown and Wodrich (2009) found that articles published in the two journals mentioned earlier often reported outcomes associated with pediatric illnesses. Critically, however, these studies included educational outcome variables collected in school settings a mere 14% of the time (another 7% of studies did include educational variables, but these data did not come from school sites per se). It was common, for instance, to encounter research concerning family dynamics, medical regime compliance, quality of life, and disease-related IQ score changes among pediatric patients. However, it was rare to locate studies about school outcomes, such as illness-related changes in school attendance, decreased work completion, or academic skill problems. Consequently, it would appear that more educational outcome data should characterize future research on common pediatric illnesses. However, if school data are to be reported, on what dimensions should the data appear? In response to this question, Wodrich, Pfeiffer, and Landau (2008) argue that there are four educational dimensions on which information about students with chronic illnesses should routinely be collected. These four dimensions, as well as examples within each, and a rationale, are presented in Table 47.1.

Table 47.1 Educational dimensions on which students with chronic illness are at risk.

Educational dimension†	*Method of measurement*
Academic (and related cognitive) development	Objective academic achievement tests, curriculum-based measurement, work products (also psychometric tests of IQ, memory, attention)
Work completion, classroom attention	Direct observation of student in class
Interpersonal adjustment at school	Direct observation, interview of students, teachers, classmates
Compromised academic instruction (time out of class, absenteeism)	Interview with teachers, students, nurses, parents, direct observation, accessing school attendance records

† From Wodrich, Pfeiffer, and Landau (2008).

Academic (and Cognitive) Development

What is meant by academic and cognitive development?

Academic development concerns emerging competence in reading, writing, and arithmetic among younger students, and content area knowledge (e.g., in English, social studies, mathematics, foreign languages) among older students. The cognitive element concerns general IQ and specific cognitive skills that develop over time, such as memory, motor coordination, and attention. Development of academic skills, of course, is a central purpose for schools' existence. Obviously, some students fail to develop these skills at a rate expected by their teachers and in a manner commensurate with their classmates. At times, academic skill failure is pervasive, extending across subjects, and at other times it is circumscribed, for example, appearing in writing or mathematics only. Similarly, some students fail to develop skills from the outset of their schooling, lagging behind classmates throughout their careers, whereas others encounter time-specific successes and failures. Often, but not always, cognitive changes accompany and constrain school success. In turn, these cognitive changes often derive from neurologic changes produced by the disease process or its treatments (e.g., medication, surgery, radiation therapy). Consequently, if healthcare and educational professionals are to understand the basis for school difficulties that accompany a host of chronic illnesses, a good starting place is to understand the academic level of ill students. Moreover, cognition is multifaceted. Pediatric illnesses might affect the brain – either persistently during the entire developmental period or more acutely when there is childhood onset – in the form of generalized or specific cognitive impairments. This means that a thorough assessment often involves objective measures of students' skill development using standardized tests, repeated data collection regarding skill acquisition in reading and arithmetic, as well as objective psychometric measurement of IQ, memory, attention, and information-processing speed. This latter set of neurocognitive skills is particularly important for students who have pediatric illnesses involving the central nervous system (e.g., sickle cell disease, epilepsy, brain tumor).

Why is academic and cognitive functioning important?

It is obvious that academic skills are essential at school. Early failure in reading has long been known to predict reading difficulties throughout a student's school years (Juel, 1988). Similarly, it is obvious that students who fail to develop foundational reading, writing, and computational skills are constrained in subsequent, higher-level classes. Those with limited literacy cannot succeed in history and English classes. Those with limited arithmetic development during the elementary years are apt to fail (or avoid enrollment) in algebra later, and they cannot succeed in science courses, such as biology, chemistry, or physics. Of course, the big picture is that failure to develop academic skills portends ongoing life difficulties. This is obvious regarding literacy (McNaulty, 2003). Less appreciated is the extent to which poor development of numerical and computational skills predicts lifelong difficulties, potentially representing lifelong barriers greater than those associated with poor reading (see Parson & Bryner, 2005).

How are risks to academic and cognitive functioning exemplified?

The impact on academics and cognition is exemplified by two conditions, epilepsy and cancer. Students with epilepsy comprise a heterogeneous group. Some students with epilepsy, especially those with idiopathic epilepsy (i.e., epilepsy associated with no specific underlying cause or other symptoms), express relatively few academic problems and rarely have impaired range IQ scores (Wodrich, Kaplan, & Deering, 2006). In contrast, those with symptomatic epilepsy (i.e., epilepsy associated with another medical condition, such as tuberous sclerosis) have relatively high rates of developmental delay (Wodrich et al., 2006). Sadly, however, even those with idiopathic epilepsy risk learning problems. For example, 41–62% of students with epilepsy (excluding those with severe problems such as mental retardation and a history of head trauma) suffered severe underachievement (compared to their IQ scores) in at least one academic subject area (Fastenau, Shen, Dunn & Austin, 2008). Degree of seizure control (Bohac & Wodrich, 2012), but not type of seizure per se (as long as those with symptomatic epilepsy are excluded), predicts academic performance (Williams et al., 1996).

Students with cancer confront a different set of academic and educationally meaningful cognitive risks. Those with brain tumors, for example, may require lifesaving treatment (e.g., surgery, chemotherapy with potential for brain toxicity, and radiation of the entire central nervous system) that might produce long-term cognitive and educational problems. When delayed, these problems are referred to as “late effects.” Research shows that late effects may manifest up to 10 years after treatment, with IQ declines being the best-studied phenomenon. Academic skill development often seems to diminish following IQ declines. For example, a meta-analysis of 39 studies found that, compared to controls, students with brain tumors (on average, aged 6.1 years at diagnosis and aged 11.1 years at the time of psychometric assessment) had notable standard score differences compared to test norms (e.g., 8.5 points lower in reading, 9.0 lower in arithmetic, 6.3 lower in spelling, and 11.6 lower in full-scale IQ; Robinson et al., 2010). Of course, circumscribed deficits also arise, which presumably vary based on individual students’ type of tumor, location, and method of treatment. Even when considering group data, it appears that some narrow cognitive and academic skills fare worse, whereas others seem to fare better. For instance, mental arithmetic, which involves working memory (e.g., *Wechsler Intelligence Scale for Children – III* arithmetic subtest), exemplifies an area of poor outcome. This was documented in a study of students with brain tumors, nearly all of whom had surgery and radiation therapy, assessed on average 5 years post-diagnosis (Briere, Scott, McNall-Knapp, & Adams, 2008). Consequently, understanding the role of general cognition, disease-related threats to it, and the impact of these on educational success is obligatory among students with many illnesses. Of course, some illnesses are only rarely associated with academic skill deficits. This is exemplified by type I diabetes mellitus (see Parent, Wodrich, & Hasan, 2009). Knowledge of individual diseases, therefore, proves essential. We revisit this theme later in the chapter.

Social and Emotional Development

What is meant by social and emotional development?

Social and emotional development are two interrelated and reciprocally influential developmental domains. Social development concerns students' ability to interact with and form ongoing, effective relationships with others. Social development at school is often viewed within the context of immediate classmates, but might also include students encountered elsewhere on campus, as well as teachers and other school personnel. Emotional development at school includes students' self-concept, self-esteem, and adjustment regarding risks such as anxiety, depression, and distorted thinking. As a group, children with chronic illness appear to be at risk for impaired social and emotional functioning; however, the risk for impairment varies greatly across diagnoses (Martinez, Carter, & Legato, 2011). For example, children with neurological disorders (i.e., epilepsy) appear to be at particular risk for social problems (Martinez et al. 2011), and encounter elevated levels of psychological dysfunction (Pinquart & Shen, 2011) compared to children with non-neurological disorders (e.g., diabetes, asthma). In addition, noteworthy within-illness variation also exists; there does not appear to be distinctive illness-specific emotional symptom patterns (Northam, 1997). Instead, impairment in social and emotional functioning may coincide with changes in neurological functions caused by illness onset or illness-related medications (Hysing, Elgen, Gillberg, & Lundervold, 2009). Furthermore, variables such as changes in physical appearance, life-style modifications, interruption of daily activity, and restriction of physical activities may be more predictive of social and emotional adjustment than specific illnesses (La Greca, 1990). In other words, asthma itself may not predict social or emotional difficulties at school as accurately as restrictions in school activities among asthma sufferers with severe allergies (e.g., prohibitions against field trips and outdoor physical education) or physical changes (e.g., Cushing-like appearance associated with chronic steroid use). Positively, social support provided by classmates has been found to be associated with later psychosocial success for children with some types of chronic illness, such as cancer (Schuman & La Greca, 1999).

Why is social and emotional functioning important?

Social and emotional functioning are important aspects of childhood for several reasons. The first is the unequivocal advantage of maximizing subjective feelings of happiness and social attachment for all youngsters, including those with chronic illness. Second, improved social and emotional functioning also appears to be related to students' academic functioning. Third, success on social and emotional variables also appears to harbinger successful adjustment later in life. For example, children's development of positive peer relationships has been found to predict higher levels of academic achievement, self-esteem (King, MacDonald, & Chambers, 2010), and relatively good adjustment in adolescence and adulthood (Martinez et al., 2011). Moreover, compared to those accepted by peers, students rejected by peers tend to exhibit more classroom difficulties as well as higher levels of psychological problems (King et al., 2010). In addition to positive peer relations, psychological well-being is also predictive of academic achievement; students diagnosed with certain psychological disorders, such as depression and anxiety, have been found to be at greater risk for school underperformance (Caplan et al., 2005). Even more disconcerting is that development of psychological disorders and emotional problems is associated with a negative impact on children's overall quality of life (Ekinci, Titus, Rodopman, Berkem, & Trevathan, 2009).

How are risks to social and emotional functioning exemplified?

Risks to social and emotional functioning are clearly demonstrated by two pediatric illnesses, epilepsy and cancer. Students with epilepsy appear to be at especially high risk for social and emotional problems. Epilepsy is often associated with a high degree of social stigma that can lead to low self-esteem (Weinstein & Gaillard, 2007). Furthermore, low self-esteem and negative attitudes toward their condition have been found to predict academic underachievement among students with epilepsy (Sturniolo & Galletti, 1994). In addition to low self-esteem, the risk for psychopathology (i.e., depression, anxiety) is three to six times greater for children with epilepsy (21–60%) than children in general (6.6%), and surpasses the rates found among children with non-neurological illnesses (11.6%; Ekinci et al., 2009). Perceptions of stigma, feelings of lost control, negative attitude toward illness, and multiple seizure medications may contribute to the development of psychopathology in children with epilepsy (Ekinci et al., 2009). Indeed, interpersonal problems may be especially problematic for children with epilepsy regarding bullying, a widespread problem at school. For example, one study recently found that twice as many children with epilepsy (42%) reported being bullied compared to healthy controls (21%); the percentage was again far lower for those with a non-neurological illness (i.e., chronic kidney disease, 18%; Hamiwka et al., 2009).

Risks to social and emotional development for students with cancer are less clear than those for students with epilepsy. It is intuitively obvious that social and emotional consequences vary by type of cancer and whether the student is currently undergoing treatment or is in remission. For students currently undergoing treatment, those who endure physical changes (e.g., hair loss, amputation, weight loss or gain) appear to be more prone to social isolation at school (Abrams, Hazen, & Penson, 2007; Prevatt, Heffer, & Lowe, 2000; Seitz, Besier, & Goldbeck, 2009). Furthermore, a recent survey found that 40% of children with cancer recalled unpleasant experiences regarding classmates' attitudes toward their illness (Lähteenmäki, Huostila, Hinkka, & Salmi, 2002). In contrast, many studies report that students with cancer enjoy good post-treatment social adjustment, although social anxiety may ensue, and there is risk of diminished close friendships (Barrera, Shaw, Speechley, Maunsell, & Pogany, 2005; Gurney et al., 2009). In addition to social adjustment, other aspects of long-term emotional adjustment are characterized by an unclear empirical literature; some studies report mood instability and low self-esteem, whereas others report no evidence of such problems. A recent summary of three decades of research concluded that problems with mood and self-esteem were secondary to post-treatment physical problems (i.e., motor functioning and physical liveliness). Nonetheless, post-treatment differences were still found between cancer survivors and healthy children regarding anxiety (which tends to diminish with time), and, to a lesser extent, depression, PTSD-like symptoms, and emotional stability (Wakefield et al., 2010).

Overall, children with chronic illnesses appear to be at heightened risk for social and emotional impairment in general, although there is much variability in dysfunction between and within different illnesses, and more information is needed on these risks in the context of school. Consequently, if educators are to understand students' social and emotional needs, it is important for them to be cognizant about specific illnesses and consider students' unique circumstances.

What is meant by missed instruction?

Missed instruction refers to any instance in which a student fails to access his or her classroom curriculum, which for students with a chronic illness is a high risk. Missed instruction occurs because of various reasons. One obvious reason is to attend medical appointments during school hours. Oftentimes, this is unavoidable because health providers may be unavailable outside of school hours, or treatment is necessarily received at a distant hospital. Another common reason is that the illness itself precludes class attendance. For example, students with epilepsy may experience several hours of postictal confusion, or may endure so many seizures during a day that attending class is simply not feasible. Additionally, extreme fatigue and nausea associated with chemotherapy may keep a student with acute lymphoblastic leukemia at home.

Children may also miss instruction despite being at school. Some children with type 1 diabetes mellitus, for example, leave class frequently for blood sugar monitoring and insulin injections at the nurse's office. Finally, a less common, yet important, reason for missing instruction is school refusal, which is defined as "child-motivated refusal to attend and/or difficulty remaining in class for the entire day" (Kearney & Bensaheb, 2006, p. 3). This phenomenon is highlighted among children with leukemia, some of whom experience treatment-related physical changes (e.g., hair loss) and then avoid school because they fear ostracism (Harris, 2009). In sum, students with a chronic illness often encounter barriers to full and uninterrupted access to their classroom curriculum.

Why is class attendance important?

As discussed, there are several reasons why children with a chronic illness might miss class, but what are the implications for their absences? How might this impact educational achievement, as well as social and emotional development? In general, research suggests that school attendance is linked with student achievement (Roby, 2004), and absenteeism results in poor grades, elevated dropout rates, delinquency, mental illness, and adjustment problems later in life (Kearney, 2008). Poor attendance may also compound existing learning problems, especially for those in special education, causing students to fall further behind their peers. In fact, one study found that frequent absences among students with type 1 diabetes mellitus predicted problems in reading, spelling, and arithmetic (Ryan, Longstreet, & Morrow, 1985).

In addition to its impact on academic achievement, class attendance also promotes social and emotional growth (Weitzman, 1986; Weitzman, Walker, & Gortmaker, 1986). When returning home from a long hospitalization (e.g., childhood cancer survivors), school provides an opportunity to return to a normal lifestyle and interact with friends; in general, however, the longer a student is away from school, the more difficult it is to adjust socially and emotionally to school upon return (Suzuki & Kato, 2003). These facts underscore the importance of class attendance for overall school success.

Although some children with chronic illnesses must leave class to manage their disease, no known research exists to determine the impact of this practice on academics and social and emotional functioning. Despite the lack of evidence, however, one can imagine a host of ways that frequent disruptions to classroom instruction can impact a student's learning. A trip to the nurse's office that occurs during a crucial junction in an arithmetic lesson obviously threatens acquisition of that day's computation skill development. Furthermore, if repeated, such trips may compromise the entire suite of arithmetic skills expected at a given grade level.

How is class attendance exemplified in common diseases?

Overall, students with chronic illness miss more days of school than their healthy peers. For example, several studies discovered that children with cancer missed an average of 30 days or more per school year (Noll et al. 1999; Vance & Eiser, 2002). In another study, nearly 30% of students with epilepsy missed 5 days or more of school during a 6-month period, with medical appointments, epilepsy tests, or same-day seizure occurrences listed as the most common reasons (Serdari et al., 2009). Among students with diabetes, several studies have found about 8 days or more of school missed per year than healthy classmates (Yu, Kail, Hagen, & Wolters, 2000). Another study similarly found students with type 1 diabetes missing nearly 10% of scheduled school days during the last year (Parent et al., 2009). As mentioned earlier, some students also spend considerable time outside of class managing their disease, which adds to the total time away from class.

Overall, students with chronic illnesses are at an increased risk for missed instruction, which places them at a higher risk for school failure. Parents and educators need to work together to ensure that children are able to attend school each day. Additionally, these children need opportunities to make up assignments and to receive instruction missed when absent. This may entail added work for the teacher, but this extra support is arguably necessary for school success. It should be emphasized that these students did not choose their condition and thus they should not be penalized for it.

What is classroom attention and work completion?

Work completion is a student's rate of success in completing his or her schoolwork as assigned. Attention is the student's ability to selectively attend to material and sustain focus in class. Attention appears to be a necessary precondition to work completion. An important distinction is made here between skill development (i.e., the acquisition of skills in reading and math, for example) and classroom performance (i.e., the successful and timely completion of classwork). This is sometimes cast as a skill vs. performance distinction, and it is an important one for students with chronic illness. For example, if researchers simply study the extent to which students acquire academic skills, they may fail to detect legitimate problems among students with satisfactory overall skill development but current problems focusing attention and completing work. Of course, an array of neurologic and non-neurologic chronic illnesses might involve students with just such problems (see the following text).

Why is attention and work completion important?

Work completion is important because it allows students to practice learned material and contributes to their long-term success in the classroom. In addition, attention is essential for thinking, learning, and memory processes, and is of utmost importance for school success in all academic areas (Commodari, 2012; Pingault et al. 2011). Conversely, inattention has been found to play a role in the development of academic difficulties and learning disabilities in healthy children (Merrell & Tymms, 2001) and in children with chronic illnesses, such as epilepsy (Williams et al., 2001). Furthermore, normal classroom functioning presupposes that all students are capable of a degree of self-direction and focus, and that all (or most) will complete the work asked of them. When this is impossible, the overall functioning of the class is called into question. For example, if a teacher plans to work with nine of her 26 students in a reading group while the other 15 independently complete worksheets at their desks, then problems arise if some of the 15 students are severely inattentive and require the teacher's efforts, which she had intended to deploy exclusively to the reading group.

How are risks to work completion and attention exemplified?

Risks to attention and work completion vary by type of illness. One pediatric illness that is associated with impaired attention and work completion is epilepsy. Overall, students with epilepsy perform worse on measures of auditory attention, sustained attention, concentration, and verbal short-term working memory than healthy classmates (Hermann et al. 2008; Williams et al., 2001). Students with epilepsy may also have deficits in information processing, which can impede their ability to complete schoolwork (Sturniolo & Galletti, 1994). Seizures themselves can interrupt students' classroom attention and work completion. For example, some types of seizures may occur throughout the day (e.g., absence, complex partial) and may cause directions to be missed or slow down students in their work (Wodrich et al., 2006). In addition, a postictal (post-seizure) period characterized by limited arousal and awareness often follows seizures and can constrain student attention and learning (Wodrich et al., 2006). Some students with epilepsy also suffer from brief (e.g., 3-second) and intermittent subclinical brain discharges, known as transitory cognitive impairments, which can impair attention and memory and prevent students from mastering academic skills (Williams, 2003). Lastly, work completion and attention can further be hindered by lethargy and daytime sleepiness produced by the side effects from anti-epileptic drugs (AED) or nighttime seizure sleep disturbances. Indeed, students who must take more than one AED tend to experience more problems with attention (Titus & Thio, 2009). As a group, children with epilepsy appear to be at higher risk for problems with attention and work completion than healthy children. In addition, difficulties in these areas have been found regardless of type of epilepsy and type of seizures, although children with symptomatic epilepsy and higher seizure severity seem especially impaired (Williams et al., 2001).

Less well studied is hemophilia, a sex-linked disorder affecting males, which carries a risk of attention problems. For example, a study using a clinic sample found that 29% of children and teens had a prior diagnosis of ADHD and 38% were participating in special education when their files were reviewed, both percentages far exceeding the prevalence rate for boys in general (Wodrich, Recht, Gradowski, & Wagner, 2003). When the researchers had parents and teachers complete standard ADHD rating scales concerning inattention and hyperactivity–impulsivity, they found elevations on the latter dimension only when parents', but not teachers', ratings were considered. This implied that classroom productivity problems may have only been intermittently evident and that impulsivity and over-activity is the predominant problem. Follow-up research, which used more sophisticated procedures and a control group, found that borderline ADHD symptoms seemed to characterize many of these boys at school and was often associated with some degree of reading and math problems. As in the earlier study, impulsivity–hyperactivity problems (rather than inattention) seemed dominant (Spencer, Wodrich, Schultz, Wagner, & Recht, 2009). Although these findings are important in their own right, this research highlights the prospect that the character of common classroom attention and productivity problems might differ among diseases; type 1 diabetes mellitus appears to be associated with inattention in class (Parent, Wodrich, & Hasan, 2009), whereas hemophilia appears associated with hyperactivity–impulsivity.

Role of Teachers When a Student Has a Chronic Illness

Teachers of students with chronic illnesses necessarily assume an array of roles. Consider the examples of epilepsy and type I diabetes mellitus. For students with epilepsy, three interrelated teacher roles were detected from a review of the literature and systematic input from epilepsy experts (Wodrich, Jarrar, Buchhalter, Levy, & Gay, 2011). The first of these concerned students' medical needs, such as teachers' capability for emergency actions, implementation of safety precautions, and for recognition of when a seizure is occurring. The second role, regarding interpersonal status and emotional adjustment, concerns ability for meeting students' (patients') in-class emotional needs, allaying classmates' apprehensions during an in-class seizure, and minimizing the student's (patient's) embarrassment if a seizure happens at school. A final role concerns teachers' unique instructional obligations, such as an ability to formulate classroom accommodations, know about possible drug side effects that might threaten learning and attention, and recognize other epilepsy-related barriers to progress. US teachers currently instructing a student with epilepsy generally rated themselves as "somewhat confident" regarding these roles, whereas those not now instructing a student with epilepsy claimed slightly less confidence, with values most closely matching the anchor "between confident and unsure." Teachers who possessed more factual knowledge about epilepsy, regardless of whether teaching a student with epilepsy or not, endorsed higher confidence levels ($r = .43$ between confidence and knowledge). Unfortunately, this study found that participating teachers knew relatively few educationally important facts about epilepsy (i.e., responded correctly to just 8.7–10.6 of 25 fact items). Several older US and foreign studies also confirm limited teacher confidence and epilepsy knowledge (e.g., Bannon, Wildig, & Jones, 1992; Prpic et al., 2003).

Teachers of students with type 1 diabetes confront similar roles, although particulars differ. Specific tasks include vigilance for signs of unstable blood sugar, capability for emergency management, facility in generating classroom accommodations, and cognizance of the stigmatizing effects of diabetes among classmates. Evidence appears mixed regarding US teachers' ability to fulfill these roles. For example, when Wagner, Heapy, James, and Abbott (2006) surveyed parents of students with diabetes, 42% indicated that their child's school staff lacked instruction in "routine non-emergent diabetes care," and 22.8% of surveyed students themselves reported difficulty with school staff properly attributing school problems to diabetes, incorrectly calling attention to diabetes during class, and for conveying inaccurate information about diabetes to the other students. In another study, US students likewise voiced concern about being treated differently; nearly one-half indicated they felt their school staff had prevented them from performing standard diabetes care (Schwartz, Denham, Heh, Wapner, & Shubrook, 2010). The same study, however, found parents viewed school personnel as highly supportive of their youngsters.

Appraisal of teachers' knowledge about diabetes come from other studies in the Western, industrialized world; 27.7% of urban Brazilian teachers did not know clinical manifestations of diabetes, therapeutic approaches (33.70%), or the main procedures to be used in adverse diabetes situations (42.40%; Simones et al., 2010). In Madrid, Spain, 47% of teachers felt insecure about teaching a pupil with diabetes because they lacked a plan to manage diabetes-related complications. Although almost all teachers knew the meaning of hypoglycemia, only 67% and 57% indicated, respectively, that they knew how to recognize signs of it and what they should do if such signs were observed (Gomez-Manchon, Gomez-Carrasco, Ramirez-Fernandez, Diez-Fernandez, & Garcia de Frias, 2009). Beyond the examples of epilepsy and diabetes, similar patterns seem to exist across a broader assortment of diseases. When Nabors, Little, Akin-Little, and Iobst (2008) surveyed US teachers about 13 common pediatric illnesses, they found that teachers felt least knowledgeable about renal failure and cystic fibrosis, with just 3.3% and 5% of regular education teachers, respectively, indicating they were "very well informed," (although special education teachers claimed to be more knowledgeable about renal failure than their regular education counterparts). In contrast, teachers perceived themselves to be most knowledgeable about asthma, chronic allergies, and diabetes, with 34.2%, 25.4%, and 22.1%, respectively, asserting themselves to be very well informed (again, more special education teachers claimed to be highly knowledgeable about allergies). Regarding confidence, teachers expressed the least confidence in meeting academic needs of students with renal failure, cystic fibrosis, and spina bifida, with just 19.5%, 20.3%, and 20.7%, respectively, indicating that they were "very confident."

Ways to Help Teachers of Students with Chronic Illness

Share diagnoses

In general, informing school personnel, including teachers, about the presence of a pediatric illness makes sense. Information can be transmitted in any number of ways. The most common manner, however, appears to be simply for a parent or guardian to himself/herself inform the local school office, school nurse, administrator, or the classroom teacher about the presence of illness. Although it is true that some teachers harbor negative stereotypes about individuals with certain diagnoses (e.g., HIV-AIDS), and although teachers may fail to understand classroom manifestations of diseases (see the following text), disclosure still makes sense most of the time. Several analog studies, in which teachers are randomly assigned to experimental conditions, and then asked to respond to real-world-like practice situations, demonstrate this point. Work by Wodrich (2006), Cunningham and Wodrich (2006), and Cunningham and Wodrich (2012) demonstrate the negative impact of withholding from teachers diagnoses of type I diabetes and epilepsy when one their students is expressing disease-related classroom problems. In these studies, when diagnosis-specific information was added to a student's cumulative folder that teachers read as part of the study, teachers generally performed better. Improvement encompassed better understanding of the nature of students' classroom problems (i.e., attributing the student's problem correctly to a "health problem") and more numerous and better crafted classroom accommodations to promote learning; however, teachers only made more accurate judgments about academic skill development and or mastery of educational standards if they were also provided clear anchors they could use to size up a student's academic skill level. These studies also help to reveal some of what teachers might incorrectly infer when they are left relatively uniformed. For example, teachers who were denied access to a diagnoses often misattributed health problems to alternative factors. Thus, a student with diabetes-associated or epilepsy-associated learning problems may be thought to suffer from ADHD, laziness, or conflicts at home. Obviously, such faulty attributions hold potential to spawn poor classroom practices that themselves may produce untoward educational and psychological outcomes for a misunderstood, chronically ill student.

A number of experts offer models for students returning to school after an illness or hospitalization (e.g., Sexson & Madan-Swain, 1995), as well as more general templates for clinic–school cooperation to minimize potential negative effects of illnesses on education (e.g., Drotar, Palermo, & Barry, 2004). In general, sharing information is key to these approaches. However, exceptions to the general proviso of "it's best to share" may exist. For example, physicians sometimes advise the family of a student with well-controlled epilepsy to not mention his/her epilepsy to anyone at school, including teachers. The self-evident intent is to avoid stigma. Indeed, there is evidence of stigma's pernicious effects at school. When Katzenstein, Fastenau, Dunn, and Austin (2007) studied 92 teachers who were aware of their students' epilepsy diagnoses and 33 who had no such information about their students with epilepsy, the latter group held up higher expectations for their students. Importantly, teachers' expectations were held up even though students' actual achievement levels did not differ.

Of course, there is a risk that lowered expectations, or other unhelpful teacher attitudes, may themselves foment decrements in achievement. In fact, work by Bohac and Wodrich (2012) suggests this may occur. These authors found that, when teachers held more negative attitudes on the topic of individuals with epilepsy (e.g., endorsed epilepsy stereotypes), their students with epilepsy indeed performed more poorly academically than students with epilepsy whose teachers possessed more positive attitudes. It may be for reasons such as this that nearly one-quarter of caregivers reported withholding their child's epilepsy diagnosis (Baker et al., 2008). Other disorders are also associated with negative stereotypes, and accordingly it may make sense to sometimes withhold information from teachers or classmates. As a case in point, those who remember the 1980s may recall the devastating social consequences when school personnel and classmates learned that an Indiana teen, Ryan White, was HIV-positive. Thus, careful judgment is in order and individual circumstances are determinative regarding sharing diagnoses with school personnel.

Share information about the illness

Although sharing diagnoses alone is helpful, the research cited in the preceding text demonstrates the supplemental advantages associated with sharing information about a disease's nature, the associated threats to classroom success, and methods of minimizing those threats. This appears to be true even when the information conveyed is slight. For example, in the Wodrich (2005) study cited earlier, the presence of information in cumulative school folders revealing the presence of an epilepsy diagnosis did nothing to help teachers recognize that the student's classroom problems were due to a health problem. However, teachers did benefit from a few concise statements in the cumulative folder about how epilepsy might appear in school (i.e., that epilepsy can produce problems with memory, lethargy, slowed thinking, diminished concentration, poor fine motor control, and mood instability). Even when provided all of this information, however, 35.3% of teachers still failed to attribute a student's classroom struggles (e.g., penmanship, forgetfulness, inconsistent performance, inattentiveness, and lethargy) to his or her health status. In some ways, the situation may be even worse regarding type 1 diabetes. For example, even with diagnosis disclosure, plus facts about diabetes-related problems typical in school appearance, and a tight match with the hypothetical student's classroom problem, 60% of teachers still failed to recognize that a health problem was the most likely root cause of an ill student's difficulties. These findings imply that teachers benefit from information, but that the benefit may only be partial.

Encourage classroom accommodations

It makes intuitive sense that school accommodations often help students with chronic illness. Sensible accommodations, for example, might improve any of the four dimensions mentioned earlier in this chapter (i.e., academics, classroom productivity, emotional adjustment at school, and attendance and time in class). Narrowly considered instructional accommodations might be defined as "an adjustment designed to assist the student in overcoming classroom and learning problems that can be applied in a regular educational setting without the use of special education services or funding (e.g., modifications of assignment length, alterations in seating patterns, revised grading practices)" (Cunningham & Wodrich 2006). More broadly, however, accommodations may be concerned with access to medical equipment and procedures, transportation, and related services. However conceived, accommodations would seem most helpful if they included several characteristics. First, accommodations should rest on a thorough understanding of the nature of each student's strengths and weaknesses as these relate to the expectations of schooling. Consequently, prior to formulating accommodations for each candidate student, he or she should be evaluated on the dimensions cited earlier in this chapter (e.g., academics, cognition, emotional), the resultant barriers detected, and ways to circumvent these barriers devised, as needed. This means that school personnel require expertise in assessment and planning (formal psychometric evaluation, observation, etc.) and access to health-related information. A working relationship between school and clinic is thus mandatory. Second, accommodations should be stated clearly, concisely, and provided in a format accessible to all educators who are expected to implement them (e.g., teachers, instructional aides, physical therapists). Practically, this suggests a simple checklist, indicating that things such as "additional time on tests," "preferential seating," or "modify grading" are patently insufficient. The inadequacy of these barebones descriptors is compounded when such simple checklists are filed in a student's administrative folder, rarely to be seen by frontline educators. In contrast, accessible descriptions of accommodations that indicate precisely what actions are to be taken, under what circumstances, and by whom, are infinitely more satisfactory. Third, accommodations should include a method of assessing their effectiveness. This might be as simple as collecting work samples (and determining the accuracy of a student's work, such as in math or reading) before and after implementation of an accommodation. Alternatively, for a frequently absent student, rate of attendance before and after an accommodation's onset might be used. How to measure progress, as with the nature of the accommodations themselves, needs to be tailored to circumstances. A special education teacher or school psychologist might help with measurement and post-implementation status and also help interpret whether improvement has occurred, and if any such changes are legitimately attributable to the accommodation. Fourth, accommodations should include a method for determining the fidelity of their implementation. Fidelity of implementation entails the manner in which the intervention is designed to be delivered in the classroom, with only some interventions in fact implemented with fidelity (Gresham, MacMillan, Beebe-Frankenberger, & Bocian, 2000). This means that, without verification, an accommodation is actually implemented correctly, and that implementation fidelity is not assumed. Fidelity checks might be as simple as randomly scheduled scrutiny by a second party, periodic use of a log indicating when and how accommodations are used, or more formal fidelity checks, such as those used in educational research.

Studies are limited, and conclusions elusive, regarding the use and effectiveness of accommodations for students with chronic illness. For example, Wodrich and colleagues (2006) found almost no use of in-classroom accommodations for students with epilepsy; however, in an analog study, Cunningham and Wodrich (2006) found that providing teachers with information about the students' diabetic status, and models for classroom accommodations, boosted the rate of effective accommodations. Wodrich and DuPaul (2007) found that pediatricians possessed limited knowledge and low rates of advocacy for the use of classroom accommodations for their chronically ill students; Wodrich and Spencer (2007), in contrast, found school psychologists familiar and disposed to use such accommodations for chronically ill students. Clearly, more research is required in this area if practice is to be guided on the basis of empirical literature.

Provide information about special service options

One way to ensure that classroom accommodations – as well as related tutorial and support services – are actually provided is to advocate for the generation of a formalized plan. Two obvious ways in which formalized plans come about is via special education designation (and an accompanying individualized education program [IEP]) and via a Section 504 plan (and a formal "accommodation plan"). First turning to OHI, the formal definition is as follows: *Other health impairment* means having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, which (i) is due to chronic or acute health problems such as asthma, attention-deficit disorder or attention-deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, or Tourette syndrome; and (ii) adversely affects a child's educational performance. [§300.8(c)(9)].

Unfortunately, it appears that the special education vehicle (using OHI) and use of an IEP are rare among students with pediatric illnesses. Since the 1990s, when special education mandates for students in the "other health impairment (OHI)" category arose, surprisingly, few students have received formal OHI designations and accompanying IEPs. The meager numbers are exemplified in a recent *Annual Report to Congress on the Implementation of IDEA* (US Department of Education, 2011), which showed that just 0.9% of students were designated with an OHI. This percentage is in striking contrast to the rates reported by the Centers for Disease Control. For example, when even a just few conditions (e.g., asthma, cancer, epilepsy, sickle cell, hemophilia, irritable bowel syndrome) are summed, the values far exceed all students enrolled in OHI services. Moreover, it appears that many recipients of OHI are actually diagnosed with attention-deficit hyperactivity disorder (ADHD), rather than with one of the common pediatric illnesses. For example, Wodrich and Spencer (2007) found that 84.5% of school psychologists had helped secure OHI services for a student with ADHD during the past 12 months, but only 26.7% had done so for a student with epilepsy, and only 21.4% for a student with asthma, the next two most used diagnoses following ADHD. Consequently, it appears that more knowledgeable populace, coupled with stronger advocacy for OHI services by healthcare providers, school personnel, state educational agencies, and parents, is needed to redress this drastic OHI underuse. Unless steps such as these are taken, it is argued that the rights, protections, and services guaranteed to students with health-related disabilities will continue to go unmet.

Another vehicle for acquiring services is by virtue of Section 504 of the Rehabilitation Act of 1973, although the frequency of its use and the pediatric conditions for which it is used do not appear to be subjects of research. Section 504 requires that students with disabilities receive the same access to education as their non-disabled classmates. This is typically accomplished through the use of related aids and services (see Mandali & Gordon, 2009). To qualify, a student must first be determined to (1) have a *physical or mental impairment* that substantially limits one or more *major life activities*, (2) have a record of such an impairment, or (3) be regarded as having such an impairment [34 CFR 104.3 (j)(i)]. According to this definition, it seems plausible that most students with chronic illnesses qualify. For example, such students might be affected by a "disorder or condition" that is "neurological . . . cardiovascular" (34 CFR 104.3[j][i]) (e.g., epilepsy or rheumatic fever) that affects a "major life activity . . . learning . . . thinking . . . communicating" (34 CFR 104.3 [j] 2[ii]). If a student with a pediatric illness fails to qualify under IDEA, schools should determine if he or she is eligible under Section 504. However, it should be kept in mind that a medical condition does not guarantee eligibility under Section 504; rather, a formal evaluation adhering to the evaluation procedures specified in Section 504 regulatory provision at 34 CFR 104.35 is necessary to make this determination. Once a team establishes eligibility, school districts are required to provide free and appropriate public education to meet the student's unique educational needs. Typically, a multidisciplinary team convenes to develop a 504 plan. This plan specifies services that might include regular classroom placement with supplementary services, modifications, and/or accommodations. In addition, students may be provided with special education and related services, although it appears that many educators are reluctant to permit access to formal special education programs when Section 504 plan (but no IEP) exists. For students with pediatric illnesses who qualify, a 504 plan might include trained staff to address nutritional accommodations, to ensure academic adjustments after school absences, to assist during field trips, or even for special transportation. School success typically hinges on the availability of such services; thus, school personnel are encouraged to use great diligence when planning and implementing a 504 plan.

Conclusion

A substantial minority of students encounter a health problem at some point during their school years. As a result, schools, parents, and health providers frequently confront noteworthy challenges. To assist all of those involved, a small, but growing, research base is available that can be use to help anticipated risks for students with common illnesses on dimensions important at school: academic and cognitive development, ability to pay attention and complete work in class, social relations with classmates and teachers, and one's own school adjustment and attendance patterns. Research is also beginning to indicate the roles that teachers may need to play to maximize their ill students' success. Here, it is proposed that teachers be provided access to ill students' diagnoses and other educationally relevant information about their illness, and that teachers and other stakeholders advocate for necessary special services for ill students.

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