The Handbook of

HEALTH BEHAVIOR CHANGE

THIRD EDITION

Sally A. Shumaker
Judith K. Ockene
Kristin A. Riekert

Editors

The Handbook of Health Behavior Change

3 EDITION

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This book is dedicated to all of the people who work hard to maintain a healthy lifestyle in the midst of multiple personal, social and cultural challenges—and to all the health care professionals who work hard to help their patients succeed in meeting the challenges of healthy living.

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Preface

The first edition of this book was published in 1988, growing out of a recognition in medicine and public health that many acute and chronic diseases can be prevented or at least have their impact lessened by increased attention to the adoption and maintenance of behaviors for optimal health. This recognition evolved from the many epidemiologic investigations demonstrating the existence of a strong relationship among the onset, progression, and exacerbation of diseases and alteration of lifestyles, such as smoking cessation, developing healthy eating habits, taking medications as prescribed, increasing physical activity, and practicing safe sex. There was also increased awareness that for the adoption of healthy behaviors to occur and be sustained there were not only demands and responsibilities placed on the individual at risk. There were also demands placed on the health care system and its providers; on other channels within the community such as schools, worksites, and churches; and on the social and political context in which change occurs. That first edition included 24 chapters covering theory, lifestyle interventions, obstacles to change and adherence, population-specific issues, and what we then termed "the broader context."

More than 20 years later, a comparison of this third edition to the original provides a vivid view of just how much this field has grown and, to a lesser degree, how many challenges remain the same. There is no question that research on behavior change and adherence has become more central to clinical research and care—no longer a peripheral or add-on element but recognized as an essential part of the health and well-being of the public. Further, there is an increased recognition of just how complex the issue of behavior change and maintenance is, and how embedded this issue is in the entire fabric of a society—going far beyond the ability of a single individual to change his or her approach to preventive care and treatment. And yet people and their health professionals continue to struggle with achieving optimal lifestyles and adhering to the medical regimens and health behaviors that will minimize diseases and their impact. This book provides an updated and substantially expanded view of the theoretical and empirical literature on the factors that influence the adoption of healthy behaviors and the individual, interpersonal, social, and cultural factors that can inhibit or promote behavior change. In keeping with the evolution of this field, we have added a number of new chapters to fully reflect this important area of health research and care.

Chapters 1–9 in Section I of the book provide a review of past and current theoretical models of health behavior change, disease prevention, disease management, and relapse prevention. In addition, models of the maintenance of new behaviors are considered. Reviews are provided of some of the more current techniques used to enhance adherence are provided—such as motivational interviewing and shared decision-making.

Chapters 10–15, Section II, focus on a range of some of the more critical areas of health behaviors—providing updated reviews and the complexities of these specific lifestyle interventions among diverse patient populations. Health behaviors considered include tobacco use, diet, physical activity, safer sexual practices, and stress reduction. Recognizing that healthy lifestyles most often encompass multiple behaviors and are best considered within the context of their interdependence, the final chapter tackles the complexities of multiple risk behavior change.

In the earlier two editions of this book, measurement issues were addressed within other chapters or as a single chapter within a section as there was limited information on this topic at that time. As a further demonstration of the growth of this field, the current edition dedicates a full section to measurement. Chapters 16–19 in Section III review adherence assessment in both clinical care and research, assessing physical activity and substance abuse reliably, and some of the statistical issues addressed when measuring and analyzing adherence behavior in the research setting.

In Section IV, chapters 20–24 address the factors that predict or serve as obstacles to lifestyle change and adherence. Authors consider individual patient characteristics, biological and psychosocial factors, the social context, and the unique challenges associated in trying to change physician practices in clinical settings to be more congruent with best practices as they relate to health behavior recommendations. With the growing recognition of the multiple levels of influences—from intrapersonal to societal and policy—in determining behavior, all of the authors in this section ground their presentations in this broader and, admittedly, more complex view of behavior change and maintenance.

Chapters 25–29 in Section V consider the unique and similar issues associated with maintained behavior change within specific populations. Populations considered include: the young, the elderly, adults with cognitive impairments, and adolescents with chronic diseases. In addition, the final chapter addresses the complicated interrelationships among health disparities, minority status, and heath behavior change.

Medical regimen adherence is a major problem in clinical care and research. In Section VI (chapters 30–35), authors discuss the challenges associated with adhering to the often complicated health regimens faced by people with chronic diseases. These include patients with chronic obstructive pulmonary disease (COPD), diabetes, cancer, and HIV. In addition, chapter 34 looks at adherence issues among patients with multiple chronic diseases, while chapter 35 considers the role of cognition in adherence behavior among patients with type 2 diabetes.

In the final section of the book (chapters 36–40), authors consider the issues of behavior change and adherence within a broader context. The first chapter addresses the subtle interaction between placebo effects and adherence and the implications of this interaction for any behavior change believed by an indi-

vidual to be health enhancing. In the second chapter, authors consider the value of social determinants of health coupled with community-based participatory research in realizing the full potential of achieving lasting lifestyle changes. The role of ethics is explored as it relates to the issue of adherence and how it is framed—particularly with respect to the clinical versus research setting. The final two chapters of the book ask two very different but critical issues that, in some ways, bring us back to the beginning: Does adherence matter? And, have we really learned anything in our years of research on this topic?

In total, this book represents an updated and thorough examination of the factors that influence people's choices to change their behaviors in order to enhance their health, and the intrapersonal, interpersonal, sociocultural, and policy factors that can both positively and negatively affect the choices made and one's ability to achieve a desired behavior. This book is particularly valuable at the graduate student level in the fields of public or population health, health psychology, health communications, and medical sociology and anthropology. In addition, advanced-level undergraduate students in or population health-related courses within the social sciences will find this of value. The content of this book will also be informative to clinical investigators, behavioral and social scientists, and practitioners who grapple with the issues confronting individuals who must make well-informed decisions regarding their health-related behaviors, change many difficult health habits, and adopt new behaviors.

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Acknowledgments

The editors kindly acknowledge the following individuals who contributed to making this new edition possible:

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The following people provided content expertise in reviewing chapters in *The Handbook of Health Behavior Change* (3rd ed.):

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Health Behavior Change and Maintenance: Theory and Techniques

Section

1

Judith K. Ockene
Editor

Chapters in Section I provide a detailed review of a wide variety of theories of behavior change addressing cognitive, interpersonal, social, and cultural factors that are proposed to have an effect on an individual's behavior and change of those behaviors. Section I also includes chapters that address specific strategies that help facilitate behavior change.

Theories attempt to explain cause-effect relationships and help to provide a basis for understanding and predicting behavior, behavior change, and maintenance; for developing interventions to achieve changes in health-risk behaviors; and for evaluating the outcomes of the interventions. No single theory is all-encompassing.

The first chapter in Section I, by Curry and Fitzgibbon, provides "Theories of Prevention" that the authors posit is needed to close the "gap between what we can achieve and what we do achieve for disease prevention." The second chapter, by Clark and Houle, "Theoretical Models and Strategies for Improving Disease Management by Patients," reviews several models and theories that have been used to address adherence in self-management of health and disease. Other chapters present the transtheoretical model of behavior change, multilevel theories of behavior change, and models of provider-patient interaction and shared decision-making. Chapters addressing techniques for health behavior change and maintenance also are included. The techniques include intervention for relapse prevention and maintenance, motivational interviewing, and e-health strategies to support adherence. There also is a chapter on the influence of culture on behavior.

Even though there are many theories and models available, there is still much we have not been able to explain or prove about why and how people make changes in health-risk behaviors and, just as importantly, maintain those changes. To fill in the black box of behavior change, we must be able to move outside the box. Theories can be used to guide us but should not constrain our creativity. We must be open to integrating, expanding, and testing our theories in order to expand our base of knowledge and to using what we learn from practice to alter our theories.

Theories of Prevention

Susan J. Curry and
Marian L. Fitzgibbon

At the beginning of the 20th century, the three leading causes of death were pneumonia/influenza, tuberculosis, and gastritis. These three diseases accounted for more than a third of all deaths at the time (Brownson & Bright, 2004). Advances in microbiology formed the foundation for infectious disease prevention during the first half of the 20th century. Following Koch's work in the late 1800s on the anthrax bacillus showing how bacteria could cause disease, numerous pathogenic organisms were discovered, and the germ theory of prevention emerged as a driving force in medicine and public health (Bullough & Rosen, 1992). Some prevention efforts were derived from advances in the biomedical sciences after the discovery that antibodies from infected organisms could be used to inoculate healthy individuals against pathogen-borne diseases. By identifying environmental sources of exposure to disease-causing

bacteria, the germ theory of prevention also spurred wide-scale investments in the public health infrastructure to create healthier environments (e.g., clean water, better sanitation, improved nutrition).

The success of interventions derived from the germ theory of prevention were evident by the mid-20th century. By 1951, death rates from infectious diseases had fallen dramatically, and increases in life expectancy also were evident. In 1900, average life expectancy at birth was 46 years for males and 48 years for females. By 1950, life expectancy had increased to 66 and 71 years, respectively (National Center for Health Statistics, 2006).

Currently, heart disease, cancer, and stroke are the leading causes of death, and they account for approximately two-thirds of all deaths (Brownson & Bright, 2004; Brownson, Remington, & Davis, 1998). The shift from infectious to chronic diseases as major causes of premature morbidity and mortality necessitated a shift in theories of prevention. Chronic diseases, in contrast to infectious diseases, are characterized by a noncontagious origin, a long period of illness or disability, a prolonged latency period between exposure to the risk factors and negative health outcome, and multiple risk-factor etiology (McKenna, Taylor, Marks, & Koplan, 1998).

Three tenets of this chapter are that (1) a significant proportion of premature morbidity and mortality from chronic disease is preventable; (2) there is a substantial gap between what we can achieve and what we do achieve for disease prevention; and (3) closing this gap may be facilitated by a simple and clearly articulated "health behavior theory of prevention."

What do we mean by a health behavior theory of prevention? Let's start with what we mean by theory. First, there is nothing magical or mystical about theory. It is simply a statement about causal relationships. The validity of these causal relationships may or may not be *conclusively* proven (Deutsch & Krause, 1965). Theories of prevention, therefore, are statements about causal relationships between exposures or risk factors and disease incidence (primary prevention) and progression (secondary prevention). Given our focus on health behavior, we can narrow this definition further by defining a health behavior theory of prevention as statements about causal relationships between health behaviors and disease incidence and progression.

Prevention theory enhances our work as scientists and practitioners in many ways. Theory helps us build the science of prevention by directing our hypotheses and research questions and informs the selection of appropriate populations to study. Ultimately, theories of prevention determine intervention approaches including individual treatments, models of health care delivery, public health practice, and health policy.

In the years following World War II, epidemiologists began to focus on the etiology of chronic diseases, particularly lung cancer and coronary heart disease (CHD) (Susser, 1985; White, 1990). The epidemiological evidence for an association between cigarette smoking and lung cancer initially received the most attention as a behavioral risk factor, because it posed a challenge to a large and powerful industry that was then perceived to be invulnerable (Glantz, Slade, Bero, Hanauer, & Barnes, 1996; Kluger, 1996). Early studies that suggested this association encountered numerous objections. The objections resulted, in part, from the fact that the conclusions were based on statistical correlations from observational studies, which could never in themselves prove causation,

and the fact that cigarette smoking as a single behavior was linked to a large number of chronic disease outcomes (Berkson, 1958; Doll, 1999). However, strong and consistent evidence for the association continued to emerge from laboratory studies and autopsy reports, as well as from observational studies. In 1957, a national scientific study group concluded that there was a causal relationship between smoking and cancer (Study Group on Smoking and Health, 1957). However, the tobacco industry and some scientists continued to argue that none of the studies had actually demonstrated a causal relationship. Their response contributed inadvertently to an overdue expansion in methodological rigor in the fields of statistics and epidemiology and a related increase in our understanding of how epidemiologic research can support laboratory studies and clinical research (Cornfield et al., 1959). Ultimately, there was consensus that this groundbreaking research had demonstrated that tobacco use, particularly cigarette smoking, causes or contributes to a number of chronic diseases (Parascandola, 2004; Talley, Kushner, & Sterk, 2004; White, 1990).

These first epidemiologic studies conducted in the 1940s and 1950s led an advisory committee to the U.S. Surgeon General to conclude that cigarette smoking was a cause of lung and laryngeal cancer and the primary cause of chronic bronchitis (Surgeon General, 1964). This information ultimately culminated in the Surgeon General's Report on smoking and health and led to a number of advances, including increased research into the development of chronic disease and tobacco use, evaluation of prevention and cessation programs, campaigns to reduce or prevent smoking, and the dissemination of this information to the public (Brownson & Bright, 2004).

On a related but somewhat different pathway, researchers began to think in terms of "risk factors" for the development of coronary heart disease, with the idea that certain behaviors moderated the probability of disease. For example, in the 1940s, the Framingham Heart Study was launched as a major, prospective epidemiological study to determine the major risk factors for heart disease. The study identified six major risk factors, including hypertension, elevated blood lipids, cigarette smoking, sedentary lifestyle, obesity, and diabetes (Bullough & Rosen, 1992). The concept of "risk factors" forced researchers to think of chronic disease as the outcome of multiple factors and required a strategic change in thinking about chronic diseases and their complications as being preventable rather than inevitable (Brownson & Bright, 2004). In other words, a reduction in chronic disease could best be achieved by altering factors that place a person at increased risk. Burgeoning research in this area has led to a better understanding of the tremendous influence that certain behaviors can exert upon health.

By 1979 the Surgeon General's Report on Health Promotion and Disease Prevention noted that an analysis of the 10 leading causes of death in the United States in 1976 indicated that as much as half of mortality was due to unhealthy behavior or lifestyle (U.S. Department of Health Education and Welfare, 1979). The health behavior theory of disease prevention had emerged.

Disease Prevention Through Health Behavior Change

In 1993, McGinnis and Foege published an analysis of the actual causes of death in the United States (McGinnis & Foege, 1993). They showed that tobacco use,

unhealthy diet and activity patterns, and alcohol use are the top three actual causes of death in the United States. Together these health behaviors account for nearly 40% of all deaths. Extrapolating from their data, each hour, we can conclude that as many as 85 Americans die prematurely due to tobacco use, poor nutrition, and inactivity.

In addition to the devastating human costs, the health care costs associated with treating chronic diseases are staggering. The combined total of private, public, and personal dollars spent on health care in the United States is almost $2 trillion dollars per year, which amounts to more than 15% of our gross domestic product (GDP) (Heffler et al., 2005). No other industrialized nation spends more than 10% of its GDP on health care. Fries and colleagues estimated that preventable illnesses were responsible for 70% of all medical care spending, and health insurance claims are higher for individuals with at least one behavioral risk factor than for individuals with no behavioral risk factors (Fries et al., 1993; Millman & Robertson Inc., 1995). Unfortunately, spending all of this money does not lead to better health outcomes. The United States ranks behind 44 other countries in life expectancy and 41 countries in infant mortality (Central Intelligence Agency, 2007). In a recent study, out of 13 countries studied, the United States ranked 12th when compared on 16 health indicators (Starfield, 2000).

Disease prevention is not new, and links between behavior and prevention have been articulated for thousands of years. For example, traditional Chinese medicine's (TCM) focus on prevention dates back more than 2,500 years and recommends eating healthful foods, engaging in physical labor, and doing breathing exercises (Selin, 2003). More than 2,000 years ago, Hippocrates (c. 460–377 B.C.) taught that "If we could give every individual the right amount of nourishment and exercise, not too little and not too much, we would have found the safest way to health." The following sections focus on the evidence for three behavioral risk factors for a number of chronic diseases: tobacco use, unhealthy diets, and physical inactivity.

The Top Three Behavioral Risk Factors

Tobacco Use

Tobacco use remains the leading cause of preventable morbidity and mortality in the United States and is responsible for more than 30% of all cancer deaths (American Cancer Society, 2005). For the most part, smoking prevalence has declined, but recently there has been a troubling leveling off. Currently, approximately 21% of the adult population, or 45 million adults, smoke cigarettes (American Cancer Society, 2007). Even with the dramatic decline in prevalence from 60% before World War I, tobacco-related diseases still contribute to approximately 440,000 premature deaths each year (American Cancer Society, 2007). Current smokers have 20 times the rate of lung cancer of those who have never smoked (U.S. Public Health Service, Office of the Surgeon General, 1989) The risk of lung cancer among cigarette smokers increases with the duration of smoking, as well as with the number of cigarettes smoked per day (Doll & Peto, 1978). In a model developed by Doll and Peto, duration of smoking increased the probability of disease more than the number of cigarettes smoked per day (Doll

& Peto, 1978). Therefore, individuals who initiate smoking at a young age have a greater likelihood of developing lung cancer than those who started later (U.S. Department of Health and Human Services, 1988). This strongly suggests that approaches that delay the age of onset of smoking in a population or prevent smoking altogether could have a substantial impact on the incidence of lung cancer by shortening the average duration of smoking. That said, numerous studies have also shown that cigarette smokers can derive benefit by quitting at any age (U.S. Public Health Service, Office of the Surgeon General, 1989). And it is clear that the likelihood of developing lung cancer is lower among people who quit smoking than among those who continue to smoke (U.S. Department of Health and Human Services, 1990).

Diet and Nutrition

In addition to smoking, it is now widely understood that unhealthful diets and physical inactivity play a significant role in the causation and progression of chronic disease, although the numbers attributable to these causes vary (Centers for Disease Control & National Center for Chronic Disease Prevention and Health Promotion, 2003). The concentrated focus on changes in nutrition and physical activity as avenues to promote heath is relatively recent. Until the 1970s and the hearings held by the U.S. Senate Select Committee on Nutrition and Human Needs, the focus of nutrition policy had been on undernutrition, rather than chronic disease prevention (Brownson, Remington, & Davis, 1998). Since the controversial dietary goals for the United States were published in 1977, numerous scientific papers have supported the relationship between a typical U.S. diet and chronic diseases such as heart disease, cancer, diabetes, and stroke (U.S. Senate Select Committee on Nutrition and Human Needs, 1977) These efforts have contributed to improvements in the dietary habits of Americans.

Overall, a diet that includes a large variety of fruits, vegetables, and whole grains has been strongly associated with reductions in coronary heart disease, stroke, and type 2 diabetes (Michels, 2005). However, the results of studies attempting to isolate nutritional factors related to cancer prevention have been less compelling (McCullough & Giovannucci, 2004). This may be because specific nutrients do not exert a protective effect in isolation. Protective effects may also depend on dose, timing, and duration of exposure or nutrient status (Kushi et al., 2006). On the other hand, diets low in fat and high in fruits, vegetables, and whole grains are consistent with energy balance and may contribute to a lower body weight (Rolls, Ello-Martin, & Tohill, 2004). An unhealthful diet, overall, appears to be an independent risk factor for certain chronic diseases but also plays a crucial role in its effect on chronic disease through the influence on the development and maintenance of obesity by altering energy balance (Centers for Disease Control & National Center for Chronic Disease Prevention and Health Promotion, 2003).

Physical Activity and Energy Expenditure

Energy expenditure, while also an independent risk factor for certain chronic diseases, is also an important component of energy balance (Hill & Wyatt, 2005). Unfortunately, it is estimated that only 38.5% of adults in the United States meet the national guidelines for physical activity (Simpson et al., 2003). A recent

study found that physically inactive women had a rate of all-cause mortality that was 52% higher than that of physically active women; their risk of cardiovascular mortality was doubled, and their risk of cancer-related mortality was 29% higher (Hu et al., 2004).

When energy intake is balanced with energy expenditure, body weight remains constant. Thus, overweight and obesity can occur when energy intake is greater than energy expenditure for a sustained period of time (Hill & Wyatt, 2005). However, there are gaps in our knowledge about the health risks of obesity, and deaths attributable to obesity are difficult to calculate for a variety of reasons. Body mass index (BMI) is influenced by energy intake and energy expenditure levels, which may affect health in ways independent of or mediated by BMI. Estimates of the number of deaths attributable to obesity have ranged from 112,000 (Flegal, Graubard, Williamson, & Gail, 2005) to 280,000 (Allison, Fontaine, Manson, Stevens, & Van Itallie, 1999) to 400,000 (Mokdad, Marks, Stroup, & Gerberding, 2004; Mokdad, Marks, Stroup, & Gerberding, 2005). These disparate findings in obesity-attributable deaths underscore the need to develop more sophisticated approaches that could lead to more consistent estimations. Nonetheless, despite the varying estimations, there is no doubt that a decrease in unhealthful dietary and sedentary behavior patterns could translate into a lowering of the elevated risk of morbidity and mortality associated with obesity.

Excess body weight is an independent risk factor for cardiovascular disease, as well as a contributor to other risk factors such as hypertension and type 2 diabetes (Eckel, 1997). Moreover, in 2002, a working group at the International Agency for Research on Cancer concluded that there was convincing evidence that being overweight (body mass index [BMI] ≥ 25 kg/m^2) or obese (BMI ≥ 30 kg/m^2) is associated with risk of cancers of the endometrium, colon, and kidney (Calle, Rodriguez, Walker-Thurmond, & Thun, 2003). Recent data also suggest that successful weight loss and the avoidance of adult weight gain could translate into significant reductions in breast cancer rates (Harvie et al., 2005). Calle and colleagues estimated that 90,000 deaths due to cancer could be prevented annually if individuals could achieve and maintain a BMI of 25 kg/m^2 (Calle et al., 2003).

While there is widespread debate as to how individuals can best achieve energy balance, it is clear that the balance between energy intake and energy expenditure through physical activity is a critical component in the maintenance of a healthy body weight (Hill & Wyatt, 2005). The consistency of the energy balance message, along with similar messages from the American Heart Association (Mosca et al., 2004; Pearson et al., 2002; Williams et al., 2002), the National Cholesterol Education Program Adult Treatment Panel (Expert Panel on Detection Evaluation and Treatment of High Blood Cholesterol in Adults, 2001), and the American Academy of Pediatrics (Krebs, Jacobson, & the American Academy of Pediatrics Committee on Nutrition, 2003) underscores the incontrovertible evidence that the burden of illness today due to chronic disease is, in part, preventable (McGinnis & Foege, 1993).

National Prevention Priorities

Because a considerable number of early deaths among Americans could be prevented through modification of behavioral risk factors, there needs to be a

commitment, combined with a comprehensive plan, to make the changes possible (McGinnis & Foege, 1993). Decisions about smoking, level of activity, and dietary intake are fundamentally and intrinsically linked to individual, cultural, environmental, and commercial factors (Ammerman et al., 2003). Therefore, messages related to preventive health care need to address these root causes of chronic disease in a format that can enhance motivation and promote and monitor effective action (Ammerman et al., 2003; McGinnis & Foege, 2004). Efforts to set health objectives that can be monitored are a recent phenomenon. A 1978 paper published by the Institute of Medicine (IOM) was the first to establish objectives for public health (Nightingale, Cureton, Kalmar, & Trudeau, 1978). The work of the IOM in this area led to the 1979 *Surgeon General's Report on Health Promotion and Disease Prevention* (U.S. Department of Health Education and Welfare Public Health Service, 1979) and culminated in 1990 in the publication of *Healthy People 2000*, which contained 22 priority areas and 319 health objectives to be achieved by the year 2000 (U.S. Department of Health and Human Services, Public Health Service, 1990). Many of the objectives of *Healthy People 2000* were achieved (U.S. Department of Health and Human Services, 2000). However, phenomena such as increasing overweight and obesity rates, as well as an increase in the incidence of diabetes, ultimately led to a set of objectives that focused more specifically on lifestyle behavior change (U.S. Department of Health and Human Services, 2000).

Currently, the U.S. Public Health Service has established two primary health goals for the year 2010: (1) to increase quality and years of health life; and (2) to eliminate health disparities among Americans. In an effort to achieve these goals, the U.S. Public Health Service has published 467 health objectives divided into 26 specific areas (U.S. Department of Health and Human Services, 2000). The core of the objectives for *Healthy People 2010* is based on the scientific evidence documenting the relationship between behavioral risk factors and the development of chronic disease. In fact, 5 of the 10 leading indicators for the health of the nation are health behaviors. The objectives for these behaviors are quite ambitious and include reducing the prevalence of smoking among adults by 50%, doubling the percentage of adults who engage in regular physical activity, and reducing the proportion of overweight and obese children by at least 50% and the proportion of such adults by 35%.

While there is considerable debate regarding the effectiveness of setting ambitious and, some believe, unachievable goals, there is little doubt that modification of behavioral risk factors will make the largest contribution to reductions in morbidity and mortality from the major diseases. For example, Byers and colleagues estimated achievable reductions in cancer incidence and mortality rates between 1990 and 2010 (Byers et al., 1999). Overall, 47% of the achievable reductions in cancer incidence and 51% of the achievable reductions in cancer mortality came from reductions in tobacco use. A similar analysis for coronary mortality conducted in the United Kingdom indicates that 44% of achievable reductions would come from reductions in tobacco use (Critchley & Capewell, 2003).

Indeed, over the past few decades, there have been substantial improvements in chronic disease morbidity and mortality rates (Strong, Mathers, Leeder, & Beaglehole, 2005). For example, deaths from cardiovascular disease have been reduced significantly (Minino, Heron, & Smith, 2006), and cancer mortality also has declined (Minino et al., 2006). While the reasons for this improvement are

multifaceted, health behavior changes have contributed to the decline, particularly adherence to recommendations involving diet, physical activity, and abstinence from smoking.

In summary, the underlying science is available to support the health behavior theory of prevention. Over the past several decades, our knowledge of the causes of chronic disease, including effective intervention techniques, has increased exponentially. However, we continue to face challenges in translating preventive health knowledge into improved health (Glasgow, Lichtenstein, & Marcus, 2003). A more rapid translation of scientific results could significantly reduce the burden of chronic disease, as well as the health disparities in chronic disease that exist for many underserved segments of our population (Kumanyika & Morssink, 2006).

From Theory to Action

High-Risk and Population-Based Prevention Strategies

The previous section highlights evidence for two basic tenets of a health behavior theory of prevention: reductions in the prevalence of health risk behaviors are associated with reductions in premature morbidity and mortality (e.g., declines in smoking prevalence and decreases in lung cancer and cardiovascular disease), and increases in the prevalence of health risk behaviors are associated with increases in premature morbidity and mortality (e.g., increased weight from unhealthful diets and lack of physical activity and increases in the incidence of type 2 diabetes). Unfortunately, science and practice are not inextricably linked. A fundamental challenge for the health behavior theory of prevention is moving from theory to action, which involves pull-through from research to practice. In this section we consider two types of prevention strategies—high-risk and population-based approaches.

In his seminal book, *The Strategy of Preventive Medicine,* Geoffrey Rose introduces the high-risk approach to prevention in the context of "the prevention paradox," which he defines as "a preventive measure that brings large benefits to the community offers little to each participating individual" (Rose, 1992). One way to deal with this paradox is to adopt a high-risk strategy that focuses on identifying individuals or groups of individuals known to be at high risk for disease and concentrates prevention and intervention efforts on reversing or reducing their risk level. Individuals with no or mildly elevated risk are essentially left alone. Examples of high-risk strategies for behavioral risk-factor modification include tobacco cessation interventions targeted at smokers with genetic markers of susceptibility to lung cancer (e.g., Bize, Burnand, Mueller, & Cornuz, 2005), diet and physical activity interventions targeted to nondiabetic individuals with elevated blood glucose and body mass indices greater than 25 (e.g., Diabetes Prevention Research Group, 2002), and interventions to increase compliance with mammography screening targeted at women with a family history of breast cancer (e.g., Curry, Taplin, Barlow, Anderman, & McBride, 1993). Appealing aspects of a high-risk approach to prevention include its practicability, appropriateness, cost-effectiveness, and potentially high benefit-to-risk ratio. Wilson and Jungner elaborated these advantages 40 years ago and noted

that targeting interventions to clearly identified high-risk individuals can be easily integrated into the current organization and culture of health care, provides a cost-effective use of resources, provides interventions that are appropriate to the individual, and avoids "interference" with those who are not at special risk (Wilson & Jungner, 1968). Moreover, because all interventions bring some costs and possible adverse effects, the benefit-to-risk ratio for prevention interventions is likely to be higher in populations where the potential benefits are greatest.

The prospective advantages of a high-risk prevention strategy are tempered by several potential limitations. Wilson and Junger raise concerns that if prevention becomes "medicalized," there may be negative effects on individuals who are "labeled" and that high-risk strategies focus primarily on individuals and so can fail to address key contextual determinants of risk factors and/or diseases. As a result, the high-risk approach can "isolate" high-risk individuals by asking them to adopt behaviors that have minimal social and environmental supports. Most important is their observation, echoed by many others, that the high-risk approach is limited by imprecise prediction; most risk, including behavioral risk, is probabilistic, not deterministic. This means that some (even many) "high-risk" individuals will stay well and that some low-risk individuals will get sick. Rose aptly summarizes the implications of imprecise risk as a fundamental axiom of preventive medicine: "A large number of people exposed to a small risk may generate many more cases than a small number exposed to a high risk." He further notes that in the context of this axiom a high-risk prevention strategy would be addressing only the margins of the problem (Rose, 1992).

The information in Table 1.1 helps to illustrate this axiom and the potential limitations of a high-risk prevention strategy. These are data for men aged 40 to 59 years who were screened for risk factors related to myocardial infarction (MI), as well as for the presence of early disease. The second column of the table indicates that among all men in this group, 15% were found to have elevated risk factors and 2% were found to have elevated risk factors plus early disease. Thus, 85% of the population would be considered risk-free. The third column shows the percentage of men who had an MI in the 5 years following screening. Among those with elevated risk factors and early disease, nearly one-quarter,

1.1	5-Year Myocardial Infarction (MI) Risk and Risk Factors		
Screening Result	% of men	% with MI	% of all MIs in this group
All men	100	4	100
Elevated risk factors	15	7	32
Elevated risk factors + early disease	2	22	12

Note. From *The Strategy of Preventive Medicine*, by G. Rose, 1992, p. 50. New York: Oxford University Press. Copyright 1999 by Oxford University Press. Reprinted with permission.

22%, of them had an MI, whereas 7% of those with only elevated risk factors had an MI. Across the entire population of men, there was a 4% incidence of MI. The last column of the table shows the percentage of all MIs that are accounted for by those in the elevated-risk categories; 32% of all MIs occurred among men with elevated risk factors, and 12% occurred among those with elevated risk factors and early disease.

Thus, the majority of MIs (~68%) occurred in men with no known risk factors. These data lead to two important observations. First, even among men with elevated risk factors, the majority did not have MIs (93% and 78%, respectively). Second, a high-risk prevention approach, even if 100% successful, would prevent only one-third of all future MIs.

As the name implies, a population-based approach to prevention targets all individuals, regardless of risk status, with the goal of shifting the entire risk factor distribution in a positive direction. In many ways, the strengths and limitations of a population-based prevention strategy are the mirror image of those outlined for the high-risk approach. On the plus side, population-based prevention takes a less "medical-model" approach and includes social, organizational, environmental, and policy strategies that change the context and social norms for individual change. Conversely, a population-based strategy may be less cost-effective; since resources are allocated for a much broader spectrum of the population, it may fail to leverage the resources and influence of the health care system, and, by exposing more individuals to interventions with potential adverse effects, may have a smaller overall benefit-to-risk ratio (cf. Jeffery, 1989; Lichtenstein & Glasgow, 1992). In essence, a population-based prevention strategy brings us to a fundamental question derived from the prevention paradox: will moderate and achievable change in the population as a whole lead to reductions in the prevalence and negative consequences of disease?

With regard to behavioral risk factors, Rose points out that this question can be addressed by observing the correlation between the population average and the prevalence of deviance (Rose & Day, 1990). Population averages can be calculated without the "outliers" to reduce the influence of extreme values (which determine the prevalence of deviance) on the observed associations. Using data from a large, longitudinal cohort study, Rose reports correlations between the prevalence of high blood pressure and population averages of salt intake, weight, and alcohol intake that range from .64 to .78. Extrapolating further, he calculates the expected reduction in the prevalence of risk factors associated with changes in the population average. For example, Rose calculated a 25% reduction in the prevalence of obesity with an average loss of 1 kg (2.25 lbs) in the population and a 25% drop in the prevalence of heavy drinking if the average intake of all drinkers fell by 10% (Rose, 1992, p. 65). These data lend support to population-based approaches to behavioral risk factor modification that aim for modest changes across a broad spectrum of individuals.

Of course, high-risk and population-based approaches are not mutually exclusive. Optimal health outcomes through behavioral risk-factor modification are more likely to be achieved by the two approaches combined. Moreover, as definitions of risk and disease are modified to encompass larger proportions of the general population, the distinction may become increasingly blurred. The trend toward defining "pre-disease" (e.g., prehypertension, prediabetes) as well as toward lowering diagnostic thresholds (e.g., hypercholesterolemia, type 2

diabetes, overweight, and obesity) results in a decrease in the proportion of the population defined as "well" (Kaplan, 2005). One estimate is that lower thresholds for hypercholesterolemia, hypertension, type 2 diabetes, and overweight would result in fully 75% of the entire U.S. adult population qualifying for a chronic disease diagnosis (Kaplan, Ganiats, & Frosch, 2004). Given the common pathway of health behaviors as important for both the prevention and the management of chronic disease, we can see that the population and high-risk approaches may very well converge.

Health Behavior Theory of Prevention and Emerging Paradigms of Disease Prevention

Thought leaders in health psychology point to the need for health psychologists to "look beyond current concepts and methods in prevention science" to achieve the considerable potential of health psychology, which includes health behavior theory (Smith, Orleans, & Jenkins, 2004). Dr. Elias Zerhouni, Director of the National Institutes of Health, presents a vision for the future of NIH in the context of the "4 Ps" of medicine that "will be more predictive, personalized, preemptive, and participatory" (Zerhouni, 2006; Zerhouni, 2007). Dr. Zerhouni describes a transformation of the health care process in which there is a "continuous participation of individuals, communities, and healthcare institutions as early as possible in the natural cycle of a disease process." By identifying biomarkers (e.g., genetic variants, molecular changes, individual-level measures of environmental exposures) that are predictive of later development of serious disease, the vision is for biological "preemption" of disease before it occurs. Notably absent in this vision is any explicit attention to prevention beyond the level of individual biology (Glasgow, Fisher, Haire-Joshu, & Goldstein, 2007).

What we can see in this vision is a merging of the population and high-risk approaches to prevention. In essence, all individuals become "high risk" as they are monitored throughout the life cycle for "predisease," and the indicators of predisease will largely be at the molecular level. However, behavior will still play a large role in the translation and adoption of biomedical advances, particularly as associations between molecular markers of disease and known environmental factors are articulated. Moreover, the predictive, personalized, and preemptive vision raises a number of key questions that an expanded health behavior model of prevention can address (cf. McBride, 2005). At what point in the life span should intensive screening for biomarkers of disease begin? What are the criteria for determining the value of a biomarker in formulating a prevention strategy at the individual level? Important considerations include issues of sensitivity and specificity of a biomarker in predicting future disease, the potential for detecting "pseudodisease" (i.e., markers of disease that do not affect overall life expectancy and quality of life; Black & Welch, 1997), and the availability of proven preventive interventions and their risk-benefit profiles (cf. Mahadevia, Kamanger, & Samet, 2003). How can we communicate complex biomedical information to individuals with average to low health literacy? What are the psychological consequences of looking for markers of predisease and of finding "false positive" indications? Will individuals avoid the health care system for fear of being labeled "at risk" and losing health coverage, employment opportunities, and so on? Will more precise feedback on the risk of

serious disease result in meaningful reductions in behavioral risk factors? Will this expanded medical model of disease prevention overload the medical system logistically and financially?

None of these are new questions; they are critical issues for effective translation from theory practice. It is notable that even with our rich scientific evidence that behavioral risk factors contribute substantially to premature morbidity and mortality, that improvements in rates of heart disease and cancer are inextricably linked to reductions in tobacco use, and that the increased prevalence of type 2 diabetes is associated with increased rates of overweight and obesity, the biomedical community has not embraced the health behavior theory of disease prevention. There is a wide translational gap between what we as a society can do and what we actually do to address behavioral risk factors (Curry, 2004). Our health behavior research is often "chasing the bus" of new knowledge, for example, trying to understand why individuals fail to obtain recommended screening tests or how to better achieve successful behavior change. Accelerated translation of findings from these emerging prevention paradigms will occur only if the theory, science, practice, and policy related to a health behavior theory of prevention are an integral part of the transdisciplinary collaboration for actualizing this new vision.

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Theoretical Models and Strategies for Improving Disease Management by Patients

2

Noreen M. Clark and
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It is apparent that the ultimate success of efficacious preventive and curative regimens is dependent upon individuals' willingness to undertake and maintain the required behaviors. Unfortunately, data indicate that poor adherence to professional advice often occurs wherever some form of discretionary action or self-administration is involved. Scheduled appointments for treatment are missed about 35% of the time, and significant numbers of patients do not take prescribed medications in accordance with instructions (DiMatteo, 2004). Adherence to recommended changes for lifestyle behaviors is disappointing. For instance, smoking cessation programs are considered to be unusually effective if 20% of the participants have stopped smoking for at least 1 year

(U.S. Department of Health and Human Services [USDHHS], 2000); fewer than one-half of adults engage in recommended levels of physical activity (Sapkota, Bowles, Ham, & Kohl, 2005); and large percentages drop out of weight-control programs (Dansinger, Tatsioni, Wong, Chung, & Balk, 2007).

Given the extensive documentation of suboptimal public participation in screening, immunization, and other preventive health efforts, as well as low levels of individual adherence to prescribed medical therapies (cf. Kimmel et al., 2007; Osterberg & Blaschke, 2005; Sackett & Snow, 1979) it is not surprising that behavioral scientists devote extensive conceptual and empirical effort toward the explanation and prediction of individuals' health-related decisions. In the past three decades, discussions of the concept of compliance or adherence to use of medicines as prescribed by clinicians have been expanded to include a wider range of activities patients must undertake to manage their health problems more effectively. Therefore, this chapter reviews theoretical and conceptual frameworks that have been used to address adherence in self-management of health and disease. Given the need to increase the impact of effective preventive and curative therapies population-wide, a challenge for the future is to evolve models that integrate community-wide and individual-level health behavior change. To this end, this chapter also includes a discussion of decision making and action through community coalitions as a means to address the systems, policies, and other large-scale measures necessary to ensure that significant numbers of people have the access and assistance required to prevent and control disease. Important approaches and techniques have been identified that help health professionals to ameliorate problems in adherence and effective patient management of disease, but these are not covered in this chapter since they are covered in chapter 6 in this book.

Models of Adherence and Disease Management

The reasons individuals voluntarily elect to engage in health-directed activities were categorized years ago (Kasl & Cobb, 1966) into three major classes:

1. To prevent illness or to detect it at an asymptomatic stage ("health behavior");
2. In the presence of symptoms, to obtain diagnosis and to discover suitable treatment ("illness behavior"); and
3. In the presence of defined illness, to undertake/receive treatment aimed at restoration of health or at halting disease progression ("sick-role behavior").

More recently, the first category (health behavior) has been discussed as "health promotion and preventive behavior" (Glanz, Rimer, & Lewis, 2002). Illness and sick-role behavior are often referred to as "disease management" by patients (Clark, Gong, & Kaciroti, 2001; Lorig et al., 1999).

Health Belief Model

The Health Belief Model (HBM) was developed in the early 1950s by a group of social psychologists at the U.S. Public Health Service (Rosenstock, 1974) in

an attempt to understand "the widespread failure of people to accept disease preventives or screening tests for the early detection of asymptomatic disease" (p. 328); it was later applied to patients' responses to symptoms (Kirscht, 1974) and to following prescribed medical regimens (Becker, 1974).

The basic components of the HBM are derived from a well-established body of psychological and behavioral theory whose various models hypothesize that behavior depends mainly upon two variables: (1) the value placed by an individual on a particular goal, and (2) the individual's estimate of the likelihood that a given action will achieve that goal (Maiman & Becker, 1974). When these variables were conceptualized in the context of health-related behavior, the correspondences were (1) the desire to avoid illness (or, if ill, to get well), and (2) the belief that a specific health action will prevent (or ameliorate) illness (i.e., the individual's estimate of the threat of illness and of the likelihood of being able, through personal action, to reduce that threat).

The HBM consists of the following dimensions (Figure 2.1).

Perceived susceptibility, or one's subjective perception of the risk of contracting a condition; *perceived severity,* or feelings concerning the seriousness of contracting an illness (or of leaving it untreated) (while low perceptions of seriousness might provide insufficient motivation for behavior, very high perceived severity might inhibit action); *perceived benefits,* or beliefs regarding the effectiveness of the various actions available to reduce disease threat; *perceived barriers,* or the potential negative aspects of a particular health action that may act as impediments to undertaking the recommended behavior; and *cues to action,* or stimuli to trigger the decision-making process.

In the HBM context, it is understood that diverse demographic, personal, structural, and social factors are capable of influencing health behaviors.

2.1

The Health Belief Model.
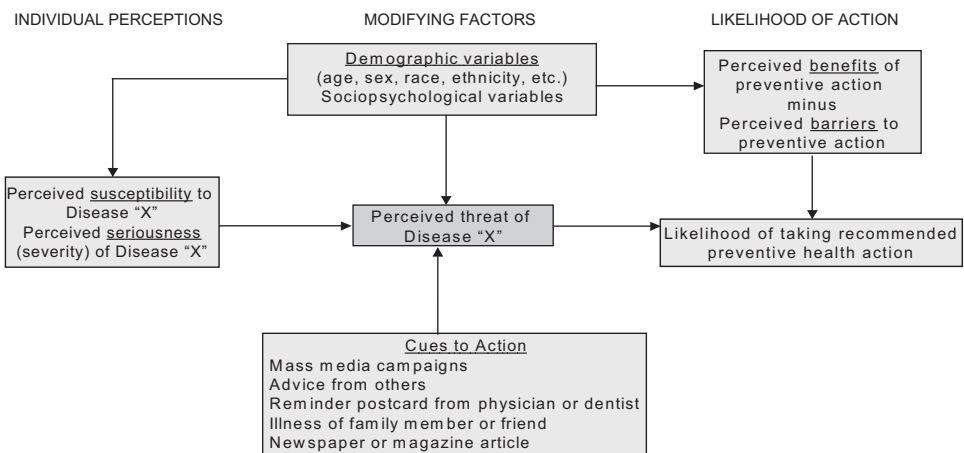
Note. From "A New Approach to Explaining Sick-Role Behavior in Low-income Populations," by M. H. Becker, R. H. Drachman, & J. P. Kirscht, 1974, *American Journal of Public Health, 64,* p. 206. Copyright 1974 by the American Public Health Association. Reprinted with permission from the American Public Health Association.

However, these variables are believed to work through their effects on the individual's health motivations and subjective perceptions, rather than functioning as direct causes of health action (Becker et al., 1977).

The HBM has received extensive research attention (cf. Menon, Champion, Monahan, Daggy, Hui, & Skinner, 2007; Silk et al., 2006). A large body of evidence has accumulated in support of the HBM's ability to account for individuals' undertaking preventive health actions, seeking diagnoses, and following prescribed medical advice (i.e., adhering to regimens), although the variance in difference it accounts for has not always been great. In the mid-1980s, a critical review summarized findings from 46 HBM-related investigations (18 prospective, 28 retrospective) and provided considerable empirical support for the model (Janz & Becker, 1984). Of all the HBM dimensions, "perceived barriers" proved the strongest predictor across all studies and behaviors. A systematic review of studies in the early 1990s found the model inconsistent in predictive power for a number of behaviors (Harrison, Mullen, & Green, 1992).

While the frequency of application has declined in recent years, the Health Belief Model continues to be widely used in published studies and program descriptions. In more current research, the model has been shown to be associated with a range of preventive behaviors, for example, cancer screening (Janz, Wren, Schottenfeld, & Guire, 2003); condom use (Hounton, Carabin, & Henderson, 2005); vaccination (de Wit, Vet, Schutten, & van Steenbergen, 2005); malaria chemoprophylaxis (Farquharson, Noble, Barker, & Beherns, 2004); and dental behavior (Barker, 1994; Pine et al., 2000). Constructs from the HBM have also predicted disease management for heart disease (George & Shalansky, 2007), diabetes (Pinto, Lively, Siganga, Holiday-Goodman, & Kamm, 2006), and HIV disease (Barclay et al., 2007; Catt, Stygall, & Catalan, 1995).

Investigators have examined the HBM constructs in combination with constructs from other theoretical models, such as Social Cognitive Theory. Specifically, self-efficacy, that is, the confidence people have in their ability to undertake given behaviors, has been explored in combination with HBM constructs by numerous researchers. Clark and colleagues (1988) added self-efficacy to dimensions of the HBM and found that the variance explained in the management of asthma by school-age children did not increase significantly. Adih and Alexander (1999), however, found self-efficacy along with constructs from the HBM was a significant predictor of condom use among youth. Although never explicitly incorporated into the original model, self-efficacy may prove to be a useful addition to the model when the focus is on long-term behavior change (Janz, Champion, & Strecher, 2002).

Despite the body of findings relating HBM dimensions to health actions, the HBM is a psychosocial model; as such, it is limited to accounting for as much of the variance in individuals' health-related behaviors as can be explained by their attitudes and beliefs. It is clear that other forces influence health actions as well; for example: (1) some behaviors (e.g., cigarette smoking, tooth brushing) have a substantial habitual component, obviating any ongoing psychosocial decision-making process; (2) many health-related behaviors are undertaken for what are ostensibly non-health-related reasons (e.g., dieting to appear more attractive); and (3) economic or environmental factors may prevent the individual from undertaking a preferred course of action (e.g., a worker in a hazardous environment; a resident in a city with high levels of air pollution). The model is based on

the premises that "health" is a highly valued concern or goal for most individuals and that "cues to action" are widely prevalent; where these conditions are not satisfied, the model may not be useful in, or relevant to, predicting behavior.

Theory of Reasoned Action and the Theory of Planned Behavior

In the approach taken by Ajzen and Fishbein (1980), intention to perform a behavior is the central determinant of that behavior. More specifically, the Theory of Reasoned Action (TRA) focused on intention as predicted by the individual's attitude toward the behavior (i.e., the person's beliefs that the behavior leads to certain outcomes and the value attached to those outcomes) and the subjective norm associated with the behavior (i.e., the person's beliefs that certain individuals or groups think that she should or should not undertake the behavior, weighted by the person's desire to comply with their wishes). The relative influence of attitude and subjective norms on intention is dependent on the behavioral goal. For some behaviors, the attitudinal component will be the major determinant of intention, while for others, more external factors apply; the more the individual believes that significant others are in favor of his behavioral attempt, the stronger will be his intention to try. As with the HBM, sociodemographic factors operate only through their influences on the determinants of behavioral intention. This model also emphasizes normative influences that might affect intention for any reason, health-related or otherwise, thus adding a strong cultural component to the prediction of behavior.

The TRA has been effectively applied to explain and predict a variety of health behaviors, including preventive oral health behavior (Syrjala, Niskanen, & Knuuttila, 2002); breast-feeding (Swanson, Power, Kaur, Carter, & Shepherd, 2006); sun protection (Steen, Peay, & Owen, 1998); and condom use (Albarracin, Johnson, Fishbein, & Muellerleile, 2001).

The Theory of Planned Behavior (TPB) is an extension of Ajzen and Fishbein's Theory of Reasoned Action and considers both volitional and nonvolitional behaviors. This model proposes that intention is not the exclusive determinant of behavior where an individual's control over the behavior is imperfect. Ajzen and colleagues (Ajzen, 1991; Ajzen & Driver, 1991) added the dimension of perceived behavioral control to the TRA as an additional predictor of intention, reflecting the notion that factors outside an individual's control can affect both intention and behavior. Control includes both personal and external factors that influence the behavior, such as having a workable plan, skills, social support, knowledge, time, money, willpower, and opportunity. Consistent with the TRA, intention to try to perform the behavior is the immediate determinant of an attempt to perform the behavior in the Theory of Planned Behavior. Intention is seen as a function of individuals' attitudes toward trying and their subjective norms.

In summary, the Theory of Planned Behavior states that individuals will try to perform a behavior if they believe that the benefits of success are outweighed by the benefits of failure and if they feel that significant others (with whom they want to comply) believe they should attempt to perform the behavior. Successful performance of the behavior will be the end result if individuals have

sufficient control over internal and external factors that influence such performance. The Theory of Planned Behavior is posited as more appropriate when the probability of success and actual control over performance of a behavior are less than perfect.

A meta-analytic review of the 185 studies published through 1997 that examined the theory found that the TPB accounted for 27% of the variance in behavior and 39% of the variance in intention, although the study was not limited to health behavior (Armitage & Conner, 2001). In recent years, the TPB has proven increasingly useful in predicting both intention and actual health behavior. Constructs from the model have predicted intentions related to cancer screening (Steele & Porche, 2005), bicycle helmet use (O'Callaghan & Nausbaum, 2006), and fruit consumption (Brug, de Vet, de Noorijer, & Verplanken, 2006). Elements from the TPB have also predicted actual behavior, including sexual risk behaviors (Koniak-Griffin & Stein, 2006), safe-lifting behavior (Johnson & Hall, 2005), and physical activity (Armitage, 2005). In summary, it is evident from the multitude of studies applying the model that the TPB provides a useful framework for conceptualizing factors that determine a wide range of health behaviors.

Health Decision Model

Proposed as a "third generation model of patient behavior that focused more specifically on health decisions" (Eraker, Kirscht, & Becker, 1984, p. 260), the Health Decision Model attempted to combine decision analysis, behavioral decision theory, and health beliefs to yield a unifying model of health decisions and resultant behavior. The model was the first to include contributions from the "patient preferences" literature (Eraker & Politser, 1982), and interest continues to build around health care decision making conducted in a manner that incorporates these preferences (Institute of Medicine [IOM], 2003). Decision analysis provides quantitative means for patients to communicate their preferences about critical trade-offs between benefits and risk—and, at times, between quantity and quality of life (Hunink, 2001; Weinstein & Fineberg, 1980). Behavioral decision theory extends this quantitative emphasis by identifying a number of general inferential rules that patients use to reduce difficult mental tasks to simpler ones (Eraker & Sox, Jr., 1981).

Eraker and colleagues (1985) have observed that the relationships among health beliefs, decision analysis, and behavioral decision theory were demonstrated in a study on patient preferences as related to variations in the way information is presented to patients. For example, McNeil, Pauker, Sox, and Tversky (1982) examined the results of surgery and radiation treatment for lung cancer and found that preferences for alternative therapies shifted when the outcomes were framed in terms of probability of living or the probability of dying. The investigation also found that people relied more on preexisting beliefs regarding the treatments than on statistical data presented to them. These preexisting beliefs may help to explain why some patients, based on decision-analysis criteria, are treated in a manner not reflecting their underlying preferences.

The Health Decision Model also recognizes the importance of other factors affecting health decisions and behavior, such as knowledge, experience, and social and demographic variables. The bidirectional arrows and feedback

loops reflect the notion that adherence behavior can change health beliefs. The model also includes concepts related to the efficacy of the prescribed regimen, motivational variables involving the person's assessment of the importance of good health, and "cues to action" that refer specifically to the patient-physician interaction (Eraker, Becker, Strecher, & Kirscht, 1985).

Self-Regulation Model

Leventhal and colleagues (1980, 1998) view self-regulation as a solution to dealing with the basic problem of locus of control in adherence theory. The fundamental notion is that:

> *The individual functions as a feedback system. He or she establishes behavioral goals, generates plans and responses to reach these goals, and establishes criteria for monitoring the effects of his/her responses on movement toward or away from the goal. This information is then used to alter coping techniques, set new criteria for evaluating response outputs and revise goals. The individual is, therefore, an information processing system that regulates his/her relationship to the environment. (1980, p. 34)*

Leventhal, Leventhal, and Contrada (1998) posit that:

> *(1) People are active problem solvers, they see and define their worlds, select and elaborate coping procedures to manage threats, and change the way they represent problems when they obtain disconfirming feedback; (2) Problem-solving processes occur in context; and (3) The energy expended or motivation to enhance health and to prevent and cure disease is directed to what is perceived to be the most immediate and urgent threat and is limited by resources and a satisfaction rule. (p. 718)*

The analogy provided is one of the person as scientist—formulating hypotheses about physiology and the effects of illness and creating a mental picture of ability to take actions to prevent or cure illness.

Leventhal's self-regulation model contains components that depict a process that an individual goes through: (1) extracting information from the environment; (2) generating a representation of the illness danger to oneself; and (3) planning and acting, which involves imagining response alternatives to deal with the problem and emotions it generates, then taking selected actions to achieve specific effects. Here the feedback loop is achieved by the last step: (4) monitoring or appraising how one's coping reactions affected the environmental problem and oneself.

In a self-regulation model, patients' adherence to a regimen is thought to be influenced by their perceptions and evaluations of the presence or absence of health threats, for example, symptoms. Using the model, Halm, Mora, and Leventhal (2006) have shown that individuals who conceptualized asthma as an acute, episodic illness were significantly more likely than individuals who did not see it as an acute episodic illness to report lower rates of adherence to inhaled corticosteroids at three separate time periods and after controlling

for factors thought to affect medication adherence. Similarly, Brewer, Chapman, Brownlee, and Leventhal (2002) have demonstrated relationships between LDL cholesterol control and the degree to which patients' mental models of disease were similar to those of experts (i.e., physician-like).

In a study of 366 men and women using a clinic of a University Hospital, Cameron, Leventhal, and Leventhal (1995) found that care seeking was a function of the characteristics of the symptoms patients identified as distinctive signs of illness and not of the level of life stresses they experience. Also, this model relies to a fair degree on Bandura's formulations regarding reciprocal determinism and self-regulation, and both this work and Bandura's (1986) Social Cognitive Theory arise from a common theoretical heritage that strongly suggests the importance of the approach to understanding adherence behaviors.

Social Cognitive Theory

Bandura's (1986, 1997, 2004) discussion of social learning attempts to explain and predict behavior using several key concepts: incentives, outcome expectations, and efficacy expectations. Bandura (1977) outlined the roles of these concepts in a paradigm of a person engaging in a behavior that will have a consequent outcome; here, behavior change and maintenance are a function of (1) expectations about the outcomes that will result from engaging in behavior, and (2) expectations about one's ability to engage in or execute the behavior. Thus, "outcome expectations" consist of beliefs about whether given behaviors will lead to given outcomes, whereas "efficacy expectations" consist of beliefs about how capable one is of performing the behavior that leads to those outcomes. The two have been shown to be linked in predicting, for example, exercise behavior (Hallam & Petosa, 2004) and self-management of diabetes (Ianotti et al., 2006). It should be emphasized that both outcome and efficacy expectations reflect a person's beliefs about capabilities and the connections between behavior and outcome. Thus, it is these perceptions, and not necessarily "true" capabilities, that influence behavior. In addition, it is important to understand that the concept of self-efficacy relates to beliefs about one's capacity to perform specific behaviors in particular situations (Marks, Allegrante, & Lorig, 2005); self-efficacy does not refer to a personality characteristic or to a global trait that operates independent of contextual factors (Bandura, 1986, 1997). This means that individuals' efficacy expectations will vary greatly depending on the particular task and context that confronts them.

Bandura (1997) argued that perceived self-efficacy influences all aspects of behavior, including the acquisition of new behaviors (e.g., a sexually active young adult learning how to use a particular contraceptive device), inhibition of existing behaviors (e.g., decreasing or stopping cigarette smoking), and disinhibition of behaviors (e.g., resuming sexual activity after a myocardial infarction). Self-efficacy also affects people's choices on behaviors settings, the amount of effort they will expend on a task, and the length of time they will persist in the face of obstacles. Finally, self-efficacy affects people's emotional reactions, such as anxiety and distress and thought patterns. Thus, individuals with low self-efficacy about a particular task may ruminate about their personal deficiencies,

rather than thinking about accomplishing or attending to the task at hand; this, in turn, impedes successful performance of the task.

Efficacy expectations are learned from four major sources (Bandura, 1977, 1986, 1997). The first, termed "performance accomplishments," refers to learning through personal experience in which one has achieved mastery over a difficult or previously feared task and thereby enjoys an increase in self-efficacy. Performance accomplishments attained through personal experience are the most potent source of efficacy expectations.

The second source is "vicarious experience," which includes learning that occurs through observation of events or other people. These events or people are referred to as "models" when they display a set of behaviors or stimulus array that illustrates a certain principle, rule, or response. In order for modeling to affect an observer's self-efficacy positively, however, it is important that the model can be viewed as having overcome difficulties through determined effort rather than with ease and that the model be similar to the observer with regard to other characteristics (e.g., age, gender). "Verbal persuasion" constitutes the third source of efficacy expectations. This method is quite familiar to all health workers who have exhorted patients to persevere in their efforts to change behavior. Finally, one's "physiological state" provides information that can influence efficacy expectations. Bandura noted that because high physiological arousal usually impairs performance, people are more likely to expect failure when they are very tense and viscerally agitated. For example, people who experience extremely sweaty palms, a racing heartbeat, and trembling knees prior to giving a talk find that their self-efficacy plummets; to someone just beginning an exercise program, fatigue and mild aches and pains may be mistakenly interpreted as a sign of physical inefficacy.

Individuals' sense of self-efficacy has been shown to predict asthma outcomes (Mancuso, Rincon, McCulloch, & Charlson, 2001); HIV risk behavior among low-income women (Sikkema et al., 1995); exercise behavior among arthritis patients (Gyurcsik, Estabrooks, & Frahm-Templar, 2003); disease management of older women with heart disease (Clark & Dodge, 1999); and glycosylated hemogoblin (HbA1c) levels among young adults with diabetes (Johnston-Brooks, Lewis, & Garg, 2002), among other outcomes.

A Model of Disease Self-Management

Drawing from Social Cognitive Theory and especially the construct of self-regulation, Clark (1997), Clark and Gong (2000), Clark, Gong, and Kaciroti (2001), and Clark and colleagues (1988) have proposed a framework for conceptualizing disease management by patients with acute or chronic conditions. In the refined version of this model (see Figure 2.2), self-regulation is viewed as a means by which patients determine what is effective and what isn't, given their specific goals. They make these determinations influenced by their social context and according to the resources they have available. The model is based on three assumptions. First, several factors predispose one to manage a disease. Second, patient management is the conscious use of strategies to manipulate situations to reduce the impact of disease on daily life. One learns which strategies do or do not work through processes of self-regulation. Third, a person is motivated

2.2

The continuous and reciprocal nature of self-regulation processes in disease prevention and management.
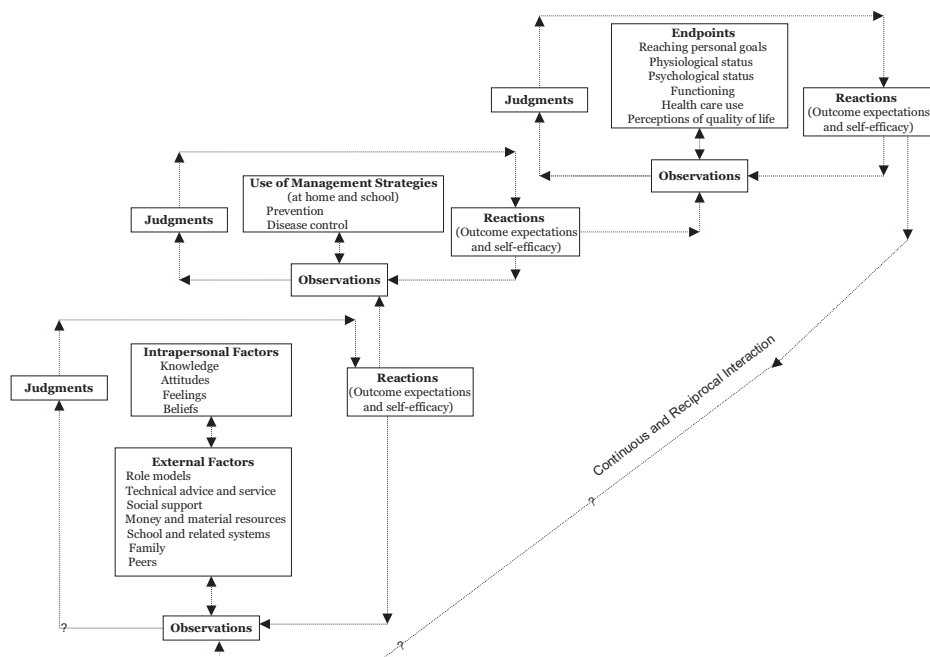
Note. Based on the model from "A Model of Self-Regulation for Control of Chronic Disease" by N. M. Clark, M. Gong & N. Kaciroti, 2001, *Health Education & Behavior*, 28, pp. 769–782. Copyright.

to be self-regulating by a desired goal or end point. The more salient the goal, the more self-regulating a person will try to be. The model is also predicated on the idea that the processes that make up self-regulation are continuous and reciprocal. Information, behavior, understanding, feelings, and conclusions generated from any one element of self-regulation as defined in the model (i.e., observation, judging, reacting) continually influence the other elements.

The model posits that, when taking a disease management action, people are influenced by internal factors, that is, information and beliefs concerning the specific problem. The action is also influenced by what they believe to be the benefits of engaging in the behavior to reach their personal goals and their beliefs that the benefits outweigh the costs. The extent to which people hold the requisite knowledge and beliefs to support an action depends, in part, on a range of external factors. These include interpersonal relationships through which emotional and instrumental (social) support is given and received. Almost certainly involved is technical advice from a clinician who provides therapeutic recommendations. Availability of money and other resources (e.g., the price of medicine and the ability to get to a pharmacy) also influence behavior. It also must be noted that while knowledge, attitudes, and feelings are the basis for action, these can also change as a result of behavior (Bandura, 1986).

Management strategies comprise the individual's means to keep the disease and its effects under control (Clark, Gong, & Kaciroti, 2001). These strategies

may be effective or ineffective and may be consistent with clinicians' recommendations or not. Strategies evolve from people's observations, judgments, and reactions given the aforementioned internal and external factors. Others can influence the strategy chosen, but, in the end, individual personal goals, combined internal and external resources, and degree of self-regulation will dictate which management strategy will be derived and further employed. An example is a child who wants to play full-court basketball who believes he is susceptible to respiratory problems, thinks medicines will help and so uses them preventively, works out a procedure for taking a breather when active, seeks moral support from friends and coaches, and uses other strategies that enable him to reach his personal goal. The child learns which strategies are effective through self-regulation. Self-regulation may be particularly important in diseases where there is no sure-fire formula that an individual can use to control symptoms or deal with crucial interpersonal relationships. In these illnesses, patients (and families) must exercise a high level of decision making in the absence of health professionals. The self-regulatory processes in which they engage entail observing situations where the disease contributes to problems in reaching their goals; judging what types of actions might ameliorate the situation; using management strategies, that is, trying out new behaviors; and drawing conclusions or reacting to the effects of the behavior. Two important reactions are that the behavior resulted in the desired effect and that one can effectively carry out the behavior, that is, self-efficacy (as defined by Bandura, 1997, 2004). Using strategies to prevent symptoms, to manage them effectively, and to manage the interpersonal relationships needed to control the effects of the disease should lead to important outcomes.

The motivating factor in taking disease management action is a personal goal. Goals are highly idiosyncratic. When an educator or clinician (or any other person attempting to assist with disease management) has a goal that is different from that of the individual, the opportunity for successful goal attainment is attenuated. Usually, the clinician has a clinical goal, but this end point is not likely to be as important to the patient as her personal goal. When an educator or clinician focus on achieving the patient's personal goal, the chances are greater that the therapeutic regimen will appeal to the interests of the patient and that she will implement it.

This model was developed in an effort to delineate the discrete elements of self-regulation (observation, judgment, reaction). The assumption of the model presented here is that enabling people to be the best managers of their disease requires helping them to improve their self-regulation skills and modifying external factors so that these influences enhance the patient's ability to be self-regulating. Elements of the model have been shown to be predictive of disease self-management outcomes (cf. Cabana et al., 2006; Clark, Evans, Zimmerman, Levison, & Mellins, 1994; Clark, Gong, & Kaciroti, 2001).

Behavior Modification

Finally, an approach to understanding and influencing adherence behaviors that is substantially different from the cognitive themes emphasized in the previously described models and frameworks is represented by behavior modification. This approach emphasizes the roles played by habit and skill in attempts to modify

undesirable personal (or "lifestyle") behaviors and brings to bear a wide variety of techniques (e.g., contingency contracting, self-monitoring, counterconditioning, covert sensitization, relaxation, environmental engineering) (Miltenberger, 2007). It is not reasonable to suggest a single "model" for behavior modification, although the concepts of behavioral consequences and stimulus control are fairly common elements of them. The general plan that this approach frequently follows is this: identify the problem and describe it in behavioral terms; select a target behavior that is measurable; identify the antecedents and consequences of the behavior; set behavioral objectives; devise and implement a behavior-change program; and evaluate the program. Since cognitive and behavioral models and approaches both have much to offer, it seems reasonable to assume that our best bets for effective interventions will be strategies that combine elements of both.

A Community Decision-Making and Action Model

Given the need to have a broader impact on population health and to reach large numbers of people, an important question is whether there are decision-making models for community-wide health behavior change? The challenge of public health, especially given advances in life sciences that will enable the most refined tailoring of medical therapies to an individual's biological profile, is developing interventions that can be highly specific to individuals but at the same time reach across populations. A health provider can help individual patients and families, but, to effect large-scale change, there must be effective systems, policies, and practices in place that extend assistance to all patients. Communities are finding it increasingly effective to work collectively to bring about policy and system change to prevent and control health problems by developing partnerships and collaborations. Community coalitions are one example (see, e.g., Clark, Malveaux, & Friedman, 2006).

Coalitions as a means to improve health status are widely evident in public health for a range of conditions, and there is an extensive literature regarding coalitions as vehicles for amassing community resources, influence, and energy in pursuit of a health goal (Clark et al., 2006). The key feature of such efforts is collaboration (Alexander et al., 2003), that is, the willingness of stakeholders in a problem to work together cooperatively toward its solution.

Coalition does not refer to the type of stakeholders engaged in collaboration. Rather, the term depicts a way of working. The type of coalition most discussed currently in the literature and, indeed, most often promoted in the field of public health is that which aims to give voice to constituencies not often at the table when the health problems affecting them and their families are considered. By employing this term, Butterfoss, Goodman, and Wandersman (1993) wished to describe a type of coalition that is representative of a given, defined community whose membership reflects all segments of that community's population, not just one sector or type of stakeholder. Reflected in the term is the idea that much of the know-how for resolving problems rests with those who experience them most directly and that they and their experience must be acknowledged in decisions about solutions. These stakeholders can be individuals with the problem or representatives of community-based organizations that understand

the problem in its most compelling form. Implicitly, *community coalition* appears to mean that the given coalition (a) serves a defined community (usually having a common location or experience) recognized by those within it as a community, (b) is purposeful and has a time-specific duration, (c) exists to serve the broader community, (d) is viewed by community residents as representing and serving them, (e) reflects the diversity evident in the community, (f) addresses the problem(s) systematically and comprehensively, and (g) builds community independence and capacity. In bringing about change, coalitions must attend to how they function as a collective of members, as well as how they use strategies to achieve their change goals (Butterfoss, Kelly, & Taylor-Fishwick, 2005).

A comprehensive review conducted by Roussos and Fawcett (2000) identified a number of studies that provide population-wide outcomes where improvements appeared to be attributable to the efforts of a coalition. Examples include declines in lead poisoning in New York City (Freudenberg & Golub, 1987), reduction of infant mortality in Boston (Plough & Olafson, 1994), and improvements in the physical fitness of older adults (Hooker & Cirill, 2006).

A model referred to as the Allies model (Clark et al., 2006) for functioning of coalitions is presented in Figure 2.3. It holds still for an instant the dynamic movement of many factors that are thought to contribute to changed policies, enhanced systems, and improved practices of individuals thought to enable

2.3

Allies coalition model.
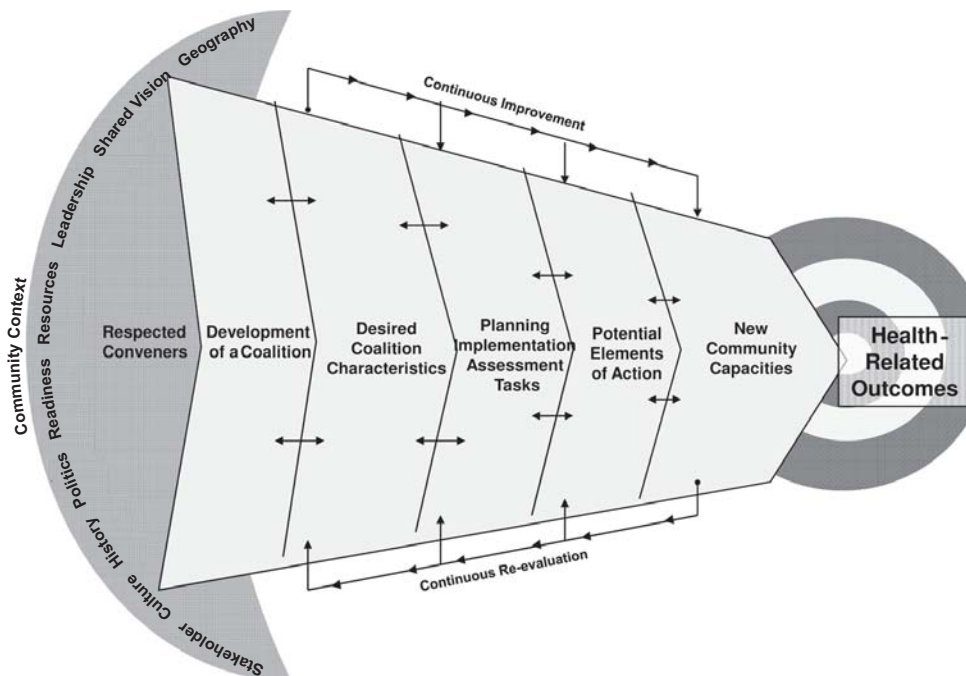
Note. From "Community Coalitions to Control Chronic Disease Allies Against Asthma as a Model and Case Study," by N. M. Clark, L. J. Doctor, A. R. Friedman, L. L. Lachance, C. R. Houle, X. Geng, et al., 2006, *Health Promotion Practice, 7*(2 suppl.), pp. 145–225. Copyright 2006 by Sage Publications. Reprinted with permission.

communities to reach health goals. However, it is important to acknowledge that it is only in the figure that the elements are static. Each factor influences every other one continually and over time within the turbulent field that constitutes any community. Nonetheless, it is likely that, at given moments over the life of a community coalition, it is possible to get very rough measures of these factors.

A pervasive factor for any coalition is the collective characteristics of the community where it strives to do work. A set of community characteristics provides a backdrop for the coalition's efforts and can either support or inhibit its success. It is, therefore, important for coalitions to pay attention to these characteristics, particularly during the formative stage.

Another important asset is the respected convener(s). Is there a respected person or agency seen by the community as important to resolving the problem and at the same time not closely associated with perspectives, factions, or authorities that are not trusted?

There is a need for ongoing internal leadership. Members must have an adequate understanding of the magnitude and importance of the problem the coalition is addressing. An infrastructure for functioning must be developed and maintained. Credibility in the wider community and participation that is diverse and representative of the entire community must be engendered. Stakeholders' commitment to the mission must be elicited and maintained. Trust levels must be sufficient to enable real collaboration, and mutual benefit must be recognized. Communication must be adequate and benefits for participation clear. Expert assistance must be available and used as needed.

When optimal structures and internal procedures are in place and a coalition reflects the organizational characteristics of success, it effectively moves toward its goals. Careful planning that draws on the collective wisdom, experience, and skills of the stakeholding members is necessary. Strategies to translate the plan into action and taking the indicated actions are required.

A coalition's characteristics reflect the intrapersonal characteristics described in self-regulation models. An additional similarity between the Allies coalition model and the previously discussed self-regulation model of disease self-management is evident. The elements of self-regulation—observation, judgment, trial behavior, and reaction—are clearly part of the Allies model as they are carried out community-wide. For example, ongoing evaluation and continuous feedback about the extent or level of the characteristics of a coalition is crucial to effective stakeholder engagement and commitment, and ongoing evaluation and continuous feedback are necessary to continually refine and modify plans and strategies the coalition has implemented or as it puts new ones into place.

Through these "self-regulating" features, a coalition structures itself and takes effective action. Action can take the form of coordination and integration of community services, establishment of exemplar programs or services, leadership in advocacy, or policy formation. Coalition action has been documented to include coordinating and providing systemic services for children with asthma and their families in seven communities around the United States, as well as providing families in the community with the skills they need to manage respiratory disease, and training health providers to both practice at the standard of care and support family self-management efforts (Clark et al., 2006). These were achievements institutionalized through policy changes that ensured adequate provision of quality care and directed resources for asthma

control. More comprehensive studies are needed to illuminate the connection between aspects of coalition functioning and changes in community-wide behavior, health care systems, and health-related conditions.

Summary

This chapter has summarized and depicted the major elements of a number of well-known and widely employed psychological, behavioral, and sociological models of health-related decision making and action and has summarized some of the major strategies advanced in the empirical literature for increasing adherence and self-management. While further theoretical conceptualization and empirical investigation regarding behavioral determinants of (and strategies for influencing) patient health status are certainly still needed, the variables identified and suggestions offered in this chapter provide the foundation for programs that can be implemented by health care providers and public health planners wishing to improve levels of patient cooperation and ability to use health-related recommendations.

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Culture and Health-Related Behavior

3

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Culture, defined as *what is learned, shared, transmitted intergenerationally, and reflected in a group's values, beliefs, norms, behaviors, communication, and social roles,* can affect health-related behaviors both directly and indirectly (Kreuter & Haughton, 2006). In clinical settings, health care providers are responsible for delivering evidence-based care that meets their patients' needs for maintaining health, preventing and managing chronic disease, and decreasing human suffering. Given the increasing diversity of the American population, clinical trials must provide evidence of efficacy and effectiveness of health-enhancing interventions in diverse samples and populations. Evaluating the generalizability of research findings across diverse groups (Office of Minority Health & U.S. Department of Health and Human Services, 2007) is an important stepping stone to decrease health disparities.

Current literature on culture and health, and particularly health behaviors, is very limited. However, interest in culture is growing due to numerous findings that ethnic minority patients are less likely to receive, or have differential outcomes from, preventive, diagnostic, medical, or surgical interventions, even after adjusting for severity of illness, access to care, and poverty (Ang, Ibrahim, Burant, Siminoff, & Kwoh, 2002; Escarce, Epstein, Colby, & Schwartz, 1993; Ford & Cooper, 1995; Hannan et al., 1999; Keppel, 2007; Lee, Gehlbach, Hosmer, Reti, & Baker, 1997; Shi, 1999; Smedley, Stith, & Nelson, 2003; Suarez-Almazor et al., 2005). An understanding of an individual's or a group's cultural context is essential for targeting health behavior change and decreasing health disparities, an important public health issue. Although there has been a movement in many disciplines to increase cultural competence, many researchers and clinicians still do not assess or understand culture appropriately.

In this chapter, we approach the topic of culture from an empirical and a theoretical perspective and discuss the importance of conducting theory-based research to enhance our understanding of cultural influences on behavior. The first section of this chapter is a review of commonly used culture-related concepts and definitions. The second section presents empirical evidence of the influence of culture on screening and preventive behaviors, illness and symptom perception, and disease management behaviors. The third section summarizes some of the most frequently cited theoretical models of behavior, which can be useful in accounting for the effect of culture on behavior. Last, we conclude with implications of culture for health care and for clinical and population research.

Culture-Related Definitions

Cultural Influence

Cultural influence refers to the degree to which the values, beliefs, norms, and traditions common to a particular group affect or sway the behavior of the individual members of the group. Culture can influence behavior through its influence on values and beliefs and traditional roles and social customs and its impact on what people see as acceptable, appropriate, and desirable behavior. These values, beliefs, and roles ultimately guide how someone acts (Haviland, 1999).

Cultural Change

There is a certain degree of permanency in cultures. However, cultures are not static. Changes in culture can occur to various degrees and at varying rates. Aspects of a culture may change and affect other aspects of that culture; for example, changes in politics often affect economics. Likewise, the learning of a new language (an important cultural symbol) by a group can bring on the adoption of other behaviors (e.g., greater engagement in the health care system) among members of that group. Cultural changes such as changes in beliefs and behaviors also can occur as a result of "lived experiences," that is, experiences that people (or groups of people) go through as they live their lives (Garro, 2000). At

the individual level, these can include but are not limited to acquisition of education or migration to a new country, county, or region. Recent examples at the group level include disasters that affect regions (Hurricane Katrina's effect on the Gulf Coast or the effect of 911 on New York City and the United States).

Society and Subcultures

Society is defined as a group of people who have a common homeland, are dependent on one another for survival, and share a common culture often referred to as "mainstream" culture (Haviland, 1999). However, no member of a society experiences the same exact culture; culture shared by members of a society is not uniform, and multiple subcultures coexist within a single society. An example of one aspect of the mainstream American culture (or society) that affects Americans from all subcultures is the high number of fast-food chains. Many researchers believe that the high accessibility of calorie-dense food has contributed enormously to the obesity epidemic.

Individuals can belong to many different cultures and subcultures (Haviland, 1999). A subculture is defined as a group within a society that functions by its own distinctive standards of behavior, while at the same time sharing some standards in common with the general culture (Haviland, 1999). For example, although members of a society may share a common homeland and language (e.g., English in the United States), multiple subcultures exist and are represented by age (e.g., senior citizen), gender, religion, sexuality, occupation, social class, and regional (e.g., northeast) groups, among other factors. Although race and ethnicity are often considered proxies for culture, they exhibit great subgroup variation. For example, regional and socioeconomic differences between groups may be more important in determining behavior and some health disparities than racial or ethnic differences (Coughlin et al., 2006; Foster, 2006; McGory, Zingmond, Sekeris, Bastani, & Ko, 2006; Parikh-Patel, Bates, & Campleman, 2006); likewise, significant differences among Hispanic groups exist, organized by country of origin (birthplace) and socioeconomic status (Caban & Walker, 2006).

Culture Transmission

Transmission of culture is the process by which specific aspects of a culture (i.e., language, beliefs, rituals, appropriate behavior) are passed down from one generation to the next. Multiple factors affect the transmission of culture, including the family, peers, schools, work groups, geography, politics, and societal forces such as the media. Transmission of a culture begins soon after a child is born, through enculturation and socialization (Berry, Poortinga, Segall, & Dasen, 1992). Early in a child's life, the most important role models and transmitters of culture are the child's parents and siblings, who shape the child's behavior. As the child ages and begins to spend more time outside the home, other influences become important. These include rewards experienced for adherence to cultural standards in the form of "social acceptance," which can become especially important during adolescence. Transmission of culture also occurs via the media. This has a powerful effect shaping the views and attitudes of individuals in and across societies in the world (Wilson, Gutierrez, & Chao, 2003).

Acculturation

Transmission of a new culture can also occur later in life (as an adult) and after one has already become rooted in a different culture. This usually results when an individual changes geographic location and has to adapt to new cultural sanctions. Acculturation is the degree to which cultural elements of a mainstream culture are adopted by another group (e.g., a migrant group). Individuals may have varying levels of acculturation to a mainstream culture. Degree of acculturation has been measured by a combination of factors, including language spoken at home, years in the United States, citizenship status, and place of birth, as well as along various psychosocial measurements. The impact of acculturation on health has been studied particularly among Hispanics and Asian Americans, and an association between level of acculturation and health and health behaviors has been shown (Borrayo & Guarnaccia, 2000; Elder et al., 1991; Goel et al., 2003; Gonzalez, Haan, & Hinton, 2001; Lara, Gamboa, Kahramanian, Morales, & Bautista, 2005). It is likely that, as the United States continues to increase in diversity, acculturation will be an important variable to examine in health care settings and research.

Ethnocentrism

Transmission of culture from one generation to the next depends, to some extent, on how individuals feel about their culture. Ethnocentrism is the belief that one's own culture is superior to all others. This belief is adaptive for transmission of a culture or preserving key aspects of a particular culture. However, ethnocentrism can also become a barrier when one needs to understand or gain information about another culture. This is relevant to developing health promotion or disease management interventions that meet the needs of individuals of a particular culture. In order to gain an unbiased view of someone else's culture and thus understand individuals in their own cultural terms, researchers and health care providers must be able to see their own cultural biases and suspend judgment on culture-related practices of targeted individuals or groups. This process is referred to as cultural relativism (Haviland, 1999).

Cultural Competence

Cultural competence is having the capacity to function effectively as an individual or an organization within the context of the cultural beliefs, behaviors, and needs presented by a particular group or community (U.S. Department of Health and Human Services & Office of Minority Health, 2001). It requires (1) awareness of one's own cultural values and biases, (2) knowledge of others' views and perspectives, and (3) the skills to design and effectively deliver culturally appropriate interventions (Harris-Davis & Haughton, 2000).

Cultural Sensitivity

Cultural sensitivity refers to the extent to which ethnic and cultural aspects of a target population, as well as relevant historical, political, environmental, and social forces, are incorporated in the design, delivery, and evaluation of targeted

interventions, materials, and programs (Resnicow, Baranowski, Ahluwalia, & Braithwaite, 1999). There are two types of cultural sensitivity: surface structure and deep structure. Surface-structure strategies involve matching behavioral interventions to characteristics of a target population. For example, an intervention for promoting physical activity among African American women based on surface structure may include materials that show pictures of African American women walking or lifting weights, with no attention to values and beliefs of the population of interest. Deep-structure strategies, on the other hand, target beliefs and values and incorporate messages to the population of interest that are in line with their beliefs and values as a culture (Resnicow et al., 1999). For instance, some within the African American community believe that the government is somehow facilitating the spread of HIV among members of their community (Bogart & Thorburn, 2005). Thus, a deep-structure culturally sensitive intervention would need to directly address this belief.

Empirical Evidence of Cultural Influences on Health-Related Behaviors

In this section, we review empirical evidence suggesting that elements of culture influence health behaviors and, ultimately, can have an impact on health disparities. There is much evidence to suggest that, even when the effects of socioeconomic status (SES) factors are accounted for, numerous racial and ethnic differences still exist in health outcomes and behaviors (Smedley et al., 2003). We review this evidence as it pertains to definitions of disease and disorders and to a variety of health-related behaviors, including use of health screenings, disease prevention and disease management, and treatment behaviors.

Culture and Health Screening Behavior

Health screenings are an important component of preventive care, yet adherence to health screening guidelines is suboptimal among certain groups and contribute to health disparities (Ata et al., 2006; Boltri, Okosun, Davis-Smith, & Vogel, 2005; Finney, Tumiel-Berhalter, Fox, & Jaen, 2006; Neal, Magwood, Jenkins, & Hossler, 2006).

An example of how cultural beliefs influence screening behaviors can be observed among Asian Americans. Asian Americans are the only racial group in the United States to experience cancer as the leading cause of death (Centers for Disease Control, 2004b; Fried, Prager, MacKay, & Xia, 2003). Rates of both breast and cervical cancer screening are very low among this population (Kagawa-Singer & Pourat, 2000). In fact, the proportion of Asian American women who receive mammograms and who adhere to cancer screening guidelines is the lowest among any of the racial or ethnic groups (MacLean, 2004). The cancer burden that affects this group might be significantly reduced by increasing earlier detection. Attitudes and beliefs of Asian American women have been found to be related to cancer screening rates. For instance, cultural traditions such as Buddhism, Taoism, and Confucianism, which focus on acceptance of the natural order of life (Allinson, 1989; Graham, 1990), lead Asians to view disease and illness as a part of the life cycle and as something out of their

control, which is likely to influence engagement in screening behaviors (Kwok & Sullivan, 2006). In the Chinese culture, for instance, people often explain life events, including health and illness, in terms of luck, fortune, or fate (Allinson, 1989). These culturally influenced perceptions are likely to influence Asian individuals' perceptions of health screenings.

Culture and Preventive Behavior

The current medical literature provides ample evidence that several prevalent and costly diseases can be prevented, or their onset delayed, through interventions (e.g., lifestyle, medications) that decrease disease risk factors (Davidson & Toth, 2004; Ferdinand, 2005; Khan et al., 2006; Knowler et al., 2002; Turnbull, 2003). Thus, behavioral adherence to preventive interventions may be key to prolonging health and quality of life.

Empirical evidence of the influence of culture on prevention can be observed in the area of HIV prevention. In the United States, the African American community is disproportionally affected by HIV/AIDS, with a higher incidence of new AIDS cases and a death rate from AIDS seven times that of Whites (Centers for Disease Control and Prevention, 2001, 2002). This is despite the significant advances that have been made in the treatment of HIV/AIDS, in particular the availability of Highly Active Anti-Retroviral Treatment (HAART). Cultural factors may partially explain these disparities. Evidence exists that several minority groups (i.e., African Americans and Hispanics) (Bogart & Bird, 2003; Bogart & Thorburn, 2005; Herek & Capitanio, 1994; Klonoff & Landrine, 1999; Ross, Essien, & Torres, 2006) hold common conspiracy beliefs about HIV, including the belief that HIV is created by the government and planted in Black communities, that a cure is being withheld from the poor, that people who take new medications are guinea pigs for the government, that a lot of information about AIDS is being withheld from the public, and that medicines that are used to treat HIV actually cause AIDS (Bogart & Bird, 2003; Bogart & Thorburn, 2005; Herek & Capitanio, 1994; Herek & Glunt, 1991; Klonoff & Landrine, 1999). These conspiracy beliefs have been associated with negative attitudes toward condoms and inconsistent condom use in African American populations, thus minimizing the effect of HIV prevention interventions.

Although the examples described here illustrate ways in which culture can negatively impact adherence to prescribed health behaviors, there also is evidence of positive cultural influences on preventive behaviors. Evidence exists that Hispanics have lower rates of smoking than most other racial and ethnic groups with the exception of Asian Americans (Centers for Disease Control and Prevention, 2005a). Among Hispanics who do currently smoke, reports suggest that they smoke fewer cigarettes per day (Haynes, Harvey, Montes, Nickens, & Cohen, 1990; Marcus & Crane, 1985; Perez-Stable, Marin, & Marin, 1994), have lower average serum cotinine levels, and have lower nicotine addiction (Palinkas et al., 1993; Perez-Stable, Marin, Marin, & Benowitz, 1992; Winkleby, Schooler, Kraemer, Lin, & Fortmann, 1995). The Hispanic culture may in part explain differential prevalence rates of smoking. For example, Hispanics were more likely to cite family and interpersonal relationships as important reasons to quit smoking, suggesting that the interdependence (traditionally emphasized over independence) and the importance of the family

(*familialismo*) that are characteristic of the Hispanic culture may, at least partly, explain the fact that Hispanics have lower smoking rates than do Whites. Likewise, lack of family approval has been shown to keep many young Hispanics from initiating smoking (Foraker, Patten, Lopez, Croghan, & Thomas, 2005). The wish to avoid or minimize interpersonal conflict (*simpatia*), another traditional trait of Hispanic cultures, may be another motivator in a Hispanic person's decisions not to start smoking (Perez-Stable, Marin, & Posner, 1998).

Culture, Illness Perception, and Disease Management

Individuals from different cultures may have different experiences or interpretations of bodily symptoms, what constitutes a disease, and what interventions and treatments are acceptable (Betancourt, 2006; Surbone, 2006; Waite, 2006; Ward, 2007). Interventions to treat or manage diseases, especially chronic diseases, require that a patient follow a set of behavioral prescriptions, including taking the appropriate medications in the prescribed dosage and schedule, undergoing diagnostic tests, adhering to lifestyle changes, and scheduling and attending medical visits, among other behaviors. In this section, we summarize empirical evidence that support the impact of cultural factors on illness perception and diagnosis, treatment-seeking behaviors, treatment choice, and adherence.

Perceptual differences potentially affect what individuals from different cultures do and what interventions they are willing to adhere to in the face of specific bodily symptoms or health conditions. These differences pose difficulty for health care providers who may not be aware of diverse cultural definitions of illness. Culture-bound syndromes are a clear example of this issue. The Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association (DSM-IV) defined these as "recurrent, locality-specific patterns of aberrant behavior and troubling experience that may or may not be linked to a particular DSM-IV diagnostic category" (American Psychiatric Association, 1994, p. 844). Many of these patterns are indigenously considered to be "illnesses," or at least afflictions, and most have local names. One example of a culture-bound syndrome is susto, which is present in Latin American or Hispanic populations. Susto is usually associated with a broad array of symptoms, including nervousness, anorexia, insomnia, listlessness, despondency, involuntary muscle tics, and diarrhea. The causes of susto are thought to be fright that results in a loss of soul from the body and can result from natural or supernatural events. For instance, susto may occur after one is in a near-accident or an actual accident or after one has witnessed a supernatural phenomenon such as a ghost. The symptoms associated with susto are often misinterpreted by health care providers, and the most frequent diagnosis that is given in the United States for these symptoms is tuberculosis (Rubel, O'Nell, & Collado-Ardon, 1984).

Symptom reporting and coping among various cultural groups may affect providers' response to patients and the interventions and treatments prescribed. For example, a review of cross-cultural studies (Calvillo & Flaskerud, 1991) concluded that White Americans of northern European origin react to pain stoically and withdraw if pain intensifies. This response to pain has become the cultural norm in the United States and is the behavior that providers expect and value.

Treatment preferences for common medical conditions also are influenced by the patient's culture. An example of this is the considerable influence of ethnicity on whether one chooses knee replacement as the treatment for knee osteoarthritis. Joint replacements, the number one most common procedure among hospital discharges in the United States, are elective procedures that provide substantial benefits in pain relief and quality of life (Callahan, Drake, Heck, & Dittus, 1995). However, despite these benefits, Hispanic and African Americans patients are half as likely as Whites to undergo surgery, even after controlling for income and access to care (Ibrahim, Siminoff, Burant, & Kwoh, 2002a, 2002b). African American patients in particular are the least likely to consider surgery, despite reporting more severe symptoms, even when significant physician counseling has been provided (Ibrahim et al., 2002a, 2002b). Willingness to undergo surgery is related to beliefs about the efficacy of the procedure, expectations of postsurgical pain and functional difficulties, and whether one knows individuals in one's close social environment who has undergone the procedure (Ibrahim et al., 2002a, 2002b; Suarez-Almazor et al., 2005). Also, perception of prayer as helpful in coping with arthritis has been associated with willingness to undergo surgery among African Americans (Ang et al., 2002).

Another example of the impact of culture on disease management is the use of pharmacotherapy for depression in Hispanic and African American populations. Depression is a highly prevalent condition, affecting 20% of Americans at some point in their lives (Gotlib & Hammen, 2002), and the burden of depression is especially high among the poor and minorities (Cooper et al., 2003; Falcon & Tucker, 2000; Lagomasino et al., 2005; Miller et al., 2004; Miranda & Cooper, 2004). Although African Americans and Hispanics may be less likely to receive appropriate treatment for depression than Whites (Miranda & Cooper, 2004; Simpson, Krishnan, Kunik, & Ruiz, 2007), even when primary-care providers recommend depression treatment, African American and Hispanic patients are much less likely to accept antidepressant treatment than their White counterparts (Miranda & Cooper, 2004) and are less likely to adhere to antidepressant therapy once they begin treatment (Diaz, Woods, & Rosenheck, 2005).

Hispanics consider antidepressant medication a less acceptable treatment than do Whites (whose rates of antidepressant use tripled between 1988–1994 and 1999–2000) (Centers for Disease Control, 2004a). As explained by Kleinman's model (Kleinman, Eisenberg, & Good, 1978), the physician and the patient are operating under two different explanations of the symptoms. Health care providers of Western medicine who prescribe antidepressant medications for treatment of depressive symptoms operate under the belief system that depression is a disease. Patients, on the other hand, may be operating under a different set of beliefs regarding the reason for their symptoms. For example, findings from qualitative research suggest that both cultural beliefs, including spiritual and religious attitudes, and stigma may explain the lack of acceptability of, and low adherence to, treatment with antidepressant medication in these populations (Cooper-Patrick et al., 1997). These cultural differences are likely to lead to noncompliance, strained patient-provider relations, and untreated symptoms. Kleinman's model is one way to view and explain the disparities in mental health treatment, especially in the case of taking antidepressant medications, among individuals with different cultural views on medicine (Kleinman et al., 1978).

Theoretical Frameworks That Account for Cultural Influences on Behavior

As stated earlier, empirical evidence suggests an important role of culture on the health behavior of individuals. In this section, we review theoretical frameworks that help explain the specific mechanisms by which culture influences behavior. This review is limited to commonly cited theories in the fields of preventive and behavioral medicine. Traditionally, theories have emphasized intra-individual factors as they affect health behaviors. Several well-known theories emphasize the role of cognition on human behavior: the *Folk Model* (otherwise known as Cultural Model) (Shore, 1996), *Prototype Theory* (Rosch, Mervis, Gray, Johnson, & Bayes-Braem, 1976), and the *Health Belief Model* (Becker, 1974; Janz & Becker, 1984). Others, such as *Social Cognitive* (Bandura, 1986) and *Operant* (Skinner, 1953, 1969, 1983) theories, emphasize an interaction between the individual and the environment. Recently, there has been greater recognition of the need to expand current theoretical frameworks and models to include the immediate and more distant environments in our understanding of human behavior (Matson-Koffman, Brownstein, Neiner, & Greaney, 2005). An example of this is the *Ecological Model* (Stokols, 1992, 1996). These theories and models are briefly reviewed in this section.

The Folk Model

The Folk Model proposes that behavior is influenced by "cultural models," thought of as loose, interpretative frameworks or cognitive categories used by people to understand the world and human behavior. These are taught through other members of a group, both overtly and unconsciously. These models are not fixed but malleable through the individual's personal experiences, which can either reinforce existing models or challenge these models (Shore, 1996). The Folk Model (Holy & Stuchlik, 1981; Shore, 1996) can be useful in explaining phenomena such as the low rates of mammogram screening among Asian Americans described earlier. It may be that specific beliefs associated with the Asian culture, including the belief that illness and disease are part of the life cycle over which they have little control, affect their health prevention behavior. Chinese people often explain health and illness in terms of luck, fortune, or fate (Allinson, 1989), and these beliefs result from generations of learning (the Folk Model) from other members of the culture, either overtly through verbal statements regarding health or health behaviors or through watching how people deal with illness, treatment, diagnoses, and the health care system. The Folk Model can also explain individual differences in behavior among Asian women. Personal experiences (i.e., interactions with a coworker who was diagnosed with early-stage breast cancer through mammography) can modify these folk models and thus influence that individual's behavior.

Prototype Theory

Prototype Theory proposes that, given the complexity of the stimuli in our world, individuals develop categorization systems in order to understand the

environment and to deal with the overwhelming stimuli in it (Rosch et al., 1976). Individuals then base their judgments and decisions regarding a behavior, person, or object on the similarity between its features and the prototype (Cantor & Mischel, 1979). The types of prototypes that one has are likely to differ depending on one's culture. For instance, an individual's prototype of a high-socioeconomic-status (SES) middle-aged White female is likely to differ depending on (1) who the individual is and what that individual has learned through his own culture about high-SES White females, and (2) what the individual's personal experience has been like with high-SES White females. A young African American male from a low-SES background is likely to have a different prototype of high-SES White females than a woman from this "prototypical group." This prototype model has been used to explain stereotypes (Hilton & von Hippel, 1996). A stereotype is a generalization about a group of people in which identical characteristics are assigned to virtually all members of the group, regardless of actual variations among group members (i.e., characteristics of a culture are overgeneralized to all individuals of that culture). Overgeneralization of a negative characteristic is known as prejudice (Berry et al., 1992). Another type of prototype consists of "exemplary" examples for different categories (Lakoff, 1982). For instance, in discussing exercise with a patient, exemplary examples that may come to a clinician's mind at first are jogging or weight lifting. Examples of exercise that may not come to mind at first are yoga, Pilates, or marital arts. Prototype theory can be useful in understanding biases that affect perceptions and behaviors of patients and providers alike.

The Health Belief Model

The Health Belief Model (HBM) (Becker, 1974; Janz & Becker, 1984) is discussed in depth in chapter 2. Briefly, it provides a cognitive theoretical framework for understanding mediators of health-related behavior. The HBM is a value-expectancy theory that emphasizes that behaviors are mediated by thoughts and "expectations" regarding the behavior. Specifically, the model suggests that an individual's health behavior is affected by that person's desire to avoid illness or to get well (value) and the individual's belief that a specific health action available to him or her will prevent or improve illness (expectation). Accordingly, people will take action to prevent, screen for, or control their disease-health conditions if they believe that they are susceptible to disease (perceived susceptibility), that the disease will have serious consequences (perceived severity), that there are benefits to engaging in the behavior (perceived benefits), and that there are few barriers that prevent this behavior (perceived barriers). Thus, an individual will weigh her perceived susceptibility and the severity of the disease against the benefits and barriers to making the necessary changes. More recently, the concept of self-efficacy, or one's confidence in one's ability to take action, has been included in the model (Rosenstock, Strecher, & Becker, 1988). This model can be useful in our understanding of the influence of culturally based beliefs on health-related behaviors described earlier.

Social Cognitive Theory (SCT)

Social Cognitive Theory is one of the most commonly used theoretical frameworks in behavioral science (Bandura, 1986). SCT is discussed in depth in

chapter 2. It posits that human behavior is the result of a triadic, dynamic, and reciprocal interaction among personal factors, behavior, and the environment, mediated by cognitive processes. The constructs of self-efficacy (belief in one's capacity to successfully perform a particular behavior) and outcome expectations (anticipated result of performing a specific behavior) are used to explain initiation of behavior as well as the persistence of the behavior over time and in the face of challenges (Bandura, 1997). An individual's standards (learned from experiences with the environment) and social sanctions have a role in behavioral self-regulation. Behavior that is consistent with the prevailing social norms is approved and rewarded by members of the society, whereas behaviors that violate these norms are punished. Individuals behave in ways that bring self-satisfaction and refrain from behaving in ways that are inconsistent with their own set of standards (Bandura, 1997). This model has had great applicability in understanding of individual behavior and has potential for use in understanding of culturally based group behavior. For instance, the low rates of breast cancer screening among Asians and African Americans (described earlier) can be explained by weak outcome expectations regarding screening mammograms. Likewise, cultural beliefs leading to lack of trust in the health care system among African Americans can affect the beliefs that they will adhere to a prescribed medication regimen (self-efficacy) and that taking a prescribed medication (e.g., antihypertensives) will reduce their risk of stroke (outcome expectation). Also, an important feature of Social Cognitive Theory, and relevant to the study of culture and cultural transmission and acculturation, is the role of modeling. Observation of others' behavior and the consequences of those behaviors plays a role in the transfer of culture among individuals by communicating which behaviors will be rewarded and which will be punished and in what contexts (Iversen & Lattal, 1991).

Operant Theory

Operant Theory, another well-known psychological paradigm for understanding behavior, is relevant to culture and has been applied to acculturation (Landrine & Klonoff, 2004). It proposes that behavioral antecedents and consequences regulate behavior (Glenn, Ellis, & Greenspoon, 1992; Skinner, 1969, 1983). The same general principles of discriminative stimuli, reinforcers, and punishers used to explain individual behavior in accordance with Operant Theory are applied to understand the behavior of groups and entire cultures. Antecedents (also referred to as discriminative stimuli) are features of the context or environment that signal whether and what contingencies will follow a behavior, whereas consequences are events that occur contingent upon the behavior of interest and that either increase (through reinforcement) or decrease (through punishment) the probability that that behavior will reoccur (Skinner, 1953, 1969, 1983). Culture determines what events become antecedents or discriminative stimulus for the occurrence of a particular behavior. For example, it is hypothesized that antecedent factors play a role in increased drinking among acculturated Hispanic women. A combination of social acceptance (in the United States) of relatively high amounts of alcohol consumption by women and a variety of environmental cues for drinking (including media that target women) lead to higher rates of drinking among highly acculturated Hispanic women, even when they differ on country of origin (Puerto Rican, Cuban, and Mexican)

than among Hispanic women who are less assimilated (Black & Markides, 1993; Lara et al., 2005; Marks, Garcia, & Solis, 1990). With regard to consequences or contingencies, the culturally dominant values of the individual culture affect, at least partly, the reinforcing or punishing value of a contingency. Contingencies that explain how behavior at the population level is shaped (relevant to cultural transmission) are known as meta-contingencies or cultural contingencies (Skinner, 1969).

Ecological Models

Ecological models focus on the interactions of people with their physical and sociocultural environments and the impact that these transactions have on the individual's behavior (see chapter 5 for an in-depth discussion of this model). The Social Ecological Model of health behavior include the impact of culture on behavior (Stokols, 1992, 1996). This model makes four assumptions: (1) health is influenced by multiple aspects of physical and social environments, (2) environments are multidimensional, (3) human-environment interactions can be described at varying levels of organization, and (4) there is feedback across the different levels of environments and aggregates of individuals. These multilevel models can be used to understand phenomena such as neighborhood effects on behavior, where variables such as media ads that target specific groups can be studied as they affect the health behavior of those groups. Health behavior interventions based on the ecological model target the multiple levels (i.e., interpersonal, sociocultural, and environmental) of influences on health behavior.

Other Considerations and Concluding Remarks

In this chapter we have provided an overview of frequently used culture-related terminology; reviewed empirical evidence of cultural characteristics of ethnic and racial groups in the United States that may have an impact on health behaviors; and reviewed frequently used theoretical frameworks that account for the impact of culture on health behavior and adherence. Up to this point, we have discussed primarily the influence of culture on the individual behavior from the patients' perspective. However, the culture of the provider in the context of developing and delivering interventions to culturally diverse populations is also of great importance.

Increasing cultural competence and developing culturally sensitive interventions among health care providers have the potential to improve health outcomes of ethnically and culturally diverse individuals (Brach & Fraser, 2000). Culturally based beliefs, attitudes, and behaviors of health care providers are likely to influence and be influenced by cultural diversity, as well. Empirical evidence exists that providers' cultural biases have the potential to adversely affect patients. For instance, there is a greater delay in providing HIV treatment to African Americans and Hispanics than to Whites (Turner et al., 2000). Patients who are racially concordant with their physician are more likely to receive HIV treatment than are African American patients whose provider is White (King, Wong, Shapiro, Landon, & Cunningham, 2004). Stereotypical perceptions of patient adherence may account for this differential treatment; providers' beliefs

regarding poor adherence to Highly Active Anti-retroviral Treatment (HAART) among African Americans and other populations may influence their provision of prescriptions of HIV medications to these populations (Bogart, Catz, Kelly, & Benotsch, 2001; Bogart, Kelly, Catz, & Sosman, 2000; Wong et al., 2004). Thus, at a minimum, it is important to know the limits of one's cultural competencies and abilities and how personally held prototypes of certain groups impact our own behavior (Harris-Davis & Haughton, 2000).

It makes intuitive sense that awareness of ethnocentric tendencies and cultural differences may enhance the effectiveness of interventions in culturally diverse populations. However, although much has been written about the importance of cultural sensitivity in the design and implementation of health-promoting interventions, less is known about efficacious strategies to enhance cultural competency and sensitivity among clinicians and researchers working with diverse cultural groups (Beagan, 2003; Godkin & Savageau, 2001). As reviewed earlier, strategies to increase the cultural sensitivity of interventions have been proposed. However, the efficacy of these strategies has not been scientifically studied.

We remind the reader at this juncture of the multitude of cultures and subcultures that coexist in many societies, especially in the United States population. We chose to review ethnic- and race-specific cultural differences that affect health as there is overwhelming evidence that minority Americans have greater prevalence and poorer health outcomes than do White Americans from preventable and treatable conditions, including cardiovascular disease and stroke (Centers for Disease Control and Prevention, 2005b), type 2 diabetes mellitus (Cowie et al., 2006; Lanting, Joung, Mackenbach, Lamberts, & Bootsma, 2005; Mainous et al., 2006), asthma (Centers for Disease Control, 2004a; Gold & Wright, 2005; Smith, Hatcher-Ross, Wertheimer, & Kahn, 2005), HIV/AIDS (Cargill & Stone, 2005; "Racial/ethnic disparities in diagnoses of HIV/AIDS—33 states, 2001–2004," 2006) and obesity (Ogden et al., 2006; Zhang & Wang, 2004). However, significant heterogeneity exists among ethnic and racial groups, and failure to recognize and appreciate the differences within ethnic groups can lead to inappropriate conclusions. For example, when analyses of racial and ethnic data are conducted, "White" is commonly used as the referent (majority) to which all other minority groups are compared (Kumanyika & Morssink, 2006), despite the fact that there is much diversity in the ancestry and biological characteristics of the White group (Bhopal & Donaldson, 1998), as well as in their cultural traditions, belief systems, and behaviors, including health behaviors. Similar issues also exist with the ethnic label "Hispanic" or "Latino," given the great diversity among individuals classified as Hispanic or Latino. Likewise, overt and subtle cultural differences exist among many other groups in society, including groups formed according to age, gender, sexual orientation, profession, and many other classifications. Often, our need to categorize information may minimize important differences among individuals within a particular category.

As the United States continues to become increasingly diverse, a greater emphasis on addressing the health care needs of diverse populations will be critical. This will require awareness of diversity issues and a comprehensive theoretical and empirical understanding of how specific cultural factors within diverse groups influence health behaviors and, ultimately, how to utilize limited

health care resources to improve the health of our culturally diverse population. Much of our understanding of culture and its influences on behavior is atheoretical and retrospective. Future research should include the use of well-studied program planning, implementation, and evaluation models. Among these are the PRECEDE-PROCEED framework (Gielen & McDonald, 2002), which was developed in order to enable program planners and their communities to work together (Green & Kreuter, 1999) and is able to account for cultural influences that impact on program success. The PEN-3 Model (Airhihenbuwa, 1995) also can be considered, as this model is unique in its emphasis on the role of culture on health behavior. New models may be needed that facilitate our understanding of culture. It also will be important to explore models from other disciplines (such as sociology and anthropology) to address the varied culturally based needs of target groups. Although economic concerns favor capitalizing on similarities among cultures, it is unclear that a single universal model to approach cultural influences will have the impact desired.

Cultural awareness, competence, and sensitivity are likely to facilitate the influence of health care providers and researchers alike. Understanding culture will enhance patient-provider communication and potentially the effectiveness of the provider in facilitating behavior change in the patient. For researchers, cultural understanding is likely to enhance the ability to develop interventions compatible with the cultural needs and traditions of diverse populations and to test those interventions with culturally diverse groups. For example, understanding the function of behaviors of interest within a culture (such as social function of specific food-related patterns) can facilitate the understanding of factors that maintain those behaviors; capitalizing on elements of cultures that support adherence to desirable health behaviors (such as the importance of the family) can work in favor of cultural compatibility of interventions; and studying cultural factors relevant to specific groups can assist in the choice of variables, methodologies, and measurements (Rosal, Carbone, & Goins, 2003). Finally, researchers' cultural competence will be crucial to recruiting representative culturally diverse individuals into research studies and retaining these individuals until study completion so that conclusive statements can be made about the generalizability of the interventions.

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The Transtheoretical Model of Behavior Change

4

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The Transtheoretical Model (TTM) is an integrative framework for understanding how individuals and populations progress toward adopting and maintaining health behavior change for optimal health. The Transtheoretical Model uses stages of change to integrate processes and principles of change from across major theories of intervention, hence the name "Transtheoretical." This model emerged from a comparative analysis of leading theories of psychotherapy and behavior change. The search was for a systematic integration of a field that had fragmented into more than 300 theories of psychotherapy (Prochaska, 1979). The comparative analysis identified only 10 processes of change, such as consciousness raising from the Freudian tradition, contingency management from the Skinnerian tradition, and helping relationships from the Rogerian tradition.

In an empirical analysis that compared self-changers to smokers in professional treatments, we assessed how frequently each group used each of the 10 processes (Prochaska & DiClemente, 1983). Our research participants kept saying that they used different processes at different times in their struggles with smoking. These naive subjects were teaching us about a phenomenon that was not included in any of the multitude of therapy theories. They were revealing to us that behavior change unfolds through a series of stages (Prochaska & DiClemente, 1983).

From the initial studies of smoking, the stage model rapidly expanded in scope to include investigations of and applications to a broad range of health and mental health behaviors. These include alcohol and substance abuse, anxiety and panic disorders, stress and depression, partner violence and bullying, delinquency, eating disorders and obesity, high-fat diets, exercise, HIV/AIDS, use of mammography screening, medication compliance, unplanned pregnancy, pregnancy and smoking, radon testing, sedentary lifestyles, sun exposure, and the practice of preventive medicine. Over time, these studies have expanded, validated, applied, and challenged the core constructs of the Transtheoretical Model.

Core Constructs

The Transtheoretical Model has concentrated on six stages of change; 10 processes of change; the pros and cons of changing; self-efficacy; and temptation as core constructs. The Transtheoretical Model is also based on critical assumptions about the nature of behavior change and interventions that can best facilitate such change. Each core construct has been subjected to a wide variety of studies across a broad range of behaviors and populations. These core constructs and critical assumptions are discussed in this section.

Stages of Change

The stage construct is important in part because it represents a temporal dimension. Change implies phenomena occurring over time, but, surprisingly, none of the leading theories of therapy contained a core construct representing time. Behavior change was often construed as an event, such as quitting smoking, drinking, or overeating. The Transtheoretical Model construes change as a process that unfolds over time and involves progress through a series of six stages.

Precontemplation is the stage in which people are not intending to take action in the foreseeable future, a time frame usually measured as the next 6 months. People may be in this stage because they are uninformed or underinformed about the consequences of their behavior. Alternatively, they may have tried to change a number of times and become demoralized about their abilities to change. Both groups tend to avoid reading, talking, or thinking about their high-risk behaviors. They are often characterized in other theories as "noncompliant," "resistant" or "unmotivated," or "not ready" for therapy or health

promotion programs. The fact is that traditional health promotion programs were not ready for such individuals and were not motivated to match their needs.

Contemplation is the stage in which people are intending to change in the next 6 months. They are more aware of the pros of changing but are also acutely aware of the cons. This balance between the costs and benefits of changing can produce profound ambivalence that can keep people stuck in this stage for long periods of time. We often characterize this phenomenon as chronic contemplation or behavioral procrastination. These folks are also not ready for traditional action-oriented programs.

Preparation is the stage in which people are intending to take action in the immediate future, usually measured as the next month. They have typically taken some significant action in the past year. These individuals have a plan of action, such as joining a health education class, consulting a counselor, talking to their physician, buying a self-help book, or relying on a self-change approach. These are the people we should recruit for action-oriented programs in smoking cessation, weight loss, or exercise.

Action is the stage in which people have made specific overt modifications in their lifestyles within the past 6 months. Since action is observable, behavior change often has been equated with action. In the Transtheoretical Model, however, action is only one of six stages. Not all modifications of behavior count as action in this model. People must attain a criterion that scientists and professionals agree is sufficient to reduce risks for disease. In smoking, for example, the field used to count reduction in the number of cigarettes or a switch to low-tar and -nicotine cigarettes as action. Now the consensus is clear: only total abstinence counts.

Maintenance is the stage in which people are working to prevent relapse but do not apply change processes as frequently as do people in the action stage. They are less tempted to relapse and increasingly are more confident that they can continue their changes. On the basis of temptation and self-efficacy data, we estimated that maintenance lasts from 6 months to about 5 years. While this estimate may seem somewhat pessimistic, longitudinal data in the 1990 Surgeon General's report gave some support to this temporal estimate (U.S. Department of Health and Human Services, 1990). After 12 months of continuous abstinence, the percentage of individuals who returned to regular smoking was 43%. It was not until 5 years of continuous abstinence that the risk for relapse dropped to 7%.

Termination is the stage in which individuals have zero temptation and 100% self-efficacy. No matter whether they are depressed, anxious, bored, lonely, angry, or stressed, they are sure they will not return to their old unhealthy habit as a way of coping. It is as if they had never acquired the habit in the first place. In a study of former smokers and alcoholics, we found that less than 20% of each group had reached the criteria of zero temptation and total self-efficacy (Snow, Prochaska, & Rossi, 1992). These criteria may be too strict, or it may be that this stage is an ideal goal for the majority of people. In other areas, like exercise and weight control, the realistic goal may be a lifetime of maintenance. Since termination may not be a practical reality for a majority of people, this stage has not been given as much emphasis in our research.

Processes of Change

These are the covert and overt activities that people use to progress through the stages. Processes of change provide important guides for intervention programs, since the processes are like the independent variables that people need to apply to move from stage to stage. Ten processes have received the most empirical support in our research to date.

Consciousness raising involves increased awareness about the causes, consequences, and cures for a particular problem behavior. Interventions that can increase awareness include feedback, education, confrontation, interpretation, bibliotherapy, and media campaigns.

Dramatic relief initially produces increased emotional experiences, followed by reduced affect if appropriate action can be taken. Psychodrama, role playing, grieving, personal testimonies, and media campaigns are examples of techniques that can move people emotionally.

Self-reevaluation combines both cognitive and affective assessments of one's self-image with and without a particular unhealthy habit, for example, as a couch potato and as an active person. Value clarification, healthy role models, and imagery are techniques that can move people evaluatively.

Environmental reevaluation combines both affective and cognitive assessments of how the presence or absence of a personal habit affects one's social environment, for example, the effect on others of smoking. It can also include the awareness that one can serve as a positive or negative role model for others. Empathy training, documentaries, and family interventions can lead to such reassessments.

As an example, here is a brief television spot from California's antitobacco campaign, designed to help smokers in precontemplation to progress. A middle-aged man clearly in grief says, "I always worried that my smoking would cause lung cancer. I was always afraid that my smoking would lead to an early death. But I never imagined that it would happen to my wife." Then on the screen is flashed the message, "50,000 deaths per year due to passive smoking—California Department of Health."

There are no action directives in this intervention, but there is (1) consciousness raising—"50,000 deaths per year"; (2) dramatic relief—around the grief, guilt, and fear that can be reduced if appropriate action is taken; (3) self-reevaluation—examination of how individuals think and feel about themselves as smokers; and (4) environmental reevaluation—how individuals feel and think about the effects of their smoking on their environment.

Self-liberation is both the belief that one can change and the commitment and recommitment to act on that belief. New Year's resolutions, public testimonies, and multiple, rather than single, choices can enhance what the public calls "willpower." Motivative research indicates that people with two choices have greater commitment than people with one choice; those with three choices have even greater commitment; but having four choices doesn't enhance willpower (Miller, 1985). So, for smokers, for example, three excellent action choices are quitting cold turkey, nicotine fading, and nicotine replacement.

Social liberation requires an increase in social opportunities or alternatives especially for people who are relatively deprived or oppressed. Advocacy, empowerment procedures, and appropriate policies can produce increased opportunities for minority health promotion, gay health promotion, and health promotion for impoverished people. These same procedures can also be used to help all people change, for example, by offering smoke-free zones or salad bars in school cafeterias and by providing provision of easy access to condoms and other contraceptives.

Counterconditioning requires the learning of healthier behaviors that can substitute for problem behaviors. Relaxation can counter stress; assertion can counter peer pressure; nicotine replacement can substitute for cigarettes, and fat-free foods can be safe substitutes for high-fat foods.

Stimulus control removes cues for unhealthy habits and adds prompts for healthier alternatives. Avoidance, environmental reengineering, and self-help groups can provide stimuli that support change and reduce risks for relapse. Planning parking lots that require a 2-minute walk to the office and putting art displays in stairwells are examples of reengineering that can encourage more exercise.

Contingency management provides consequences for taking steps in a particular direction. While contingency management can include the use of punishments, we found that self-changers rely on rewards much more than on punishments. Consequently, reinforcements are emphasized, since the philosophy of the stage model requires that it work in harmony with how people change naturally. Contingency contracts, overt and covert reinforcements, positive self-statements, and group recognition are procedures for increasing reinforcement and the probability that healthier responses will be repeated.

Helping relationships combine caring, trust, openness, and acceptance as well as support for the healthy behavior change. Rapport building, a therapeutic alliance, coaching calls, and buddy systems can be sources of social support.

Decisional Balance

This core construct reflects the individual's relative weighing of the pros and cons of changing. Originally, we relied on Janis and Mann's (1977) model of decision making that included four categories of pros (instrumental gains for self and others and approval for self and others). The four categories of cons were instrumental costs to self and others and disapproval from self and others. In a long series of studies attempting to produce this structure of eight factors, we always found a much simpler structure—just the pros and cons of changing.

Self-Efficacy

This is the situation-specific confidence that people have when they can cope with high-risk situations without relapsing to their unhealthy or high-risk habit. This construct was integrated from Bandura's (1982) self-efficacy theory.

Temptation

This core construct reflects the intensity of urges to engage in a specific habit when in the midst of difficult situations. In our research, we typically find that three factors account for the most common types of tempting situations: negative affect or emotional distress, positive social situations, and craving.

Critical Assumptions

The following are a set of assumptions that drive our theory, research, and practice:

1. No single theory can account for all of the complexities of behavior change. Therefore, a more comprehensive model will likely emerge from an integration across major theories.
2. Behavior change is a process that unfolds over time through a sequence of stages.
3. Stages are both stable and open to change, just as chronic behavioral risk factors are both stable and open to change.
4. Without planned interventions, most populations will remain stuck in the early stages. There is no inherent motivation to progress through the stages of intentional change as there seems to be in stages of physical and psychological development.
5. The majority of at-risk populations are not prepared for action and will not be served by traditional action-oriented prevention programs. Health promotion can have much greater impacts if it shifts from an action paradigm to a stage paradigm.
6. Specific processes and principles of change need to be applied at specific stages if progress through the stages is to occur. In the stages of change, paradigm intervention programs must be matched to each individual's stage of change.
7. Chronic behavior patterns are under usually some combination of biological, social, and self-control. Stage-matched interventions have been designed primarily to enhance self-controls.

Empirical Support: Basic Research

Stage Distribution

If we are to match the needs of entire populations, we need to know the stage distributions of specific high-risk behaviors. Results from a series of studies on smoking have clearly demonstrated that less than 20% of smokers in the United States are in the preparation stage in most populations (e.g., Velicer et al., 1995). Approximately 40% of smokers are in the contemplation stage, and another 40% are in precontemplation. The stage distribution in other countries are even more dramatic, with 70% of smokers in precontemplation in Germany, 70% in China, and 85% in Japan (Etter, Perneger, & Ronchi, 1997). These results

show that action-oriented cessation programs will not match the needs of the vast majority of smokers.

Pros and Cons Structure Across 48 Behaviors

As indicated earlier, the pros and cons of decisional balance have a much simpler structure than Janis and Mann's (1977) theory suggests. Across 135 studies from 10 countries of 50 different behaviors (e.g., ceasing smoking, quitting cocaine, controlling weight, reducing dietary fat, managing stress, using condoms, acquiring exercise, using sunscreen, testing for radon, reducing delinquency, using mammography screening, and practicing preventive medicine), the two-factor structure was remarkably stable (Hall & Rossi, 2008).

Integration of Pros and Cons and Stages of Change Across 48 Health Behaviors

Stage is not a theory; it is a variable. A theory requires systematic relationships among a set of variables, ideally culminating in mathematical relationships. Figure 4.1 presents systematic relationships between stages and pros and cons of changing from the meta-analysis on 48 behaviors (Hall & Rossi, 2008). One might expect that, given the variability across so many problems and populations, there would be too much noise for a clear signal to emerge. Instead, very predictable and clear patterns were found.

As predicted from a previous study on 12 behaviors (Prochaska et al., 1994a), the meta-analysis of 48 behaviors found that the cons of changing are higher than the pros for people in precontemplation. The pros and cons are about equal

4.1

The pros and cons (in T scores) by stages of change for 48 problem behaviors.
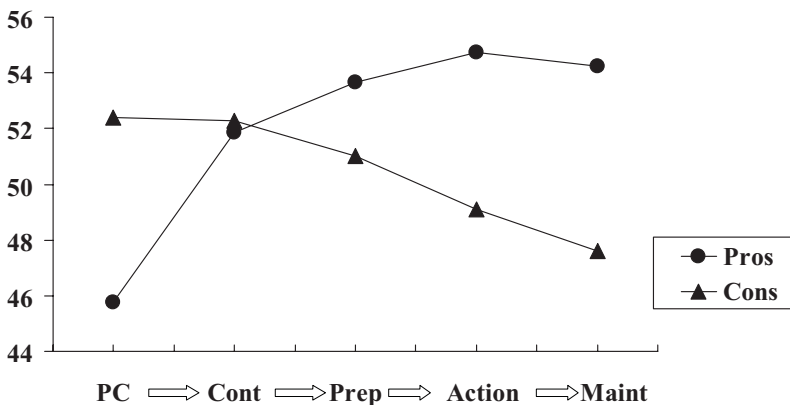
PC = precontemplation; C = contemplation; P = preparation; A = action; M = maintenance

for people in contemplation. The pros increase as people move from precontemplation to action. In contrast, as they go from contemplation to maintenance, the cons of changing are reduced. The pros of changing are higher than the cons for people in preparation through maintenance.

These basic findings suggest principles for progressing through the stages (Prochaska et al., 1994b). For people to progress from precontemplation to contemplation, the pros of changing must increase. To them to progress from contemplation to action, the cons of changing must decrease. So, for people in precontemplation, we would target the pros for intervention and save the cons until after they progress to contemplation. Before progressing to action, we would want to see the pros and cons crossing over, taking a pattern where the pros are higher than the cons as a sign that the person is well prepared for action. Having the pros high enough and the cons low enough is part of what it takes to be well prepared to progress to maintenance with a low chance of relapsing.

Strong and Weak Principles of Progress

Across the original behaviors, mathematical relationships were found between the pros and cons of changing and progress across the stages. The Strong Principle is:

$$PC \rightarrow A \cong 1 \text{ S.D.} \uparrow PROS$$

Progress from precontemplation to action involves approximately one standard deviation (S.D.) increase in the pros of changing. On intelligence tests, a one-S.D. increase would equal 15 points, which is a substantial increase. In the meta-analysis of 48 behaviors, the pros were found to increase exactly 1.00 S.D. (Hall & Rossi, 2008).

The Weak Principle is:

$$PC \rightarrow A \cong .5 \text{ S.D.} \downarrow CONS$$

Progress from precontemplation to action involves an approximately .5 S.D. decrease in the cons of changing. Across 48 behaviors, the cons decreased .53 S.D. In an analysis of two studies relating positive and negative expectancies from Social Cognitive Theory to the Stages of Change (Dijkstra et al., 1999, 2006), it was found that from precontemplation to action, positive expectancies increased 1.12 and 1.17 S.D. (Prochaska, 2006). From contemplation to action, the negative expectancies decreased .49 and .45 S.D. This is an example of how constructs from other theories can be integrated even mathematically by the stages of change (Prochaska, 2006).

One practical implication of these principles is that the pros of changing must increase twice as much as the cons must decrease. Perhaps twice as much emphasis should be placed on raising the benefits as on reducing the costs or barriers. For example, if couch potatoes in precontemplation can list only 5 pros of exercise, then being too busy will be a big barrier to change. But if program participants come to appreciate that there can be more than 50

benefits for 60 minutes a week, being too busy becomes a relatively smaller barrier.

Processes of Change Across Behaviors

One of the assumptions of the Transtheoretical Model is that there is a common set of change processes that people can apply across a broad range of behaviors. The higher-order structure of the processes (experiential and behavioral) has been replicated across problem behaviors better than specific processes have (Rossi, 1992a). Typically, we have found support for our standard set of 10 processes across such behaviors as smoking, diet, cocaine use, exercise, condom use, and sun exposure. But the structure of the processes across studies has not been as consistent as the structure of the stages and the pros and cons of changing. In some studies, we find fewer processes, and occasionally we find evidence for one or two more. It is also very possible that with some behaviors, fewer change processes may be used. With an infrequent behavior like a yearly mammogram, for example, fewer processes may be required to progress to long-term maintenance (Rakowski et al., 1998).

Relationship Between Stages and Processes of Change

One of our earliest empirical integrations was the discovery of systematic relationships between the stage people were in and the processes they were applying. This discovery allowed us to integrate processes from theories that were typically seen as incompatible and in conflict. For example, Freudian theory, which relied almost entirely on consciousness raising for producing change, was viewed as incompatible with Skinnerian theory, which relied entirely on contingency management for modifying behavior. But self-changers did not know that these processes were theoretically incompatible, and they taught us that processes from very different theories needed to be emphasized at different stages of change. Table 4.1 presents our current theoretical integration (Prochaska, DiClemente, & Norcross, 1992). This integration suggests that in the early stages of behavior change, people emphasis cognitive, affective, and evaluative processes to help them progress through the stages. In later stages, people rely more on commitments, conditioning, contingencies, environmental controls, and support to support their progress toward termination.

Table 4.1 has important practical implications. To help people progress from precontemplation to contemplation, we need to apply such processes as consciousness raising and dramatic relief. Applying processes like contingency management, counterconditioning, and stimulus control to people in precontemplation would represent a theoretical, empirical, and practical mistake. But for people in action, such strategies represent an optimal matching.

As with the structure of the processes, the integration of the processes and stages has not been as consistent as the integration of the stages and the pros and cons of changing. While part of the problem may be the greater complexity

4.1	Stages of Change in Which Change Processes Are Most Emphasized				
	Stages of change				
	Precontemplation	Contemplation	Preparation	Action	Maintenance
Processes	Consciousness raising Dramatic relief Environmental reevaluation	Self-reevaluation	Self-liberation	Contingency management Helping relationship Counterconditioning Stimulus control	

of integrating 10 processes across five stages, the processes of change need more basic research.

Applied Studies

Within a large and diverse body of applied studies utilizing TTM, several trends can be identified. The most common application involves TTM-tailored expert system communications, which match intervention messages to an individual's particular needs (e.g., Kreuter, Strecher, & Glassman, 1999; Skinner, Campbell, Rimer, Curry, & Prochaska, 1999) across all TTM constructs. For example, individuals in precontemplation could receive feedback designed to increase their pros of changing to help them progress to contemplation. These interventions have most commonly been printed either on site or mailed to participants at home (Velicer et al., 1993); however, a growing range of applications is developing and evaluating more immediate multimedia expert system programs (Redding et al., 1999) that can be delivered onsite or online.

The largest number of TTM-related intervention studies have involved smoking (Aveyard et al., 1999; Curry et al., 1995; Dijsktra et al., 1999, 2006; O'Neill, Gillespie, & Slobin, 2000; Pallonen et al., 1998; Prochaska et al., 1993, 2001a; Strecher et al., 1994), diet (Beresford et al., 1997; Brug et al., 1998; Campbell et al., 1994; Glanz et al., 1998; Horwath, 1999), and exercise (Cardinal & Sachs, 1996; Marcus et al., 1998). Recent randomized clinical trials (RCT) outcome studies have looked at stress management (Evers, Prochaska, Mauriello,

Padula, & Prochaska, 2006), medication adherence (Johnson et al., 2006a, 2006b), and bullying prevention (Prochaska, Evers, Prochaska, Van Marter, & Johnson, 2007). There is a growing range of applications, from alcohol abuse (Carbonari & DiClemente, 2000), to condom use (Centers for Disease Control, 1999; Parsons, Huszti, Crudder, Rich, & Mendoza, 2000; Redding et al., 2007, Schneider, Wolitski, & Corby, 1997), to domestic violence offenders (Levesque et al., 2008), to organ donation (Robbins et al., 2001), to multiple behavior changes (Gold, Anderson, & Serxner, 2000; Kreuter & Strecher, 1996; Steptoe, Kerry, Rink, & Hilton, 2001).

A recent meta-analysis of tailored print communications found that TTM was the most commonly used theory across a broad range of behaviors (Noar et al., 2007). TTM or Stage of Change Models were used in 35 of the 53 studies. In terms of effectiveness, significantly greater effects were produced when tailored communications included each of the following TTM constructs: stages of change, pros and cons of changing, self-efficacy, and processes of change (Noar et al., 2007). In contrast, interventions that included the non-TTM construct of perceived susceptibility had significantly worse outcomes. Tailoring on non-TTM constructs like social norms and behavioral intentions produced no significant differences (Noar et al., 2007).

While each of the major TTM constructs (stage, pros and cons, self-efficacy, and processes) produces greater effects when each is included in tailored communications, what happens when only some of the constructs are used? Spencer, Pagell, Hallion, & Adams (2002) systematically reviewed 23 interventions that used one or more of the TTM variables for achieving smoking cessation. Most of the studies used just stage of change, and, of these, only about 40% produced significant effects. Five used stage plus pros and cons or self-efficacy, and, of these, 60% produced significant effects. Another five used all of the TTM variables, and 80% of these yielded significant results. This analysis raises the important dissemination question of what it means for practice and applied research to be theory-driven. Most of these studies were variable driven (e.g., they used the stage variable). Future research is needed to determine whether applied research is most effective when a full theory like TTM is applied or whether there is an optimal number of theoretical variables that can produce the same effect sizes, while placing fewer demands on participants and practitioners.

Challenging Studies

As with any model, not all of the research is supportive. Here are samples of some of the more challenging studies. Farkas et al. (1996) and then Abrams, Herzog, Emmons, & Linnan (2000) compared addiction variables to TTM variables as predictors of cessation over 12 to 24 months. Addiction variables, like number of cigarettes smoked and duration of prior quits (e.g., more than 100 days) outpredicted TTM variables, suggesting that addiction models were preferable to TTM. Responses to these comparative studies included concerns that Farkas et al. (1996) compared 14 addiction type variables to just the single-stage variable from TTM (Prochaska & Velicer, 1996; Prochaska, 2006). The Abrams et al.

(2000) study included self-efficacy and the contemplation ladder measure of stage as part of the addiction model, but these are part of TTM. Also, from an intervention perspective, the amount of variance accounted for by predictor variables is less important than the amount of variance that can be controlled or changed. Duration of previous quits (e.g., 100 days) may outpredict stage, but there is little that can be done to change this historical variable, while a dynamic variable like stage is open to interventions.

In the first of a series of studies, Herzog, Abrams, Emmons, Linnan, & Shadel (1999) found that six processes of change were not adequate predictors of stage progress over a 12-month period. In a second report, the processes did predict stage progress, but only when the contemplation ladder was used (Herzog, Abrams, Emmons, & Linnan, 2000). In the third report, TTM measures did predict 12-month outcomes, but, as indicated, earlier self-efficacy and the contemplation ladder were not counted as TTM variables (Abrams et al., 2000). Other research has found that change processes and other TTM variables do predict stage progress (e.g., Prochaska, DiClemente, Velicer, Ginpil, & Norcross, 1985; Prochaska, Velicer, Prochaska, & Johnson, 2004; DiClemente et al., 199l; Dijkstra et al., 2006; Johnson et al., 2000; Sun, Prochaska, Velicer, & Laforge, 2007; Velicer et al., 2007a). Johnson et al. (2000) in their study explained some of the inconsistencies in the previous research, such as predictions over 6 months and those over 12 months and use of all 10 processes of change instead of a subset.

One of the productive responses to critical studies is to do more research. In response to the criticism that addiction levels are better predictors of long-term outcomes than stage of change, a series of studies has been done to determine which types of effects predict long-term outcomes across multiple behaviors. To date, four such effects have been found (Prochaska et al., 2008). The first is severity effect in which individuals with less severe behavior risks at baseline are more likely to progress to action or maintenance and 24-month follow-up for smoking, diet, and sun exposure. This effect includes the level of addiction that Farkas et al. (1996) and Abrams et al. (2000) preferred.

The second is stage effect, in which participants in preparation at baseline have better 24-month outcomes for smoking, diet, and sun exposure than those in contemplation, who in turn do better than those in precontemplation. This effect is what Farkas et al. (1996) and Abrams et al. (2000) criticized.

The third is treatment effect, in which participants in treatment do better at 24 months than those randomly assigned to control groups for smoking, diet, and sun exposure. The fourth is effort effects, in which participants in both treatment and control groups who progressed to action and maintenance at 24 months were making better efforts with TTM variables like pros and cons, self-efficacy, and processes at baseline. There were no consistent demographic effects across the three behaviors indicating that no one demographic group did better across these multiple behaviors. What these results indicate is that either/or thinking, like relying on either severity or stage, is not as helpful as a more inclusive approach that seeks to identify the most important effects, whether they are based on TTM or on an addiction or severity model.

Applying innovative dynamic typologies, Sun et al. (2007) were able to analyze longitudinal relationships of all 14 of the TTM processes and principles of change to three dynatypes (maintenance, relapse, and no change) within a

representative sample of 4,144 smokers in both TTM-tailored treatment and control groups. Assessments at every 6 months over 2 years demonstrated that the stable smokers who failed to progress to action at any assessment were applying the TTM variables least effectively at baseline and continued to apply the process variables similarly for the full 2 years. The maintainers, on the other hand, decreased their use of experiential processes like consciousness raising and self-reevaluation and decisional balance variables like the pros and cons of smoking. They increased their use of behavioral processes like countercon- ditioning and stimulus control and applied other processes like dramatic relief, environmental reevaluation, social liberation, and reinforcement management in a curvilinear pattern of increases followed by decreases. The relapsers par- alleled the maintainers in their initial use of the TTM variables but over time ended up between the maintainers and stable smokers. What was particularly striking was that, even though the treatment group outperformed the control group in terms of the percentage who remained abstinent at 2-year follow-up, the successful quitters in both the intervention and the control groups applied the 14 TTM variables in the same manner and followed common pathways to change. This research may help answer the original question that generated TTM: how very different treatments like Cognitive Behavior Therapy, Motiva- tional Interviewing, and 12-step treatments in Project MATCH (1997) can pro- duce such similar outcomes. The answer might well be that successful changes in different treatments and in control groups apply processes and principles of change in very similar ways.

Applications of the Transtheoretical Model: Smoking Cessation Interventions as Protocol Examples

Smoking is costly to individual smokers and to society. In the United States, approximately 45,000,000 Americans continue to smoke. More than 400,000 preventable deaths per year are attributable to smoking (U.S. Department of Health and Human Services, 1990). Globally, the problem promises to be cata- strophic. Of the people alive in the world today, 500,000,000 are expected to die from this single behavior, losing approximately 5,000,000,000 years of life to tobacco use (Peto & Lopez, 1990). If we can make even modest gains in our sci- ence and practice of smoking cessation, we can prevent millions of premature deaths and help preserve billions of years of life.

Currently, smoking cessation clinics have little impact. When offered for free by HMOs in the United States, such clinics recruit only about 1% of sub- scribers who smoke. When state health departments contract for free action- oriented quit lines, they typically budget for less than 1% of smokers to call each year. Such behavior health services simply cannot make much difference if they treat such a small percentage of the problem (Orleans et al., 1985).

Startled by such statistics, behavioral scientists took health promotion pro- grams into communities and worksites. The results are now being reported, and, in the largest trials ever attempted, the outcomes are discouraging. In the Min- nesota Heart Health project, for example, $40 million was spent with 5 years of intervention in four communities totaling 400,000 people. There were no sig- nificant differences between treatment and control communities on smoking,

diet, cholesterol, weight, blood pressure, and overall risks for cardiovascular disease (Luepker et al., 1994).

What went wrong? The investigators speculate that maybe they diluted their programs by targeting multiple behaviors. But the COMMIT (COMMIT Research Group, 1995) trial had no effects with its primary target of heavy smokers and only a small effect with light smokers. Similarly, the largest work-site cessation program produced no significant differences between intervention and comparison sites (Glasgow, Terborg, Hollis, Severson, & Boles, 1995). Part of the problem is that the control populations were improving, making it more difficult for the intervention groups to outperform them.

A closer look at participation rates may explain some of the disappointing results. In the Minnesota study, nearly 90% of smokers in both the treatment and the control communities had processed media information about smoking in the past year. But only about 10% had been advised to quit by their physicians (Lando et al., 1995). And only about 3% had participated in the most powerful behavioral programs, such as individualized and interactive clinics, classes, and contests. In one of the Minnesota Heart Health studies, smokers were randomly assigned to one of three recruitment methods for home-based cessation programs (Schmidt, Jeffrey, & Hellerstedt, 1989). These announcements generated 1% to 5% participation rates, with a personalized letter generating the best results. We cannot have much impact on the health of our communities if we interact with only a small percentage of those populations that are at high risk for disease and early death.

Such disappointing impacts have led governments, health plans, and employers to rely on bans in public places, increased taxes on cigarettes and health insurance for smokers, and mass-media counteradvertising. These interventions are population-based, while cessation treatments were designed only for motivated smokers. The most recent U.S. Clinical Guidelines for the Treatment of Tobacco (Fiore et al., 2000) identified a broad range of evidence-based treatments for motivated smokers, defined as those in the preparation stage. There were no evidence-based treatments for the 80% or more of smokers who were not motivated or prepared to quit.

Our TTM alternative was to shift from an action paradigm to a stage paradigm in order to increase reach and interact with a much higher percentage of populations at risk. Let us examine how the stage paradigm has been applied to five of the most important phases of planned interventions.

Recruitment

Recall that cessation programs falter in this first phase of intervention and produce low participation rates. Stage distributions can help explain such low rates. Across four different samples, 20% or less of smokers were in the preparation stage (Velicer et al., 1995). When we advertised or announced programs, we were explicitly or implicitly targeting less than 20% of a population. The other 80% plus were left on their own.

In two home-based programs with approximately 5,000 smokers in each study, we reached out either by telephone alone or by personal letters followed by telephone calls if needed and recruited smokers to stage-matched interven-

tions. For each of five stages, these interventions included self-help manuals, individualized computer feedback reports based on assessments of the pros and cons, processes, self-efficacy, and temptations and/or counselor protocols based on the computer reports. Using these proactive recruitment methods and stage-matched interventions, we were able to generate participation rates of 82% to 85%, respectively (Prochaska, Velicer, Fava, Rossi, & Tsoh, 2001a; Prochaska et al., 2001b). Such large increases in participation rates provide the potential to generate unprecedented impacts with entire populations of smokers.

Population impact equals participation rate times the rate of efficacy or action. If a program produced 30% efficacy (such as long-term abstinence), historically it was judged to be better than a program that produced 25% abstinence. But a program that generates 30% efficacy but only 5% participation has an impact of only 1.5% (30% × 5%). A program that produces only 25% efficacy but 60% participation has an impact of 15%. With health promotion programs, this would mean a 1000% greater impact on a high-risk population.

The stage paradigm would shift our outcomes from efficacy alone to impact. To achieve such high impact, we needed to shift from reactive recruitment, where we advertised or announced our programs and reacted when people reach us to proactive recruitments where we reached out to interact with all potential participants.

Proactive recruitment alone doesn't work. In the most intensive recruitment protocol to date, Lichtenstein and Hollis (1992) had physicians spend up to 5 minutes with each smoker just to get the person to sign up for an action-oriented cessation clinic. If that didn't work, a nurse spent 10 minutes to persuade each smoker to sign up, followed by 12 minutes with a videotape and health educator and even a proactive call from a counselor if necessary. The base rate was 1% participation. This proactive protocol led 35% of smokers in precontemplation to sign up. But only 3% showed up, and 2% finished the program. When smokers in contemplation and preparation are combined, 65% signed up, 15% showed up, and 11% finished the program.

To optimize our impacts, we need to use proactive protocols to recruit participants to programs that match the stage they are in. Once we generate high recruitment rates, we then have to be concerned about high retention rates, lest we lose many of the initial participants in our health promotion programs.

Retention

One of the skeletons in the closet of psychotherapy and behavior change interventions is their relatively poor retention rates. Across 125 studies, the average retention rate was only about 50% (Wierzbicki & Pekarik, 1993). Furthermore, this meta-analysis found few consistent predictors of which participants would drop out prematurely and which would continue in therapy. In studies on smoking, weight control, substance abuse, and a mixture of DSM-III disorders, stage-of-change measures proved to be the best predictors of premature termination. For example, when we look at stage profiles of groups of therapy participants, we find that the pretreatment stage profile of the entire 40% who dropped out prematurely as judged by their therapists was that of patients in precontemplation. The 20% who terminated quickly but appropriately had a profile of pa-

tients in action. Using pretreatment-stage-related measures, we were able to correctly classify 93% of the groups (Brogan, Prochaskam, & Prochaska, 1999).

We simply cannot treat people with a precontemplation profile as if they were ready for action interventions and expect them to stay in treatment. Relapse prevention strategies are indicated with smokers who are taking action. But those in precontemplation are more likely to need drop-out-prevention strategies.

The best strategy we have found to promote retention is to match our interventions to stage of change. In four smoking cessation studies using such matching strategies, we found that we were able to retain smokers in the precontemplation stage at the same high levels as those who started in the preparation stage (Prochaska et al., 2001a).

Progress

The amount of progress participants make following health promotion programs is directly related to the stage they were in at the start of the interventions. This *stage effect* is illustrated where smokers initially in precontemplation show the smallest amount of abstinence over 18 months and those in preparation progress the most. Across 66 different predictions of progress, we found that smokers starting in contemplation were about two-thirds more successful than those in precontemplation at 6-, 12-, and 18-month follow-ups. Similarly, those in preparation were about two-thirds more successful than those in contemplation at the same follow-ups (Prochaska, Velicer, Prochaska, & Johnson, 2004).

These results can be used clinically. A reasonable goal for each therapeutic intervention with smokers is to help them progress one stage. If over the course of brief therapy they progress two stages, they will be about 2.66 times more successful at longer-term follow-ups (Prochaska et al, 2004).

Process

To help populations progress through the stages, we need to understand the processes and principles of change. One of the fundamental principles for progress is that different processes of change need to be applied at different stages of change. Classic conditioning processes like counterconditioning, stimulus control, and contingency control can be highly successful for participants who are ready to take action but can produce resistance in individuals in precontemplation. More experiential processes, such as consciousness raising and dramatic relief, can move these people cognitively and affectively and help them shift to contemplation (Prochaska, Norcross, & DiClemente, 1994a).

After 15 years of research, we have identified 14 variables on which to intervene in order to accelerate progress across the first five stages of change (Prochaska et al., 1994b). At any particular stage, we need to intervene with a maximum of six variables. To help guide individuals at each stage of change, we have developed computer-based expert systems that can deliver individualized and interactive interventions to entire populations (Velicer et al.,

1993). These computer programs can be used alone or in conjunction with counseling.

Outcomes

In our first large-scale clinical trial, we compared four treatments: one of the best home-based action-oriented cessation programs (standardized); stage-matched manuals (individualized); expert system computer reports plus manuals (interactive); and counselors plus computers and manuals (personalized). We randomly assigned by stage 739 smokers to one of the four treatments (Prochaska, DiClemente, Velicer, & Rossi, 1993).

In the computer condition, participants answered by mail or telephone interview 40 questions, and their responses were entered in our central computers and generated feedback reports. These reports informed participants about their stage of change, their pros and cons of changing, and their use of change processes appropriate to their stages. At baseline, participants were given positive feedback on what they were doing correctly and guidance on which principles and processes they needed to apply more in order to progress. In two progress reports delivered over the next 6 months, participants also received positive feedback on any improvement they made on any of the variables relevant to progressing. This way, demoralized and defensive smokers could begin progressing without having to quit and without having to work too hard. Smokers in the contemplation stage could begin taking small steps, like delaying their first cigarette in the morning for an extra 30 minutes. They could choose small steps that would increase their self-efficacy and help them become better prepared for quitting.

In the personalized condition, smokers received four proactive counselor calls over the 6-month intervention period. Three of the calls were based on the computer reports. Counselors reported much more difficulty in interacting with participants without any progress data. Without scientific assessments, it was much harder for both clients and counselors to tell whether any significant progress had occurred since their last interaction.

Figure 4.2 presents point prevalence abstinence rates for each of the four treatment groups over 18 months with treatment ending at 6 months (Prochaska et al., 1993). Those in the two self-help-manual groups paralleled each other for 12 months. At 18 months, the group with the stage-matched manuals had moved ahead. This is an example of a *delayed action effect,* which we often observe with stage-matched programs specifically and which others have observed with self-help programs generally (Glynn, Anderson, & Schwarz, 1992). It takes time for participants in the early stages to progress all the way to action. Therefore, some treatment effects as measured by action will be observed only after considerable delay. But it is encouraging to find treatments producing therapeutic effects months and even years after treatment ended.

The computer-alone group and the computer-plus-counselor group paralleled each other for 12 months. Then, the effects of the counselor condition flattened out, while the computer-condition effects continued to increase. We can only speculate as to the delayed differences between these two conditions. Participants in the personalized-condition group may have become somewhat de-

4.2

Point prevalence abstinence (%) for four treatment groups at pretest and at 6, 12, and 18 months.
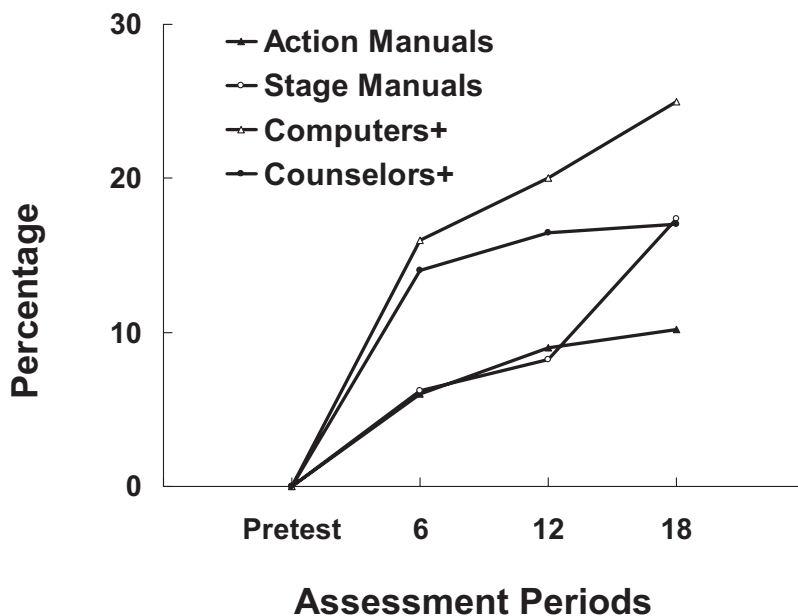
ALA + = standardized manuals; TTT = individualized stage-matched manuals; ITT = interactive computer reports; PITT = personalized counselor calls.

pendent on the social support and social control provided by the calls from the counselor. The last call came after the 6-months assessment and benefits were observed at 12 months. Termination of the contact with the counselors might have led to the cessation of progress because of the loss of social support and control. The classic pattern in smoking-cessation clinics is that rapid relapse begins as soon as the treatment is terminated. Some of this rapid relapse may well be the result of the sudden loss of social support or social control provided by the counselors and other participants in the clinic.

In this clinical trial, smokers were recruited reactively. They called us in response to advertisements, announcements, and articles. How did their results compare to those of smokers proactively recruited to our programs? Most people would predict that smokers who call us for help would be more successful than smokers whom we called to help.

In fact, the results of a comparison between smokers in a study who called (reactive) (Prochaska et al., 1993) and those in a study whom we called (proactive) (Prochaska, Velicer, Fava, Rossi, & Tsoh, 2001a) were remarkable. Both groups received the same home-based expert system computer reports delivered over a 6-month period. While the reactively recruited subjects were slightly more successful at each follow-up, what was striking was how similar were the abstinence curves over long-term follow-up.

Outcomes With Diverse Groups

In a small pilot study of a multimedia TTM-tailored smoking cessation expert system in urban primary-care medical clinics, good rates of participation and quitting among a group composed primarily of African American, older smokers were found (Hoffman et al., 2006). These promising data led us to offer a comparable interactive smoking-cessation system to women at risk for or infected with HIV. Although we cannot yet evaluate quit rates, early participation rates have been good in this sample with multiple comorbidities and health challenges (Goldberg, Weber, Redding, & Cohen, 2006).

Outcomes with diverse groups were part of an analysis that combined data from five effectiveness trials in which 2,622 smokers were proactively recruited and all received the same TTM-tailored intervention plus stage-matched manuals. The intervention produced a consistent 22%–26% long-term cessation rate across the five studies with a mean of about 24% (Velicer, Redding, Sun, & Prochaska, 2007b). There were no significant differences in abstinence rates between females (24.6%) and males (23.6%). There were no significant differences between African Americans (26.3%) and Whites (24.9%) or between Hispanics and non-Hispanics. The oldest smokers (65 and older) had abstinence rates (35.2%) that were 45% higher than the mean. College graduates had abstinence rates (30.1%) that were significantly higher than average.

The Surgeon General's Report (U.S. Department of Health and Human Services, 1994) on Adolescent Smoking basically concluded that teenage smokers would not participate in treatment, and if they did, they would not quit. Hollis et al. (2005) were able to proactively recruit 65% of teens in primary care to a smoking-cessation program based on our TTM tailored communications. At long-term follow-up, the regular smokers receiving treatment had significantly higher cessation rates (23.9%) than the randomized control group (11.4%). Furthermore, their quit rate of 23.9% was essentially the same as the average quit rate in our adult treatment groups (Hollis et al., 2005).

The Clinical Guidelines for the Treatment of Tobacco (Fiore et al., 2000) identified no evidence-based treatments for smokers with mental illness, even though such smokers consume nearly 50% of all cigarettes in the U.S. Hall and colleagues (2006) reached out to smokers who were being treated for depression in clinics at UC San Francisco. Those randomized to treatment received our TTM-tailored program plus counseling and nicotine replacement therapy. At 24-month follow-up, the treatment group had significantly higher abstinence rates (24.6%) than the controls (19.1%), and its quit rates were remarkably similar to those of our average treated adults (Hall et al., 2006).

These outcomes with diverse groups receiving similar TTM-tailored treatments challenge stereotypes that assume that some groups do not have the same ability to change. Minorities, the elderly, adolescents, and mentally ill groups are often assumed not to have the same ability to change as other populations. These results suggest that the issue may not be their ability to change. The issue may be their accessibility to quality change programs.

If these results continue to be replicated, health promotion programs will be able to produce unprecedented impacts on entire populations. We believe that such unprecedented impacts require scientific and professional shifts:

1. From an action paradigm to a stage paradigm;
2. From reactive to proactive recruitment;
3. From expecting participants to match the needs of our programs to having our programs match participants' needs;
4. From efficacy trials for select samples to more inclusive population trials;
5. From clinic-based to community-based behavioral health programs that apply the field's most powerful individualized and interactive intervention strategies.

With these types of shifts in health promotion, we may be better prepared to respond to the huge unmet needs and the great opportunities related to the prevention of chronic diseases and premature death (Prochaska, 2008).

Future Research

While we are encouraged by the research results to date, much still needs to be done to advance the Transtheoretical Model. Basic research needs to be done with other theoretical variables, such as perceived risk, subjective norms, and severity of the problem, to determine whether such variables relate systematically to the stages and whether they predict progress across particular stages. More research is needed on the structure of the processes and on the stages of change across a broad range of health behaviors. What modifications are most needed for specific types of behavior (e.g., having fewer processes for infrequent behaviors, such as annual mammograms)? What additional behaviors, beyond the 50 already studied, can be understood from a stage perspective?

Can the stage model be useful in describing, explaining, and predicting changes beyond the individual level, such as changes in couples, families, organizations, and communities? What happens when two or more people are trying to change together and they are in different stages? Can social policies be made more effective by matching policies to a community's stage of readiness to change? Are there particular types of public health campaigns, such as media campaigns, that can best produce progress in communities in the early stages of change?

At the individual level, much more research needs to be done on the most cost-effective interventions for producing progress through the stages across a variety of health behaviors. What are the minimum interventions needed to accelerate progress at each stage?

The Transtheoretical Model is a dynamic theory of change, and it must remain open to modification as more students, scientists, and practitioners apply the stage model to a growing number of theoretical and public health problems.

Summary

Research to date supports the Transtheoretical perspective that the adoption and maintenance of health behavior change involves progress through a series of stages. Such progress can be accelerated and facilitated by tailoring particular processes and principles of change to populations and individuals at each stage of change. Proactively applying TTM tailoring interventions for multiple behaviors can greatly increase participation, retention, progress, and impact rates in entire populations at risk for chronic disease and premature death.

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Multilevel Theories of Behavior Change: A Social Ecological Framework

5

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and Daniel Stokols

Social ecological analyses of health and health behavior have gained increasing prominence in the fields of health education, behavioral medicine, and public health from the 1990s onward (cf. Green, Richard, & Potvin, 1996; McLeroy, Bibeau, Steckler, & Glanz, 1988; Sallis & Owen, 1997; Smedley & Syme, 2001; Stokols, Allen, & Bellingham, 1996; Winnett, King, & Altman, 1989). The emergence of ecological models of health, behavior, and disease has been fueled by a growing recognition among scientists and practitioners that the etiology of contemporary public health problems is jointly influenced by diverse causative factors situated at multiple levels of analysis (e.g., ranging from molecular and genetic to behavioral, environmental, and societal levels). It is now widely acknowledged among health scholars and professionals that chronic diseases including diabetes, cardiovascular disease, cancer, and the threats to public health

posed by community violence must be approached from a multilevel, ecological systems perspective to adequately understand their diverse etiologic underpinnings and to develop effective strategies for preventing or ameliorating them (Abrams, 2006; Best et al., 2003; Breslow, 1996; Glass & McAtee, 2006; Schneider & Stokols, 2000; Stokols, Grzywacz, McMahan, & Phillips, 2003).

The present chapter highlights the core assumptions and principles of multilevel ecological analyses of health and health-behavior change. Unlike earlier *biomedical* and *biopsychosocial* models that focus on the interplay among genetic, physiological, psychological, and social factors in health and illness, *social ecological* analyses place greater emphasis on the role of environmental conditions that influence an individual's or group's health status (Schwartz, 1982; Stokols, 2000). Environmental influences on health and health behavior are found both in the immediate, *micro-level settings* of everyday life (e.g., in one's home or workplace) and in the more distal, *macro-level conditions* that are pervasive in one's community (e.g., levels of unemployment, social capital, and income disparities existing within a particular society (cf. Kaplan, 1998; Kawachi & Berkman, 2003; Macintyre, 2003). Moreover, contextual influences on health behavior and illness symptoms include features of *built* as well as *natural* environments (e.g., exposure to urban traffic congestion vs. living in a rural wilderness area). *Objective* attributes of these environments (e.g., the spatial and social density of a dwelling measured in terms of its square footage and the number of residents living there), as well as individuals' *perceptions* of them (e.g., perceived crowding and related feelings of stress), must be considered in ecological analyses, since both have the capacity to influence health behaviors and outcomes (Lazarus, 1966; Lepore, Evans, & Palsane, 1991; Stokols, 1972). Thus, the environmental contexts of health are multifaceted, encompassing objective and subjective features of built and natural settings, and distributed across different levels of geographic scale; they influence well-being both directly and through their interaction with biogenetic and psychological factors.

Social ecological analyses also emphasize *systems processes* in health and illness, such as the ways in which chronic exposure to environmental stressors and coping challenges can undermine immunologic functioning and deplete the individual's capacity to resist or recover from a variety of health threats (McEwen, 2006; Miller, 1978; Seeman, McEwen, Rowe, & Singer, 2001). Systems processes of *adaptation, homeostasis,* and *coping behavior* regulate individuals' interactions with their everyday surroundings and are a major facet of ecological analyses of human resistance and vulnerability to disease (Antonovsky, 1987; Lazarus & Folkman, 1984; Selye, 1956).

The social ecological perspective on health behavior is also inherently *interdisciplinary* in its approach to scientific research and its translation into practice. Social Ecology spans several different fields, including neuroscience, medicine, epidemiology, health psychology, sociology, anthropology, health education, and community health promotion. Moreover, social ecological analyses emphasize not only *personal* health decisions and behavior but also *other-directed* behaviors enacted by physicians, case managers in health maintenance organizations, corporate managers, and elected officials that have a direct bearing on the well-being of hundreds and sometimes thousands of other people (Stokols, 1996).

In the following sections of the chapter, social ecological principles of health and behavior change are illustrated in relation to a variety of health

risks, behaviors, and illnesses including obesity, smoking, diabetes, cardiovascular disease, cancer, and the common cold. Implications of social ecological analyses of these health problems for disease prevention, wellness promotion, and public policy are also discussed. Finally, we discuss unresolved conceptual and methodological issues and identify high-priority directions for future social ecological research on health behavior formation, maintenance, and change.

Foundations of the Social Ecological Framework

A 1993 report by McGinnis and Foege (1993), replicated and updated in 2004 by Mokdad and colleagues (2004), showed that the top causes of death in the United States are tobacco use, poor nutrition, physical inactivity, and alcohol consumption. This report represented a paradigm shift, in which causes of mortality were depicted not in terms of the diseases that lead to organ failure (i.e., cancer, heart disease, stroke) but in terms of the behaviors that contribute to the development of disease. Moreover, these behaviors were recognized as calling for comprehensive intervention strategies that integrate medical, psychological, organizational, cultural, and regulatory perspectives. The Social Ecological Framework (SEF) has emerged as an approach toward behavior change that encourages researchers to incorporate these disparate influencing factors into a causative web that spans multiple disciplines and extends across levels from the microscopic (i.e., cellular) to the global (i.e., economic and environmental). Research in the area of tobacco use, for example, has demonstrated that smoking behavior is influenced by genetic susceptibility to nicotine addiction (MacLeod & Chowdhury, 2006); stress, social influence, and depression (Schepis & Rao, 2005); and the consumer price of cigarettes (Ding, 2005; Siegel, 2002).

The danger inherent in this inclusive approach is that the causative web becomes so unwieldy that its very complexity reduces its utility. Thus, there is a tension between the practitioner's desire to identify an intervention target and the theorist's drive to delineate all possible avenues of influence. In recognition of this tension, the SEF has as its aim the goal of detecting "high-impact leverage points" (Stokols, 1992). These targets of intervention represent especially promising pathways for stimulating positive health behavior change. An assumption, then, of the SEF is that each element in a model should be examined with respect to its relative utility for affecting behavior change as compared to other elements in the model.

Bronfenbrenner's (1992) Bioecological Systems Theory of child development illustrates both the promise and the pitfalls of an expansive approach to model building. Bronfenbrenner's theory features multiple "layers" of environment, each of which influence child development (see Figure 5.1). In this model, the *microsystem* includes structures with which the child has direct contact, such as family, school, or neighborhood environments. These structures shape the child's behavior and, in turn, may be shaped by the child's behavior. There are also connections between the various structures within the child's microsystem, which Bronfenbrenner designates as the *mesosystem*. The *exosystem* is the larger social system with which the child does not interact directly but by which the microsystem may be influenced, such as parent worksite policies that

5.1

Depiction of Bronfenbrenner's Bioecological Systems Theory.
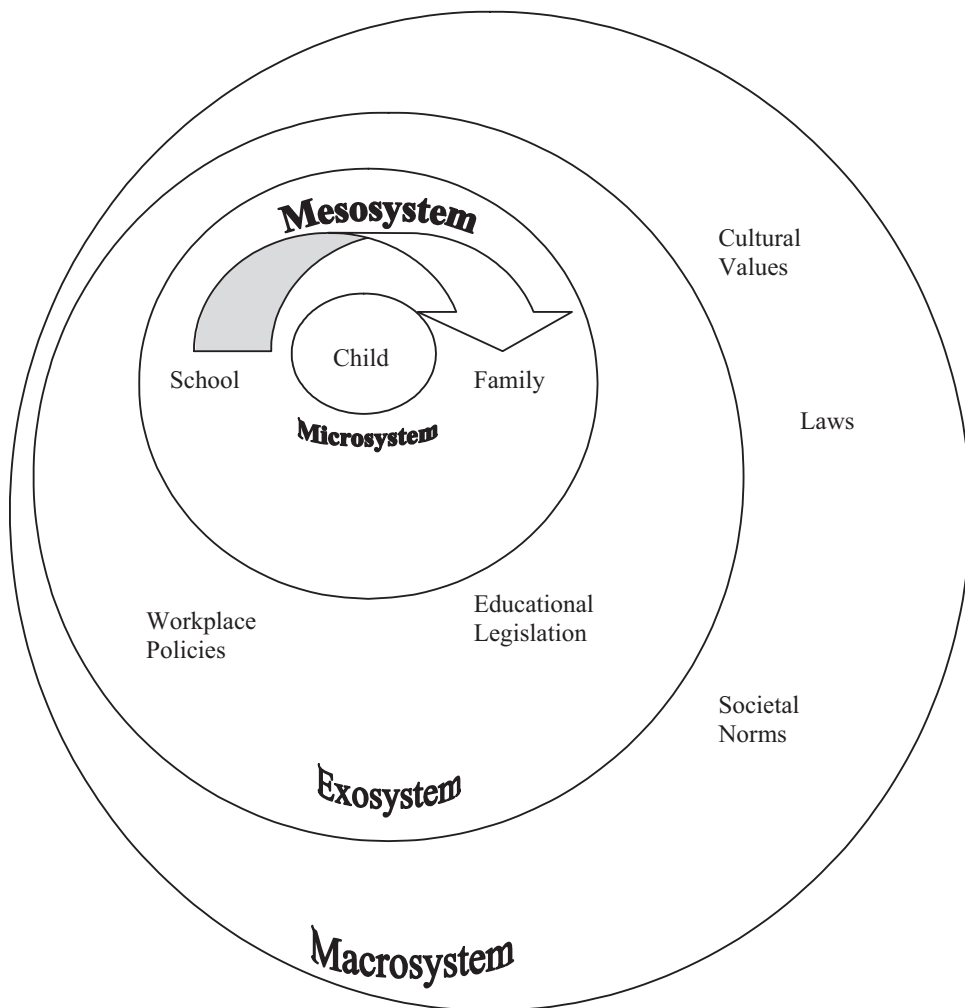
may limit a parent's availability to the child during work hours. The outermost layer of the child's environment is the *macrosystem,* composed of cultural values, customs, and laws. The effect of these distal influences on the child is mediated by the micro-, meso-, and exosystems. Overall, Bronfenbrenner's model is an elegant example of incorporating multiple levels, yet it also demonstrates the downside to complex model building: the potential for becoming overwhelmed by its very complexity, and the unanswered question as to which of the model's variables offer the greatest potential for improving health.

Recently, Glass and McAtee (2006) proposed an even more elaborate depiction of the "society-behavior-biology nexus" (p. 1653). Their representation of

the many influences on human behavior features several layers of factors residing within the individual (the genomic substrate, the subcellular/molecular level, the cellular level, and the multi-organ system level), as well as a temporal dimension from conception to old age. These additional dimensions of complexity serve simultaneously to expand the range of theoretically significant pathways of influence and to emphasize the critical importance of seeking out pathways of greater potential influence.

Both Bronfenbrenner's and Glass and McAtee's models embody the SEF in that they include influences from the immediate to the more distal environment and emphasize the bidirectional nature of the relationships between the individual and the environment. Both models also emphasize the role that the social environment plays in influencing health behavior. The Glass and McAtee (2006) representation, however, goes further in terms of acknowledging the physical environment as a contextual variable that should be considered. They point out, for example, the contribution that both the built environment and the local food environment make to the behaviors that lead to obesity. In this recognition of the physical environment as an integral part of the forces shaping health behavior, Glass and McAtee's model exemplifies the approach of the SEF.

The Impact of Environmental Context on Health

The concept that individual susceptibility to disease is influenced by both the social and the physical environment has long been recognized. Cassel (1976) posited that the social context within which an individual resides has a non-specific impact on health; that is, the social environment can increase or reduce susceptibility to a wide array of chronic diseases (cf. Kawachi & Berkman, 2003; Smedley & Syme, 2001). More recently, Cohen's research on the moderating effect of life stress on susceptibility to colds (Cohen et al., 1998; Cohen, Tyrrell, & Smith, 1991) showed that, indeed, individuals exposed to a cold virus under controlled conditions are more likely to develop viral infections and more severe cold symptoms if they have recently been experiencing great amounts of psychological stress, thus demonstrating that viral susceptibility is contextually moderated rather than absolute.

The Impact of Environmental Context on Health Behavior

It has taken some time and accumulated experience, however, for behavior change researchers to begin including contextual variables into their conceptual models and empirical studies. The accumulation of a number of failed large-scale behavioral interventions (e.g., Multiple Risk Factor Intervention Trial Research Group [MRFIT], 1982; The COMMIT Research Group, 1995) has starkly illustrated how difficult it is to influence individual health behavior through interventions that ignore context. The MRFIT trial, for example,

delivered a resource-intensive lifestyle change program to high-risk men over 6 years. Despite the enormous effort put into helping the men change their behavior, little actual behavior change occurred, and at the end of the trial there was no statistical difference in heart disease rates between the intervention and the control groups.

The lessons learned from this and other disappointing efforts to target individual health behavior on a large scale have inspired a new wave of studies that highlight community and environmental influences on health and behavior (cf. Macintyre, 2003; Woods, Montgomery, Herring, Gardner, & Stokols, 2006; Yen & Syme, 1999). A recent study demonstrates the contextual approach and identifies neighborhood safety as a crucial intervention target for changing urban children's health behavior (Wilson, Syme, Boyce, Battistich, & Selvin, 2005). Moreover, efforts to understand and address the low levels of physical activity characteristic of the majority of Americans have turned toward the pervasive and influential role of the built environment (cf. Frank, Engelke, & Schmid, 2003; Frumkin, Frank, & Jackson, 2004; Jackson & Kochtitzky, 2002; Killingsworth, 2003). This emphasis on the physical and social context within which behavioral choices are made is characteristic of the SEF.

Overview of Social Ecological Theory

Definition of Social Ecology

Social ecology is a *meta-theoretical perspective* that encompasses several interrelated themes and research strategies for understanding illness etiology, health behavior, and well-being: namely *contextualist, systems-oriented, interdisciplinary, multilevel action research* analyses incorporating both qualitative and quantitative research methods and a variety of experimental and nonexperimental research designs. In lay terms, social ecology is based on the assumption that the answer to questions such as "how do we get people to wear sunscreen?" is, in essence, "it depends" (cf. English et al., 2005; Milne, Johnston, Cross, Giles-Corti, & English, 2002). The answers to such questions depend upon the physical and social environment within which the target population lives and works, upon the genetic and phenotypic predispositions that individuals bring to the situation, upon the institutional, legislative, and economic constraints that envelop the persons we are interested in influencing, and even upon the disciplinary perspective of those who are trying to answer these questions. Finally, and perhaps most essential to the SEF, the answers to these types of questions depend upon the ways in which all of these multiple factors interact with one another.

It is important to note that the SEF represents a heuristic device that is intended to stimulate the formation of specific models or theories of health behavior in which multiple levels of influence and interactions between theoretical components are considered. At each level, existing theories may be used or new theories posited to select salient variables. Many theories already exist to guide investigators in the identification of critical variables at the level of the individual. Far fewer models are available to inform variable selection at the environmental levels, and there is much work to be done in terms of coming up with conceptual and operational definitions of factors that operate at the meso

and macro levels. Thus, one function of the SEF is to provide the impetus for researchers to measure, test, and compare alternative theories and influencing factors at the meso and macro levels.

Historical Context of Social Ecology

Baranowski and colleagues (2003) provide an overview of the evolution of behavior change models that places social ecology within an historical context. As depicted in this review, the SEF represents an attempt to respond to the inadequate explanatory power of primarily cognitive models of behavior change (e.g., the Knowledge-Attitude-Behavior model and the Health Belief Model) and social-cognitive models of behavior change (e.g., Social-Cognitive Theory, the Theory of Planned Behavior, and the Transtheoretical Model), all of which focus primarily on the individual as the unit of analysis and yield recommendations for intervention that are limited in scope and impact (Breslow, 1996; Glanz, Rimer, & Lewis, 2002; National Cancer Institute, 2005; Sallis & Owen, 1997). The innovation of the SEF lies in its attention to etiologic influences on health and behavior ranging from molecular and cellular to global levels, *and on the interactions among these factors*.

Core Assumptions of the SEF

Social ecological models of health and health behavior change are guided by a number of underlying assumptions (Stokols, 1992):

1. Social ecological models are multiplicative rather than simply additive. That is, they provide a conceptualization of *interactions* among variables situated at multiple analytic levels, from the micro to the macro. For instance, Rashad and Grossman's (2004) analysis of the obesity epidemic in the United States highlights the synergistic influence of multiple physical and social environmental factors on levels of obesity in the population, including economic determinants of food supply in the United States, the increasing participation of women in the U.S. labor force, technological changes such as the advent of microwave ovens, the presence of fast-food restaurants in a family's neighborhood, and the social characteristics of households, including the number of working adults residing at the same address.
2. The relative scale and complexity of environments that influence health behaviors and outcomes can be characterized in terms of their physical and social attributes, objective versus perceived qualities, and relative immediacy to individuals and groups (ranging from proximal to distal settings). Independent attributes of environments are relevant, such as lighting, temperature, noise, space arrangement, and group size. Furthermore, these independent attributes may combine to result in a characteristic behavior setting or social climate (cf. Barker, 1968; Moos, 1979). The impact of such a composite may go beyond a simple adding together of the independent effects of each attribute.
3. The SEF takes into account both the interdependencies that exist among immediate and more distant environments and the dynamic interrelations between people and their environments (Miller, 1978; Von Bertalanffy, 1950).

That is, people-environment transactions are characterized by cycles of mutual influence, whereby the physical and social features of settings directly influence their occupant's behavior, and concurrently the participants modify the healthfulness of their surroundings through their individual and collective actions (Lazarus & Folkman, 1984; Stokols & Shumaker, 1981).

4. Elements of the micro-, meso-, exo-, and macrosystems facilitate and/or impede individual behaviors and, therefore, individuals' ability to "choose" their behavior can be substantially determined by the social and environmental context. In the MRFIT trial (Multiple Risk Factor Intervention Trial Research Group, 1982), it was assumed that lifestyle behavior could be changed by providing individuals with skills training, such as instruction in how to prepare low-fat meals, combined with health education. This approach failed, perhaps because participants remained in the same environment that had shaped their original (unhealthy) behavior to begin with, and their ability to "choose" a healthier lifestyle was limited by this environment. Acknowledging the limited power of choice that individuals have over their own health behavior opens the door to interventions that are less focused on changing health behavior and more oriented toward facilitating healthful behavior. These interventions may include entirely passive approaches that require no decision making on the part of the individual, such as adding fluoride to the water supply (Williams, 1982). They may include regulatory approaches that make certain behavioral choices very costly, as when legislation is passed to increase the penalties for drunk driving or the cost of cigarettes (Breslow & Johnson, 1993; Siegel, 2002). There can also be a combination of behavioral restrictions plus opportunities for obtaining support in behavior change, as when companies establish worksite nonsmoking policies in conjunction with smoking cessation classes. All of these approaches have in common an acceptance of the premise that simply targeting the individual with persuasive communication is seldom an effective method for achieving health behavior change.

5. The wide range of individual behavioral responses that typically occur within a given physical and/or social environment are evidence for the importance of individual differences in physiology, personality, and cognitions as mediators of environmental influences on behavior. Taking these individual differences into account lays the foundation for more finely tuned designs of intervention programs or materials. In the area of tobacco use, social influences may play a significant role in determining the likelihood that an adolescent will experiment with smoking cigarettes (Bricker, Peterson, Sarason, Andersen, & Rajan, 2007), whereas individual genetic susceptibility to nicotine addiction may be instrumental in determining whether experimentation leads to regular smoking (Koopmans, Slutske, Heath, Neale, & Boomsma, 1999). Understanding individual differences can facilitate advances in creating tailored interventions that are targeted toward specific subgroups of a population (cf., Kreuter et al., 2006; Kreuter et al., 2005; Noar, Benac, & Harris, 2007; Strecher & McPheeters, 2006). The SEF incorporates individual level differences along with contextual factors in order to identify the most promising avenues of intervention for a given population.

6. The SEF acknowledges the multifaceted and dynamic nature of behavior itself. At times, behaviors may cluster, so a change in one behavior may

facilitate a change in a related behavior. This may be the case for the association between drinking coffee and smoking cigarettes (Fernandez et al., 1997). Moreover, behavioral choices are played out in continuous interaction with and adaptation to a changing environment. Therefore, efforts to influence behavioral choices cannot be static or "one size fits all" (Noar, Benac, & Harris, 2007). Behaviors also cannot be described as all-or-none phenomena; an individual may pass through a series of "stages" or behavioral approximations on the way to adopting a new behavior (Prochaska & Velicer, 1997). A useful model of behavior change, then, must be flexible enough to reflect that the behavioral target is likely to be neither fixed nor isolated.

These core assumptions of the SEF provide a conceptual basis for constructing models of health behavior that feature diverse influencing factors spanning multiple levels as well as reciprocal lines of causation connecting the model components. Key principles that guide the translation of social ecological theory into health-enhancing policies and programs are summarized in the next section.

Translating Social Ecological Theory Into Effective Strategies for Health Promotion

A distinguishing feature of the SEF is its emphasis on identifying "high-leverage" intervention targets that have the greatest potential for bringing about positive health behavior change (Stokols, 1996). Beyond simply highlighting the great variety of influencing factors that should be considered in determining how best to intervene to promote healthful behavior, the SEF encourages researchers to examine the relative utility of targeting each of the variables in the model. In this emphasis, the SEF is consistent with "solution-oriented research" (Robinson & Sirard, 2005). Solution-oriented research is characterized by studies that have clear implications for intervention and are likely to lead to changes in clinical practice or public health policy. In the imagery of Krieger (1994), rather than being content with simply identifying the causative web, researchers should strive to unmask the spider behind its pattern.

The SEF also stresses the implementation of health-promotive interventions that involve the coordination of individuals and groups acting at different levels. Thus, leverage points at different levels of analysis should be targeted simultaneously in order to achieve a synergistic effect. School-based interventions are a good illustration of this point. A classroom-based educational program that teaches students the benefit of eating well is likely to have a much greater impact if it is accompanied by changes in the school food service at the same time. That is, an educational intervention may be effective if delivered in the context of environmental change that facilitates the targeted behavior.

It should be noted that in order to effectively identify the most salient influencing factors, appropriate assessment tools and analytic methods must be developed that enable investigators to examine not only the relative impact of individual factors but also their joint and/or interactive effects (Glass & McAtee, 2006). Currently available assessment tools are inadequate to describe potentially relevant dimensions of the social and physical environment.

Similarly, traditional linear analytic models are insufficient for capturing the nested relationships and complex interactions that may typify a fully elaborated model of any health behavior (Ockene et al., 2007).

Applications of the SEF to Contemporary Health Problems

An illustrative and timely example of a behavior-based health problem that calls out for multilevel, cross-disciplinary, and interactive explanatory models is childhood obesity. Childhood obesity has traditionally been depicted as the result of an imbalance between energy in and energy out. That is, excessive body fat accumulates when the calories burned are outnumbered by the calories ingested. This reductionist perspective results in attempts to correct the imbalance by engaging in health education, specifically, "planned learning experiences that facilitate voluntary changes in behavior" (Green, 1999). These attempts may be made clinically, as in the case of physician-based counseling interventions (cf. Patrick et al., 2006) or on a public health scale, as in the case of mass-media communication campaigns (e.g., Huhman, Potter, & Wong, 2005). Whether applied on an individual or a group level, however, the health education approach fails to address the contextual factors that to a large degree shape the behaviors that directly influence childhood obesity, namely dietary intake and physical activity.

More recent analyses of the factors contributing to the contemporary unprecedented increase in childhood obesity have emphasized environmental influences and have focused attention on facets of the "obesogenic environment" (Rashad & Grossman, 2004; Swinburn, Caterson, Seidell, & James, 2004). This relatively new term refers to the elements in the environment that contribute to the development or maintenance of obesity. While still acknowledging that individual behavior is at the crux of the obesity problem and is therefore central to its solution, many researchers are pointing out and finding evidence for the contextual factors that curtail both the likelihood that individuals will engage in recommended dietary and activity practices and their ability to do so. More specifically, recent reviews have highlighted physical environmental factors that are more distal from the target behavior, such as urban design and transportation infrastructure (Brug, van Lenthe, & Kremers, 2006; Papas et al., 2007), as well as social environmental influences that are more proximal to the target behavior, such as supportive home and school environments (Swinburn et al., 2004). These multilevel models of obesity identify promising intervention leverage points both in the political arena (e.g., modifying children's food preferences by changing food marketing) and in the personal arena (e.g., reducing children's sedentary behavior by removing TVs from their bedrooms) (Anderson & Butcher, 2006).

Encouraged by several theoretical articles published in the 1990s (Breslow, 1996; O'Donnell, 1996; Sallis & Owen, 1997; Stokols, 1996), the field of obesity prevention has embraced the SEF. Initially, this perspective was reflected in a wave of correlational studies examining the multilevel environmental and psychosocial influences on obesity (Blanchard et al., 2005; Fleury & Lee, 2006). That is, researchers have conducted cross-sectional studies in which they have

shown that obesity is related to a variety of influences, including urban design (Sallis, Kraft, & Linton, 2002), food marketing (Anderson & Butcher, 2006), and television watching (Marshall, Biddle, Gorely, Cameron, & Murdey, 2004). As the utility of the SEF for identifying relevant sources of influence on obesity has been confirmed, recommendations and models for adopting this approach to the development of health promotive interventions have emerged (Best et al., 2003; Nigg et al., 2005; Whittemore, Melkus, & Grey, 2004). As a result, recent interventions targeting childhood obesity are more likely to employ a "com-bination of educational and environmental supports for action and conditions of living conducive to health" (Green, 1999). For example, an NIH-funded trial intended to promote physical activity among adolescent females (Elder et al., 2007) was designed to "create environments at school and in the community that facilitate physical activity, enhance social support in those environments, and provide the girls with the motivation and skills to seek out activity in all settings" (p. 162).

A provocative article addressing the causes of childhood obesity (Lustig, 2006) provides a clear illustration of the explanatory value that can be added by combining a biomedical understanding of a disease process with an appreciation for the environmental context. Lustig discusses a biochemical theory of obesity in which an individual's hormonal signaling may be inappropriately triggering a starvation response (see Figure 5.2). This response causes the body to move energy into adipose tissue and reduce energy expenditure while simultaneously stimulating an appetitive drive. Thus, a child may be gaining weight because of a biochemical imbalance that is causing her to experience hunger and sluggish-ness even though she is ingesting more calories than should be required to meet her metabolic needs.

This biochemical explanation for childhood obesity takes on new resonance when described in the context of the environmental factors that may trigger this metabolic imbalance. Lustig theorizes that the dysfunctional biochemistry is related to chronic hyperinsulinemia brought about by a combination of: (1) stress; (2) low physical activity (associated with the sedentary lifestyle that has emerged within the context of car-centered urban design, individual reliance on the automobile, and the popularity of sedentary forms of entertain-ment); and (3) a food environment that is characterized by high-energy-density foods (i.e., foods that contain relatively few essential nutrients per calorie), foods with significant fat and fructose, and foods low in fiber. As a model, this multilevel, multidisciplinary, and interactive theory of childhood obesity illus-trates the promise of expanding upon a biomedical model of a disease process by examining the context within which people reside and within which people make behavioral choices. In this way, Lustig offers a demonstration of how the SEF can be employed to yield a number of potential leverage points for inter-vention that can be explored in future research.

Physical activity is one of the behaviors that has been extensively studied in response to the rise in obesity. Many different models have been applied to gain insight into why some people are more active than others. Much of the past work in this area has focused on characteristics of the individual, such as Body Mass Index or perceived self-efficacy. These studies have resulted in the identification of a large number of behavioral mediators that have generally been found to explain a small percentage of the variance in physical activity

5.2

Postulated algorithm describing the vicious cycle wherein stress, poor diet, and low physical activity all contribute to hyperinsulinemia and obesity, which then feeds back, via impaired leptin sensitivity, to further exacerbate the cycle.
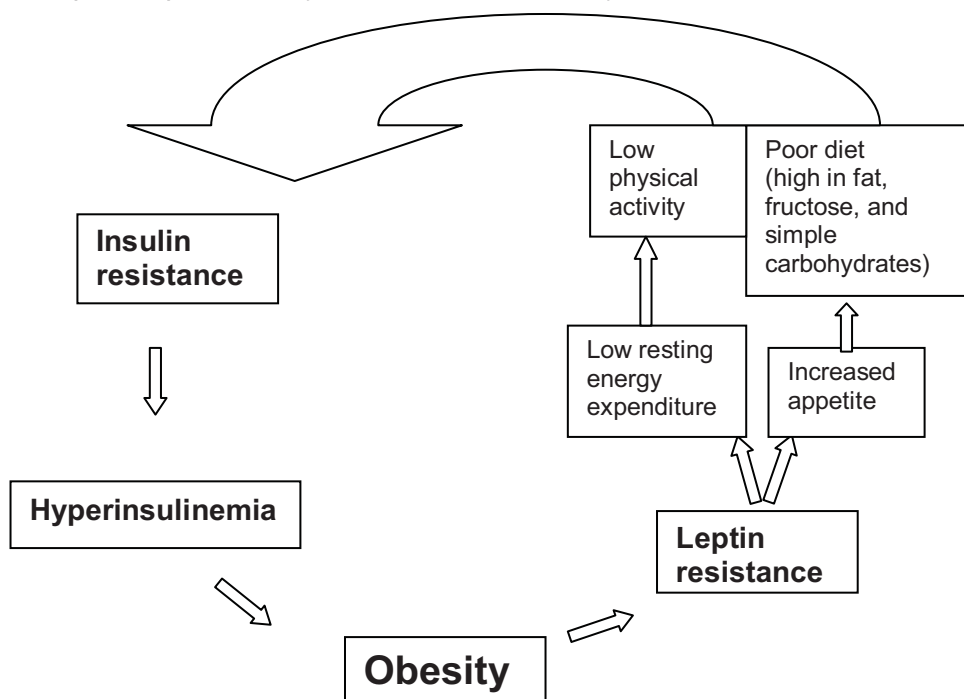
Note: Adapted with permission from image originally from American Heart Association.

levels (King, Stokols, Talen, Brassington, & Killingsworth, 2002). The past decade has seen an increasingly contextual paradigm being adopted in this area, as researchers have looked to the environment to help explain physical activity behavior (cf. Sallis & Owen, 1999). One discipline that has emerged as a fruitful partner in this endeavor is that of urban planning (Dannenberg et al., 2003; Frank et al., 2003; Hoehner, Brennan, Brownson, Handy, & Killingsworth, 2003). Initial evidence supports an association between urban form (indexed in terms of residential density, intersection density, land use mix, commercial and recreational space, and urban sprawl) and physical activity (Frank, Kerr, Chapman, & Sallis, 2007; Frumkin et al., 2004; Saelens, Sallis, & Frank, 2003).

It is worth noting that an individual study may yet embody social ecological principles, even in the absence of environmental variables. Individual studies can contribute toward a social ecological analysis of behavior by examining a particular slice of what, in its more elaborated form, would be a model that included environmental influence. For instance, a recent study on the factors that influence voluntary exercise participation (Bryan, Hutchison, Seals, & Allen, 2007) exemplifies certain principles of social ecology even though it does not include the social or physical environment as measured variables. This study

employs a multidisciplinary model that integrates genetic, physiological, and psychological correlates of voluntary exercise. The authors hypothesized that "the physiological effects (e.g., changes in body temperature, heart rate) of exercise influence the subjective experience of exercise (e.g., changes in mood, perceived exertion, perceived reward), which in turn are important determinants of motivation to exercise (e.g., higher self-efficacy for exercise behavior and higher intentions to exercise) and of future exercise behavior" (p. 30). The authors further explain that the model is "both circular and dynamic [and that] genetic factors are included in the model as potential mediators or determinants of the physiological effects of exercise as well as the subjective experience of exercise" (p. 30).

This multidisciplinary study, then, exemplifies several of the underlying principles of the social ecological approach. By incorporating a genetic component, the research speaks directly to the importance of understanding the etiology of a behavior and appreciating the importance of individual differences. If, in fact, there are certain genotypes that are associated with having a negative affective response to exercise, this dynamic could inform strategies designed to increase physical activity. Moreover, the investigators have incorporated concepts from systems theory in their depiction of the relationships between these different influencing factors as both iterative and interactive. The inclusion of factors derived from multiple levels (genetic, physiological, psychological) and the use of diverse methodologies (genetic analysis, experimental manipulation of mood and heart rate) further exemplifies some of the principles that are central to the SEF.

Although this study lacks the contextual component, it is important to recognize that pragmatic limits exist on the number and scope of variables that can be included in a single study and that the SEF can be applied to an entire field of study, such that the cumulative results of many studies will yield a more comprehensive model incorporating elements from the level of genetics to the level of global economic policy. Thus, the SEF can provide overarching guiding principles for a field of study which, if they are consistently applied, should reveal useful avenues for intervention in the quest to modify health behavior and promote well-being.

Future Directions of Social Ecological Research on Health Behavior Change

In ecological studies of health and health behavior change, a basic unit of analysis is the *environment(E)-behavior(B)-physiology(P)-health outcomes(H) pathway*.

Each category within the EBPH pathway can be further differentiated (e.g., in terms of objective vs. perceived, built vs. natural, micro vs. macro features of the environment; personal vs. other directed health behaviors). In some cases, the effects of environmental factors on health outcomes are direct (e.g., exposure to environmental asbestos induces pulmonary symptoms and increases one's susceptibility to lung cancer), whereas, in other instances, environmental influences on health status are mediated or moderated by behavioral factors (e.g., exposure to environmental asbestos combined with smoking cigarettes

on a regular basis increases the individual's susceptibility to lung cancer in a multiplicative fashion [Grunberg, 1991]). Moreover, behavioral influences on health are sometimes direct, as in cases of lethal behavior directed toward oneself (suicide) or toward others (homicide); in other cases, behavioral impacts on health are mediated in a more gradual fashion through cumulative physiological processes (e.g., high cholesterol intake precipitating atheroslerotic processes that eventually lead to acute myocardial infarction).

Each individual's or group's ecology of health is uniquely made up of certain highly influential EBPH pathways. For instance, one family may live close to exercise facilities and neighborhood parks, which enables them to engage in physical activity regularly, whereas another may reside far from such facilities or parks and, instead, live close to several fast-food restaurants, which may encourage frequent consumption of high-fat, low-fiber meals (Corti, Donovan, & Holman, 1997; Rashad & Grossman, 2004). A particular challenge in ecological analyses of health and health behavior is to identify the *effective context* of health, or those EBPH pathways that exert the greatest influence on an individual's or group's health behaviors and outcomes (cf. Stokols, 1987). An important strength of the SEF is that it provides a broad conceptualization of environmental and behavioral factors, physiological processes, and health outcomes within each segment of the EBPH pathway. At the same time, however, a major challenge facing ecological analyses of health is to pare down potentially lengthy lists of etiologic factors within the E, B, P, and H categories and to develop more parsimonious and powerful conceptualizations of *high-leverage* variables in those categories (and situated at multiple levels of analysis) that have the greatest bearing on important health behaviors and outcomes.

The EBPH pathway is a useful analytic tool for examining both the progress that has been made to date toward developing broad conceptualizations of ecological influences on health, as well as the conceptual, methodological, and translational challenges inherent in the SEF that remain to be addressed in future research. These issues are outlined in the next sections.

Development of the SEF: Progress to Date

Important strides have been made in identifying and measuring environmental influences on health behavior and outcomes at micro-, meso-, and macrosystem levels.

At the macrosystem level, for example, operational measures of urban sprawl have been developed and the impact of sprawl on levels of physical activity and body mass index (BMI) in the population have been demonstrated empirically (Frank, Kerr, Chapman, & Sallis, 2007; Frumkin, Frank, & Jackson, 2004). Similarly, a recent study by O'Neill and colleagues (2007) indicates that exposure to elevated levels of ambient air pollution exacerbates inflammatory processes among diabetic individuals, thereby heightening their susceptibility to cardiovascular events. Also, research by Jerrett and colleagues has linked air pollution exposure to higher rates of cancer and atherosclerosis (Jerrett & Burnett, 2007; Jerrett et al., 2005; Krewski et al., 2005; Künzli et al., 2005). At the micro- and mesosystem levels of analysis, as well, a wide range of environmental stressors and their effects on individuals' health risk behaviors and physiology have been documented (Evans, 1999).

At the same time, pivotal health risk behaviors have been identified and shown to exert significant impacts on disease etiology, from Belloc & Breslow's (1972) early studies of healthy and unhealthy lifestyles to more recent reports identifying the major causes of chronic illness in developed countries (McGinnis & Foege, 1993; Mokdad et al., 2004). After several decades of research, poor nutrition, physical inactivity, consumption of alcohol and tobacco, and sleep disturbances have emerged as high-risk behaviors that exert a disproportionate impact on premature morbidity and mortality. What is distinctive about the more recent studies, however, is that we now know much more about the physiological processes that are triggered by these pivotal health risk behaviors. For instance, sleep deprivation in adolescents has been found to be associated with elevated levels of C-reactive protein and leptin, which are physiological precursors of inflammation and hyperinsulinemia (Larkin et al., 2005; Prinz, 2004). Moreover, it is becoming increasingly clear that chronic processes of inflammation, metabolic syndrome, and hyperinsulinemia are common precursors of multiple illnesses, including diabetes, heart disease, and cancer. Thus, in addition to classifying and measuring important environmental, behavioral, and physiological influences on health, ecologically oriented research is now beginning to document the empirical links between environmental and behavioral variables, on the one hand, and physiological processes and health outcomes, on the other.

Another indicator of progress in ecologically oriented research on health behavior and outcomes is the recent emphasis on identifying *synergistic processes* involving multiple environmental and behavioral factors that have a multiplicative or interactive impact on health outcomes. One example of this synergistic orientation is Evans's (2004) analysis of the "environment of childhood poverty," which emphasizes multiple and closely interrelated environmental factors (e.g., poor housing quality, substandard school environments, frequent exposures to toxins and environmental stressors, food insecurity) that jointly undermine the health outcomes of children and their parents. Chronic exposure to these multiple contextual dimensions of poverty result in elevated levels of allostatic load—that is, cumulative environmental demands that jeopardize health status when experienced over an extended period (McEwen, 2006; Seeman et al., 2001).

A synergistic orientation also is reflected in recent studies of the interactive health impacts of multiple risky behaviors. For instance, the combination of sleep deprivation and unhealthy diet increases adolescents' susceptibility to early-adult phase cardiovascular disease beyond the risks associated with poor nutrition and obesity alone (Larkin et al., 2005). Similarly, the synergistic influence of environmental and behavioral factors is reflected in a recent study of heath outcomes in mice and primate populations, which demonstrated that chronic exposure to environmental stressors amplifies the obesogenic influence of a high fat, high sugar diet (Kuo, Abe, & Zukowska, 2007; Kuo, Kitlinska, et al., 2007).

Refinement of the SEF: Priorities for Future Research

Clearly, substantial progress has been made in recent decades toward identifying and measuring multiple environmental, behavioral, and physiological

determinants of health and the interrelationships among them. At the same time, ecological research on health behaviors and outcomes face at least three kinds of challenges in the coming years: *conceptual, methodological, and translational*. At a conceptual level, analyses that are broad-gauged (i.e., span macroenvironmental through microphysiological levels) as well as parsimonious and powerful (i.e., identify the highest-leverage influences on health situated at each analytic level) are needed. The tradeoffs between broad conceptual scope and theoretical parsimony remain to be better balanced or resolved in future research. As well, ecological analyses of health must continue to identify and document the most powerful synergies among multiple environmental, behavioral, and physiological factors that have the greatest cumulative influence on personal and aggregate indicators of well-being.

At a methodological level, broader-gauged research designs are needed to document the empirical links among all segments of the EBPH pathways for a particular individual or group. This is not to say that all ecological studies must encompass the full array of EBPH categories and their interrelations. As noted earlier, studies focusing on the links among more limited subsets of E, B, P, and H factors have been instrumental in advancing the SEF. Nonetheless, a larger number of broad-gauged studies encompassing the full range of hypothesized variables within a particular EBPH pathway should be designed and supported by health research funding agencies and foundations in the future. More expansive field-experimental studies that address all segments of the EBPH pathway are essential for documenting their empirical links and for moving the study of ecology and health forward in future years.

A major translational challenge facing ecological research on health is the design and evaluation of multilevel, multicomponent programs and policies that explicitly modify high-leverage environmental, behavioral, and physiological precursors of health status among individuals and groups. To date, broadly conceived disease prevention and health promotion programs that target facets of the macro-, meso-, and microenvironment and their effects on health behaviors, physiological processes, and well-being have been lacking, partly because these kinds of studies are notoriously labor- and time-intensive and financially costly to implement and sustain. Those constraints notwithstanding, the design, implementation, and evaluation of more comprehensive health improvement interventions that encompass the full range of factors within the EBPH pathway remain as important and valuable goals for future research.

Finally, broad-gauged studies of health enhancement and disease prevention programs will require close collaboration among cross-disciplinary teams of scientists, clinicians, and community decision-makers (Abrams, 2006; Stokols, 2006). Earlier studies of team science suggest that the effectiveness of cross-disciplinary collaboration in health research, training, and the translation of scientific knowledge into clinical practices and policies is highly variable and depends on several contextual factors that either facilitate or constrain teamwork (Kessel & Rosenfield, 2006; Stokols, Harvey, Gress, Fuqua, & Phillips, 2005) and influence the impact and sustainability of evidence-based community interventions (Altman, 1995; Kerner, Rimer, & Emmons, 2005). Strategies for sustaining effective collaboration extending across multiple academic and professional fields will need to be implemented

and refined as a basis for advancing social ecological research on health out-comes and health behavior in future years.

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Models of Provider-Patient Interaction and Shared Decision Making

6

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Health care providers have the potential to play a central role in influencing and supporting their patients' efforts to adopt, change, or maintain health behaviors. Data from the 2000–2001 U.S. National Health Interview Survey indicate that 83% of adults 18–64 years of age report that they have a usual source of care, a place where they usually go when they are "sick or . . . need advice about health"(National Center for Health Statistics, 2003). Moreover, there is increasing evidence that clinical interventions to address health risk behaviors and support patient self-management of chronic illnesses are efficacious (Bodenheimer, Lorig, Holman, & Grumbach, 2002; M. G. Goldstein, Whitlock, & DePue, 2004; Whitlock, Orleans, Pender, & Allan, 2002). In addition, patients report that their physicians have considerable influence regarding their health behaviors (Davis et al., 2002). The behaviors that may be influenced by providers

fall along a very broad spectrum and include health risk behaviors (e.g., risky drinking, cigarette smoking, sedentary behavior); chronic illness self-management behaviors (e.g., monitoring symptoms and test results and adjusting regimens appropriately, medication taking, pacing, coping with emotional changes); preventive behaviors (e.g., participating in screening tests, wearing seat belts, practicing safer sex); and health-promoting behaviors (e.g., healthy diet, stress management).

Despite the evidence for effectiveness of health behavior counseling interventions in primary care, several population-based surveys have reported relatively low rates of provider intervention to address health risk behaviors. For example, results from the 2001–2003 National Ambulatory Medical Care Surveys (NAMCS) indicate that smoking cessation counseling was received by only 20% of patients who smoke (Thorndike, Regan, & Rigotti, 2007). Surveys of patients with chronic conditions suggest that providers are regularly missing opportunities to offer and provide tests and referrals recommended by practice guidelines (Committee on Quality of Health Care in America, 2001; Davis et al., 2002).

In this chapter, we first briefly describe barriers to delivery of health behavior change interventions in health care settings. Then, we describe several conceptual models of provider-patient interactions that have generated effective or promising provider-delivered health behavior change interventions. These include patient-centered models, approaches that focus on supporting self-management, models of shared decision making, and the 5 As approach to health behavior counseling. The provider-patient interaction models discussed here have been derived and informed by a variety of health behavior change theories and models that are comprehensively addressed in other chapters of this volume and are only touched upon here. Though we refer to Motivational Interviewing (MI) (Miller & Rollnick, 2002) and brief motivational strategies based on MI (Rollnick, Miller, & Butler, 2008), the reader is referred to chapter 8, on MI, for a more complete discussion of these approaches.

After reviewing these conceptual models of provider-patient interactions, we broaden our focus and briefly describe a conceptual model, the Chronic Care Model, that focuses on the organizational level of health care delivery. This system-level model integrates patient and provider factors with health care delivery system and organizational factors that influence the delivery of care and patient outcomes.

Barriers to Provider Delivery of Effective Health Behavior Change Interventions

Barriers to provider involvement in health behavior change interventions can be categorized as deficits in knowledge, deficits in skill, attitudinal barriers, and organizational barriers. These are listed in Table 6.1.

While many clinicians recognize the importance of health risk behavior change, they often have limited knowledge of effective communication, behavior change counseling, and self-management support skills and strategies (Bodenheimer, Lorig, et al., 2002). Until recently, physicians also had little exposure to organizational models and strategies for improving the effectiveness

6.1 Barriers to Provider Involvement in Behavior Change Interventions

Physician barriers

Knowledge deficit

> Behavior change principles
> Effectiveness of physician intervention
> Intervention methods
> Resources for patients—materials and referrals
> Organizational and system models for supporting behavior change and self-management

Skill deficit

> Interviewing/assessment/diagnostic skills
> Patient education skills
> Behavioral counseling skills
> Maintenance/relapse prevention skills

Beliefs and attitudes

> Belief that patients don't want to change or can't change
> Perceived ineffectiveness in helping patients follow through with treatment or change
> Lack of confidence in helping patents adhere or change
> Emphasis on final outcomes
> Disease-oriented biomedical approach
> Provider-centered, directive style
> Moralistic view of behavior problems

Poor personal health habits
Dearth of role models practicing preventive care

Organizational barriers

Limited use of reminder systems, tracking logs
Little or no reimbursement for patient education, counseling, or preventive services
Poor coordination with self-help and behavioral treatment programs
Limited involvement of office staff in patient education and health promotion activities

Note. From "Behavioral Medicine Strategies for Medical Patients" by M. G. Goldstein, L. Ruggiero, B. J. Guise, & D. B. Abrams, in *Clinical Psychiatry for Medical Students* (2nd ed., pp. 671–693), A. Stoudemire (Ed.), 1994, Philadelphia: J. B. Lippincott.

and quality of care (Wagner, Glasgow, et al., 2001). Knowledge is a prerequisite to learning these skills and organizing care to provide effective and efficient health behavior change interventions. Lack of specific skills in health behavior counseling and self-management support is a second important barrier to provider effectiveness. Training in these skills during professional training has been neglected, particularly in medical schools (Waldstein, Neumann, Drossman, & Novack, 2001). Many providers manifest attitudinal barriers, such as low confidence or self-efficacy to engage in health behavior counseling (Orleans, George, Houpt, & Brodie, 1985). Lack of confidence is related to lack of knowledge and the presence of other attitudes, such as perceived lack

of effectiveness and a tendency to measure their success by final outcomes, such as abstinence from smoking, rather than recognizing that lasting behavior change occurs only after multiple trials and through intermediate steps (Bandura, 2004). Perceived lack of effectiveness fuels the attitude that patients don't want to change or can't change. Provider attitudes are also shaped by the prevailing model in medicine, the biomedical model, which emphasizes a focus on diagnosis and treatment of disease and undervalues the role of psychological, behavioral, and social factors in health and disease (Waldstein et al., 2001). Despite an increased emphasis in recent years on the teaching of prevention, there are very few role models who emphasize patient education and counseling, contributing to the belief that health promotion activities are outside providers' role. Providers may also harbor negative or moralistic attitudes toward patients who exhibit problematic behaviors or who don't follow their recommendations. These attitudes may interfere with their willingness or capacity to assist these patients to change. Finally, providers with negative personal health practices are less likely to counsel patients regarding prevention (Frank, Rothenberg, Lewis, & Belodoff, 2000).

Organizational barriers to provider involvement in behavior change counseling and self-management are also listed in Table 6.1. Organizational factors are key factors in determining the success of interventions to address health risk behaviors and self-management and can undermine or enhance the efforts of individual providers. The effectiveness of reminders on the delivery of preventive services by physicians and other health care providers has been conclusively demonstrated in multiple studies (Grimshaw et al., 2001). Despite the promise of information technology for enhancing the delivery of high-quality medical care, most medical care settings have not yet adopted integrated platforms that support the delivery of educational and health behavior change interventions across multiple health behaviors and conditions (Pronk, Peek, & Goldstein, 2004). In the following sections, we review models for provider-patient interaction that may be employed to develop and test interventions to address and overcome these barriers to delivering effective health behavior change interventions in health care settings.

Models of Provider–Patient Interaction

The Patient–Centered Model

The landmark 2000 Institute of Medicine (IOM) report, "Crossing the Quality Chasm: A New Health System for the 21st Century," suggested that a redesigned quality health care system must be patient centered as well as safe, effective, timely, efficient, and equitable (Committee on Quality of Health Care in America, 2000). The IOM defined patient-centered care as care that is respectful of and responsive to individual patient preferences, needs, and values; care that ensures that patient values guides all clinical decisions (Committee on Quality of Health Care in America, 2001). Thus, the delivery of patient-centered care is considered to be a core value or principle of high-quality care.

Stewart and colleagues at the University of Western Ontario, Canada, have described a Patient-Centered Model that embodies the principles of patient-

centered care as defined in the IOM report (Stewart et al., 1995). This patient-centered approach has origins in the work of Carl Rogers (1951). A number of other educators and researchers have described models of clinician-patient communication (Makoul, 2001), patient education and counseling (Grueninger, Duffy, & Goldstein, 1995; Ockene & Zapka, 2000), and self-management support (Roter & Kinmonth, 2002) that are closely aligned with the Patient-Centered Model.

The Patient-Centered Model emphasizes a collaborative process of provider-patient interaction: developing a common, shared understanding of the problem or illness; addressing the patient's feelings, beliefs, expectations, and concerns; knowing the "whole person" and his family and social context; and collaboratively choosing among options for treatment, behavior change, and follow-up (Stewart et al., 1995). These elements reflect a process characterized by partnership, collaboration, and respect; a process that seeks to understand the meaning of the patient's experiences, needs, values, and preferences; and a process that shares control and responsibility for decision making.

Substantial research supports the relationships between these patient-centered provider-patient communication principles and a wide range of outcomes, including diagnostic accuracy, symptom control, patient satisfaction, patient follow-through with treatment recommendations, and health behavior change (DiMatteo, 1994; Ockene & Zapka, 2000; Roter & Kinmonth, 2002; Safran, Taira, Rogers, Kosinski, & Tarlov, 1998; Stewart et al., 2000; Whitlock et al., 2002).

Self-Management Support: A Patient-Centered Approach for Enhancing Chronic Illness Care

Self-management has emerged as a central concept in chronic illness care and has become a core component of interventions to improve the outcomes for patients with chronic conditions (Bodenheimer, Lorig et al., 2002; Lorig & Holman, 2003). Self-management is broadly defined as *all* that a patient does to manage her chronic condition and to live her life as fully and as productively as possible (Bodenheimer, Lorig et al., 2002; Lorig & Holman, 2003). Lorig and Holman have described three general domains of self-management: (1) managing symptoms and disease activity (medical management); (2) carrying out normal activities as a parent, worker, student, and so on (role management); and (3) coping with emotions (emotional management) (Lorig & Holman, 2003). To address these general domains, patients must engage in a wide variety of self-management behaviors and activities. The American Association of Diabetes Educators (AADE) has specified seven sets of self-management behaviors, the "AADE 7 Self-Care Behaviors™": Healthy Eating, Being Active, Monitoring, Taking Medication, Problem Solving, Healthy Coping, and Reducing Risks. It has also proposed standards and outcome measures for each (American Association of Diabetes Educators, 2003).

Note that the term "adherence" is not listed among the tasks of self-management, while medication taking is included. Many educators, clinicians, and researchers in chronic illness care have moved away from describing patient behavior as adherent or nonadherent (Anderson & Funnell, 2000; Glasgow

& Anderson, 1999), terms that appraise patient behavior from the provider point of view. "Nonadherence" to provider prescriptions and recommendations is a rather judgmental or pejorative way to describe patient behavior, especially in light of evidence that providers frequently fail to adequately educate patients and enlist them in a process of informed decision making (Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999; Street, Gordon, Ward, Krupat, & Kravitz, 2005). Though the term "adherence" is less objectionable than "compliance," we prefer to use terms that simply describe patient behavior (e.g., medication taking).

As proponents of the self-management concept point out, all patients self-manage, though some manage more effectively than others (Bodenheimer, Lorig et al., 2002; Lorig & Holman, 2003). Competence in self-management does not happen overnight; developing competence is a developmental process that evolves over the course of a patient's illness (Hibbard, Mahoney, Stockard, & Tusler, 2005; Hibbard & Tusler, 2007; Lorig & Holman, 2003). Hibbard has described four developmental levels or stages of "patient activation" that reflects a patient's capacity to self-manage: (1) unaware of the value or importance of taking an active role in self-management; (2) aware, but with limited knowledge, skills, and confidence to self-manage; (3) has knowledge and is beginning to take action, but has limited confidence; (4) has adopted new behaviors and is gaining confidence in sustaining behavior change (Hibbard et al., 2005; Hibbard & Tusler, 2007). As many as 40% of patients with a chronic illness are in the first two stages of patient activation; these patients are less likely to engage in a wide variety of self-management behaviors (Hibbard et al., 2005; Hibbard & Tusler, 2007) and have poorer health (Mosen et al., 2007). On the other hand, longitudinal studies have found that patients who progress to a higher stage of patient activation are more likely to adopt self-management behaviors (Hibbard, Mahoney, Stock, & Tusler, 2007). Strategies that are tailored to a patient's stage of activation have the potential to accelerate movement to the next stage and increase effective self-management behaviors, though this has yet to be demonstrated in controlled trials (Hibbard et al., 2007; Hibbard & Tusler, 2007). Research by other investigators has demonstrated links between chronic illness outcomes and concepts related to patient activation, including patient autonomy (Williams, McGregor, Zeldman, Freedman, & Deci, 2004), empowerment (Anderson et al., 1995) and more active participation in a medical visit (Greenfield, Kaplan, Ware, Yano, & Frank, 1988). In the next section, we discuss approaches that providers may employ to support and enhance patient self-management and movement through the stages of patient activation.

Self-management support is the term used to delineate efforts to assist patients to become more effective self-managers (Bodenheimer, Lorig, et al., 2002; Lorig & Holman, 2003). According to the Institute of Medicine, self-management support is the systematic provision of education and supportive interventions to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support (Adams, Corrigan, & Committee on Identifying Priority Areas for Quality Improvement, 2003). Self-management support is best characterized as a *process* for educating and empowering patients that is quite different from more traditional information-focused educational strategies. Though self-

management support interventions are often delivered by clinicians or other health care staff within clinical settings, elements of self-management support may also be delivered in community settings by lay educators, peer counselors, or other community-based workers (Fisher et al., 2005; Glasgow, Strycker, Toobert, & Eakin, 2000; Lorig & Holman, 2003). Controlled trials of self-management support interventions have produced improvements in clinical outcomes across a number of other chronic conditions (Bodenheimer, Lorig, et al., 2002; Lorig & Holman, 2003; Warsi, Wang, LaValley, Avorn, & Solomon, 2004). Systematic reviews of educational interventions in diabetes care have documented the clear superiority of self-management-based approaches to diabetes education over more traditional didactic-information-only educational interventions (Norris, Engelgau, & Narayan, 2001; Renders et al., 2001).

What are the elements of health behavior counseling and self-management support that are necessary to produce improved patient health outcomes? Recent efforts to integrate self-management support into general health care settings suggest that the following elements are critical to individual patient and program success: (1) assessment of patient beliefs, behavior, and knowledge; (2) collaborative goal setting; (3) identification of personal barriers and supports; (4) skills teaching, including problem-solving to address barriers; (5) increasing access to resources and supports; and (6) developing a personal action plan that is based on the previous steps (Fisher et al., 2005; Glasgow et al., 2002).

Provider Communication Behaviors That Are Associated With Effective Self-Management Support

One may also look more granularly and consider the specific provider communication behaviors that are associated with effective self-management support. In a review of evidence-based self-management support interventions in diabetes care, Roter and Kinmonth identified several specific communication and counseling elements that were linked to successful outcomes: (1) hear the patients perspective; (2) provide information that is useful and relevant and check for accuracy; (3) negotiate a plan and anticipate problems; (4) offer ongoing monitoring and follow-up; (5) find problems and renegotiate solutions; and (6) offer emotional support (Roter & Kinmonth, 2002). A remarkably similar constellation of clinician-patient communication variables has been associated with increased patient follow-through with clinician recommendations (DiMatteo et al., 1993; Safran et al., 1998; Squier, 1990). Of particular note is the strong association between clinician empathy (defined behaviorally as responding to, supporting, and respecting patients' feelings and concerns) and patient follow-through (Squier, 1990). Supporting patient autonomy, for example, by offering treatment options in a patient-centered and noncontrolling way, also appears to promote follow-through and successful behavior change (Williams, McGregor, King, Nelson, & Glasgow, 2005). Note the alignment between these communication elements, the elements of the Patient-Centered Model and the elements of successful self-management support interventions described earlier. A distillation of the effective components of self-management support may be found in the list of "Core Competencies for Self-Management Support" that

6.2   Core Competencies for Self-Management Support

- Relationship building
- Exploring patients' needs, expectations, and values
- Information sharing
- Collaborative goal setting
- Action planning
- Skills building and problem solving
- Following up on progress

Note. From New Health Partnerships: Improving Care by Engaging Patients, a quality improvement project funded by the Robert Wood Johnson Foundation. Retrieved January 6, 2008, from www.newhealth partnerships.org.

were developed by New Health Partnerships, a quality improvement project funded by the Robert Wood Johnson Foundation. (See Table 6.2 and www.ne whealthpartnerships.org.)

Motivational Interviewing and Brief Motivational Approaches

Motivational Interviewing (MI) (Miller & Rollnick, 2002) is covered in depth in chapter 8. MI is compatible with the patient-centered models and self-management support principles described earlier and is particularly useful for the large percentage of individuals who are in the early "stages" of motivational readiness (Prochaska & DiClemente, 1986). Initially developed as an intervention for alcohol and substance use problems, the efficacy of MI has been demonstrated across multiple behavioral targets (Britt, Hudson, & Blampied, 2004; Rubak, Sandbaek, Lauritzen, & Christensen, 2005).

Brief versions of MI have been developed for use by clinicians in primary care and other health care settings (Keller & White, 1997; Rollnick et al., 2008). These versions emphasize patient-centered strategies including eliciting patient priorities, needs, and values; building rapport (i.e., reflective listening and empathy); supporting autonomy and resisting the temptation to recommend or prescribe prematurely; and tailoring counseling to address two dimensions of motivation: (1) the patient's *conviction* (or level of importance) regarding the need for change; and (2) the patient's *confidence (or self-efficacy)* about successfully changing. Assessment remains the key step of brief versions of MI, permitting clinicians to provide more efficient, tailored interventions that are matched to patients' levels of readiness and commitment to change. When both conviction and confidence are low, the primary focus of brief MI is to build conviction. To enhance conviction, clinicians may offer a menu of options (including simply thinking about change); support patient choice among options; explore ambivalence; and provide information and feedback to enhance knowledge and awareness about the value of change and the risk of not changing (Keller & White, 1997; Rollnick et al., 2008). When a patient's confidence is low, brief MI includes reviewing past experience, especially successes; encouraging small steps that

are likely to lead to initial success; and teaching problem-solving and coping skills. For all patients, a follow-up plan is essential.

Shared Decision Making

According to Frosch and Kaplan (1999), shared medical decision making is a process by which patients and providers consider outcome probabilities and patient preferences and reach a health care decision based on mutual agreement. Though definitions of shared decision making (SDM) vary, virtually all emphasize a collaborative process that actively engages patients in decisions about prevention, treatment, and self-management (Makoul & Clayman, 2006). Most descriptions and definitions of SDM also incorporate the broader principles of patient-centered communication described earlier. On the basis of an extensive review of the literature, Makoul and Clayman (2006) identified several "essential elements" of SDM in behavioral terms: define/explain the problem; present options; discuss pros/cons (benefits/risks/costs); elicit patients' values/preferences; discuss patient ability/self-efficacy; offer knowledge/recommendations; check/clarify patient understanding; make or explicitly defer a decision; and arrange follow-up.

As Makoul and Clayman note, patients and providers must come to a shared understanding of the problem, disease, and condition or preventive activity (e.g., immunization, screening test, regular physical activity) as a prerequisite to making an informed decision. Patients, and providers for that matter, also require access to evidence-informed knowledge about the risks and benefits of interventions, as well as the risks and consequences of not taking action (Epstein, Alper, & Quill, 2004; O'Connor et al., 2007). Clarifying patients' values and preferences regarding outcomes, symptoms, side effects, and so on is another key aspect of the SDM process, as values and preferences vary considerably between patients as well as within patients over the course of a condition (Levinson, Kao, Kuby, & Thisted, 2005). As Entwhistle and Watt have argued, clinicians need to explore not only what patients know but also how they feel about their role in the decision-making process (Entwistle & Watt, 2006). In a large population-based sample of patients, 96% preferred to be offered choices and to be asked about their opinions. However, 44% preferred to rely on physicians for medical knowledge rather than seeking out information themselves, and about half (52%) preferred to leave final decisions to their physicians (Levinson et al., 2005). Results of this survey also found that preferences for an active role in decision making increased with age up to 45 years and then declined, while women, more educated, and healthier people were more likely to prefer an active role in decision making. Preferences for participation in decision making also varies across cultural and ethnic subgroups (Charles, Gafni, & Whelan, 1999; Levinson et al., 2005). The wide variability in preferences for participation in decision making that has been documented in these studies supports the view that providers must assess individual patient preferences and tailor their approach to decision making accordingly (Charles et al., 1999; Levinson et al., 2005).

Decision-making aids can assist providers to meet the requirements of fully informed SDM (O'Connor et al., 2007), but aids alone are insufficient to ensure that patients have an opportunity to participate in the process of decision making at the level of involvement they need or desire (Epstein et al., 2004). Patients' age, cognitive capacity, educational level, and literacy also impact their capacity

to fully participate in SDM (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007; Epstein et al., 2004).

The 5 As of Health Behavior Counseling: A Unifying Framework

The U.S. Preventive Services Task Force Counseling and Behavioral Interventions Work Group has recommended the 5 As framework (i.e., Assess, Advise, Agree, Assist, Arrange follow-up) as a unifying conceptual framework for evaluating and describing health behavior counseling interventions in primary and general health care settings (Whitlock et al., 2002). The 5 As have been applied to a wide variety of individual health behavioral counseling targets (Goldstein et al., 2004) as well as the self-management component of chronic illness care (Glasgow, Davis, Funnell, & Beck, 2003; Glasgow et al., 2002). See Table 6.3 for a summary of the 5 As construct, adapted from the

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6.3 The 5 As for Behavioral Counseling and Health Behavior Change

Assess
- Assess behavioral risk factors to identify patients in need of intervention
- Assess beliefs, behaviors, knowledge, motivation, and past experience

Advise
- Offer clear, specific, personalized behavior change advice
- Link to patient's expressed concerns, values, beliefs, experiences
- Adapt to level of health literacy

Agree
- Offer options for behavior change goals and methods to achieve goals
- Collaboratively choose specific behavior change goals and methods

Assist
- Provide motivational interventions when needed
- Offer self-help resources and materials and links to community resources
- Review options for formal treatment programs
- Develop a specific action plan to accomplish goals
- Identify and address barriers using problem-solving strategies
- Teach skills for achieving behavior change (including problem-solving skills)

Arrange follow-up
- Specify a follow-up plan including when, how, and with whom

Note. From "Assessing Delivery of the Five 'As' for Patient-Centered Counseling," by R. E. Glasgow, S. Emont, & D. C. Miller et al., 2006, *Health Promotion International, 21*(3), pp. 245–255; "Multiple Behavioral Risk Factor Interventions in Primary Care; Summary of Research Evidence," by M. G. Goldstein, E. P. Whitlock, & J. DePue, 2004, *American Journal of Preventive Medicine, 27*(2 Suppl), 61–79; "Evaluating Primary Care Behavioral Counseling Interventions: An Evidence-Based Approach," by E. P. Whitlock, C. T. Orleans, N. Pender, & J. Allan, 2002, *American Journal of Preventive Medicine, 22*(4), 267–284.

USPSTF Counseling and Behavioral Interventions Work Group report and other publications (Glasgow, Emont, & Miller, 2006; Goldstein et al., 2004; Whitlock et al., 2002).

A notable and important difference between the Patient-Centered Model and the 5 As is the absence of a specific relationship building component among the 5 As. As previously discussed, provider use of empathy is strongly linked to positive outcomes of communication and counseling interventions (Roter & Kinmonth, 2002; Squier, 1990). However, the easily remembered and concise 5 As framework has advantages as a tool for learning and dissemination.

Interventions that have included training providers in the 5 As counseling approach have been shown to be effective across multiple health behavior targets (Ockene et al., 1999; Whitlock et al., 2002). However, provider training alone is not sufficient to produce significant changes in patients' health behaviors; system-based strategies to prompt, document, and support provider interventions are required to produce benefits at the patient and population levels (Glasgow, Goldstein, Ockene, & Pronk, 2004; Ockene & Zapka, 2000; Pronk et al., 2004).

In the next section, we briefly discuss the Chronic Care Model (CCM), a model that addresses the organizational or system-level elements and factors that influence and support provider-patient interactions.

An Organizational Model of Provider–Patient Interaction

The Chronic Care/Planned Care Model

The Chronic Care Model (CCM), also known as the Planned Care Model, was developed by Edward Wagner and colleagues at the MacColl Institute for the Robert Wood Johnson Foundation-funded Improving Chronic Illness Care (ICIC) program (Wagner, 1998). (See Figure 6.1 and the ICIC website:http:// www.improvingchroniccare.org.)

Since its introduction, in the mid-1990s, the CCM has emerged as a key evidence-based conceptual model for understanding how forces at the community, organizational, provider, and patient levels interact to influence health care quality (Wagner, 1998; Wagner, Glasgow, et al., 2001). More recently, the CCM model has also been applied to preventive care (Glasgow, Orleans, & Wagner, 2001). The CCM, depicted graphically in Figure 6.1, posits that "productive interactions" between "informed activated patients" and a "prepared, proactive practice team" are the basis for generating positive health outcomes (Bodenheimer, Wagner, & Grumbach, 2002; Wagner, 1998; Wagner, Glasgow, et al., 2001). Productive interactions, in turn, are supported by several essential elements at the health care organizational level: (1) self-management support (see section of this chapter on self-management support for a definition and description); (2) delivery system design (e.g., planned regularly scheduled visits for patients with chronic illnesses, follow-up telephone contact for patients making a behavioral change); (3) decision support (e.g., care guidelines available at the point of care, provider training); (4) clinical information systems (e.g., patient registries, computerized reminder systems for patients and clinicians); (5) the overall organization of health care (e.g., leadership, support for quality improvement at all levels); and (6) community linkages and resources (Bodenheimer, Wagner, et al., 2002;

6.1

The Chronic Care Model.

The Chronic Care Model

Community
Resources and Policies

Health Systems
Organization of Health Care

Self-Management Support

Delivery System Design

Decision Support

Clinical Information Systems

Informed, Activated Patient

Productive Interactions

Prepared, Proactive Practice Team

Improved Outcomes
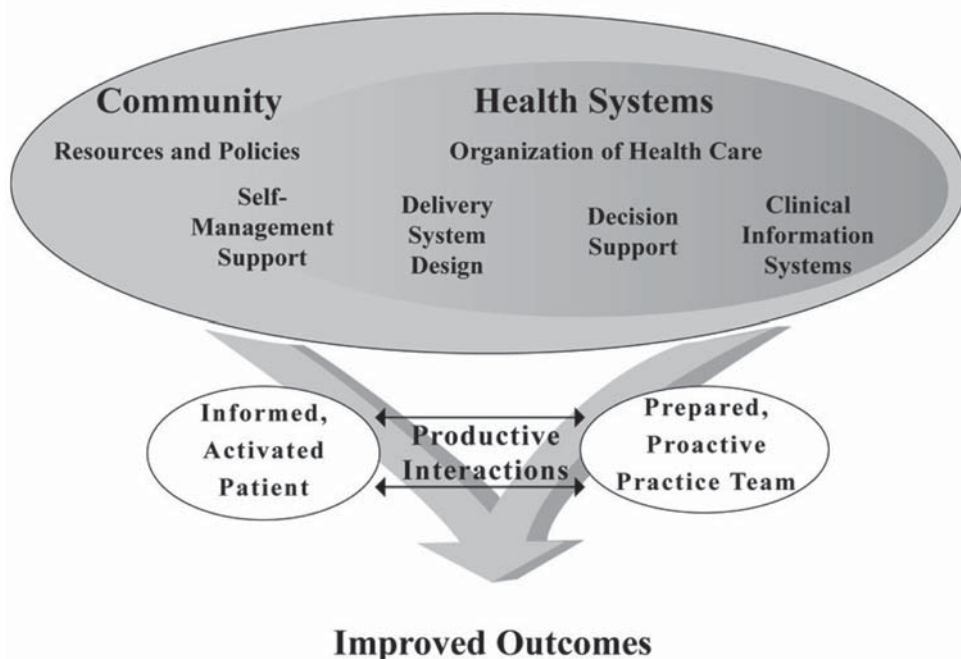
Note. From "Chronic Disease Management: What Will it Take to Improve Care for Chronic Illness?" by E. H. Wagner, 1998, *Effective Clinical Practice, 1,* pp. 2–4. Copyright 1998 by ACP-ASIM Journals and Books. Reprinted with permission.

Wagner, 1998; Wagner, Glasgow, et al., 2001). The overarching principles that cut across all six CCM elements include planned care, rather than responding only to issues that are raised; proactive care (e.g., outreach to identifying needs and encourage regular contact); population-based care (i.e., focused on an entire panel of patients rather than only those who appear in the exam room); and patient-centered care (informed by patient needs and priorities and individually relevant assessment data) (Wagner, 1998; Glasgow, Goldstein, et al., 2004).

The elements of the CCM interact in a complex and synergistic manner to produce positive health outcomes (Bodenheimer, Wagner, et al., 2002; Wagner, 1998; Wagner, Glasgow, et al., 2001). For example, to consistently provide high-quality self-management support, providers need training in self-management support core competencies (decision support); information systems that identify and track patients with chronic conditions through registries and provide a means for clinicians to document outcomes and self-management goals in the health record (information systems); provider teams that determine which team member will provide patients with follow-up to determine progress toward goals (delivery system design); organizational leaders who provide incentives and rewards for provider delivery of self-management

support interventions (organizational support); and a way to help patients identify community resources that will support and enable achievement of self-management goals (community linkages).

Through a variety of quality improvement projects, ICIC has developed, tested, and refined a package of *change strategies* that link to each of the key elements of the CCM. System and organizational strategies derived from the CCM that link most directly to supporting patient self-management and health behavior change have been documented in a number of publications (Bodenheimer, 2005; Fisher et al., 2007; Fisher et al., 2005; Glasgow & Toobert, 2000) and can also be found at the RWJF-funded New Health Partnerships Web site, http://www.newhealthpartnerships.org.

When considering the *delivery system design* element of the CCM, it is important to specify the role that each member of the clinical team will have in delivering elements of self-management support, both within specific types of visits (e.g., routine planned care visits) and over the course of a patient's illness over time (Bodenheimer, 2005; Bodenheimer, Wagner, et al., 2002; Glasgow et al., 2003). To efficiently utilize office staff and resources to meet patient needs and deliver comprehensive care, some have advocated adopting a "microsystem" approach that focuses on organizing and redesigning care within small units of providers, office staff, and patients (Wasson, Godfrey, Nelson, Mohr, & Batalden, 2003). For example, medical assistants might take on the Assess element of the 5A, the primary-care clinician might accomplish the Advise and Agree steps, and a medical assistant, nurse, or health educator (if available) might complete the Assist and Arrange steps of the 5 As, which might include referral to outside resources if intensive support is needed and desired by the patient (Goldstein et al., 2004; Wasson et al., 2003; Whitlock et al., 2002). Specifying and systematizing a follow-up plan, including identifying the member of the team who provides follow-up, by what method and when, is crucial to achieving positive outcomes of health behavior change and self-management support interventions (Bodenheimer, 2005; Bodenheimer, Wagner, et al., 2002; R. E. Glasgow et al., 2003).

Innovations in delivery system design also include group medical visits for patients with a specific chronic condition that allow various members of the heath care team (e.g., medical assistant, physician, nurse, nutritionist, peer educator) to efficiently provide education and self-management support while also providing patients with an opportunity to support and learn from one another (Clancy, Huang, Okonofua, Yeager, & Magruder, 2007; Wagner, Grothaus, et al., 2001). Another promising delivery system design innovation is a "previsit" conducted by a medical assistant (MA) following standard orders signed by a practice physician (Langford, Sawyer, Gioimo, Brownson, & O'Toole, 2007).

Clinical information systems, another key element of the CCM, can also be employed to enhance the system's capacity to address patient needs. The use of previsit health risk appraisal instruments, questionnaires, or interactive computer-based systems may be employed to reduce burden on the primary-care clinician (Glasgow, Bull, Piette, & Steiner, 2004; Pronk et al., 2004). Computer-based information systems and some electronic health records permit questionnaire data that are collected in the office to be rapidly analyzed and fed back to the provider and patient to aid tailoring of patient education and counseling interventions (Glasgow, Bull, et al., 2004). The integrated use of patient assessments also provides a useful way of prompting both the patient and the

provider to address health behaviors and self-management during the subsequent clinical interaction (Bodenheimer, 2003; Grimshaw et al., 2001; Ockene & Zapka, 2000; Walsh & McPhee, 1992).

Tools (e.g., assessments, action plans), training, technology, and delivery system design strategies derived from the CCM (e.g., group visits, educational programs) can support a clinical team to promote self-management and health behavior change. For example, a completed action plan not only prompts, reminds, and supports patients to work on progress toward goals; it also serves as a useful format for sharing information among providers across multiple visits over time (Bodenheimer, MacGregor, & Sharifi, 2005; Glasgow et al., 2002; Glasgow, Goldstein, et al., 2004). See Figure 6.2 for a graphic depiction of how the core competencies of self-management support can be translated into a cyclical process that centers around the creation of a living, evolving action plan that is shared with both patients and providers over multiple encounters over time (Bodenheimer et al., 2005; Glasgow et al., 2002; Glasgow, Goldstein, et al., 2004).

Recent adaptations of the CCM have emphasized the importance of expanding, strengthening, and deepening linkages between the health care systems and these other potential sources of support (i.e., family, social networks, community, and the local environment) (Fisher et al., 2007; Fisher et al., 2005). (See chapter 37 for further discussion of the effect of the environment on behavior.)

The CCM and a specific strategy for driving quality improvement through rapid-cycle testing and collaborative learning networks, developed in collaboration with the Institute for Healthcare Improvement (Glasgow et al., 2002; Wagner,

6.2

Self-management support: An ongoing process.
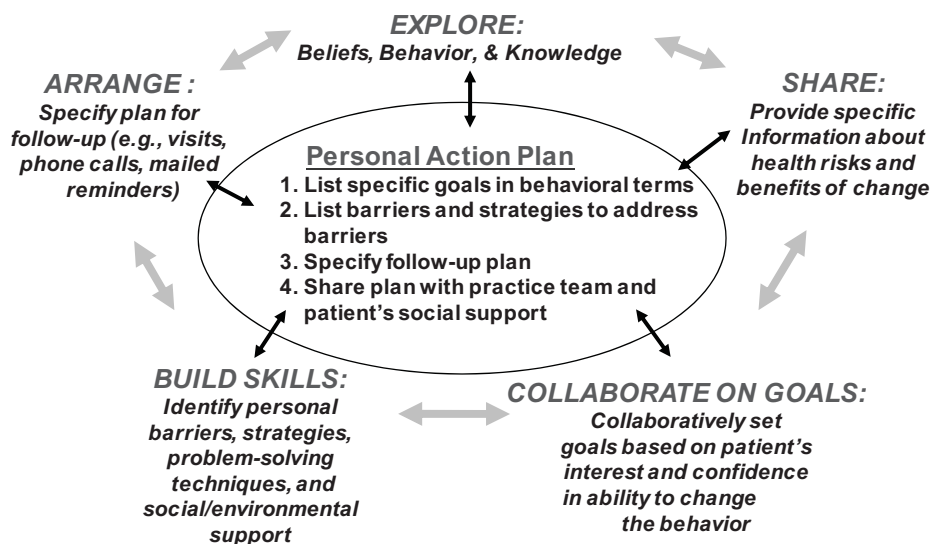
Note. From "Self-Management Aspects of the Improving Chronic Illness Care Breakthrough Series: Implementation With Diabetes and Heart Failure Teams," by R. E. Glasgow, M. M. Funnell, A. E. Bonomi, C. Davis, V. Beckham, & E. H. Wagner, 2002, *Annals of Behavioral Medicine, 24*(2), 80–87.

Glasgow, et al., 2001), have produced positive effects on process measures (e.g., performing recommended blood tests, documenting self-management goals), though there is less evidence for an effect on disease outcomes (Landon et al., 2007). Emerging results of an ongoing comprehensive evaluation of ICIC collaboratives can be found at http://www.rand.org/health/projects/icice/. The reader is referred to the ICIC Web site, http://www.improvingchronic care.org, for links to the CCM "Change Package" and other resources that health care organizations may utilize to implement the CCM.

In summary, the Chronic Care Model offers useful ways to consider how to integrate and organize care to support productive, patient-centered interactions between clinical teams and patients and families. The CCM emphasizes teamwork, organizational systems, and tools to support counseling and the important roles multiple members of the office staff team can play in the delivery of health behavior counseling and self-management support. Moreover, the CCM features elements that extend the influence of the provider-patient interaction beyond the exam or consultation room, both within and between visits. The CCM includes links between the health care system and myriad potential sources of care and support within spheres of influence that exist outside the health care system within the community (Fisher et al., 2007; Fisher et al., 2005).

As depicted in the Chronic Care Model, the final pathway to effective clinical and functional outcomes rests on effective and productive interactions between prepared proactive provider teams and activated informed patients and families (Wagner, 1998). As noted in the sections of this chapter on the Patient Centered Model, Brief Motivational Interviewing, Self-Management Support, the 5 As, and Shared Decision Making, each of these provider-patient interaction models offer principles and strategies that providers may employ to maximize the impact of their interactions with patients and families. The integration of these patient-provider interaction models and strategies with systems, tools, and strategies at the organizational level shows the greatest promise for achieving desirable changes in health behavior outcomes.

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Relapse Prevention and the Maintenance of Optimal Health

7

Christian S.
Hendershot,
G. Alan Marlatt, and
William H. George

Relapse prevention (RP) is a tertiary intervention strategy for reducing the likelihood and severity of relapse following the cessation or reduction of problematic behavior. This chapter reviews RP as a method for facilitating health behavior change. We begin with a concise overview of the historical and theoretical foundations of the RP model and a brief summary of intervention strategies. Next, we review the major theoretical, methodological, and applied developments related to RP that have transpired since the last iteration of this chapter (Marlatt & George, 1998). A large portion of the current chapter is devoted to describing recent empirical findings that coincide with key tenets of

the RP model. We conclude by summarizing current and future directions in the study and prevention of relapse.

Overlaying these topics are two themes unique to the present version of this chapter. First, emphasis is placed on the reformulated cognitive-behavioral model of relapse (Witkiewitz & Marlatt, 2004) as a framework for conceptualizing relapse as a dynamic process. Second, consistent with the theme of this book, we focus our empirical review on studies investigating health behavior or its antecedents. Predictably, the prime focus is on addictive behaviors, for which RP was initially conceived. However, findings from health domains such as diet, exercise, and HIV are also incorporated. In emphasizing health behavior, we forgo a detailed discussion of other behaviors and disorders to which RP approaches have been extended (e.g., sexual offending, depression, gambling) and refer readers to other sources (Marlatt & Donovan, 2005; Witkiewitz & Marlatt, 2007a) for further detail on the growing range of RP applications.

Relapse as a Barrier to Health Behavior Change

Definitions of relapse are varied, ranging from a dichotomous treatment outcome to an ongoing, transitional process (Brownell, Marlatt, Lichtenstein, & Wilson, 1986; Witkiewitz & Marlatt, 2004). As a testament to the complexity of relapse, a sizable volume of research has yielded no consensus operational definition of the term (Maisto & Connors, 2006; Piasecki, 2006). For present purposes we define *relapse* as a setback that occurs during the behavior change process, such that progress toward the initiation or maintenance of a behavior change goal (for instance, abstinence from drug use) is interrupted by a reversion to the target behavior. However defined, relapse poses a fundamental barrier to health maintenance by constituting the modal outcome of behavior change efforts (Orleans, 2000; Polivy & Herman, 2002).

Originating from early research with alcohol-dependent individuals (Marlatt, 1978), RP has been studied and applied largely in the context of addictive behaviors. However, the implications of RP for health maintenance extend well beyond this domain. Initial formulations of RP stressed its relevance to the emergent field of health psychology (Marlatt, 1982), and the seminal overview of the model appeared in a behavioral medicine text (Marlatt & Gordon, 1980). Subsequently, RP principles have been extended to a widening range of health domains, including diet, exercise, diabetes, and sexual risk taking. Clinical applications will inevitably vary across health behaviors owing to differences in the definition, rates, correlates, and implications of relapse. Nonetheless, the universal difficulty of sustaining modifications to long-standing behaviors (Polivy & Herman, 2002) renders RP a fundamental and broadly applicable approach for most researchers and clinicians with interests in health behavior change.

Relapse Prevention: Overview of the Model

The RP model developed by Marlatt and Gordon (1980, 1985) provides both a conceptual framework for understanding relapse and a set of treatment strategies designed to limit relapse likelihood and severity. Detailed accounts of the

model's historical background and theoretical underpinnings have been published elsewhere (e.g., Cummings, Gordon, & Marlatt; 1980; Dimeff & Marlatt, 1998; Marlatt, 1996; Marlatt & Gordon, 1985). The following section offers a concise review of the model's history, core concepts, and clinical applications. For simplicity, RP theory and approaches are discussed specifically in relation to substance use behavior.

Historical Foundations

RP was initially conceived as an outgrowth and augmentation of traditional behavioral approaches to studying and treating addictions. Based on the cognitive-behavioral model of relapse, the RP model was distinctive in its blending of basic learning principles with emerging theory from social psychology, cognitive psychology, and stress-and-coping perspectives. The evolution of cognitive-behavioral theories of substance use witnessed notable changes in the conceptualization of relapse, many of which departed from traditional (i.e., disease-based) models of addiction. For instance, whereas traditional models often attribute relapse to endogenous factors like cravings or withdrawal (construed as symptoms of an underlying disease state), cognitive-behavioral theories emphasize contextual factors (e.g., environmental stimuli, cognitive processes) as proximal relapse antecedents.

Cognitive-behavioral theories also diverged from disease models in rejecting the notion of relapse as a dichotomous outcome. Whereas disease models tend to view relapse as a state or endpoint signaling treatment failure, cognitive-behavioral theories consider relapse as a fluctuating process that begins prior to and extends beyond the return to the target behavior (Larimer, Palmer, & Marlatt, 1999). From this stance, the initial return to a problematic behavior after a period of volitional abstinence (a *lapse*) is seen not as a dead end but as a fork in the road. Though an initial lapse can prompt a full-blown relapse, another possible outcome is that the problem behavior is corrected and the desired behavior re-instantiated—an event referred to as *prolapse*. A key implication is that lapses, rather than signaling a breakdown or failure in the behavior change process, can be considered temporary setbacks that present opportunities for new learning. In viewing relapse as a common (albeit undesirable) event, emphasizing contextual antecedents over internal causes, and asserting that relapse does not amount to treatment failure, RP introduced a comprehensive, flexible, and optimistic alternative to traditional models.

Theoretical Basis

Marlatt and Gordon (1985) proposed that relapse is influenced both by *immediate precipitants* and *covert antecedents*. In terms of immediate precipitants, the RP model assumes that lapses typically occur during *high-risk situations,* broadly defined as any context that confers increased vulnerability for engaging in the target behavior. High-risk contexts can include emotional or cognitive states (e.g., negative affect, diminished self-efficacy), environmental contingencies (e.g., interpersonal events, exposure to conditioned drug cues), or physiological states (e.g., acute withdrawal). Although some high-risk situations appear nearly universal across addictive behaviors (e.g., negative affect; Marlatt, 1978;

Baker, Piper, McCarthy, Majeskie, & Fiore, 2004), high-risk situations are likely to vary across behaviors, across individuals, and within the same individual over time (Witkiewitz & Marlatt, 2007a). Whether a high-risk situation culminates in a lapse depends largely on another situational factor: the individual's capacity to enact an effective *coping response,* globally defined as any compensatory strategy (cognitive or behavioral) that reduces the likelihood of lapsing.

While emphasizing situational antecedents, the RP model also posits that the relapse process begins prior to the onset of a high-risk situation. *Covert antecedents* refer to ongoing factors that influence one's overall risk for relapse. A significant distal influence is one's overall level of lifestyle balance, defined as the equilibrium between day-to-day activities perceived as external demands ("shoulds") and those activities perceived as voluntary or pleasurable ("wants") (Marlatt and Gordon, 1985). For instance, a lifestyle encumbered with perceived "shoulds" may foster a sense of self-deprivation and a corresponding desire for gratification, which can manifest as urges or cravings. Covert antecedents can also take the form of subtle decision-making tendencies. Apparently Irrelevant Decisions (AIDs) refer to seemingly innocuous choices that serve to set up a relapse (e.g., purchasing alcohol "just in case guests drop by"). Overall, covert antecedents can contribute to relapse by facilitating exposure to high-risk situations and/or undermining one's motivation to cope with them (Larimer, Palmer, & Marlatt, 1999).

The RP model further stresses the role of cognitive factors as proximal and/or distal influences. For example, successful navigation of high-risk situations may increase *self-efficacy* (one's perceived capacity to cope with an impending situation or task; Bandura, 1997), in turn decreasing relapse probability. Conversely, a return to the prohibited behavior can undermine self-efficacy, increasing the risk of future lapses. *Outcome expectancies* (e.g., anticipated effects of substance use; Goldman, Darkes, & Del Boca, 1999) also figure prominently in the RP model. Finally, attitudes or beliefs about the causes and meaning of a lapse may influence whether a full relapse ensues. Viewing a lapse as a personal failure may lead to feelings of guilt, perceived helplessness, and abandonment of the behavior change goal (Larimer, Palmer, & Marlatt, 1999). This reaction, termed the Abstinence Violation Effect (AVE) (Marlatt and Gordon, 1980, 1985), may be more likely when one holds a dichotomous view of relapse and/or neglects to consider situational explanations for lapsing. In sum, the RP framework emphasizes high-risk contexts, coping responses, self-efficacy, affect, expectancies, and the AVE as primary relapse influences.

Intervention Strategies

The RP approach assumes that the initiation and maintenance of behavior change represent separate processes governed by unique contingencies (e.g., Brownell et al., 1986; Rothman, 2000). Thus, specific cognitive and behavioral strategies are often necessary to maintain initial treatment gains and minimize relapse likelihood. RP strategies fall into two broad categories: specific intervention techniques, often designed to help the patient anticipate and cope with high-risk situations, and global self-control approaches, intended to reduce relapse risk by promoting positive lifestyle change. It should be noted that this emphasis on posttreatment maintenance and overall lifestyle balance renders

RP a potentially useful adjunct to various treatment modalities (e.g., cognitive-behavioral therapy, 12-step programs, pharmacotherapy), irrespective of the strategies used to enact initial behavior change.

An essential starting point to treatment is a thorough assessment of the client's substance use patterns, high-risk situations, and coping skills. Other important targets of assessment include the client's self-efficacy, outcome expectancies, and readiness to change, along with concomitant factors that may complicate treatment (e.g., comorbid disorders, neuropsychological deficits). Using high-risk situations as a starting point, the therapist works backward to identify immediate precipitants and distal lifestyle factors related to relapse and forward to evaluate coping responses (Larimer, Palmer, & Marlatt, 1999; Marlatt & Gordon, 1985). Ideally, this approach helps clients to (a) recognize high-risk situations as discriminative stimuli signaling relapse risk, and (b) identify possible cognitive and behavioral strategies to obviate these situations or minimize their impact. Examples of specific intervention strategies include enhancing self-efficacy (e.g., by setting achievable goals) and eliminating myths and placebo effects (e.g., challenging misperceptions about the effects of substance use). The client's postlapse reaction also serves as a pivotal intervention point, since it can determine whether a lapse escalates or desists. Establishing lapse management plans can aid the client in self-correcting soon after a slip, and cognitive restructuring can help clients to reframe the meaning of the event and minimize the AVE (Larimer, Palmer, & Marlatt, 1999).

The final thrust in the RP program is the global intervention of lifestyle balancing, designed to target more pervasive factors that can function as relapse antecedents. To reiterate, relapse risk is often heightened when individuals perceive their lifestyle as predominated by obligations and lacking in commensurate pleasurable activities. A useful way to assess lifestyle imbalance is for clients to monitor their behavior, keeping a daily log of both obligations and indulgences, to highlight disequilibrium between "shoulds" and "wants." Clients are encouraged to integrate pleasurable activities and "positive addictions," like exercise or meditation, into their daily routine. The psychological and health benefits derived from positive addictions may enhance self-efficacy, in turn reducing relapse risk. As implied by the strategies discussed, RP is characterized by a highly ideographic treatment approach, a contrast to the "one size fits all" perspective typical of other treatments (e.g., 12-step programs).

Recent Developments in Relapse Prevention

The decade since the last edition of this volume (Shumaker, Schron, Ockene, & McBee, 1998) has seen several noteworthy developments related to RP. A significant milestone was the publication of *Relapse Prevention,* 2nd ed. (Marlatt & Donovan, 2005). This updated volume reflects the expanding range of RP applications, with new chapters devoted to specific drugs (stimulants, opioids, cannabis, and "club" drugs) and nonsubstance-use behaviors (gambling, eating disorders/obesity, sexual offending, and sexual risk behavior). The volume was developed in tandem with *Assessment of Addictive Behaviors,* 2nd ed. (Donovan & Marlatt, 2005), which serves as its companion text.

The continual influence of RP is evident in its broad dissemination and increasing accessibility. RP modules are standard to virtually all psychosocial interventions for substance use (McGovern, Wrisley, & Drake, 2005) and an increasing number of self-help manuals are available to assist both therapists and clients. A new text designed for practicing clinicians discusses RP techniques across a range of behavior domains (Witkiewitz & Marlatt, 2007a). RP strategies have been disseminated using simple but effective methods; for instance, mail-delivered RP booklets are shown to reduce smoking relapse (Brandon, Collins, Juliano, & Lazev, 2000). Researchers and clinicians continue to extend RP applications by tailoring treatment approaches to specific populations (Witkiewitz & Marlatt, 2007a). Finally, the broad influence of RP is evident in the clinical vernacular, as "relapse prevention" has evolved into an umbrella term synonymous with most skills-based interventions addressing high-risk situations and coping responses.

Conceptualizing Relapse as a Dynamic Process

Greater efforts to develop, test, and refine theoretical models are critical to enhancing the understanding and treatment of relapse (Maisto & Connors, 2006; Orleans, 2000). A noteworthy development in this respect was the reformulation of Marlatt's cognitive-behavioral relapse model to emphasize dynamic processes (Witkiewitz & Marlatt, 2004).

Whereas most theories presume linear relationships among constructs, the dynamic model views relapse as a complex, nonlinear process in which various factors act jointly and interactively to affect relapse timing and severity. Similar to the original RP model, the dynamic model centers on the high-risk situation. Against this backdrop, both tonic (stable) and phasic (fluctuating) influences can act to determine relapse likelihood. Tonic processes include *distal risks,* or stable background factors that determine an individual's "set point" or initial threshold for relapse (Hufford, Witkiewitz, Shields, Kodya, & Caruso 2003; Witkiewitz & Marlatt, 2004). Personality, genetic or familial risk factors, drug sensitivity and metabolism, and physical withdrawal profiles are examples of distal variables that may influence one's a priori relapse liability. Tonic processes also include cognitive factors showing stability over time, such as outcome expectancies, global self-efficacy, and personal beliefs about abstinence or relapse. Whereas tonic processes may dictate relapse susceptibility, its occurrence is determined largely by *phasic responses*—proximal or transient factors that serve to actuate (or prevent) a lapse. Phasic responses include cognitive and affective processes that can fluctuate across time and contexts—such as urges and cravings, mood, situational self-efficacy, and motivation—as well as momentary coping responses. Substance use and its immediate consequences (e.g., impaired decision making, the AVE) are additional phasic processes that are set into motion once a lapse occurs. To summarize, tonic processes usually determine *who* is vulnerable for relapse, whereas phasic processes determine *when* relapse occurs (Hufford et al., 2003; Witkiewitz & Marlatt, 2004).

A key feature of the dynamic model is its emphasis on the complex interplay between tonic and phasic processes. As indicated in Figure 7.1, distal risks may influence relapse either directly or indirectly (via phasic processes). The model also predicts feedback loops among hypothesized constructs. For instance, the return to substance use can have reciprocal effects on the same

7.1

Dynamic model of relapse.
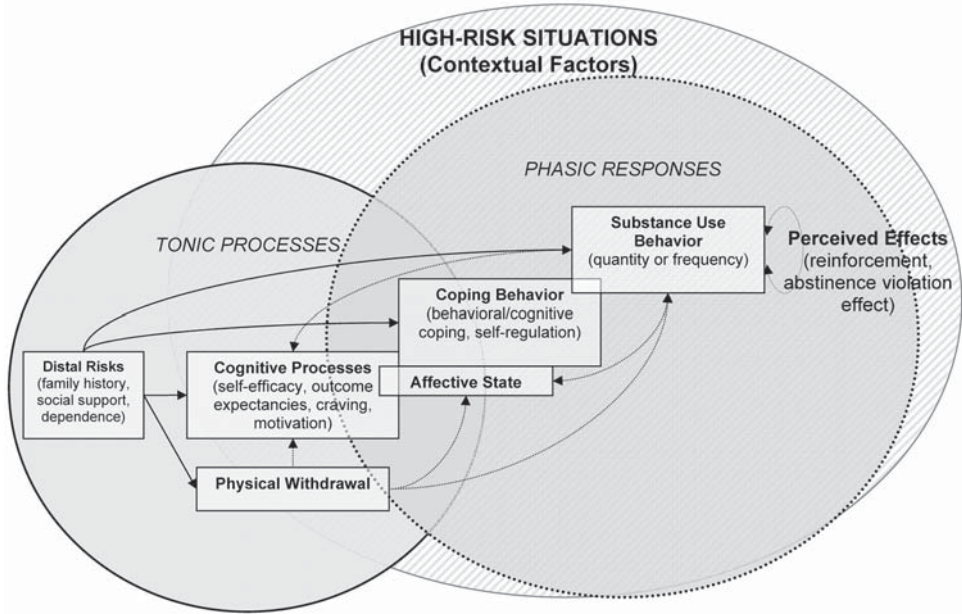
Note. From "Relapse Prevention for Alcohol and Drug Problems: That was Zen, This is Tao," by K. Witkiewitz & G. A. Marlatt, 2004, *American Psychologist, 59,* pp. 224–235. Copyright 2004 by American Psychological Association. Reprinted with permission.

cognitive or affective factors (motivation, mood, self-efficacy) that contributed to the lapse. Lapses may also evoke physiological (e.g., alleviation of withdrawal) and/or cognitive (e.g., the AVE) responses that in turn determine whether use escalates or desists. The dynamic model further emphasizes the importance of nonlinear relationships and timing/sequencing of events. For instance, in a high-risk context, a slight and momentary drop in self-efficacy can have a disproportionate impact on other relapse antecedents (negative affect, expectancies) (Witkiewitz & Marlatt, 2004, 2007a). Furthermore, the strength of proximal influences on relapse may vary based on distal risk factors, with these relationships becoming increasingly nonlinear as distal risk increases (Hufford et al., 2003). This notion assumes that relapse can take the form of sudden and unexpected returns to the target behavior, a prediction that concurs both with clinical observations and with contemporary learning models stipulating that recently modified behavior is inherently unstable and easily swayed by context (Bouton, 2000). While maintaining its footing in cognitive-behavioral theory, the dynamic model also draws from nonlinear dynamical systems theory (NDST) and catastrophe theory, both approaches for understanding the operation of complex systems (Witkiewitz & Marlatt, 2007a, b). Detailed discussions of relapse in relation to NDST and catastrophe theory are available elsewhere (Hufford et al., 2003; Witkiewitz, van der Maas, Hufford, & Marlatt, 2007; Witkiewitz & Marlatt, 2007a, b).

Empirical Support for the RP Model

Driven by methodological and theoretical advances, the literature on relapse has grown substantially over the past decade. Since the volume and scope of this work preclude an exhaustive review, the following section summarizes a select body of findings reflective of the overall literature. First, major review studies and large-scale clinical outcome trials are summarized. Next, findings from smaller studies are presented, with an emphasis on recent findings pertinent to the dynamic model's predictions and theoretical assumptions.

Systematic Reviews and Large-Scale Treatment Outcome Studies

As of the preceding edition of this volume (Shumaker et al., 1998), the most comprehensive review of RP studies was Carroll's (1996) descriptive account of 24 treatment outcome studies focusing on substance use. This review found consistent support for the superiority of RP over no treatment, inconsistent support for its superiority over discussion control conditions, and consistent evidence that RP was as efficacious as other active treatments. Carroll concluded that RP, though not consistently superior to other active treatments, showed particular promise in three areas: reducing relapse severity, enhancing durability of treatment gains, and matching treatment strategies to client characteristics. RP also showed delayed emergence effects in some studies, suggesting that it may outperform other treatments during the maintenance stage of behavior change (Carroll, 1996).

Appearing shortly after Carroll's review was a meta-analysis of 26 RP treatment outcome studies totaling 9,504 participants (Irvin, Bowers, Dunn, & Wang, 1999). The authors examined two primary outcomes, substance use and psychosocial functioning, and evaluated several treatment moderators. Effect sizes indicated that RP was generally successful in reducing substance use ($r = .14$) and improving psychosocial functioning ($r = .48$), consistent with its purpose as both a specific and global intervention approach. Moderation analyses suggested that RP was consistently efficacious across treatment modalities (individual vs. group) and settings (inpatient vs. outpatient). RP was most effective for reducing alcohol and polysubstance use and less effective for tobacco and cocaine use—a contrast to Carroll's (1996) finding of comparable efficacy across drug classes. In addition, RP was more effective when delivered in conjunction with pharmacotherapy, when compared to wait-list (vs. active) comparison conditions, and when outcomes were assessed soon after treatment. Though some findings were considered tentative due to sample sizes, the authors concluded that RP was broadly efficacious (Irvin et al., 1999).

An increasing number of large-scale trials have allowed for statistically powerful evaluations of psychosocial interventions for alcohol use. Project MATCH (Project MATCH Research Group, 1997) evaluated the efficacy of three interventions—Motivational Enhancement Therapy (MET), 12-Step Facilitation (TSF), and Cognitive Behavioral Therapy (CBT)—for treating alcohol dependence. The CBT intervention was a skills-based treatment containing elements of RP. Spanning nine data collection sites and following more than

1,700 participants for up to 3 years, Project MATCH was the largest psycho-therapy trial ever conducted. Multiple "matching hypotheses" were tested to see whether treatments showed differential efficacy as a function of theoreti-cally relevant client attributes. Only 1 of 16 primary matching hypotheses was supported: outpatients with less severe psychiatric diagnoses fared better in TSF than in CBT during the year following treatment (Project MATCH Re-search Group, 1997). Though impressive in its design and implementation, the study provided relatively little justification for tailoring alcohol treatments on the basis of the client attributes examined.

More recently, the COMBINE Study (Anton et al., 2006) tested the individ-ual and joint efficacy of two pharmacological treatments (naltrexone and acam-prosate) and a combined behavioral intervention (CBI) for alcohol dependence. CBI represented a blending of established behavioral approaches including RP. A total of 1,383 individuals with alcohol dependence were randomly assigned to conditions crossing medication (naltrexone, acamprosate, naltrexone plus acamprosate, placebo) and behavioral (CBI vs. none) interventions. Participants in these eight groups also received medication management in a primary-care format. A ninth group received CBI without medication management. Inter-ventions were delivered in a 16-week outpatient program, and drinking was assessed for 1 year posttreatment. Both CBI and naltrexone reduced drinking, but results showed no incremental efficacy of combined treatments, and those receiving CBI alone actually fared worse than those in the placebo condition. Although overall treatment effects diminished over time, some trends emerged in the 1 year follow-up period: those receiving naltrexone were less likely to return to heavy drinking, and the CBI groups showed marginally greater absti-nence than the medical management groups, suggesting that both naltrexone and CBI may reduce relapse occurrence prospectively (Anton et al., 2006).

Recent Findings in Support of RP Model Components

The following section reviews selected empirical findings that support or co-incide with tenets of the RP model. We emphasize findings relevant to the dy-namic model of relapse, building upon other such reviews (Witkiewitz & Mar-latt, 2004, 2007a) by including studies from several health behavior domains and by providing an expanded discussion of neurocognitive and genetic fac-tors as components of distal relapse risk. Sections are organized in accordance with major model constructs. It should be noted that, although dynamic pro-cesses likely play a role in relapse for most or all health behavior domains, the specific constructs and findings discussed here may vary in relevance across behaviors. Researchers and clinicians should consult current theory and re-search to determine the constructs and processes that are likely to be most relevant for any given health behavior.

Psychiatric Comorbidity

A well-established risk factor for relapse is the presence of a psychiatric disor-der (Drake, 2005). Comorbid disorders are exceedingly common (McGovern et al., 2005) and can be conceptualized from various etiological perspectives (Mueser, Drake, & Wallach 1998). For instance, co-occurring disorders may reflect common

genetic, personality, and/or neurobiological risk factors. Comorbidity may also influence relapse indirectly by introducing other biopsychosocial risk factors (e.g., cognitive deficits, lack of housing, low social support) (Drake, Wallach, & McGovern, 2005). Some research suggests that relapse antecedents (i.e., high-risk situations) differ for those with dual diagnoses compared to those without such diagnoses (Tate, Brown, Unrod, & Ramo, 2004). Additionally, substance use and other behavior disorders can be reciprocally maintained over time. For example, indicators of conduct disorder in adolescence predict later substance use (Myers, Brown, & Mott, 1995), which in turn can serve to maintain antisocial behavior in adulthood (Hussong, Curran, Moffitt, Caspi, & Carrig, 2004).

Both static and dynamic processes may contribute to relapse among individuals with comorbid disorders. One study of adolescents examined baseline psychiatric diagnoses as well as symptom changes preceding relapses (McCarthy, Tomlinson, Anderson, Marlatt, & Brown, 2005). Proximal symptom severity predicted relapse to certain drugs, and relapse in some cases predicted subsequent psychiatric symptoms, suggesting reciprocal relationships. A similar study with adults also found that relapse tended to exacerbate psychiatric symptoms (Tomlinson, Tate, Anderson, McCarthy, & Brown, 2006). Effects of psychiatric disorders on substance use may also be mediated by cognitive-behavioral constructs. For example, the influence of preadolescent indicators of conduct disorder on substance use may be explained by coping skills and lifestyle factors (Myers et al., 1995). Detailed reviews of theory and interventions for co-occurring disorders are available (Drake, 2005; Mueser et al., 1998).

Neurocognitive and Genetic Factors

Predominating models of health behavior derive largely from social-cognitive perspectives; therefore, an important goal is to augment existing theoretical models by including relevant biological variables (Bryan, Hutchison, Seals, & Allen 2007). Although neurocognitive and genetic factors are historically acknowledged by the RP model, only recently have such variables been studied in relation to relapse and its antecedents. Neurocognitive functioning is relevant to relapse insofar as it can affect one's ability to appraise high-risk situations and enact effective coping responses (Tapert, Brown, Myers, & Granholm, 1999). Prospective research suggests that neurocognitive performance can interact with coping skills to predict relapse (Tapert et al., 1999). Also, recent theory and research suggest that *cognitive control* processes are critical for the ability to resist well-rehearsed, appetitive responses in favor of novel and adaptive behaviors, a concept with clear implications for relapse (Curtin, McCarthy, Piper, & Baker, 2006).

Functional magnetic resonance imaging (fMRI) techniques have been instrumental in identifying neural correlates of substance use. Several studies indicate differential patterns of cue-elicited neural activation among individuals with and without substance use disorders (e.g., Tapert, Brown, Baratta, & Brown, 2004; Tapert et al., 2003). Patterns of neural responding have also been linked to phenomena implicated in drinking behavior, including alcohol expectancies (Anderson, Schweinsburg, Paulus, Brown, & Tapert, 2005), level of response to alcohol (Tapert, Pulido, Paulus, Schuckit, & Burke, 2004), and craving (Hommer, 1999). A recent study of treatment-seeking methamphetamine users provided

initial evidence that fMRI can be used to predict relapse (Paulus, Tapert, and Schuckit, 2004). In this study, researchers examined fMRI activation during a decision-making task and obtained information on relapse more than 1 year later. On the basis of activation patterns in several cortical regions, they were able to correctly identify 17 of 18 participants who relapsed and 20 of 22 who did not.

It is likely that distal relapse risk is influenced largely by genetic factors. Accumulating evidence suggests that genetic polymorphisms (variations at a given allele) can influence relapse-related phenomena. Among the genes receiving the most attention to date are the dopamine regulatory genes *DRD4* and *DRD2* and the μ-opioid receptor gene (*OPRM1*). One study found that after exposure to smoking cues, individuals with the long-repeat version of the *DRD4* VNTR polymorphism (*DRD4* L) reported elevated craving and arousal, greater attention to smoking cues, and lower positive affect than those homozygous for the short-repeat version (*DRD4* S) (Hutchison, LaChance, Niaura, Bryan, & Smolen, 2002). Another study linked *DRD4* L to cue-induced craving for food (Sobik, Hutchison, & Craighead, 2005). The *OPRM1* Asp40 allele has been linked to increased alcohol-related craving (van den Wildenberg et al., 2007). Notably, this study found that the Asp40 allele predicted cue-elicited craving among individuals low in baseline craving but not in those high in initial craving, suggesting that tonic craving could interact with genotype to predict phasic responses to drug cues. Collectively, these studies provide a basis for inferring genetic influences on craving in natural contexts.

Genetic variations may also influence relapse by moderating the effects of pharmacotherapy. Olanzapine (a dopamine antagonist) has been found to reduce alcohol-related craving in *DRD4* L individuals but not in *DRD4* S individuals (Hutchison et al., 2003, 2006), and in a randomized trial olanzapine led to significantly improved drinking outcomes in the former but not in the latter group (Hutchison et al., 2006). Studies of pharmacotherapy for smoking have found that *DRD2* variations predict withdrawal symptoms, medication response, and time to relapse (e.g., Lerman et al., 2003). A placebo-controlled trial of naltrexone for alcohol use found that *OPRM1* gene status moderated pharmacotherapeutic response such that individuals with the Asp40 allele had a longer time until the first heavy drinking day and were half as likely to relapse as those homozygous for the Asn40 variant (Oslin et al., 2003). In a study of smoking cessation, those with the Asp40 variant had higher rates of abstinence, less weight gain, and reduced negative affect compared to Asn40 individuals (Lerman et al., 2004). In this study, post hoc analyses indicated that Asp40 carriers were more likely to regain abstinence following a lapse than those without the variant, suggesting a possible role of genotype in predicting prolapse.

In addition to modulating craving and pharmacotherapy response, genetic factors could influence relapse in part via cognitive-affective processes. For instance, variants of the *DRD2* and *GABRB3* genes have been associated with alcohol expectancies and drinking-related self-efficacy (Young, Lawford, Feeney, Ritchie, & Noble, 2004). A study of physical exercise showed that *BDNF* gene variation moderated cognitive and physiological responses during physical exertion and that these responses in turn predicted motivation for future exercise (Bryan et al., 2007). Overall, these findings provide initial evidence that genetic variations can influence health behavior and relapse-related outcomes. Notably, human laboratory studies offer early indication that these variations can

influence phasic relapse processes, supporting examination of genetic factors in the context of the dynamic model. Further characterizing the role of neuro-cognitive and genetic factors in relapse stands as an intriguing and important research direction (McKay et al., 2006; Piasecki, 2006), and integration of these factors within existing psychosocial theories will aid in bridging biological and behavioral perspectives on relapse.

Withdrawal

Withdrawal typically develops early in the course of addiction (Baker et al., 2004) and symptom profiles can vary based on stable intra-individual factors (Piasecki, Jorenby, Smith, Fiore, & Baker, 2003), suggesting the involvement of tonic processes. Despite serving as a chief diagnostic criterion, withdrawal often does not predict relapse, perhaps partly explaining its de-emphasis in contemporary motivational models of addiction (Piasecki et al., 2000). However, recent studies show that withdrawal profiles are complex, multifaceted, and idiosyncratic and that, in the context of fine-grained analyses, withdrawal indeed can predict relapse (Piasecki, Fiore, & Baker, 1998; Piasecki et al., 2000). Such findings have contributed to renewed interest in negative reinforcement models of drug use (Piasecki et al., 2003).

Although withdrawal is usually viewed as a physiological process, recent theory emphasizes the importance of behavioral withdrawal processes (Baker, Japuntich, Hogle, McCarthy, & Curtin, 2006). Whereas physiological withdrawal symptoms tend to abate in the days or weeks following drug cessation, the unavailability of a conditioned *behavioral* coping response (e.g., the ritual of drug administration) may leave the former user ill equipped to cope with ongoing stressors, thus exacerbating and/or prolonging symptoms (Baker et al., 2006). Current theory and research indicate that physiological components of drug withdrawal may be motivationally inert, with the core motivational constituent of withdrawal being negative affect (Baker et al., 2004, 2006). Thus, examining withdrawal in relation to relapse may only prove useful to the extent that negative affect is assessed adequately (Piasecki et al., 2000).

Outcome Expectancies

Expectancies (anticipated outcomes of a given behavior or experience) are central to the RP model and have been studied extensively in the domain of alcohol use (Goldman et al., 1999). Alcohol expectancies are shown to anticipate drinking initiation (Christiansen, Smith, Roehling, & Goldman, 1989) and to predict drinking prospectively (Sher, Wood, Wood, & Raskin, 1996). Further supporting a causal process, expectancy manipulations can produce changes in drinking behavior (Darkes & Goldman, 1993). In theory, expectancies are shaped by various distal factors (e.g., environment, culture, personality, genetics) and mediate these antecedent influences on drinking (Goldman et al., 1999). Research supports that expectancies partially mediate influences of personality factors (Katz, Fromme, & D'Amico, 2000), familial risk for alcohol dependence (Sher, Walitzer, Wood, & Brent, 1991), genetic variations (McCarthy et al., 2000), and negative affect (Cohen, McCarthy, Brown, & Myers, 2002) on drinking. Expectancies have been linked to a range of health behaviors and outcomes outside the domain of addictions, including exercise, diet, and HIV symptom progression.

Studies have historically shown that expectancies can undergo changes over long periods (e.g., Sher et al., 1996). However, there is increasing interest in studying dynamic expectancy processes over shorter intervals. One study found that participants engaged in a behavioral intervention for obesity lost more weight during weeks in which outcome expectancies for weight loss were more positive (Carels et al., 2005). In the first study to examine how daily fluctuations in expectancies predict relapse, Gwaltney, Shiffman, Balabanis, & Paty (2005) assessed positive outcome expectancies for smoking (POEs) among participants during a tobacco cessation attempt. Lower POEs on the quit day were associated with greater abstinence likelihood, and POEs decreased in the days following the quit day. Lapses were associated with higher POEs on the preceding day, and, in the days following a lapse, those who avoided a full relapse showed decreases in POEs, whereas those who relapsed did not (Gwaltney, Shiffman, Balabanis, & Paty 2005).

Expectancy research is increasingly focusing on implicit cognitive processes (i.e., those that can operate outside conscious awareness) (Wiers & Stacy, 2006). Implicit measures of alcohol-related cognitions can discriminate among light and heavy drinkers (Kramer & Goldman, 2003) and predict drinking above and beyond explicit measures (McCarthy & Thompsen, 2006). One study found that smokers' attention to tobacco cues predicted early lapses during a quit attempt, but this relationship was not evident among people receiving nicotine replacement therapy, who showed reduced attention to cues (Waters et al., 2003). Research on implicit cognitions stands to enhance understanding of dynamic relapse processes (Curtin et al., 2006) and could ultimately aid in predicting lapses during high-risk situations.

Self-Efficacy

Self-efficacy (SE), the perceived ability to execute a given behavior in a specified context (Bandura, 1997), is a principal determinant of health behavior according to social-cognitive theories. In theory, SE is a fluctuating and dynamic construct (Bandura, 1997). However, most studies rely on static measures of SE, preventing evaluation of within-person changes over time or contexts (Shiffman et al., 2000). Shiffman, Gwaltney, and colleagues have used ecological momentary assessment (EMA; Stone & Shiffman, 1994) to examine temporal variations in SE in relation to smoking relapse. Findings from these studies suggested that participants' SE was lower on the day before a lapse and that lower SE in the days following a lapse in turn predicted progression to relapse (Gwaltney et al., 2005a; Shiffman et al., 2000). One study reported increases in daily SE during abstinent intervals, perhaps indicating mounting confidence as treatment goals were maintained (Gwaltney, Shiffman, Balabanis, & Paty 2005).

The first study to examine relapse in relation to phasic changes in SE (Gwaltney, Shiffman, & Sayette, 2005) found results that appear consistent with the dynamic model of relapse. During a smoking cessation attempt, participants reported on SE, negative affect, and urges at random intervals. Findings indicated nonlinear relationships between SE and urges, such that momentary SE decreased linearly as urges increased but dropped abruptly as urges peaked. Moreover, this finding appeared attributable to individual differences in baseline (tonic) levels of SE. When urge and negative affect were low, individuals with low, intermediate, or high baseline SE were similar in their momentary

SE ratings. However, these groups' momentary ratings diverged significantly at high levels of urges and negative affect, such that those with low baseline SE had large drops in momentary SE in the face of increasingly challenging situations. These findings support that higher distal risk can result in bifurcations (divergent patterns) of behavior as the level of proximal risk factors increase, consistent with predictions from nonlinear dynamic systems theory (e.g., Hufford et al., 2003; Witkiewitz & Marlatt, 2007b).

Negative Affect

A large literature attests to the role of negative affect (NA) in the etiology and maintenance of addictive behaviors. NA is consistently cited as a relapse trigger in retrospective reports (e.g., Marlatt, 1978; Shiffman, Paty, Gnys, Kassel, & Hickcox, 1996a), although participants may sometimes misattribute lapses to negative mood states (Piasecki, 2006; Shiffman et al., 1997). In one study, individuals who were unable to sustain a smoking cessation attempt for more than 24 hours reported greater depressive symptoms and NA in response to stress and displayed less perseverance during experimental stress inductions than did those with a sustained quit attempt (Brown, Lejuez, Kahler, & Strong 2002). Supporting the dynamic influence of NA on relapse, Shiffman and Waters (2004) found that smoking lapses were not associated with NA in the preceding days but were associated with rising NA in the hours leading up to a lapse. Evidence further suggests that negative affect can promote positive outcome expectancies (Cohen et al., 2002) or undermine situational self-efficacy (Gwaltney et al., 2001), outcomes which could in turn promote a lapse. Moreover, Baker and colleagues propose that high levels of negative affect can interfere with controlled cognitive processes, such that adaptive coping and decision making may be undermined as negative affect peaks (Baker et al., 2004; Curtin et al., 2006).

Knowledge about the role of NA in drinking behavior has benefited greatly from daily process studies in which participants provide regular reports of mood and drinking. Such studies have shown that both positive and negative moods show close temporal links to alcohol use (Armeli, Tennen, Affleck, & Kranzler, 2000). Hussong, Hicks, Levy, and Curran (2001) found evidence suggesting a feedback cycle of mood and drinking whereby elevated daily levels of NA predicted alcohol use, which in turn predicted spikes in NA. These findings were moderated by gender, social context, and time of week. Other studies have similarly found that relationships between daily events and/or mood and drinking can vary based on intra-individual or situational factors (Armeli et al., 2000), suggesting dynamic interplay between these influences. Research also indicates that relationships among daily events, mood and drinking are moderated by naltrexone (Armeli, Feinn, Tennen, & Kranzler, 2006). The sophisticated methods evidenced in these studies could serve as a model for researchers investigating the effects of NA on other health behaviors.

Coping Responses and Abstinence Violation Effects

Strengthening coping skills is a goal of virtually all cognitive-behavioral interventions for substance use (Morgenstern & Longabaugh, 2000). Several studies have used ecological momentary assessment (EMA) to examine coping

responses in real time. O'Connell, Hosein, Schwartz, and Leibowitz (2007) found that momentary coping differentiated smoking lapses from temptations, such that coping responses were reported in 91% of successful resists but only 24% of lapses. Similarly, a study of dieters found that momentary coping responses distinguished temptations from lapses (Carels, Douglass, Cacciapaglia, & O'Brien, 2004). Shiffman and colleagues (1996b) found that restorative coping following a smoking lapse decreased the likelihood of a second lapse the same day. Exactly how coping responses reduce the likelihood of lapsing remains unclear. One study found that momentary coping reduced urges among smokers, suggesting a possible mechanism (O'Connell et al., 2007). Some studies find that the number of coping responses is more predictive of lapses than the specific type of coping used (Litt, Kadden, & Stephens, 2005; O'Connell et al., 2007). However, despite findings that coping can prevent lapses, there is scant evidence to show that skills-based interventions in fact lead to improved coping (Morgenstern & Longabaugh, 2000).

Several studies have examined abstinence violation effects (AVEs) following lapses. Shiffman and colleagues (1996a) found no evidence for AVEs after smoking lapses, though a subsequent study reported decreased self-efficacy after lapses (Shiffman et al., 2000). A study of binge eating found clear evidence for AVEs, with prospective analyses suggesting that attributing lapses to internal, global causes predicted subsequent binges (Grilo & Shiffman, 1994). Similarly, Carels and colleagues (2004) found evidence for AVEs among women engaged in a weight-loss intervention.

Some researchers propose that the self-control required to maintain behavior change strains motivational resources and that this "fatigue" can undermine subsequent self-control efforts (Muraven & Baumeister, 2000). Consistent with this idea, EMA studies have shown that social drinkers report greater alcohol consumption and violations of self-imposed drinking limits on days when self-control demands are high (Muraven, Collins, Shiffman, & Paty, 2005). Limit violations were predictive of AVE responses the following day, and greater distress about violations in turn predicted greater drinking (Muraven et al., 2005). Findings also suggested that these relationships varied based on individual differences, suggesting the interplay of static and dynamic factors in AVE responses.

Using Nonlinear Methods to Model Relapse

Most studies of relapse rely on statistical methods that assume continuous linear relationships, but these methods may be inadequate for studying a behavior characterized by discontinuity and abrupt changes (Witkiewitz et al., 2007). Several studies suggest advantages of nonlinear statistical approaches for studying relapse. In one, researchers used catastrophe models to examine proximal and distal predictors of posttreatment drinking among individuals with alcohol use disorders (Hufford et al., 2003). Catastrophe models accounted for more than double the amount of variance in drinking than that predicted by linear models. Similar results have been found using the much larger Project MATCH dataset (Witkiewitz & Marlatt, 2007b).

Another recent analysis of the MATCH dataset showed that nonlinear approaches can detect processes that may go unobserved in the context of linear models. Witktiewitz and colleagues (2007) used catastrophe modeling and latent growth mixture modeling to reassess one of the matching hypotheses that

was not supported in the original study—that individuals low in baseline self-efficacy would respond more favorably to cognitive-behavioral therapy (CBT) than to motivational enhancement therapy (MET) (Project MATCH Research Group, 1997). Catastrophe models provided the best fit to the data, and latent growth analyses confirmed the predicted interaction: frequent drinkers with low initial self-efficacy had better outcomes in CBT than in MET, while those high in self-efficacy fared better in MET (Witkiewitz et al., 2007).

Critiques of the RP Model

The widespread application of RP in the 1980s and 1990s largely outpaced efforts to systematically validate the model and test its underlying assumptions. Recognizing this limitation, NIAAA sponsored the Relapse Replication and Extension Project (RREP), a multisite study aiming to test the reliability and validity of Marlatt's original relapse taxonomy. Efforts to evaluate the construct validity (Maisto, Connors, & Zywiak, 1996) and predictive validity (Stout, Longabaugh, & Rubin 1996) of the taxonomy failed to generate supportive data. However, these findings were qualified by methodological and conceptual limitations of the RREP. In focusing on the relapse taxonomy, the RREP failed to provide a comprehensive evaluation of the full RP model (Donovan, 1996). Furthermore, the study defined relapse in a way that violates a crucial assumption of the RP model. Whereas RP is designed for individuals making a volitional attempt at behavior change, the RREP made no effort to verify whether periods of abstinence represented voluntary quit attempts. Nevertheless, these studies were useful in identifying limitations and qualifications of the RP taxonomy and generated valuable suggestions for improving the model (Donovan, 1996).

The recently introduced dynamic model of relapse (Witkiewitz & Marlatt, 2004) takes many of the RREP criticisms into account. Still, some have suggested limitations to the revised model. Stanton (2005) criticized the model for not emphasizing interpersonal factors as proximal or phasic influences. Other critiques include that nonlinear dynamic systems approaches are not refined enough to be of clinical utility (McKay et al., 2006) and that the theory and statistical methods characterizing these approaches are too esoteric to be of use for most researchers (Maisto & Connors, 2006). Rather than signaling weaknesses of the model, these issues likely reflect methodological challenges that researchers must overcome in order to better understand dynamic aspects of behavior (e.g., Gwaltney, Shiffman, Balabanis, & Paty 2005).

Future Directions

Characterizing Dynamic Relapse Processes

As the foregoing discussion suggests, researchers are only beginning to evaluate dynamic relapse processes. Currently, the dynamic model can be viewed as a hypothetical, theory-driven framework that awaits empirical evaluation. Testing the model's components will require that researchers avail themselves of innovative assessment techniques (such as EMA) and pursue cross-disciplinary collaboration in order to integrate appropriate statistical methods. It should also be

noted that experimental paradigms (e.g., Hutchison et al., 2002, 2003) have shown considerable early promise in identifying dynamic processes relevant for relapse but have likely been underutilized overall. Even sophisticated approaches like EMA cannot effectively address causal relationships in the absence of random assignment. Experiments are therefore necessary to complement correlational studies, which presently dominate the health behavior literature (Weinstein, 2007). Irrespective of study design, greater integration of distal and proximal variables will aid in modeling the interplay of tonic and phasic influences on relapse outcomes.

Mechanisms of Treatment Effects

Elucidating the "active ingredients" of CBT treatments remains an important and challenging goal. Changes in coping skills, self-efficacy, and/or outcome expectancies are the primary putative mechanisms by which CBT-based interventions work (Longabaugh et al., 2005). However, few studies support these presumptions. One study, in which substance-abusing individuals were randomly assigned to RP or 12-step (TS) treatments, found that RP participants showed increased self-efficacy, which accounted for unique variance in outcomes (Brown, Seraganian, Tremblay, and Annis, 2002). Despite isolated findings like this, most studies fail to show that theoretical mediators account for salutary effects of CBT on health behavior, indicating that researchers should strive to consider alternative mechanisms, improve assessment methods, and/or revise theories about how CBT-based interventions work (Litt et al., 2005; Morgenstern & Longabaugh, 2000).

Mindfulness-Based Relapse Prevention

Mindfulness-based intervention approaches are receiving increasing popular and empirical attention (Lau & Segal, 2007). The merging of mindfulness and cognitive-behavioral approaches holds both theoretical and practical appeal; many Buddhist principles are highly compatible with cognitive-behavioral perspectives (Marlatt, 2002), and mindfulness-based interventions can be simple and cost-effective. Mindfulness interventions have been examined in various patient populations, including individuals coping with eating disorders, heart disease, multiple sclerosis, cancer, and HIV. Data supporting the efficacy of mindfulness interventions is growing, particularly in the areas of chronic pain and relapse of depression (Lau & Segal, 2007). Encouraged by these findings, research on mindfulness-based relapse prevention (MBRP) for substance use is gaining momentum. In contrast to cognitive restructuring, MBRP stresses nonjudgmental attention to thoughts or feelings, such that urges and cravings are labeled as transient events that need not be acted upon reflexively. This stance is exemplified by the "urge surfing" technique (Marlatt, 2002), whereby clients are taught to view urges as analogous to an ocean wave that rises, crests, and diminishes. Rather than being overwhelmed by the wave, the goal is to "ride" its crest as if on a surfboard, attending to thoughts and sensations as the urge peaks and invariably subsides. Results from a preliminary, nonrandomized trial at the University of Washington support the potential utility of MBRP for reducing substance use. In this study, incarcerated individuals were offered

the chance to participate in an intensive 10-day course in Vipassana meditation (VM); those participating in VM were compared to a treatment-as-usual (TAU) group on measures of postincarceration substance use and psychosocial functioning. At follow-up, the VM group reported significantly lower levels of substance use and alcohol-related consequences, as well as improved psychosocial functioning compared to the TAU group. (Bowen et al., 2006). A larger, randomized trial is currently under way at the University of Washington to evaluate the efficacy of MBRP for substance use.

Conclusion

Relapse prevention is a cognitive-behavioral approach designed to help individuals anticipate and cope with setbacks during the behavior change process. The broad aim of RP, to reduce the incidence and the severity of relapse, subsumes two basic goals: to minimize the impact of high-risk situations through increasing awareness and building coping skills and to limit relapse proneness by promoting a healthy and balanced lifestyle. Given its ideographic approach and emphasis on maintaining treatment gains, RP is applicable to most health behaviors for which there is a need to establish and sustain long-term change. Over the past decade, RP principles have been incorporated across an increasing array of health domains. Many of the model's basic tenets have received support, and findings regarding its clinical effectiveness have generally been supportive. While these developments encourage confidence in the RP model, additional research is needed to test its predictions and limitations and to evaluate its applicability across health behaviors. Continued refinement of the model's theoretical assumptions and clinical applications will further enhance its utility for understanding and facilitating the maintenance of optimal health.

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Motivational Interviewing

8

Claire A. Lane and
Stephen Rollnick

Patients usually understand that they need to make changes to improve their health, yet time and again they return to see their clinicians having not implemented any of the changes discussed in the consultation. Others may choose not to return, feeling that they have failed and thinking that they "cannot face another lecture" about what they should be doing. For these reasons, talking with patients about making changes to the unhealthier aspects of their lifestyles can often be a difficult, sometimes frustrating experience.

This chapter provides an overview of Motivational Interviewing (MI) (Miller and Rollnick, 2002). Following some background information about the situations in which MI might be useful, the rationale behind the method is described, and examples of how MI can be incorporated into clinical practice are provided. The evidence that MI can facilitate behavior change also is discussed.

Ambivalence in Health Behavior Change

Before addressing MI, it is important to consider one reason why behavior change may be challenging (for practitioners and patients alike) within health care settings. In many cases, patients may be ambivalent about making changes to their lifestyles.

What Is Ambivalence?

In relation to behavior change, the term "ambivalence" refers to the notion of having mixed feelings and therefore feeling unsure or indecisive. Many people can think of a time in their lives when they have had to make a decision and have felt torn between taking one course of action or another. This may have led to feelings of inner conflict about which course of action is the best or a sense of hopelessness when neither path seems to lead to a satisfactory outcome—"I'm damned if I do, and I'm damned if I don't."

Discussions About Behavior Change
With Ambivalent Patients

Many clinicians consult with ambivalent patients on a daily basis. Most can see the damage patients are doing to themselves through behaviors such as smoking, drinking too much alcohol, eating unhealthy foods, and not getting enough exercise. It is natural to want to stop patients from taking part in these harmful activities—after all, it is often the desire to help and to improve the health of others that draws people into careers in health care in the first place. The practitioner may try to persuade patients to live a healthier life by telling them about the damage a particular behavior is doing to their body and in turn prescribing a course of action to "rescue" them from such harm.

If the patient does not implement the advice that has been given to them, it is understandable that the clinician may feel a number of different emotions—ranging from worry and concern, through to frustration and helplessness. Many may feel that the patient is apathetic about his health or is unmotivated.

In reality, however, the patient may feel several different ways about making those changes. They can see how changing will be beneficial to their health and will improve their overall quality of life. Conversely, however, they may also see that it will be hard to change. Such changes may affect other family members and have a perceived negative impact on their social life. They may not enjoy some of the things they have been told they should do or feel unhappy about giving up a behavior that until now has been pleasurable or enjoyable. This is the essence of ambivalence about making changes to health behaviors, which often makes the decision to change a difficult one.

Readiness, Importance, and Confidence

For change to occur, patients need to be ready, willing, and able to make the change (Miller & Rollnick, 2002).

The first question to ask is how ready the patient is to make changes to her lifestyle. Is changing her behavior her number one priority, or are there more

pressing issues in her life at the moment? (For further discussion on readiness, please see the chapter "The Transtheoretical Model of Behavior Change.") The next question that needs to be asked is how willing the patient is to make changes to her lifestyle? Does she want to make changes, or is she happy to remain as she is (importance)? One final question concerns how able the patient feels to succeed with these changes (confidence)? Does she truly believe she can make the changes she needs to make? The importance of these two questions has been illustrated by one study that involved interviews with smokers in a primary-care setting (Rollnick, Butler, & Stott, 1997). The researchers asked smokers how ready they were to make changes to their smoking and asked them if they could describe what factors influenced their readiness. *Importance* (or "willingness") and *confidence* (or "ability") were two major themes that emerged in this data in regard to readiness. This supports other research in the field (Keller & White, 1997), showing that, in general, if importance and confidence are both high, the patient will feel more ready to make changes. If importance and confidence are both low, the patient will not feel at all ready to make changes. If importance and confidence are somewhere in between high and low, or if one factor is high but the other is low, the patient is likely to be *ambivalent* about making changes. Having the confidence to achieve change is recognized as a major factor in making lifestyle changes. If an individual believes she cannot change, she may not even try (Bandura, 1995).

Motivation

In the guidelines developed within Motivational Interviewing, the degree of importance and confidence individuals attribute to making changes can influence how motivated they are to change (Rollnick et al., 1997). Most practitioners recognize that some patients are more motivated than others and that this apparent motivation is related to whether they succeed in changing their lifestyle. The more patients increases the weight they allocate to the importance of changing, and the greater their confidence about making changes, the more motivated they will be (Rollnick, Mason, & Butler, 1999). Motivational Interviewing incorporates a number of skills that a practitioner can utilize in helping patients explore their own reasons for why they might make changes. These are described later in the chapter.

Resistance

Resistance to change is often seen by health care providers as the patient being difficult. It is often associated with concrete behaviors that the patient may exhibit in the consulting room, such as denial, arguing, objecting, disengagement, defensiveness, and reluctance. Most clinicians can recall a patient who claims that his great uncle smoked until he was 107 years old and was never ill, presenting this as a rationale for refusing to give up smoking.

Why does this resistance occur? Both the patient and the practitioner can contribute to the degree of resistance encountered. Patients may feel under pressure to change their behavior before they even enter the consulting room and may perceive talking about such issues to be a threat. Equally, other patients may not object to talking about these matters in the clinical environment but may become resistant if the topic is dealt with insensitively. Perhaps

the practitioner has wrongly assumed that the patient is more ready to make changes than he actually is.

In either case, resistance should be a signal to practitioners that the rapport they have with the patient has broken down. Confrontational behavior is likely to worsen this relationship and in turn lead to an increase in resistance. A skillful practitioner can take measures to reduce resistance in the consultation, should it occur, by avoiding confrontation or by "rolling with the resistance." This is discussed in more detail later.

Communication Styles and the Role of Guiding

How does a method like Motivational Interviewing fit into the everyday practice of a psychologist, counselor, nurse, or other health care practitioner? One answer to this question lies in the recent construction of a simple three-styles model for understanding how practitioners approach problem-solving in everyday practice (Rollnick et al., 2007):

- Directing
- Guiding
- Following

Practitioners, it seems, shift quite naturally between the three styles according to need. A *directing* style is widely used in health and social work to solve problems. It involves the delivery of expert advice and help and, done skillfully, is well timed, personally relevant, and based on good rapport with the patient or client. A *following* style is also used naturally in many situations, for example, when responding to someone who is upset. Listening is a core skill here, where the agenda of the practitioner is not to solve a problem immediately but to follow the other as a means of providing support and encouragement. Breaking bad news is probably the most common scenario in health care which this style is used. A third, perhaps less well-used style is *guiding,* where the two parties work collaboratively to help the patient identify solutions to a problem. It's this style that is particularly well suited to addressing problems like skill acquisition or difficult health behavior change challenges, and this is where Motivational Interviewing fits in; it has been defined as a refined form of guiding, enabling practitioners to understand how it might fit into their everyday practice. Shifting between styles according to need is a marker of skillfulness, and a focus on guiding when it comes to health behavior change is likely to be most effective.

Motivational Interviewing

Motivational Interviewing is "a client-centered, directive style for enhancing intrinsic motivation to change by exploring and resolving ambivalence" (Miller and Rollnick, 2002). It evolved from the work of the psychologist Carl Rogers (Rogers, 1959) on the client-centered counseling framework. In delivering psychotherapy to his patients, Rogers found that his clients often had improved results if he listened more and allowed them to determine the rate of treatment.

In turn, he believed that a flexible attitude to treatment was important. By encouraging clients to be self-aware and to make independent choices, he enabled them to gain a better understanding of the problem at hand.

MI is similar to the client-centered counseling framework in that it "does not focus on teaching new coping skills, reshaping cognitions or excavating the past. It is quite focused on the person's present interests and concerns. Whatever discrepancies are explored and developed have to do with incongruities among aspects of the person's own experiences and values" (Miller & Rollnick, 2002, p. 25). Motivation for change is drawn from the client, rather than imposed. However, MI differs from the client-centered counseling framework in that it is purposely directive in nature: "Motivational interviewing involves selective responding to speech in a way that resolves ambivalence and moves the person toward change" (Miller & Rollnick, 2002, p. 25). It has thus been described as a refined form of the naturally used guiding style (Rollnick et al., 2007).

Why Might MI Help With Ambivalent Patients?

Miller and Rollnick (2002) argue that as ambivalence can be a barrier to making changes, resolving ambivalence can in turn be a key to change. Instead of approaching patients as individuals who do not want to change, MI focuses on trying to elicit what patients do want and how they think they might be able to achieve it.

Background

MI has traditionally been conducted within specialist, help-seeking clinical settings, with consultation times ranging from approximately 30 minutes to an hour in length. In recent times, however, MI has been adapted for use in briefer consultations in a range of other environments, including general health care.

When patients are talking about their ambivalence, they are likely to produce two main kinds of talk regarding changing their behavior. If patients talk about the costs of changing their behavior or the benefits of not changing, this is referred to as *sustain talk*. On the other hand, they may produce *change talk,* which is talk about the benefits of changing their behavior or the costs of not changing. In using MI, the practitioner uses a number of skills to encourage the production of patient change talk, which in turn helps patients increase their motivation to change their behavior. This is accomplished through a variety of means, such as asking open-ended questions, making summaries, and skillfully using reflective listening to both express empathy and to direct the patient in producing change talk. This does not mean however, that sustain talk is avoided in MI. Patient autonomy is respected throughout, and sustain talk is accepted as part of the process of exploring ambivalence to change. However, unlike change talk, sustain talk is not purposely elicited by the practitioner.

One common misconception about MI is that it is a set of techniques that can be inflicted on a patient without genuine empathy and understanding. MI is a clinical skill, rather than a tool. To further define the nature of MI, Miller and Rollnick (2002) describe the *spirit* of MI (or a "way of being" with a patient), and present four *principles* (or "conventions guiding practice") behind the method.

Spirit

MI spirit is divided into three components. These are:

- Collaboration
- Evocation
- Autonomy

Collaboration refers to the patient and practitioner working together in partnership, not against each other (for example, with the practitioner advocating for change and the patient arguing why change is not a good idea). *Evocation* describes the process whereby the practitioner elicits the patient's goals, thoughts, and feelings about behavior change, rather than providing information as to how and what the patient should feel about change. *Autonomy* signifies the practitioner's respect for the patient's rights as an individual. Patients know their own mind and should be allowed to choose what to do about their behavior—there is recognition that any changes that patients do decide to make are entirely their choice and that the practitioner is not there to force them to do anything. Should the patient decide that he does not want to make any changes to his behavior, the practitioner in turn has to respect this decision.

Principles

The four principles to be followed while conducting MI are as follows:

1. Express empathy
2. Roll with resistance
3. Support self-efficacy
4. Develop discrepancy

Expressing empathy describes how the practitioner should demonstrate her understanding of the patient's perspective. This is mainly achieved through the use of active, reflective listening techniques, which demonstrate that the practitioner understands what the patient has told her (for example, "It sounds like you have had enough of people telling you what you should do"). *Rolling with resistance* is the approach taken to avoid confrontation with a patient. It could be described as "going along with what the patient says for a bit" while demonstrating understanding of the resistance as a means of reducing it (for example, "You think I'm going to try to force you to do things you're not happy with"). As well as eliciting the patient's motivation to change, the practitioner should *support* the patient's *self-efficacy* (a person's belief that he has the ability to do something) and build on the patient's confidence in achieving change without telling him what to do (for example, "So, despite finding it really tough this week, you've still managed to lose a few pounds. That must feel pretty good"). *Developing discrepancy* is the most complex of the principles underlying Motivational Interviewing. It requires the practitioner to listen carefully to what patients say about their personal values and to illustrate how this is at odds with their current behavior. This is often achieved by highlighting how the behavior in question does not fit in with patients' perception of how they would like to be

(for example "So, on the one hand, smoking is a big thing in your life, and you can't imagine not doing it. Yet you love your family, and you hate feeling that you are letting them down by smoking").

Using an MI Approach to Health Behavior Change

As mentioned earlier, MI is a clinical skill, rather than a set of magic-bullet techniques for making people change. When using an MI approach to discuss health behavior change with a patient, it is important to remember the following.

You Cannot *Make* Somebody Change

The decision to change lies ultimately with the individual. A practitioner cannot force a patient to change. That decision is, and always will be, the patient's to make. As Pascal noted, "People are generally better persuaded by the reasons which they themselves discovered, than by those which have come into the mind of others" (Pascal, 1623–1662). Theories such as "reactance theory" suggest that trying to take away another person's personal choice may have a counteractive effect and may indeed motivate patients to choose to perform the behavior they are being told not to do (Brehm, 1966). This can also increase the degree of resistance encountered in the consultation. Reasons for change should be elicited from, rather than imposed on, the patient.

The Patient Is the Expert

Closely related to the preceding point is the idea that patients are the ones who are considering making changes. They know best about what changes they feel they are able to make, what changes will fit in with their life, and how to cope in difficult situations. This therefore puts them in the role of the expert in changing their own behavior. If patients can find ways in which they can make small changes and can imagine doing this in their daily lives, this may in turn help them to succeed (Bem, 1972).

Establish a Good Rapport

If the practitioner builds a good rapport with patients, helping them to feel at ease to talk about their behavior, free of coercion and judgment, patients will find it easier to explore and resolve their ambivalence about change.

Dance. Don't Wrestle!

MI should be a collaborative partnership between the patient and the clinician working together, rather than a fight with one side advocating for change and the other for staying the same. MI trainers often explain to trainees that the consultation should feel like a dance between the practitioner and the patient, rather than a wrestling match. The second a practitioner feels like he is wrestling, he should take it as a signal that the rapport with the patient is taking a turn for the worse, and steps should be taken to remedy this (see the discussion of "rolling with resistance").

MI Inside the Consultation

To explore ambivalence about behavior change with patients, the practitioner needs to take on a curious mind-set. To be able to demonstrate that she understands how patients feel about change, the clinician needs to listen effectively to them, to encourage them to describe their feelings, and to avoid the urge to prescribe a course of action without their permission.

Building on the spirit and principles of MI, the practitioner can make use of a number of skills in the consultation to help patients explore and resolve their ambivalence about behavior change. These are outlined in this following sections. For more detailed descriptions of these skills, the reader should consult Miller and Rollnick (2002) and/or Rollnick et al. (1999).

Open vs. Closed Questioning

Closed questions are those that encourage brief answers, whereas open questions encourage longer answers. For example, a closed question might be "Do you enjoy exercising?" whereas an open question would be "How do you feel about exercising?" Throughout the consultation, the practitioner should use mainly open, rather than closed, questions, because they encourage patients to explore how they feel about a particular behavior and help the practitioner to gain a deeper understanding of how patients feel about making changes.

This is not to say that closed questions should not be used ever, under any circumstances! In the real world, there may be occasions where closed questions are necessary and can be asked skillfully. However, given that the aim of MI is to help patients explore and resolve ambivalence, closed questions should be kept to a minimum to encourage this exploration.

The Importance of Listening

Asking open questions is an excellent way of gathering information from the patient. However, asking too many questions could lead patients to feel a little interrogated and thus increase resistance in the consultation. Another way of demonstrating understanding and encouraging patients to elaborate without asking questions is through the use of *reflective listening,* one of the most important skills used in MI. Miller and Rollnick (2002) recommend that a ratio of one question to two or three reflective listening statements should be used, as this may help to prevent resistance or confrontational behavior within the consultation.

Listening is generally a passive process—the listener remains quiet and hears what the other person has said. By contrast, reflective listening is an active process and involves making a statement in reply to what the patient has just said. Figure 8.1, adapted from the work of Gordon (1970), shows how the process of reflective listening works. It involves making a statement that bridges the gap between the practitioner's understanding and what the patient is saying or meaning.

Reflective listening is done through a series of statements, not questions (i.e., the practitioner's intonation must go *down* at the end of a statement, not up as at the end of a question). It takes practice to get used to making these

8.1

Reflective listening.
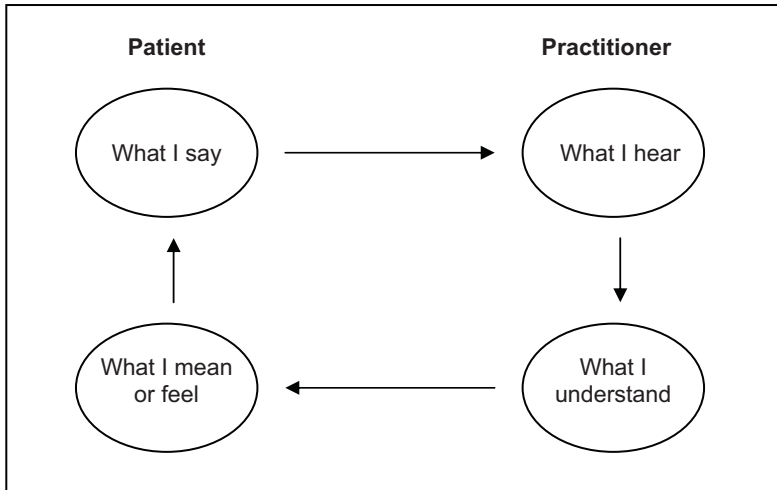
statements, but statements have the advantage of being less interrogative and in turn reduce the risk of confrontation.

Miller and Rollnick (2002) describe a number of different forms of reflective listening statements that could be used. For the purposes of this chapter, two broad kinds of reflection are described (Dr. Gary Rose, personal communication, 2004):

- *Content reflections*—short summaries of what the patient has said
- *Meaning reflections*—reflections of what the patient has meant

For example, if a patient said something like "I want to give up smoking because I don't want another heart attack; I want to see my kids grow up," a *content reflection* of this statement would be something like "You see a connection between your smoking and the possibility of having another heart attack." A possible *meaning reflection* could be "Your children are important to you, and you'll go to great lengths to be there for them." Both statements encourage the patient to elaborate further about her reasoning and in turn to explore her ambivalence about change.

In addition to reflections, another way to demonstrate understanding and encourage exploration of ambivalence is through the use of *summaries*. These are lengthier than reflections and are conducted periodically through the consultation. They can be used to bring together all the things the patient has said regarding a particular issue, to link some things a patient has said with other things he has said at another point in the session, or to bring a discussion to a close.

Reflections and summaries are useful tools in the elicitation of change talk, as they can be used to highlight what patients perceive to be the benefits of changing and the costs of staying the same are and then encouraging them to

elaborate on these further. They can also be used to affirm patients by demonstrating appreciation and supporting their achievements.

Rolling With Resistance

When talking about behavior change, from time to time a patient may disagree with the practitioner or become defensive about their behavior. One of the principles of MI is to "roll with resistance," or rather to respond to resistance without confrontation.

Rolling with resistance can be done in several ways. The use of reflective listening statements usually helps, as they encourage patients to tell the practitioner how they are feeling and why, which in itself can lower resistance.

Resistance often occurs when patients feel that their freedom is being taken away (Brehm, 1966). Therefore, reassuring patients that they are free to make their own choices and that they are under no obligation to make changes to their behavior can also be helpful (for example, "I'm not here to force you to change. The decision to change is and always will be entirely yours"). It can also help to shift focus by acknowledging that patients are obviously not happy to talk about the particular issue in hand at the moment and asking them if there is anything else they would prefer talk about, instead, again emphasizing personal freedom and choice (for example, "It sounds like you aren't really very happy to talk about your smoking at the moment. What would you prefer to talk about instead?").

Another factor that may evoke resistance from patients is a sense that the practitioner has misunderstood how ready they are to change. Should this be the case, it can be useful to go back and reassess the patient's readiness.

If a patient is becoming resistant, this may reflect that the practitioner and the patient have different views on the subject at hand, and a different approach may be needed to resume the "dance."

Setting the Agenda, and Asking Permission to Talk About Behavior Change

Choosing to talk about behavior change should ultimately be the patient's choice. Given the importance of patient choice in lowering resistance, the practitioner should always ask permission to talk about the behavior with patients, rather than just telling them that today there will be a discussion about their health behavior.

In Motivational Interviewing, patients are encouraged to set the agenda for talking about behavior change. This is particularly important if there are a number of different lifestyle issues to be addressed. For example, a cardiac rehabilitation patient may have been identified as having a number of risk factors that may have contributed to a myocardial infarction. He may need to make dietary changes, do more exercise, and cut down on the amount of alcohol consumed to try to reduce his risk of having another heart attack. It is often easier to make changes gradually, rather than trying to make a number of substantial changes all at one time.

Individuals may even be at different stages of readiness to change different aspects of one health behavior (Rollnick et al., 1999), or they may have

other issues that are more important for them to talk about and that are affecting their readiness to change, such as worries in other aspects of their life.

Achieving small changes can increase self-efficacy (Bandura, 1995) and make patients feel more able to make other small changes. It is therefore important to start where patients feel most comfortable and encourage them to suggest what area they would like to talk about, rather than selecting what the health care practitioner feels is the most important issue to talk about first.

Encouraging patients to set the agenda can be initiated through the use of open questions, such as "There are a number of different things we can talk about today. I'm just wondering what aspect of your lifestyle you would like to talk about?" One clinical tool that can help with this task is an agenda setting chart (Rollnick et al., 1999), which contains a number of circles containing picture representations of various different lifestyle factors and some blank circles for other factors to be inserted by the patient. Practitioners should be prepared for the patient to raise issues that they may not have anticipated—for example, a newly diagnosed type-2 diabetic patient may be most worried about what the diagnosis might mean for her family, rather than for her personal health, at that moment.

Exploring How the Patient Feels About Change

Given the role that readiness plays in motivation to change behavior, it can be useful to gain an understanding of this. One way this can be achieved within clinical practice is by exploring how important patients feel it is to change their behavior and how confident they feel about achieving such change.

In exploring importance and confidence, many practitioners find it useful to use scaling questions. This involves asking patients, on a scale of 0–10, how important is it for them to change a particular behavior and then asking, on the same scale, how confident they feel of success in changing that behavior. Following on from this, the practitioner can ask patients why they have given themselves this score and not a higher or lower number and what they think would help them to move up the scale in terms of importance and/or confidence.

Of course, the use of scaling questions like this is not compulsory. This technique has only been described, as many practitioners find it a useful way of understanding where patients are at a particular point in time. Importance and confidence could equally be assessed by the use of skillful open-ended questions, such as "How important would you say it is for you to make changes?" and "If you made the decision that you were going to change, how confident are you that you would succeed?"

Closely related to the importance/confidence strategy is exploration of what patients like and dislike like about their current behavior, including what they feel they would gain or lose from making changes. This can also help the practitioner to understand patients' barriers to change and also offers a valuable opportunity to elicit change talk from patients.

Exchanging Information

Within health care consultations, there often comes a point where patients need information. Perhaps patients need to know something for their safety or

well-being, perhaps they have asked you for information on what they should do, or perhaps they have misunderstood something with regard to their care or recovery.

Information giving within health care is usually a process in which the patient is a passive recipient. A typical example might be "You are eating too much of x. This means that you are at a much higher risk of developing x. What I suggest you do is x." This has the advantage of being direct and to the point. However, it has the disadvantage of possibly telling the patient something she knows already or that may be misunderstood in terms of its personal relevance. It also makes the assumption that the patient will just take the advice and do as she is told, which is unlikely in the case of the ambivalent patient.

Within Motivational Interviewing, information is exchanged with patients, rather than simply provided to them. This involves the use of the "elicit-provide-elicit" method: first finding out what the patient knows already, providing information (after asking if the patient is happy for you to do this), and then finding out what the patient has made of that information. An example of this might be:

- *Elicit:* "What do you know about the complications of diabetes?"
- *Provide:* "Would it be OK if I told you a little bit more about that?"
- *Elicit:* "So, what do you think that might mean for you?"

This means that information is given in a neutral manner, building on what the patient already knows, and the interpretation of the facts is left to the patient.

Exchanging information in this way can encourage patients to actively think of how the information given applies to themselves as individuals and can even save the practitioner time, as it prevents the provision of redundant information, or "telling the patient what he knows already."

Talking About Making Changes

If patients indicate that they are ready to make changes, the most useful course of action is to elicit from them what changes they feel they would like to make. The practitioner no doubt has years of experience in clinical practice and knows exactly what the patient needs to do to achieve better health. However, as the patient is the individual who has to make these changes, it is argued that the patient is the expert in knowing what will work best for her. This process can be initiated through the use of open-ended questions such as "What sorts of things do you think you might be able to do?"

This does not mean that the practitioner cannot offer possible courses of action to the patient—the patient may indeed ask for advice about what to do. However, the practitioner should ask permission before making a suggestion, and it should be made clear to the patient that he is not obliged to follow this suggestion if he does not feel it will suit him. The patient should be an active decision maker, rather than a passive recipient of information and instruction.

It can be helpful to encourage patients to think about previous attempts to change their behavior. For example, what has worked well before, what kinds of things did not work, and why? How has the patient dealt with other life challenges before?

The focus should be on small changes that feel achievable for the patient. If patients succeed with one change, they may feel more able to face others (Bandura, 1995). If a major changes need to be made, it may be easier for patients to break these changes down into smaller tasks. This may make change feel more achievable than if they try to do everything at once.

Adaptations of MI

MI has been used in several different contexts, including (but not limited to) addictions, primary and secondary health care, and criminal justice settings. There are a number of systemic differences among these settings, which have resulted in adaptations of the method described by Miller and Rollnick (2002). To try to protect against confusion as to what is and what is not MI (Miller 2000), researchers have developed a number of different adaptations of MI (AMIs) (Rollnick & Miller, 1995; Rollnick et al., 2002).

Examples of Adaptations of MI

Examples of AMIs described in the literature include the "Drinker's Checkup" (Miller & Sovereign, 1989), and Motivational Enhancement Therapy (MET) (Miller, Zweben, DiClemente, & Rychtarik, 1992). The Drinker's Checkup is a two-session assessment and feedback of a client's drinking, delivered in an MI style. MET is also delivered as an intervention of assessment and feedback on drinking in an MI style, but it was implemented across four sessions as part of Project MATCH (Project MATCH Research Group, 1993).

In health settings, Rollnick and colleagues developed a "menu of strategies" approach based on MI for use with non-help-seeking heavy drinkers in primary care, which they termed "brief motivational interviewing," with an emphasis on utilizing MI skills in practice (Rollnick et al., 1992). Building on this, Rollnick et al. (1999) adapted MI for use with general health behaviors in health care settings, termed "behavior change counseling" (Rollnick et al., 2002), which differs slightly from traditional MI, although the skills and spirit between behavior change counseling and MI are very similar. There is less emphasis on the strategic elicitation of change talk and less elicitation of deeply held patient values but generally more elicitation of patient information needs and exchanging of information than would typically be found in an MI session.

What's in a Label?

Several AMIs have taken on different names, to try to explicitly illustrate that they contain qualitative differences from the original parent method. This has both advantages and disadvantages. It makes it clear that the intervention delivered differs from Miller and Rollnick (2002) in some way, but at the same time it can be confusing when one is trying to establish whether the study in question has drawn on the skills and spirit of MI in any way, and to what extent.

Using a different label to describe an AMI is less important than actually describing how it was designed, how it differs from MI, and which of its characteristics are consistent with MI. The importance of defining the components

of behavioral interventions has been highlighted by research guidance documents, such as the Medical Research Council's guidelines on the study of complex interventions (Medical Research Council, 2002). Failure to do so can make it difficult to interpret the implications about the efficacy and effectiveness of MI as an intervention.

Evidence for MI in Health Care Settings

Systematic Reviews and Meta-Analyses

A number of recent systematic reviews have presented growing evidence for the effectiveness of MI as an intervention. The strongest evidence is in the treatment of drug and alcohol misuse (Burke, Arkowitz, & Dunn, 2002; Burke, Arkowitz, & Menchola, 2003; Dunn, Deroo, & Rivara, 2001; Hettema, Steele, & Miller, 2005). As MI is still a relatively new method, and as it entered the general health care arena much later than the addictions field, the evidence for MI within health care settings is still somewhat limited, although the technique has shown much promise.

Rubak and colleagues conducted a systematic review of 72 randomized controlled trials in health care settings (Rubak, Sandboek, Lauritzen, & Christensen, 2005) and found that MI interventions had a significant effect on reducing BMI, cholesterol, systolic BP, blood alcohol content, and standard ethanol content, although not on the number of cigarettes smoked per day in smokers or on HbA1c in people with diabetes. Vasilaki and colleagues systematically reviewed studies that used brief alcohol interventions based on MI and concluded that MI was effective in reducing alcohol consumption in the short term with mainly risky (rather than alcohol-dependent) drinkers (Vasilaki, Hosier, & Cox, 2006). Another more recent systematic review (Knight, McGowan, Dickens, & Bundy, 2006) into the effects of MI interventions on physical activity concluded that these interventions do appear to increase exercise uptake among patients, although the poor quality of trials made this hard to determine, with just eight studies being included in the review as a result—mirroring the findings of previous reviews that have attempted to look at MI in relation to specific health behaviors (Dunn et al., 2001; Burke et al., 2002; Burke et al., 2003; Hettema et al., 2005). To date, there are more than 150 published trials of motivational interviewing (see Rollnick et al., 2007).

One salient aspect of patient behavior during an MI session that has been shown to correlate with outcomes is the amount of *commitment language* patients produce in a consultation (Amrhein, Miller, Yahne, Palmer, & Fulcher, 2003). Commitment language is a kind of change talk in which the patient indicates that he is committed to taking particular courses of action (for example, "I'm definitely going to give that a try"). It should be emphasized that commitment language is elicited from, rather than imposed upon, the patient.

Issues in the Reporting of Trials of MI

Although most studies of MI exhibit high levels of external validity, reviews of research papers have indicated that the internal validity of these trials is often

poor. Dunn and colleagues found that the evaluation of the efficacy of AMIs was difficult because of the lack of information regarding the training and skill level of practitioners who delivered the intervention (Dunn et al., 2001). Of 29 studies, only 10 reported the number of hours training given, 11 reported that training was provided but gave no indication of how much training was given, and 8 did not mention training at all. No studies mentioned practitioner skill level in delivering AMIs and how much training produced how much skill in using AMIs. Each AMI was different from the next, making it difficult to compare like with like. Burke and colleagues also highlight a lack of adequate specification of the intervention used; there is often no detail regarding the amount or nature of the training delivered, the background and credentials of the intervention providers, and the nature of the intervention delivered (Burke et al., 2002). They also state that there has been no indication of how the intervention was delivered to patients. Indeed, one earlier review of 11 clinical trials of MI questioned whether it was fair to describe the intervention delivered in some trials as an AMI (Noonan & Moyers, 1997).

To enhance the quality of such trials, more attention is being focused on the quality of the intervention actually delivered by practitioners in a number of different contexts, resulting in the development of instruments to measure practitioner skill in delivering MI (Barsky & Coleman, 2001; Lane et al., 2005; Madson, Campbell, Barrett, Brondino, & Melchert, 2005; Moyers, Martin, Manuel, Hendrickson, & Miller, 2005). Several trials of MI interventions are now using instruments and qualitative analyses to assess practitioner skill level posttraining and the fidelity of AMI delivery in practice. It is anticipated that this will contribute greatly to the interpretation of results of trials of MI and its adaptations and increase the understanding of how different features of MI might work best with individual patients.

Summary

MI is a clinical skill that has been used in a range of different contexts involving behavior change. It aims to help patients explore and resolve ambivalence to change. There are a number of microskills that can be used in consultations with patients, but it is important to adhere to the spirit of MI when employing these techniques. Evidence shows that MI is effective in the drug and alcohol field, and it has shown potential in encouraging patient behavior change in health care settings. Studies that define the intervention delivered and attempt to assess the fidelity of the intervention delivered will provide more information about what aspects of MI seem to work best in helping patients to achieve changes in their behavior.

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E-Health Strategies to Support Adherence

9

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Defining E-Health and Its Proposed Contribution to Health Care

A commonly cited definition of e-health describes the emerging field as "the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies" (Eysenbach, 2001). For clinicians, the benefits of e-health applications include improved patient information management, coordination of longitudinal care, and symptom monitoring. For patients, e-health tools have the potential to improve communication with clinicians, access to personal health information, and health education with the goal of preparing

patients to take a more active role in their care. E-health developers and be-havioral researchers and clinicians are challenged to develop easy-to-use, ac-cessible, and engaging technology that employs interactive strategies to attract and retain diverse patient users. If these goals are attained, it is plausible that e-health technologies will assume a significant future role in supporting pa-tient adherence.

Why Incorporate E-Health Strategies in Health Care?

Developing and deploying effective e-health strategies to promote adherence to healthy behaviors are priorities now because these technologies are able to reach broad numbers of people simultaneously, Web access is growing, and the demand for additional health promotion interventions persists.

E-Health Tools Have Broad Reach

Strategies are needed to increase the *reach* and *impact* of effective health pro-motion programs. Traditional prevention and chronic disease management pro-grams are labor intensive and time consuming and reach only the minority of individuals who attend in-person sessions. Thus, despite the efficacy, the cost to reach the at-risk population is often disproportionate to the small numbers of people who benefit. In contrast, the Internet, cell phones, and other e-health tools span geographic and time differences, sustain relationships, and build links between people and information (Wellman, 2001). E-mail and Internet access is available 24 hours a day, seven days a week, and information can be customized to serve the individual characteristics of the user. These technology attributes may serve the goals of both broad reach and effective impact.

Users Have Growing Access to the Internet

During the past decade, both health care providers and payers have increas-ingly incorporated information technology into their practices to serve pa-tients directly, through information and education, and indirectly through clinical data management. In addition, patients and consumers have rapidly adopted electronic technologies to obtain information, education, and disease management tools. Between 2000 and 2005, it is estimated that the number of U.S. Internet users seeking health information more than doubled, reaching 88.5 million people (Ahern, Phalen, & Mockenhaupt, 2003). Sixty-eight percent of U.S. adults, including seniors, now have access to the Internet. The Pew Study on "Older Americans and the Internet" reports that the percentage of seniors online increased by 27% between 2000 and 2004, as 8 million adults over 65 years of age (22% of those in this age group) reported Web access (Rainie & Horrigan, 2005). Furthermore, the Pew Study reports, "As Internet users in their 50's get older and retire, they are unlikely to give up their wired [Web use] ways and therefore will transform the wired senior stereotype." A recent study of

health e-mails delivered to working adults with uniform computer access offers further evidence that adults readily accept Internet-delivered health information. More than 80% of 345 employee participants opened more than half of the daily health e-mails they received during a 6 month period. Importantly, e-mail open rates did not vary by employee gender, age, income, education, ethnicity, or baseline health behavior (Franklin, Rosenbaum, Carey, & Roizen, 2006). Recent data report that Hispanic consumers report spending more time online at home than other U.S. online consumers (9.5 vs. 8.4 hours), and 43% of online Hispanics are interested in or already use the Internet for health care reasons ("Hispanics Going Online in Record Numbers," 2003). Finally, *Healthy People 2010* includes a goal of facilitating Internet access in 80% of U.S. homes by the year 2010 to support its health promotion goals (U.S. Department of Health & Human Services, 2000). Thus, as computer and Internet access spreads, widespread use of electronic technology offers an opportunity to integrate e-health technology in support of medical and self-care.

Demand for Alternative Health Promotion and Self-Care Strategies

In parallel to the emergence of electronic communication tools, the demand for health promotion and chronic disease management among an aging U.S. population is growing. It is estimated that chronic disease costs account for more than 70% of all health care expenditures and the majority of disability (Bodenheimer, 2005). Furthermore, health promotion behaviors lag behind *Healthy People 2010* goals despite targeted efforts. For example, 77% of adults report diets that include less than the recommended daily intake of fruits, vegetables, and vitamins, and more than 80% of adults are overweight or obese (National Center for Chronic Disease Prevention and Health Promotion, 2005). E-health tools offer a relatively untested mechanism to deliver patient-centered health promotion and self-management strategies widely among the U.S. population. While improving health is the primary goal of technology, significant cost savings may be possible if effective adherence strategies improve behavioral choices. In this context, it is critical to define and evaluate the appropriate roles for e-health interventions to improve adherence to health-promoting behaviors.

User-Centered Design of E-Health Interventions

E-health interventions vary in design, technology application, delivery, and content. A sample of the wide variety of e-health applications developed and in evaluation are summarized here to illustrate design, delivery, and content considerations in e-health adherence interventions. Definitive research to define the most effective formats and delivery strategies is limited at this time. Thus, each section identifies some of the relevant unanswered questions.

The nature of health promotion, disease prevention, and chronic disease management involves ongoing, consistent patient participation. Thus, it follows that e-health programs targeting health behaviors depend on repeat patient use over extended periods of time. As a result, user adherence to the e-health

intervention schedule is central to effective results. Identification of the factors that contribute to regular or appropriate use of e-health programs is critical to achieve desired health outcomes. Research is needed to both measure adherence to e-health programs and to clearly understand the essential attributes of e-health programs associated with patient and consumer use and acceptance.

User-Defined Specifications

The most important factor in the success of an e-health system is design informed by user's needs and perceptions of what works best for them, that is, a system's usability and helpfulness. In fact, an effective user evaluation of an e-health program may provide an early indication of a technology's worth and ultimate viability. Varied research methods may be used to obtain user input during the development of e-health applications. The specific method may vary depending on the nature of the application and availability of resources. Evaluation objectives may be achieved through controlled and structured methodologies (e.g., formalized and structured instruments), heuristic analyses, or cognitive walkthroughs (Nielsen, 1992; Vitalari, 1985). The most useful methods tend to be those through which users communicate their likes and dislikes directly to the designers and developers, including qualitative studies and ethnography (Beyer & Holtzblatt, 1999; Forsythe, 1995; Prasad, 1997). Focus groups, workshops, in-depth face-to-face interviews, and short- and long-duration participant observations are commonly employed. Evaluations should solicit a rich description of the users' opinions, as well as the context of use to ensure user-centered systems (Geertz, 1973). For example, clinicians and teens were asked to pretest a phone text messaging system to deliver reminders to diabetic teens to enhance self-management (Waller, Franklin, Pagliari, & Greene, 2006). Early feedback resulted in a reliable system that effectively fit into the daily life of a teen.

Should E-Health Systems Be Designed to Be Humanlike?

A common evaluation standard for e-health systems asks whether the intervention emulates an interaction with a human health professional. Anthropomorphism is enhanced in systems that are voice-based, using either a human voice or a synthesized, computerized voice. Users' tendency to anthropomorphize is higher in voice-based systems than in those that are only text based (e.g., Internet applications that use only written words). In addition, many e-health systems replicate users' typical interactions with health care professionals, including specific wording, tone, and style. Similarly, humor, concern, and expressions of support and encouragement intensify users' tendency to anthropomorphize the e-health system. Anthropomorphism is a deliberate design strategy to enhance the system's impact, as users who anthropomorphize a system tend to feel more positively toward it (Farzanfar, Finkelstein, & Friedman, 2004). Anthropomorphic attributions offer patients a useful reference to describe their experience and facilitate comparison of the system to a human health care professional.

Conversely, some evaluations of an automated telephone linked call system (TLC) have demonstrated that enhancing human-like characteristics of a system may have unintended negative consequences. Users who are not comfortable with a human health care professional will extrapolate these feelings to the system. For example, when the health topic is one that addresses sensitive topics such as diet or mental health disorders, humanlike systems may not be an advantage (Farzanfar et al., 2004; Farzanfar, 2006). In fact, some users prefer interacting with computers rather than with health care professionals when sensitive or personal issues are involved and report that automated systems are less judgmental. Whether anxiety is caused by personal or societal factors, nonjudgmental technology is less threatening to some users. For example, some sexual behaviors were more accurately reported on private questionnaires, on computer or paper, than in face-to-face interviews (Durant & Carey, 2000). Importantly, when users are not anxious, they are more receptive to the educational health messages communicated by the system.

Alleviating User Anxiety With E-Health Systems

E-health system components, including word selection, must be cautiously designed to ensure that systems do not unintentionally promote feelings of inadequacy or anxiety. For example, an automated telephone messaging system that is based on goal setting might be threatening among users who fail to achieve a goal (Farzanfar, Frishkopf, Migneault, & Friedman, 2005). We have noted that fear of criticism adversely impacts the utilization regimen specific to a system. This indicates that e-health systems that target modification of an unhealthy behavior must take into consideration users' sensitivities to words and surveillance. These findings might be extrapolated to Web-based programs using relational agents. Relational agents are animated software that imitate human-to-human communication style and interact with users in intelligent and sometimes affective ways (Bickmore, 2003). Depending on their sophistication, these intelligent software agents can function as both advisers and support systems.

In summary, to reach the design objectives, e-health programs need to be well designed and to meet users' needs and sensitivities. This can be achieved only by exploring potential users' perceptions and their understanding of an e-health program through formal evaluations.

Targeting and Tailoring Health Strategies

The power of e-health applications arises from the computer's ability to target user groups with similar needs or tailor strategies to individual attributes and context. Targeted communication is designed to reach a *group* of individuals who share a similar attribute. E-health targeting is based on stored information that the user provides. For example, in contrast to televised advertisements for antihypertensive medications that reach all viewers, with and without high blood pressure, computer-based targeting can direct messages to reach those with known prescriptions for high blood pressure treatment. Users of one popular health promotion Web site complete a health risk assessment and identify

priority behaviors they would like to improve. This Web site then delivers regular health messages to all Web site users who have identified certain suboptimal health behaviors. Targeting the e-health program to those who are most likely to benefit from the message enhances the efficiency of the message delivery.

Tailoring refers to feedback or guidance designed to address an *individual's* personal characteristics, thereby increasing the personal relevance and enhancing the potential effectiveness. Well-designed tailored programs have the potential to simulate an individualized counseling session (DeVries & Brug, 1999). Message tailoring adds greatest value when significant variability exists among the users on key attributes that will influence the intervention outcome (Kreuter, Strecher, & Glassman, 1999). Tailoring also assumes the ability to collect information about the key user attributes to be considered in refining the tailored message. Researchers have reported effective use of computer-tailored, individual feedback message programs for behaviors ranging from asthma management to alcohol use in emergency room patients to physical activity and diet (Blow et al., 2006; Kroeze, Werkman, & Brug, 2006).

Alternate Delivery Technologies for Health Interventions

Effective methods for reaching large populations of people with health-promoting messages are needed. Computers, the Internet, personal communication devices, and electronic games are being tested to meet these needs, and all offer promising results. This section briefly reviews promising e-health delivery technologies and their early evidence of success and identifies further research needs.

Studies of telephone counseling have used structured clinician phone calls to successfully modify behavior (Eakin, Lawler, Vanderlanotte, & Owen, 2007). Computer-Assisted Telephone Interviewing (CATI) technologies, in conjunction with telephone counseling, display consistent interviewer questions on a computer screen and allow the interviewer to enter the patient's responses into a database. Experience with scripted, nonlocal telephone counseling supported by computer data collection has informed the design of e-health interventions where computer protocols deliver tailored or targeted health information to patients through electronic devices, replacing one-to-one patient-provider interactions.

Internet

In the span of a few short years, the Internet has become an essential part of life for many Americans, reshaping the ways in which we communicate, locate information, and entertain ourselves (Rainie & Horrigan, 2005). Because of its familiarity, broad availability, and accessibility, the Internet is being investigated as a channel for delivering e-health programs. A review of the e-health literature reveals a wide variety of Internet-based health behavior programs have been developed and tested. Examples include programs based on a one-

time Internet session (Shegog et al., 2005), structured programs with multiple contacts over time (Baranowski et al., 2003; Block, Block, Wakimoto, & Block, 2004; Jago et al., 2006; Napolitano et al., 2003; Plotnikoff, McCargar, Wilson, & Loucaides, 2005; Tate, Wing, & Winett, 2001; Tate, Jackvony, & Wing, 2003; Winett, Tate, Anderson, Wojcik, & Winett, 2005); self-paced programs offering access to tailored Web sites (Woolf et al., 2006); programs combining in-person and Internet sessions (Baranowski et al., 2003; Jago et al. , 2006; Tate et al., 2001, 2003); virtual coaches (Tate et al., 2001, 2003; Winett et al., 2005); and e-mail messages or prompts alone plus Internet resources (Block et al., 2004; Franklin et al., 2006; Plotnikoff et al., 2005) or in combination with other electronic programs (Napolitano et al., 2003; Tate et al., 2001, 2003; Winett et al., 2005). Emerging evidence indicates that Internet-based e-health programs show promising results. These programs are able to reach broad audiences, both adults and youth, sustain participation, and address a variety of health behaviors, ranging from changing diet and physical activity to smoking cessation and asthma management.

Personal Communication Devices

Personal digital assistants (PDAs) have been investigated both as educational aids and as a method for collecting self-report data (Trapl et al., 2005; Wang, Kogashiwa, Ohta, & Kira, 2002; Wang, Kogashiwa, & Kira, 2006; Yon, Johnson, Harvey-Berino, & Gold, 2006; Yon, Johnson, Harvey-Berino, Gold, & Howard, 2007). Advantages to collecting data through PDA include simplicity of use, transportability (Jaspan et al., 2007), and immediate transferability of responses to a central database (Dale & Hagen, 2007). When compared to pen-and-paper measures, data collected via PDA appear to be more complete and to have fewer errors (Dale & Hagen, 2007). A systematic review comparing PDAs to pen-and-paper measures concluded that PDAs outperformed pen-and-paper measures in most areas and that participants generally preferred PDAs over pen and paper. The primary disadvantage was technical malfunction resulting in loss of data (Dale & Hagen, 2007). PDAs, enhanced with digital video, have successfully delivered patient education (Brock & Smith, 2006). Patients taking HIV/AIDS medication watched a 25-minute digital video on a PDA to review information about the disease, medications, and adherence. Patients liked the PDA video, suggesting that PDAs may be an effective educational method in a clinical setting. Audio-enhanced PDA data collection has also been tested; although the results were promising, more work is needed to overcome deficits in data quality across different groups (Trapl et al., 2005). PDAs containing a camera and phone cards have been investigated as a novel method for recording dietary intake (Wang et al., 2002, 2006). In one study, participants took digital photographs of foods entered in a daily diary. The data were then transmitted digitally to registered dietitians for review. Results indicate that digital photos taken on a PDA may be an effective method for recording dietary intake.

Cellular phones and "smart phones" (a handheld device that combines the features of a cellular phone, PDA, and personal computer) have also been investigated for their ability to influence health outcomes. Diabetes management appears to be an area of particular interest for this methodology. In children

with type 1 diabetes, mobile phones were tested as a way to promote self-care and parental monitoring (Gammon et al., 2005). Text messages, sent via a cellular phone, have also been tested as a component of diabetes management, with promising results (Ferrer-Roca, Cardenas, Diaz-Cardama, & Pulido, 2004; Wangberg, Arsand, & Andersson, 2006).

Finally, extensive application of interactive voice response (IVR) systems that use telephones to communicate computer-generated health messages to patients have been found to be well accepted and effective. The Telephone-Linked Communication (TLC) system has been used to educate and advise patients and to reinforce or change varied health-related behaviors, including medication management (Friedman, 1996, 1998), diet (Delichatsios et al., 2001), exercise (Jarvis, Friedman, Heeren, & Cullinane, 1997), and smoking cessation (Ramelson, Friedman, & Ockene, 1999).

Electronic Health Records and Web Portals

In the future, electronic health records (EHR) with patient portals may offer enhanced patient involvement, quality of care, and efficiency of service (Ford, Menachemi, & Phillips, 2006). Web portals allow patients to obtain access to their electronic health records and to communicate electronically with their providers (Hassol et al., 2004). A recent survey found that patients generally have positive attitudes toward use of portals and electronic communication with their provider. However, some patients expressed concerns about confidentiality and privacy. Interestingly, while patients preferred e-mail or in-person communication, physicians preferred telephone communication over e-mail (Hassol et al., 2004). A randomized controlled trial comparing a Web portal with usual care found that portal patients reported greater overall satisfaction than the usual-care patients (Lin, Wittevrongel, Moore, Beaty, & Ross, 2005). Additionally, patients indicate a willingness to pay for e-mail correspondence with their provider (Adler, 2006; Lin et al., 2005) and online access to their electronic health records, suggesting that patient portals may become important to future health care delivery.

Electronic Games

Youth enjoy electronic games (computer and video) and play them often. In a recent survey of media use among 8–18-year-olds, 59% of youth reported playing electronic games for an average of 1 hour 8 minutes each day (Roberts, Foehr, & Rideout, 2005). A 2006 report on gaming found that adults spend more time each week playing games than youth. Among 25–34-year-olds, more females than males played video games, dispelling the myth that gamers are mostly young males. For the health field, this suggests that electronic games may be a method for reaching a large proportion of the population by using a familiar, enjoyable method.

Emerging evidence suggests that electronic games can be effective at achieving desirable health outcomes. An evaluation of Squire's Quest!, a 10-session computer game to increase fruit-vegetable consumption among elementary school

youth, found that children who played the game achieved a one-serving-a-day increase in intake over those who did not play the game (Baranowski et al., 2003). Elementary school youth who played nutrition knowledge games had improvements in knowledge, practices, and consumption (Turnin et al., 2001). Paradoxically, games promoting active game play have also been effective at enhancing energy expenditure (Lanningham-Foster et al., 2006; Tan, Aziz, Chua, & Teh, 2002) although declining interest and use over time remains a concern (Madsen, Yen, Wlasiuk, Newman, & Lustig, 2007). Interim results of an action-adventure game where children were required to wear pedometers as part of game play revealed a general increase in activity after 1 week of game play (Southard & Southard, 2006). Electronic games have also shown positive effects in treatment and self-management of chronic diseases such as asthma and diabetes (Lieberman, 2001). Preliminary evidence also suggests that games can be used to decrease anxiety prior to surgery (Patel et al., 2006) and to assist in lung function measurement among young children (Vilozni et al., 2005). Not all game effects have produced the expected outcomes (Homer et al., 2000; Huss et al., 2003; McPherson, Glazebrook, Forster, James, & Smyth, 2006), suggesting that more research is needed to determine features of effective games. The ideal design of games to achieve optimal health effects is not known. It is likely that increased realism will enhance generalization of behaviors taught in a game environment to the external world (Funk, 2005). Creating game environments, story lines, characters, situations, and barriers that players are likely to encounter in real life may provide them with a protected environment within which to practice self-management skills.

Future Technologies

The sciences of artificial intelligence, robotics, and natural language processing will converge to create smart, automated entities that interact with users in various capacities. Intelligent agents have been created to help consumers with their health-related lifestyle choices, such as enhanced physical activity (Bickmore 2003), or to help clinicians with their monitoring and diagnostic tasks (Mabry, Schneringer, Etters, & Edwards, 2003). The future holds great promise for these smart entities as multiagent systems to enhance patient health, including provision of remote care for the elderly, dissemination of health information, and monitoring of diagnostic tests.

Finally, there is a great deal of enthusiasm for the deployment of personal health records (PHR) that can incorporate many of the technologies discussed. A PHR integrates and organizes a broad array of health information and is managed by the patient. Using e-health devices ensures broad access to the information (i.e., data stored on the Web or easily transferred to phone for transmission and review by multiple parties without geographic limitations). Table 9.1 summarizes the current user and design attributes of the e-health strategies discussed in this chapter. As users become more familiar with these strategies and the developers enhance the functions, all of these technologies have the potential to broadly deliver tailored, interactive health messages to support patient behaviors.

9.1 Comparison of Attributes of E-Health Strategies

	Interactive voice telephony	Web	E-mail	Smart phone/PDA	Games
User					
Acceptance					
Familiar technology	✓✓✓	✓✓	✓✓	✓	✓
Anonymity	✓	✓✓✓	✓	✓	✓
Humanlike	✓✓✓	✓✓	✓	✓✓✓	✓✓✓
Access	✓✓✓	✓✓	✓✓	✓	✓
Interactive	✓✓	✓✓	✓	✓✓	✓✓
Cost	✓	✓✓	✓✓	✓✓✓	✓✓✓
Designer					
Reach	✓✓✓	✓✓	✓✓	✓	✓
Tailored	✓✓	✓	✓✓	✓✓	✓✓
Cost	✓✓✓	✓✓	✓✓	✓✓✓	✓✓✓

Key: ✓ = Low   ✓✓ = Moderate   ✓✓✓ = High

Theory to Guide Content

Behavioral science theory can guide e-health intervention efforts to target key forces that govern behavior patterns, increasing the probability of behavior change. For example, Fishbein et al. (2001) reviewed five leading theories of health behavior change and identified eight overlapping variables that explain most of the variance in health behavior change: intention, environmental constraints, skills, anticipated outcomes (or attitude), norms, self-standards, emotion, and self-efficacy. The first three variables are viewed as necessary and sufficient for behavior change, whereas the remaining five influence the strength and direction of the change. Thus, a theory-based e-health Internet program may include a structured self-assessment of skills and intention, motivational information to emphasize anticipated outcomes, self-monitoring tools to gauge environmental constraints and self-efficacy, and individualized feedback in response to progress. An e-health Behavior Management Model has been proposed and applied to Internet applications addressing varied chronic conditions (Bensley et al., 2004). The model combines the Transtheoretical Model, aspects of the Theory of Planned Behavior, and persuasive communication and advocates matching user stage of readiness to change with existing Internet information. Although technology constraints may modify some aspects of the theoretical model, behavior change programs based on theory appear to have a greater likelihood of success (Baranowski et al., 2003). Further research is needed to clarify how current behavior change theories explain and support individual e-health interventions. Finally, at a health care system level, the application of e-health tools in chronic disease care is supported by the Chronic Care Model (CCM) that includes both

self-management support and clinical information systems as two of its key elements. The CCM hypothesizes that informed, activated patients, together with proactive health care providers, will lead to improved health outcomes (Bodenheimer, Wagner, & Grumbach, 2002; Wagner, Austin, Davis, Hindmarsh, Schaefer, & Bonomi, 2001).

Health Applications for Specific Populations

E-health applications have been tested to support self-care and adherence among patients with varied chronic diseases and health behavior challenges. A general trend toward patient acceptance, sustained use, and positive behavioral effects has been documented. The following illustrate the variation in content and delivery technology.

Diabetes Care

A wide variety of e-health applications have been successfully tested among diabetic patients. A 2005 review of diabetes self-management Web sites found 87 publicly available Internet sites hosted by a variety of institutions (Bull, Gaglio, McKay, & Glasgow, 2005). While the majority of Web sites disseminated information, few sites offered interactive assessments, social supports, or problem-solving assistance. Although the diabetes Web sites reach a broad audience, Web site designs mimic paper education and do not fully employ the power of electronic technology to individualize the material (Blonde & Parkin, 2006; Glasgow, Boles, McKay, Feil, & Barrera, 2003). In contrast, one Internet diabetes comanagement program offered patient access to its EHR, tools to upload glucose readings, an online diary for entry and tracking of medications, nutrition, and physical activity, communication with its clinicians, and educational information (Goldberg, Raston, Hirsch, Hoath, & Ahmed, 2003). This model illustrates the creative

9.1

User interaction intensity.

Continuum of interaction intensity between the e-health device and the user. At the low-intensity end, all users have open access to Web sites providing general health information. At the high end, select users receive tailored messages and provide individual feedback to the system. Depending upon the design, devices can function at different points along the continuum.

integration of multiple e-health technologies (i.e., EHR, e-mail, and Internet), behavioral strategies (i.e., self-monitoring, skills development), and self-care targets (i.e., medication, diet, and nutrition) to support diabetic patients over time (see Figure 9.1).

Asthma Care

Tailored self-monitoring and educational asthma Web sites have been evaluated in teen patients and their parents with relative success. A randomized trial of a school-based, tailored, 6 month Web program for African American teens with asthma found that participants had significantly fewer symptom days, school absences, and hospitalizations for asthma at 12 months after intervention. The authors estimated that the cost to deliver the Web program was $6.66 per participant. If these results are generalizable, e-health may play an important role in achieving significant health benefits for asthmatic teens. School and workplace delivery of health interventions also can support uniform Web access. Another team directed a tailored asthma education and self-monitoring Web site to parents of children with asthma. The Internet site was paired with monthly nurse case manager education phone calls to improve adherence to daily medication management, asthma control, and parent quality of life (Krishna et al., 2003; Wise et al., 2007; Yawn et al., 2000).

Arthritis Care

Home-based Internet interventions are well suited for persons with limited mobility due to advanced arthritis. Thus, successful face-to-face arthritis programs have been translated to Internet delivery. One-year outcome data for *both* face-to-face groups and Internet programs showed significantly lower disability, health distress, and limitations in daily activities among the intervention groups (Lorig, 2001; Lorig, Ritter, Laurent, & Plant, 2006).

Depression and Psychological Health

The high prevalence of untreated depression is a public health concern in the United States. E-health strategies may contribute to depression screening, support treatment adherence, and broaden the delivery of therapeutic interventions. Early trials of Internet interventions for depression (without therapist contact) did not successfully improve depressed mood in those studied. Thus, Clark and colleagues added periodic telephone or postcard reminders to study participants to prompt use of the "Overcoming Depression on the Internet" (ODIN) program at Kaiser Permanente. The addition of the prompts resulted in significantly improved mood among ODIN users when compared to controls. Of importance, participants with severely depressed affect at baseline reported the greatest improvement (Clark et al., 2005). Because of the relatively small number of participants from among a large pool of eligible adults, the generalizability of these findings must be tested. Others found the integration of telephone cognitive-behavioral psychotherapy with computer-based care management and medications improved treatment outcomes (Tutty, Ludman,

& Simon, 2005). Finally, an Australian Internet-based depression care program offered e-consultations, surveys to assess treatment progress, and psychoeducation. Both e-mail and telephone reminders were used to support ongoing participation. Participants reported medication adherence of more than 90% and clinical improvement from severe to mild depression following eight sessions (Robertson, Smith, Castle, & Tannenbaum, 2006). These encouraging results suggest that further evaluation of innovative e-health tools is warranted in this patient population.

Generic Chronic Disease Conditions

After an in-person chronic disease self-management program demonstrated sustained improvement in exercise, self-reported health, health distress, fatigue, disability, and role limitations, the program was adapted for Internet delivery. At 1 year, intervention participant health status was significantly improved over that of controls; results were similar to those for face-to-face group programs (Lorig et al., 2006). Of note, all participants were computer and Internet literate, and both intervention and control patients accessed health-related Web sites at a similar rate.

Dietary Modifications

Campbell (1994) found that subjects who received individually tailored computer messages had decreases in total fat and saturated fat intake greater than those of subjects in two comparison conditions. Glanz and colleagues (1998) also found that providing subjects with individualized computer-generated nutrition information and personally tailored feedback led to reduced fat intake and increased fruit and vegetable intake. A third study reported that a multimedia computer game for elementary school students was associated with those students' eating an average of 1.0 more serving per day of fruit, juice, and vegetables (Baranowski et al., 2003). These studies suggest a future role for e-health systems in efforts to facilitate improved dietary choices.

Weight Management

Wing randomly assigned patients to receive a face-to-face or an Internet-delivered weight loss maintenance program of daily weighing and self-regulation or to a control group. After 18 months, those in the face-to-face program had the smallest weight gain. However, when compared to those in the control group, fewer people in the groups that received either intervention, face-to-face or Internet, regained more than 2.3 kg (Wing et al., 2006). Importantly, this research evaluated the relative effectiveness of clinician-delivered and electronic-delivered behavioral support. Other research tested PDAs as tools for self-monitoring of diet and exercise (Yon et al., 2006, 2007) and Internet programs (Williamson et al., 2006) and obesity prevention games as tools for promoting diet and physical activity (Goran & Reynolds, 2005). The latter study found gender differences in game effect, suggesting the need to evaluate e-health intervention acceptance in demographic subgroups.

Substance Abuse

Both nicotine and alcohol abuse have been addressed with e-health programs. For example, Pallonen et al. (1998) found that use of interactive expert-system computerized reports along with a traditional intervention was more effective in promoting smoking cessation than noncomputer based interventions. In addition, a randomized trial using a computer-based survey to screen for at-risk drinkers seen in an emergency department found that tailored information plus brief direct advice was associated with a 48% reduction in average weekly alcohol consumption during the 12-month study (Blow et al., 2006). The latter study illustrates the model of computer-based screening and messaging to augment brief clinical intervention in a busy, acute environment. Additional research on mechanisms to integrate e-health supports into acute medical settings is needed.

Pharmaceutical Adherence and Biological Self-Monitoring

Medication adherence and associated errors are key quality issues for the U.S. health system. Correct dosing and timing are significant challenges for aging adults taking multiple medications. To serve aging veterans, the Veterans Affairs health system integrated its computerized pharmacy and patient records systems to create a visual medication profile to facilitate efficient and effective management of patient medications (Hornick et al., 2006). Digital photographs are used to identify individual pills for patients. Early pilots suggest that clinician-patient communication about medication changes will be improved using this system. Technology to assess and transfer a series of digital blood pressure measurements to clinicians via the Internet have been developed and shown to improve management of hypertension between physician office visits (Gardiner, 2006; Nakajima, 2006).

Issues of Participation and Delivery of E-Health Programs

A limitation of traditional health behavior programs is that the participant must make the initial contact, thus skewing participation to those already motivated to consider health behavior change. Similarly, Web-based health information requires a motivated and technically literate user to seek, find, and use Internet health tools. However, "electronic outreach" and e-mail reminders have been successfully integrated into e-health programs to reach broader populations and to sustain active participation. For example, a worksite health promotion program translated existing Web-based information to brief daily emails that were delivered to employee computers. This "push" method of delivering Web information eliminated the need for the user to initiate the search for information or to contact a health professional. Employee participants reported varied health behaviors, stages of change, and intentions to adopt health behaviors at the beginning of the program. Importantly, no variation in email opening was observed across stages of change or self-reported intention to change during the 6 month program (Franklin et al., 2006). These findings indicate the

potential for e-health promotion programs to reach less motivated adults with suboptimal behaviors. In addition, Web and email-delivery allow low-cost, yet ongoing regular delivery of health messages for sustained periods of time. The optimal length of behavioral support programs delivered through e-technology is not known. Finally, some initial attempts to integrate e-health systems into medical practice have failed, suggesting that the current organization of medical offices is not prepared to incorporate computer based behavioral systems (Sciamanna et al., 2004). However, acute care hospitals and ambulatory care offices are not designed to support self-care in chronic disease or health promotion. It is unclear whether future e-health systems will reach patients within the health care system or directly, in their homes, workplaces, and schools.

Future Research Needed to Clarify the Roles of E-Health in Adherence

Carefully designed research to identify the ideal design, content, and delivery of effective e-health adherence interventions is beginning to emerge. Ahern and colleagues (2006) report a notable lack of consensus among e-health developers regarding intervention designs, user evaluations, and health outcome measures. Under the auspices of the Health-e-Technology Initiative funded by the Robert Wood Johnson Foundation (hetinitiative.org), research studies are systematically addressing tools, delivery mechanisms, user acceptance, and health benefits of a variety of electronic technologies designed to support behavior change and adherence. Despite the early state of research in the field, clinicians and technology experts are optimistic about the potential value and efficiency of e-health interventions serving both current and traditionally underserved patient populations. Future research should include multiple perspectives of patients, clinicians, and technology experts.

Evaluation of e-health systems typically revolves around the system's acceptability to users, its impact (helpfulness and effectiveness), and whether it fulfills the vision of the designers. Depending on the evaluation question(s), however, quantitative or qualitative methods of investigation may provide different types of information about a system. Quantitative structured instruments provide useful insight into users' overall perceptions but may not adequately address the complex dimensions of system utilization (Farzanfar et al., 2004). Qualitative methods, on the other hand, explore users' perceptions in depth and detail and enable designers to uncover the meaning users make of their experience with a system, that is, information from their point of view (Guba & Lincoln, 1981; Weiss, 1994). Qualitative methods, including one-on-one in-depth interviews, periodic focus groups, and, at times, ethnography, can also address system enhancements and redesign. An alternative method is "contextual inquiry," which is commonly used for evaluating information systems (Beyer & Holtzblatt, 1997). In "contextual inquiry," the emphasis is on the researcher's presence in the user's environment while exploring and understanding the context in which a system is used through in-depth interviews and participant observation. This method can be easily employed in evaluating e-health systems to more comprehensively identify user needs and acceptance of e-health systems.

Unanswered Questions About E-Health
Design, Delivery, and Content

Several areas of research are needed to elucidate the potential effectiveness of e-health programs. First, research is needed to determine appropriate behavioral theories to guide design and delivery of e-health behavior change programs to achieve optimal results.

- Do the same theories and mediating constructs guide behavior change in e-health programs as in face-to-face programs?
- Does the delivery technology alter effectiveness? Evaluations of the relative benefits of varying delivery modes (PC, video game, video phone, or MP3 player), including comparisons to traditional clinician delivery, are needed.
- What are the optimal uses of tailored information? Are targeted and generic information adequate to foster certain behavior changes or in particular populations?

Second, methods for enhancing and quantifying e-health program dose (i.e., log-on rate and time on tasks) need to be identified. Methods are needed to define and achieve log-on rates at desirable intervals to ensure that participants receive an intervention dose needed to facilitate and sustain behavior change (Danaher, Boles, Akers, Gordon, & Severson, 2006; Thompson et al., 2007). In addition, more sophisticated use measures are needed to ascertain the depth and user benefits at each log-on session. Unanswered questions include these:

- What is the optimal interval between log-ons? Optimal length of engagement at each log-on? Optimal total number of log-ons?
- What is the role for reminders and strategies to enhance active participation?
- What measures capture understanding, depth, and benefits at each session?

Third, methods for providing equal access to e-health programs and services must be identified. Even with increasing connectivity, there is evidence of a digital divide (Fox, 2005). Only 26% of those 65 years and older use the Internet, and slightly more than half (57%) of African Americans are online, as opposed to nearly three-fourths of Whites (70%). Internet use among Hispanics varies, depending on how the data are collected. Disparities also exist by educational level. Because it is possible that populations without traditional access to medical care may benefit significantly from Internet-based applications, uniform Web connectivity is an important goal. Research may address these questions:

- Will uneven access to and comfort with e-health tools contribute to health disparities?
- Are users of e-health interventions representative of the general patient population? If not, how are nonusers engaged in e-health programs?

Finally, future evaluations should incorporate the evaluation of e-health program costs, including both the development and delivery costs, direct costs

to health care systems and indirect costs to users, such as effects on their social networks (Griffiths, Lindenmeyer, Powell, Lowe, & Thorogood, 2006). E-health programs will not realize their full potential for delivering cost-effective, convenient health programs until issues such as these are resolved. However, experiences with a variety of e-health interventions to date suggest a future role for technology to support self-care behaviors and adherence to health promotion and chronic disease management.

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Section 2

Interventions for Lifestyle Change

Judith K. Ockene
Editor

As was emphasized in chapter 1, "Theories of Prevention," the message in medicine and public health is strong: many acute and chronic diseases can be prevented, or at least have their impact lessened, by increased attention to the adoption and maintenance of health-promoting behaviors. This recognition grows out of the many epidemiologic investigations that demonstrate the existence of a strong relationship between the onset, progression, and exacerbation of disease and subsequent quality of life and alterable health-related behaviors such as smoking, diet, physical activity, sexual practices, and stress management. Using the theories and models presented in Section I, as well as theories addressing factors at the organizational and community levels that we'll read

about in Section VII, chapters in this section focus on intervention strategies designed to facilitate change in health-promoting and disease-preventing behaviors and the maintenance of these behaviors. The strategies provided demonstrate the important translation from theory and research to application in practice.

A chapter now included in Section II and not included in previous editions of this book, "Multiple Risk Behavior Change: What Most Individuals Need," is an important addition. It addresses the integration of interventions for working with individuals who have multiple risk behaviors or comorbidities. Providers in all disciplines are faced each day with patients who have a clustering of disease-promoting or comorbid behaviors. Health practitioners need integrated approaches that can be applied to patients, rather than a collection of disparate single-behavior interventions. The chapters in Section II demonstrate that, while we have learned much in the last several decades about facilitating the maintenance of healthy behaviors, such endeavors are still a challenge to health practitioners and researchers.

Researchers Jolicoeur and colleagues, in "Addressing Tobacco Use and Dependence," stress the importance of a multifaceted approach to tobacco. McCann and Bovbjerg, in "Promoting Dietary Change," stress the importance of community and organizational change for facilitating nutritional and other health-related interventions and the complementarity of individual and organizational change. Marcus and colleagues, in discussing "Adherence to Physical Activity Recommendations and Interventions," ask us to give strong consideration to patient-treatment matching models as a way of responding to the differences patients bring with them. Naughton and Rhodes, in "Adoption and Maintenance of Safer Sexual Practices," emphasize that the diversity of the population groups affected by unsafe sexual practices makes developing effective strategies for this population challenging and that societal norms and interpersonal relationships play a strong role in this behavior. The state of the science in this area is younger than for the other behaviors that are addressed in this section, and the authors suggest directions for future research. Salmon and colleagues remind us in "Intervention Elements Promoting Adherence to Mindfulness-Based Stress Reduction (MBSR) Programs in a Clinical Behavioral Medicine Setting," that we must be ever mindful of the point of view of patients when caring for them. Judith Prochaska and Janice Prochaska, in their chapter on multiple risk behavior change (MRBC), note that MRBC research is "at an early stage, with its boundaries still being defined" and with much research still to be implemented.

The authors of each of the chapters agree that long-term change is yet another challenge, one that often feels elusive.

Addressing Tobacco Use and Dependence

10

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At the national level, over the past several decades, a wide variety of tobacco control efforts have been implemented in the United States in a relatively unsystematic manner. Nevertheless, the net impact of all strategies resulted in a 50% decrease in the prevalence of smoking, from 42.4% in 1965 to 20.8% in 2006 (Centers for Disease Control and Prevention, 2006c). A population level drop in prevalence of tobacco use behavior of this magnitude within the short time span of 40 years (less than one to two generations) is an astounding public health success. Thun and Jamal (2006) estimate that the decline in tobacco-related cancers is so large as to contribute more than 40% of the variance attributable to the much-publicized reversal in the overall cancer mortality rate in the United States that has occurred for the first time since the war on cancer was declared in 1971 (Thun & Jemal, 2006). While the mortality rate attributable

to smoking has declined as a result of the reduction in smoking prevalence (Rodu & Cole, 2007), tobacco use still accounted for more than 435,000 deaths in 2000 (Mokdad, Marks, Stroup, & Gerberding, 2004, 2005).

Much urgent work remains to be completed because there were still more than 40 million current smokers in the United States in 2006 and more than a billion worldwide. Tobacco use behavior remains the leading preventable cause of premature death, disability, and unnecessary expense, despite the rise of other pressing public health challenges such as the obesity, type 2 diabetes, and HIV-AIDS epidemics. It is estimated that as many as half the current smokers, more than 20 million human beings, will die prematurely of a smoking-related disease (Camenga & Klein, 2004) unless more effective, efficient, and comprehensive tobacco use prevention, treatment, and policy initiatives are developed and aggressively deployed.

Treatment services for nicotine dependence are recommended as an integral component of the multipronged approach that has contributed to the decline in smoking (Centers for Disease Control and Prevention, 1999; U.S. Preventive Services Task Force, 2006). The Clinical Practice Guideline for Treating Tobacco Use and Dependence, published by the Public Health Service, has compiled the available research demonstrating that effective smoking cessation interventions exist, including behavioral and pharmacological treatment (Fiore et al., 2008). Using evidence-based treatment significantly increases success, from almost double to as much as fourfold the cessation rate among those who quit on their own. Despite the social climate that is making it more difficult to smoke (e.g., bans in worksites, higher taxes on cigarettes), effective cessation programs are greatly underutilized. We are at a critical junction in the journey to further reduce smoking rates. The Institute of Medicine has recommended a "comprehensive, coordinated system of care management for cessation treatment" that includes five key elements: (1) motivating tobacco users to make more frequent quit attempts, (2) educating tobacco users to use evidence-based treatments when they try to quit, (3) reducing the very high rates of relapse to tobacco use after successful quitting, (4) ensuring that all tobacco users have access to the best care available and full insurance coverage for treatment services, and (5) structuring the system of care to provide additional levels of more intensive/specialized treatment (i.e., stepped care) for tobacco users who need them (Institute of Medicine, 2007).

This chapter provides an overview of the multifaceted nature of tobacco use behavior and cessation, including biological, psychological, and social factors. We review the major components of effective individual-level interventions, including behavioral and pharmacological options ranging from minimal (e.g., self-help) to maximal (e.g., inpatient treatment) in intensity and cost. Finally, system-level interventions are addressed.

The Nature of Nicotine Dependence

Defining Dependence

Dependence as defined by the American Psychiatric Association's Diagnostic and Statistical Manual (American Psychiatric Association, 2000) (DSM-IV-R)

involves key signs and symptoms, including an inability to discontinue use despite the presence of harm, tolerance to nicotine, and withdrawal symptoms. Withdrawal symptoms are often a primary factor in the inability to quit and relapse; they include (1) dysphoric or depressed mood; (2) insomnia; (3) irritability, frustration, or anger; (4) anxiety; (5) difficulty concentrating; (6) restlessness; (7) decreased heart rate; and (8) increased appetite or weight gain (American Psychiatric Association, 2000). The appearance of withdrawal symptoms may occur very early in the life of some smokers and in the presence of intermittent smoking (DiFranza et al., 2007). Estimates of the percentage of dependent smokers can be as high as 87% (Hale et al., 1993). Greater tobacco dependence and the ability to quit are influenced by the interaction of genetic, neurobiological, psychological, social, and cultural factors.

Neurobiology of Nicotine Dependence

Nicotine produces subtle, short-term, pleasurable effects, and cigarettes in particular are a highly efficient nicotine delivery system. Carried on the tar droplets produced by cigarette smoke, nicotine is passed from lungs to heart to brain in 7–10 seconds. The physiologic effects of nicotine play a major role in the establishment and maintenance of tobacco use. The short half-life of nicotine (2 hours) drives the frequent dosing of a regular smoker in order to achieve the desired positive effects and to stave off withdrawal symptoms.

As with many other drugs of abuse, the role of the mesolimbic system of the brain appears to be the most significant and so far the best understood in nicotine dependence. Nicotine's stimulation of this system hijacks the reward pathway whose primary purpose is to ensure survival by associating pleasure with natural stimulants such as food, water, sex, and nurturing. Nicotine binds to nicotinic acetylcholine receptors (nAChRs), stimulating the release of dopamine and the sensation of pleasure (Balfour, 2004; Dani, 2001). The noradrenergic system, including the locus ceruleus, is thought to play a major role in the mediation of withdrawal symptoms.

Stimulation of nAChRs by nicotine also results in an increase in glutamate (Lambe, Picciotto, & Aghajanian, 2003), which contributes to reinforcement of the pleasurable memory. By contrast, the inhibitory effect of GABA, whose function is to regulate the amount of available dopamine, is reduced. Thus these complementary functions serve to increase and reinforce the pleasurable effects of nicotine (Kalivas & Volkow, 2005).

The role of these neurobiological processes is significant in understanding the underpinning of dependence and has led to the development of pharmacologic treatments that are beneficial in assisting with cessation (Harris & Anthenelli, 2005). Recent research is also revealing more specific genetic or cellular mechanisms involved in dependence and in individual differences in patterns of use, such as the role of $\alpha_4\beta_2$ nicotinic receptors and allelic variation in the CYP2D6 gene related to differential rates of nicotine to cotinine metabolism. Thus, new discoveries in basic science may lead to better understanding of differential use and effectiveness of cessation aids and possible gender or racial differences in addiction susceptibility, and this in turn may lead to even more effective and efficient use of genetically tailored pharmacotherapies (Lerman & Niaura, 2002).

Psychological Aspects of Dependence

Tobacco users report myriad benefits from its use. Paradoxical effects such as stress reduction and relaxation and stimulation and arousal point to the ability of the tobacco user to control its effects. It is not entirely clear if improved cognitive functioning (e.g., memory and concentration) are direct effects of tobacco use or the result of relief of withdrawal (Heishman, 2000). It is, however, very clear that the pleasurable effects of nicotine become intricately linked to daily activities, emotions, and situations (e.g., talking on the phone, driving, coping with anger). These links become "triggers" for the urge to use tobacco and strongly reinforce its habitual use. Tobacco use becomes essential to daily functioning even in the absence of conscious forethought. Identification of the triggers and the perceived benefits of tobacco use are essential during the cessation process.

For those with psychiatric and substance use comorbidities, the psychological benefits appear to be more pronounced and even more intricately linked with daily functioning. Depression, alcohol, and other substance use disorders, adult attention deficit/hyperactivity problems, psychotic disorders, and anxiety disorders are associated with increased prevalence of smoking and lower rates of cessation (J. Hughes, 1995; J. Hughes et al., 1996; J. R. Hughes, 1993). One recent population-based study estimated that 44% of cigarettes sold are consumed by persons suffering from current mental illness (Lasser et al., 2000). Smoking rates of more than 85% are observed in alcoholics, opiate addicts, and poly-drug users (Fertig & Allen, 1995) and, because of this, smoking can be considered a marker of other substance use. It is encouraging to note, however, that abstinence from tobacco appears to enhance recovery and reduce relapse to other substance use (Prochaska, Delucchi, & Hall, 2004). Although use of evidence-based interventions improves cessation outcomes for all tobacco users across the board, those who do have comorbidity and smoke more heavily are likely to require more intensive interventions in order achieve a tobacco-free status.

Social and Cultural Factors Associated With Dependence

There are a number of important individual and population-level smoker characteristics associated with differences in smoking prevalence, motivation to quit, and some cessation outcomes. Some of these factors are important in considering how best to reach more smokers, motivate them to try to stop smoking, and encourage them to use the best interventions available to increase the likelihood of success and to reduce the high rates of relapse after quit attempts. Factors include gender, education, income, age, and racial and ethnic background.

Women differ from men in their biological responses to nicotine (Perkins, Donny, & Caggiula, 1999); however, there are mixed data regarding whether women have more difficulty quitting than men (Killen, Fortmann, Varady, & Kraemer, 2002; Wetter et al., 1999). Concerns about weight gain, stress reduction, and the need for social support may contribute to differences between men and women smokers.

Educational attainment, income level, and age are among the strongest predictors of smoking, 43.2% of those with a GED, 29.9% of those living below the

poverty level (Centers for Disease Control and Prevention, 2004), and 29.0% of those 44 years of age or younger (but only 12.0% of those older than 65) are identified as smokers (Centers for Disease Control and Prevention, 1998).

There is also wide variation among cultural and ethnic groups. For example, the aggregate smoking rate for Asians/Pacific Islanders is reported as 13.3%, while community-level surveys report that 36%–56% of Vietnamese men smoke (Centers for Disease Control and Prevention, 2004; U.S. Department of Health and Human Services, 1998). The smoking rate for American Indians and Alaska Natives is 40.8% but only 16.7% for Hispanics (Centers for Disease Control and Prevention, 2004). In addition, there appear to be some biological differences between African Americans and Chinese on one hand and Whites on the other; the former metabolize nicotine at a slower rate than Whites (Benowitz, Perez-Stable, Herrera, & Jacob, 2002; Centers for Disease Control and Prevention, 1998; Perez-Stable, Herrera, Jacob, & Benowitz, 1998).

Smoking patterns among adolescents are more variable than those among adults, with many adolescents smoking intermittently rather than daily. Factors such as parental smoking and socioeconomic stress affect smoking rates among adolescents, and the most significant predictor is peer smoking (Milton et al., 2004). Ethnic and cultural differences can be seen here, as well, with the highest rates of smoking among American Indian and Alaska Native teens, followed by White teens (Centers for Disease Control and Prevention, 2006b) (see Section IV, chapter 22, for additional information about tobacco use among adolescents).

While few generalizations can be made regarding effective treatment strategies for subgroups, whenever possible both behavioral and pharmacologic treatment should be tailored and monitored in order to best meet the needs of the individual. Smokers who are at higher risk due to certain biobehavioral or socioeconomic vulnerabilities may indeed benefit from more intensive, longer, or specialized clinical interventions. The following section provides the foundation upon which effective treatment strategies at the individual and systems level are based.

Individual-Level Interventions

The vast majority of smokers who make quit attempts do so without any form of assistance, and more than 95% relapse (National Institutes of Health, State-of-the-Science Panel, 2006). Few smokers know about treatment efficacy, few use any treatments at all, and those who do use an evidence-based program may not use or have access to the best programs to address their individual requirements. Consequently, there is a need to increase the interest and motivation of smokers to make more quit attempts and to use evidence-based interventions when quitting to improve the likelihood of cessation and to reduce the likelihood of relapse (Orleans & Slade, 1993; Orleans & Alper, 2003).

Implementation of comprehensive-care management systems can ensure that each smoker receives continuity and the appropriate level of care based on screening and triage into a level and type of treatment that meets his needs (e.g., a stepped-care approach) (Abrams et al., 2003). Treatments can range from minimal/brief intensity (e.g., over-the-counter nicotine replacement,

Internet-based interventions, and brief primary care) to moderate intensity (e.g., proactive telephone) to maximum intensity (e.g., outpatient and inpatient multisession clinical care delivered by specialists trained to treat severe tobacco addiction). This should not be interpreted as an indication that a novice quitter should have access only to minimal treatment, rather that this range of treatment should be available to best meet the needs and interest of the tobacco user at the time of her quit attempt. Even a first-time quitter should have access to intensive treatment if interested in order to reduce the recycling so common among tobacco users.

Generally, there is broad consensus that smokers who use proven tobacco dependence interventions (either behavioral or pharmacologic) have roughly double the quit rate of users who do not. Combined behavioral and pharmacologic treatments can result in as much as a three- to fourfold increase in cessation outcomes. In addition to the PHS guideline (Fiore et al., 2008) that details best-practice recommendations, there are resources available to assist practitioners in developing evidence-based treatment protocols, including a comprehensive handbook for the assessment and treatment of smokers that covers program planning, assessment, and a range of treatment options, from brief motivational intervention to intensive treatment for smokers with co-morbid psychiatric conditions (Abrams et al., 2003), as well as several other manuals (McEwen, Hajek, McRobbie, & West, 2006; Perkins, Conklin, & Levine, 2007).

Recommendations for treating special populations such as adolescents (Sussman, Sun, & Dent, 2006), pregnant smokers (Lumley, Oliver, Chamberlain, & Oakley, 2004), and those with mental health disorders (Williams & Ziedonis, 2004) also have been published. In addition, a number of tobacco treatment specialist training programs now exist (see www.attud.org). All evidence-based treatment protocols address both pharmacologic treatment (except where contraindicated) and psychosocial components that are based upon many of the behavior change theories described elsewhere in this book (see Section I). A brief summary of the application of psychosocial and pharmacologic strategies for tobacco treatment is presented here.

Psychosocial Treatment Theories and Models

Cognitive Social Learning Theory (CSLT) (Bandura, 1986) describes many of the elements of behavior change that serve as the foundation of skills training considered to be key components of tobacco treatment (Vidrine, Cofta-Woerpel, Daza, Wright, & Wetter, 2006). Together with the principle of reciprocal determinism (what we think influences what we do and vice versa), self-efficacy and outcome expectancies are common pathways leading to the initiation of behavior change (Bandura, 1986, 1995). The relationship between self-efficacy and outcome expectancies may play a critical role in the response to urges and craving related to tobacco addiction (Niaura, 2000). Other self-regulatory mechanisms, such as goal setting and corrective feedback, provide intermediary steps that can serve to facilitate the process of change (Abrams, Elder, Carleton, Lasater, & Artz, 1986; Abrams, Emmons, Niaura, Goldstein, & Sherman, 1991). Integration of skills training also includes a strong focus on relapse prevention, based on the work of Marlatt and Gordon (1985).

Motivation is important for making the initial decision to change behavior, as well as for carrying out the tasks (i.e., meeting the goals) required to complete the behavior change. For example, a smoker not only needs to make the decision about whether he is ready to quit but also needs to set goals consistent with this objective, such as increasing knowledge, changing attitudes, or setting a quit day. Motivation for smoking cessation refers to both smokers' reasons for quitting and to the strength of their desire to quit (Curry, Wagner, & Grothaus, 1990). Miller and Rollnick (Rollnick, Miller, & Butler, 2007) have developed Motivational Interviewing (MI), a method that uses client-centered techniques designed to increase motivation, primarily among substance abuse patients, who are often ambivalent about stopping or decreasing their addictive behavior(s) (see Section I, chapter 8, for additional details). While the body of evidence regarding the effectiveness of MI for tobacco treatment is limited (Burke, Arkowitz, & Menchola, 2003), a combination of MI techniques and skills training is common practice. Patient-centered counseling is a similar intervention style that has demonstrated significant results when implemented by physicians as part of programs to combat smoking, poor nutrition, and alcohol use (I. S. Ockene et al., 1999; J. Ockene et al., 1994; J. Ockene et al., 1988; J. Ockene, Wheeler, Adams, Hurley, & Hebert, 1997).

Prochaska and colleagues, using a stage of change model (Prochaska, DiClemente, Velicer, & Rossi, 1993), have suggested that tailoring interventions to motivational level may increase smoking cessation among less motivated smokers. The stages-of-change model (Prochaska & Velicer, 2004) lends itself to the development of interventions tailored to the smoker's motivational readiness to change (see Section I, Chapter 4 for additional details). It also provides a useful roadmap for smokers in that it provides milestones (precontemplation, contemplation, preparation, action, maintenance) and guidelines for processes used at every phase of the journey, from smoking initiation to various patterns of use to efforts at cessation, relapse, and recycling to the ultimate success of permanent maintenance of cessation. There is some debate over the ultimate utility of a stage model of change, especially regarding its ability to accurately assess readiness to change and its prospective predictive value (e.g., Herzog & Blagg, 2007; Sutton, 2001; West, 2005). Continuous measures to assess motivation, such as the Contemplation Ladder, have also been used as an alternative to a categorical staging algorithm (Herzog & Blagg, 2007). Despite the potential limitations, outcomes research has supported some components of this model when applied to written and electronic materials for smoking cessation (Becona & Vazquez, 2001; Etter & Perneger, 2001; Prochaska, Velicer, Fava, Rossi, & Tsoh, 2001).

Behavioral Treatment Strategies

In general, greater intensity of treatment (duration and number of contacts, more modalities of intervention) improves cessation outcomes, and delivery of treatment via in-person (1:1 or group) and proactive telephone counseling are all equally effective (Fiore et al., 2008). Although the following classification is an oversimplification, for many purposes intervention intensity can be classified into three categories: (1) minimal or brief; (2) moderate; and (3) maximal. For the clinical setting, these levels can be described in relation to the Public

Health Service–recommended 5A model: *Ask* about tobacco use, *Advise* tobacco users about the risks of smoking and benefits of quitting, *Assess* readiness to change, *Assist* with cessation, *Arrange* follow-up.

Ask and *Advise,* combined with *Referral* to more intensive treatment, are the components of a brief intervention (level 1) and should be the minimum provided to all tobacco users seen in a clinical setting (see http://smokingcessation leadership.ucsf.edu). The addition of *Assess, Assist,* and *Arrange* components is consistent with moderate (level 2) and maximal service (level 3). Strategies for addressing these components are reviewed briefly in the following sections.

Assessing Motivation to Quit

Patient-Centered Counseling (PCC) using techniques such as Motivational Interviewing (MI) techniques and an understanding of stages of change help the clinician assess the tobacco user's willingness and confidence in quitting. However, despite the appeal of the stages-of-change model, it should also be noted that some smokers suddenly decide to quit smoking in an unpredictable fashion that does not follow the rational and sequential flow of a stages of change theory (West, 2006). As many as 49% of smokers may quit without any advance planning.

Tobacco users vary widely in their motivation to quit and initial interventions are most effective when clinicians take the time to actively listen to their clients and encourage them to articulate the pros and cons of tobacco use and quitting. For the tobacco user who is not ready to quit (precontemplation), this exploration may begin to open the door for future consideration of a cessation attempt. For those considering or preparing to quit (contemplation and preparation), this discussion will begin to uncover the facilitators and barriers to change that will be faced by the client. As mentioned earlier, the level of self-efficacy or confidence expressed by the client may strongly influence readiness to change. Low confidence is often a barrier, and increasing confidence will be a proximal goal. The basic PCC skills of using open-ended questions and asking the smoker to identify his own strengths, challenges, and resources are essential at this stage of the process. For a more detailed discussion of the tools available to address motivation to quit, see Emmons et al. in Abrams et al. (2003).

Assisting With Cessation

As the tobacco user moves into preparation and action, a more thorough assessment of current and past use patterns is relevant. This assessment includes reviewing the motivation and strategies related to past quit attempts and factors that contributed to relapse. Exploration of current use patterns reveals what situations, moods, and routines trigger smoking. These triggers are often identified during a period of behavioral self-monitoring, which involves recording time, place, situation, mood, thoughts, and need level associated with each instance of tobacco use.

Skill training in specific cognitive-behavioral techniques assists the tobacco user to develop strategies to address identified triggers and anticipated problems. Practical counseling focuses on developing coping strategies such as identifying and avoiding or removing oneself from high-risk situations; replacing

tobacco use with other, incompatible behaviors; using cognitive strategies and restructuring to reshape positive beliefs about smoking, counteract irrational thinking, and reduce negative moods; and developing refusal skills and other skills necessary to effectively manage triggers. For an evidence-based guide to the behavioral tools for intensive treatment and for treating smokers with co-morbid psychiatric conditions, see Brown in Abrams et al. (2003).

Pharmacotherapy

The Public Health Service Guideline recommends that all patients who are try-ing to quit be offered pharmacotherapy, unless medically contraindicated or in the presence of other special situations such as pregnancy, lactation, adoles-cence, or smoking fewer than 10 cigarettes per day. As of this writing, there are seven first-line medications approved by the FDA for use in smoking cessation: five nicotine replacement therapy (NRT) products (transdermal patch, gum, lozenge, inhaler, and nasal spray) and two non-nicotine medications (bupro-pion SR and varenicline). In this section, we discuss the role of NRT, bupropion SR, and varenicline in promoting smoking cessation and also look at the factors that facilitate or impede adherence to each form of therapy. See Table 10.1 for specific precautions, dosing instructions, and adverse effects of each product.

Determining Appropriate Medications

When recommending medication, one must assess the level of dependence, especially in relation to the use of NRT products or combination therapy. A simple assessment can include time to first cigarette (<30 minutes indicates high dependence), which has been found to be an accurate predictor of level of nicotine dependence (Heatherton, Kozlowski, Frecker, & Fagerstrom, 1991) and number of cigarettes per day. The final determination of which type of medi-cation a particular patient should use depends upon such factors as patient preference, prior experience, cost and/or insurance coverage, patient ability to comply with usage and dosing instructions, side effects, availability, and access. For additional details on the management of pharmacotherapies for smoking cessation, see Goldstein in Abrams et al. (2003).

Nicotine Replacement Therapy (NRT)

The goal of using nicotine replacement therapy (NRT) is to gradually wean the tobacco user by replacing the nicotine from tobacco products and blunting nic-otine withdrawal symptoms. There are several barriers to more widespread use of NRT products. Many smokers are not aware of the effectiveness of NRT or believe that these products are harmful. Less than 22% of smokers trying to quit used any pharmacologic aide in 2000 (Cokkinides, Ward, Jemal, & Thun, 2005). The products are relatively expensive and are not available in small quanti-ties, resulting in a high out-of-pocket expense that is particularly burdensome for low- and middle-income smokers. Many smokers do not know that NRT is available in less expensive generic forms and is legally available at lower cost online. Some health plans do not cover the cost of NRT, although in recent years coverage has been improving.

10.1 Pharmacologic Product Guide: FDA-Approved Medications

Nicotine replacement therapy (NRT) formulations

	Gum	Lozenge	Transdermal Preparations[a]		Nasal Spray	Oral Inhaler	Bupropion SR	Varenicline
Product	Nicorette[b], Generic OTC 2 mg, 4 mg; original, mint, fruit, orange, cinnamon	Commit[b], Generic OTC 2 mg, 4 mg mint, cherry	Nicoderm CQ[b] OTC 24-hour release 7 mg, 14 mg, 21 mg	Generic Patch OTC/Rx (formerly Habitrol) 24-hour release 7 mg, 14 mg, 21 mg	Nicotrol NS[c] Rx Metered spray 0.5 mg nicotine in 50 μL aqueous nicotine solution	Nicotrol Inhaler[c] Rx 10 mg cartridge delivers 4 mg inhaled nicotine vapor	Zyban[b], Generic Rx 150 mg sustained-release tablet	Chantix[c] Rx 0.5 mg, 1 mg tablet
Precautions	■ Pregnancy category: Not applicable for OTC formulations ■ Recent (≤2 weeks) myocardial infarction ■ Serious underlying arrhythmias ■ Serious or worsening angina pectoris ■ Temporomandibular joint disease	■ Pregnancy category: Not applicable for OTC formulations ■ Recent (≤2 weeks) myocardial infarction ■ Serious underlying arrhythmias ■ Serious or worsening angina pectoris	■ Pregnancy category: D for prescription patch, not applicable for OTC formulations ■ Recent (≤2 weeks) myocardial infarction ■ Serious underlying arrhythmias ■ Serious or worsening angina pectoris		■ Pregnancy category: D ■ Recent (≤2 weeks) myocardial infarction ■ Serious underlying arrhythmias ■ Serious or worsening angina pectoris ■ Underlying chronic nasal disorders (rhinitis, nasal polyps, sinusitis)	■ Pregnancy category: D ■ Recent (≤2 weeks) myocardial infarction ■ Serious underlying arrhythmias ■ Serious or worsening angina pectoris ■ Bronchospastic disease	■ Pregnancy category: C ■ Concomitant therapy with medications or medical conditions known to lower the seizure threshold ■ Severe hepatic cirrhosis Contraindications: ■ Seizure disorder ■ Concomitant bupropion (e.g., Wellbutrin) therapy ■ Current or prior diagnosis of bulimia or anorexia nervosa	■ Pregnancy category: C ■ Severe renal impairment (dosage adjustment is necessary)

					■ Severe reactive airway disease		■ Simultaneous abrupt discontinuation of alcohol or sedatives (including benzodiazepines) ■ MAO inhibitor therapy in previous 14 days	

Dosing

≥25 cigarettes/day: 4 mg *<25 cigarettes/day:* 2 mg Week 1–6: 1 piece q 1–2 hours Week 7–9: 1 piece q 2–4 hours Week 10–12: 1 piece q 4–8 hours ■ Maximum, 24 pieces/day ■ Chew each piece slowly ■ Park between cheek and gum when peppery or tingling sensation appears (~15–30 chews) ■ Resume chewing when taste or tingle fades ■ Repeat chew/park steps until most of the nicotine is gone (taste or tingle does not return; generally 30 min)	*1st cigarette ≤30 minutes after waking:* 4 mg *1st cigarette >30 minutes after waking:* 2 mg Week 1–6: 1 lozenge q 1–2 hours Week 7–9: 1 lozenge q 2–4 hours Week 10–12: 1 lozenge q 4–8 hours ■ Maximum, 20 lozenges/day ■ Allow to dissolve slowly (20–30 minutes) ■ Nicotine release may cause a warm, tingling sensation ■ Do not chew or swallow	*>10 cigarettes/day:* 21 mg/day x 6 weeks 14 mg/day x 2 weeks 7 mg/day x 2 weeks *≤10 cigarettes/day:* 14 mg/day x 6 weeks 7 mg/day x 2 weeks ■ May wear patch for 16 hours if patient experiences sleep disturbances (remove at bedtime)	*>10 cigarettes/day:* 21 mg/day x 4 weeks 14 mg/day x 2 weeks 7 mg/day x 2 weeks *≤10 cigarettes/day:* 14 mg/day x 6 weeks 7 mg/day x 2 weeks ■ May wear patch for 16 hours if patient experiences sleep disturbances (remove at bedtime)	1–2 doses/hour (8–40 doses/day) One dose = 2 sprays (one in each nostril); each spray delivers 0.5 mg of nicotine to the nasal mucosa ■ Maximum 5 doses/hour 40 doses/day ■ For best results, initially use at least 8 doses/day ■ Patients should not sniff, swallow, or inhale through the nose as the spray is being administered ■ Duration: 3–6 months	6–16 cartridges/day Individualize dosing; initially use 1 cartridge q 1–2 hours ■ Best effects with continuous puffing for 20 minutes ■ Nicotine in cartridge is depleted after 20 minutes of active puffing ■ Patient should inhale into back of throat or puff in short breaths ■ Do NOT inhale into the lungs (like a cigarette) but "puff" as if lighting a pipe	150 mg po q AM x 3 days, then increase to 150 mg po bid ■ Do not exceed 300 mg/day ■ Treatment should be initiated while patient is still smoking ■ Set quit date 1–2 weeks after initiation of therapy ■ Allow at least 8 hours between doses ■ Avoid bedtime dosing to minimize insomnia ■ Dose tapering is not necessary ■ Can be used safely with NRT ■ Duration: 7–12 weeks, with maintenance up to 6 months in selected patients	Days 1–3: 0.5 mg po q AM Days 4–7: 0.5 mg po bid Weeks 2–12: 1 mg po bid ■ Patients should begin therapy 1 week prior to quit date ■ Take dose after eating with a full glass of water ■ Dose tapering is not necessary ■ Nausea and insomnia are side effects that are usually temporary ■ Duration: 12 weeks; an additional 12 week course may be used in selected patients

10.1 Pharmacologic Product Guide: FDA-Approved Medications (*Continued*)

Nicotine replacement therapy (NRT) formulations

	Gum	Lozenge	Transdermal Preparations[a]		Nasal Spray	Oral Inhaler	Bupropion SR	Varenicline
Product	Nicorette[b], Generic OTC 2 mg, 4 mg; original, mint, fruit, orange, cinnamon	Commit[b], Generic OTC 2 mg, 4 mg mint, cherry	Nicoderm CQ[b] OTC 24-hour release 7 mg, 14 mg, 21 mg	Generic Patch OTC/ Rx (formerly Habitrol) 24-hour release 7 mg, 14 mg, 21 mg	Nicotrol NS[c] Rx Metered spray 0.5 mg nicotine in 50 µL aqueous nicotine solution	Nicotrol Inhaler[c] Rx 10 mg cartridge delivers 4 mg inhaled nicotine vapor	Zyban[b], Generic Rx 150 mg sustained-release tablet	Chantix[c] Rx 0.5 mg, 1 mg tablet
Dosing	■ Park in different areas of mouth ■ No food or beverages 15 min before or during use ■ Duration: up to 12 weeks	■ Occasionally rotate to different areas of the mouth ■ No food or beverages 15 minutes before or during use ■ Duration: up to 12 weeks	■ Duration: 8–10 weeks	■ Duration: 8 weeks		■ Open cartridge retains potency for 24 hours ■ Duration: up to 6 months		
Adverse Effects	■ Mouth/jaw soreness ■ Hiccups ■ Dyspepsia ■ Hypersalivation ■ Effects associated with incorrect chewing technique: ■ Lightheadedness ■ Nausea/vomiting ■ Throat and mouth irritation	■ Nausea ■ Hiccups ■ Cough ■ Heartburn ■ Headache ■ Flatulence ■ Insomnia	■ Local skin reactions (erythema, pruritus, burning) ■ Headache ■ Sleep disturbances (insomnia) or abnormal/vivid dreams (associated with nocturnal nicotine absorption)		■ Nasal and/or throat irritation (hot, peppery, or burning sensation) ■ Rhinitis ■ Tearing ■ Sneezing ■ Cough ■ Headache	■ Mouth and/or throat irritation ■ Unpleasant taste ■ Cough ■ Rhinitis ■ Dyspepsia ■ Hiccups ■ Headache	■ Insomnia ■ Dry mouth ■ Nervousness/difficulty concentrating ■ Rash ■ Constipation ■ Seizures (risk is 1/1,000 [0.1%])	■ Nausea ■ Sleep disturbances (insomnia, abnormal dreams) ■ Constipation ■ Flatulence ■ Vomiting

Advantages	■ Gum use might satisfy oral cravings ■ Gum use might delay weight gain ■ Patients can titrate therapy to manage withdrawal symptoms	■ Lozenge use might satisfy oral cravings ■ Lozenge use might delay weight gain ■ Patients can titrate therapy to manage withdrawal symptoms	■ Provides consistent nicotine levels over 24 hours ■ Easy to use and conceal ■ Once-a-day dosing associated with fewer compliance problems	■ Patients can titrate therapy to more rapidly manage withdrawal symptoms	■ Patients can titrate therapy to manage withdrawal symptoms ■ Mimics hand-to-mouth ritual of smoking	■ Easy to use; oral formulation might be associated with fewer compliance problems ■ Can be used with NRT ■ Might be beneficial in patients with depression	■ Easy to use; oral formulation might be associated with fewer compliance problems ■ Offers a new mechanism of action for patients who have failed other agents
Disadvantages	■ Gum chewing may not be socially acceptable ■ Gum is difficult to use with dentures ■ Patients must use proper chewing technique to minimize adverse effects	■ Gastrointestinal side effects (nausea, hiccups, heartburn) might be bothersome	■ Patients cannot titrate the dose ■ Allergic reactions to adhesive might occur ■ Patients with dermatologic conditions should not use the patch	■ Nasal/throat irritation may be bothersome ■ Dependence can result ■ Patients must wait 5 minutes before driving or operating heavy machinery ■ Patients with chronic nasal disorders or severe reactive airway disease should not use the spray	■ Initial throat or mouth irritation can be bothersome ■ Cartridges should not be stored in very warm conditions or used in very cold conditions ■ Patients with underlying bronchospastic disease must use the inhaler with caution	■ Seizure risk is increased ■ Several contraindications and precautions preclude use (see Precautions, above)	■ May induce nausea in up to one third of patients ■ Post-marketing surveillance data not yet available

10.1 Pharmacologic Product Guide: FDA-Approved Medications (*Continued*)

Nicotine replacement therapy (NRT) formulations

	Gum	Lozenge	Transdermal Preparations[a]		Nasal Spray	Oral Inhaler	Bupropion SR	Varenicline
Product	Nicorette[b], Generic OTC 2 mg, 4 mg; original, mint, fruit, orange, cinnamon	Commit[b], Generic OTC 2 mg, 4 mg mint, cherry	Nicoderm CQ[b] OTC 24-hour release 7 mg, 14 mg, 21 mg	Generic Patch OTC/Rx (formerly Habitrol) 24-hour release 7 mg, 14 mg, 21 mg	Nicotrol NS[c] Rx Metered spray 0.5 mg nicotine in 50 μL aqueous nicotine solution	Nicotrol Inhaler[c] Rx 10 mg cartridge delivers 4 mg inhaled nicotine vapor	Zyban[b], Generic Rx 150 mg sustained-release tablet	Chantix[c] Rx 0.5 mg, 1 mg tablet
Web site	www.nicorette.com	www.commitlozenge.com	www.nicodermcq.com	www.habitrol.com	www.nicotrol.com	www.nicotrol.com	- - - -	www.chantix.com
Cost/day[d]	2 mg: $3.28–$6.57 (9 pieces) 4 mg: $4.31–$6.57 (9 pieces)	2 mg: $3.66–$5.26 (9 pieces) 4 mg: $3.66–$5.26 (9 pieces)	$2.24–$3.89 (1 patch)	$1.90–$2.94 (1 patch)	$3.67 (8 doses)	$5.29 (6 cartridges)	$3.62–$6.04 (2 tablets)	$4.00–$4.22 (2 tablets)

Note. From Rx for Change: Clinician-Assisted Tobacco Cessation program. The Regents of the University of California, University of Southern California, and Western University of Health Sciences. Copyright © 1999–2008 by Rx for Change. Reprinted with permission.

[a]Transdermal patch formulations previously marketed, but no longer available: Nicotrol 5 mg, 10 mg, 15 mg delivered over 16 hours (Pfizer) and generic patch (formerly Prostep) 11 mg and 22 mg delivered over 24 hours.

[b]Marketed by GlaxoSmithKline.

[c]Marketed by Pfizer.

[d]Average wholesale price from 2007 Drug Topics Redbook. Montvale, NJ: Medical Economics Company, Inc., June 2007.

A factor that may reduce the effectiveness of NRT is the fact that the recommended dosages of NRT deliver only about half the amount of nicotine a smoker would typically receive by smoking a pack of cigarettes under typical conditions. The rate at which nicotine is delivered also varies by NRT product. For instance, the patch delivers nicotine continuously over 24 hours, whereas the nicotine nasal spray raises nicotine levels the most rapidly of all products and may be more effective in reducing acute cravings in highly dependent smokers (Pbert, Luckmann, & Ockene, 2004). Another factor affecting the effectiveness of NRT is compliance. The patch has been found to have the highest compliance rates (Henningfield, Fant, Buchhalter, & Stitzer, 2005) and can be combined with acute therapies (gum, lozenge, inhaler, spray) on an ad lib basis to manage breakthrough cravings in heavy smokers. The gum, lozenge, inhaler, and spray require multiple dosing regimens and may cause irritating side effects that may lessen compliance and require careful explanation about proper usage.

While the evidence for using NRT products in combination is mixed, the use of gum and patch together seems to do a better job of alleviating withdrawal symptoms than use of either one alone (Institute of Medicine, 2007). In practice, NRT products are frequently used in combination with no evidence of nicotine toxicity or other adverse events. In addition, NRT (all forms) and bupropion can be used together, and this combination has been found to be effective, at least in the short term (Jorenby et al., 1999).

There are few contraindications to the use of NRT (see Table 10.1). Smoking while on NRT is discouraged, but there is no evidence that persons who smoke while on the patch are at greater risk of any serious adverse event than those who do not. In fact, the Cut Down then Stop protocol approved by the British National Health Service in 2005 recommends that smokers initiate nicotine gum or inhaler use while still smoking, then gradually reduce intake to 50% of baseline at 6 weeks, aiming for cessation by 6 months and discontinuation of NRT within 12 months. Other studies (Schuurmans, Diacon, van Biljon, & Bolliger, 2004) report that smokers who used the nicotine patch for 2 weeks before quitting had higher sustained quit rates at 6 months than smokers who were not pretreated with NRT.

The *transdermal nicotine patch (TNP)* delivers nicotine at a relatively steady rate and has few barriers to adherence. A tobacco user simply puts a new patch on a different nonhairy part of the upper body every day. Generic brands are less expensive and generally work as well as name brands. The TNP does not appear to prevent postcessation weight gain, which may be of concern to many smokers. Combination therapy (patch plus gum) may be indicated in this case, as use of nicotine gum has been found to delay postcessation weight gain (Allen, Hatsukami, Brintnell, & Bade, 2005).

Nicotine gum (NG) has been shown to be effective in helping smokers quit, but there are several barriers in adhering to nicotine gum use. First, smokers may not chew enough gum for it to be effective in countering cravings. Chewing 12–15 pieces per day on a fixed schedule is recommended by the manufacturer. Second, smokers may experience uncomfortable side effects, which may cause noncompliance, although some side effects may be alleviated by using the proper "chew and park" technique. The *nicotine lozenge* is easier to use than the gum. Beginning dose is determined by time to first cigarette. Using this index, most smokers in the United States require the 4 mg lozenge (Henningfield

et al., 2005). The lozenge should not be chewed but allowed to dissolve slowly in the mouth.

The *nicotine inhaler* consists of a mouthpiece and a cartridge that contains 10 ml of nicotine. The name may be misleading since it is "puffed," not inhaled, in order to draw nicotine into the mouth through the mouthpiece. The nicotine is then absorbed through the oral mucosa, much like the nicotine gum. The *nicotine nasal spray* delivers nicotine the most rapidly of all NRTs and therefore has a greater potential for abuse and dependence. The multiple side effects, including nasal and/or throat irritation, are extremely unpleasant and may serve as a disincentive to use.

Non-Nicotine Medications

Sustained-release bupropion (Trade names Zyban, Wellbutrin, Buproban, and Budeprion) is an antidepressant demonstrated to be effective in helping smokers manage withdrawal and cravings when quitting smoking. The major contraindication for bupropion is a history of seizures or being at risk for seizures. Bupropion SR potentially postpones weight gain and reduces relapse rates, making it a good alternative for smokers with multiple failed quit attempts or those who fear weight gain (Hays et al., 2001). It has been approved for use up to 12 months following smoking cessation. Bupropion is begun 7–10 days before quit date, which appeals to many smokers.

Varenicline (Chantix), the most recently approved FDA medication, addresses nicotine dependence by stimulating dopamine release while simultaneously blocking nicotine receptors. This serves to blunt withdrawal, reduce cravings, and reduce the rewarding effects of nicotine (Foulds, Steinberg, Williams, & Ziedonis, 2006). Varenicline is an α4β2 nicotinic receptor partial agonist that is believed to aid smoking cessation by moderately increasing the release of dopamine. Varenicline has been found to be safe, effective, and well tolerated in most people (Niaura, Jones, & Kirkpatrick, 2006). However, the FDA issued a Public Health Advisory in February 2008 urging careful monitoring for possible adverse psychiatric effects (i.e. agitation, depression, suicidal thoughts and attempted/completed suicide). As with bupropion, use is started approximately 1 week before quit date to achieve steady-state blood levels. If a person has successfully quit smoking after 12 weeks, long-term abstinence can be improved by continuing varenicline for an additional 12 weeks. Because varenicline works at the nicotinic receptor sites, adjuvant use of NRT is not recommended. Varenicline has not yet been studied in populations with medical or psychiatric comorbidities, so recommendations cannot be made at this time regarding its use in higher-risk populations.

Summary

In general, all seven first-line FDA-approved smoking cessation medications produce similar efficacy rates. The one exception to this may be varenicline, which has been found to have higher quit rates in three randomized control trials (Keating & Siddiqui, 2006). The effectiveness of NRT has been demonstrated even when it is used in the absence of counseling (West & Zhou, 2007), and it

is likely that bupropion and varenicline have similar effects. However, the combination of counseling plus pharmacotherapy has been found to be superior in helping tobacco users quit and should be utilized if available.

Assisting Special Populations

Some evidence supports the concept that tailoring of interventions to individual smoker characteristics or targeting of intervention to group characteristics (e.g., race or ethnic background, gender, age) improves outcomes. Using proven behavioral and pharmacologic methods may be especially important for tobacco users with comorbidity (e.g., psychiatric problems, alcohol, substance abuse). Persons with a history of mental health or substance use disorders may need higher levels of medications for longer periods of time and require more monitoring (Hughes, 2008). Persons suffering from depression or a history of depression may do well with bupropion because of its antidepressant qualities.

Behavioral strategies should be considered the preferred treatment approach for pregnant women. Use of pharmacotherapy in pregnant women is usually not recommended unless the woman and her physician agree that the risks of continuing to smoke outweigh the possible risks of using pharmacotherapy (Fiore et al., 2008). Note that all the first-line prescription medications are FDA-rated C or D, so caution is warranted.

Additionally, while pharmacotherapy has been found to be safe in adolescents, studies to date have not found it to be particularly effective (Grimshaw & Stanton, 2006).

Relapse Prevention

Interventions for smoking typically consist of discreet periods of treatment leading to abstinence or relapse. Relapse is all too common: between 65% and 95% of quit attempts end in relapse (Pierce & Gilpin, 2003), with the greatest proportion of relapse (44%) occurring within 14 days (Garvey, Bliss, Hitchcock, Heinold, & Rosner, 1992) of a serious quit attempt.

Although repeated quit attempts are common, overall results of studies encouraging repeat quit attempts (recycling) have been discouraging. Lando and colleagues (1996) reported that a telephone support intervention significantly increased recycling but not long-term abstinence. Tonneson and colleagues (1996) found that introducing nicotine replacement after 1 year did not appreciably increase abstinence (6% for nasal spray and 0% for patch). Relapse prevention and recycling represent a huge public health opportunity, but the research base to inform effective and efficient recycling/relapse prevention intervention is sparse (Brandon, Herzog, & Webb, 2003).

Relapse should be regarded as part of the learning experience along the pathway to cessation. Just as with learning to ride a bicycle for the first time, persistent effort, practice, and openness to the correction of past mistakes will lead to eventual mastery and success (Bandura, 1997). If one falls off the bicycle, one has to get back on and try again to become proficient at negotiating the curves and the bumps in the road. Thus, the idea of recycling smokers who have slipped back into smoking should be included in the treatment planning process. The Internet may be an especially useful new modality of intervention

to reduce relapse and improve recycling because those who are engaged in the quitting process or have recently quit can have 24/7/365-day-a-year access to online resources. Such resources include social support and self-help coping-skills programs available through interactive computer expert systems. In one preliminary study, a very strong correlation was reported between use of chat rooms for support and successful maintenance of cessation at 3-month follow-up (Cobb, Graham, Bock, Papandonatos, & Abrams, 2005).

Systems-Level Interventions

Smoking prevalence is lower than the national average (20.8%) in those states with strong, visible, comprehensive, and sustained antismoking programs (e.g., 14.9% in California and 17.8% in Massachusetts) (Institute of Medicine, 2007). Access to effective tobacco treatment resources is a key component of such comprehensive programs. The full impact of cessation interventions on the intended target population is a product of the proportion of the population reached and the efficacy and fidelity of implementation of the intervention delivered (Impact = Reach x Efficacy) (see Abrams et al., 2003; Abrams et al., 1993, for details). Thus, in addition to trying to motivate more smokers to make quit attempts, there is an enormous opportunity to further increase cessation outcomes by implementing systems-level interventions that reach more smokers and increase access to treatment. Diverse strategies that include clinical, medical, and community interventions can contribute significantly to improving the health of the public (Ockene et al., 2007).

Interventions by health care providers are among the factors related to smokers' interest in receiving counseling to help with a quit attempt (Weber et al., 2007). Despite this, the national rate at which physicians provide advice and assistance to their patients who smoke has remained low (Thorndike, Regan, & Rigotti, 2007). A common rationale for this includes physicians' lack of time and resources. However, studies have demonstrated the feasibility of developing linkages between clinical settings and community-level services (Bentz et al., 2006; Perry, Keller, Fraser, & Fiore, 2005). An example of such a program is QuitWorks, currently operating in Massachusetts through collaboration between the Massachusetts Tobacco Control Program and major health plans in the commonwealth. QuitWorks coordinates clinical and community-based efforts by linking patients, clinicians, and a proactive telephone counseling quitline through the use of faxed referrals forms (Centers for Disease Control and Prevention, 2006a). Linking quitline services with free NRT also has proved to be an effective method of reaching large numbers of smokers. Frieden and colleagues (2005) reported on the effectiveness of a large-scale distribution of free NRT patches in New York City. Using a conservative intent-to-treat (ITT) analysis (all nonrespondents were considered to be smoking at 6-month follow-up), the cessation rate was 20%. Those who received counseling were also more likely to quit than those who did not (38% vs. 27%). A study of the Minnesota QUITPLAN Helpline before and after the availability of free NRT found that participation in counseling, use of medications, and abstinence rates all increased (An et al., 2006). Easy access to free NRT cessation medication in diverse populations can help large numbers of smokers to quit.

The Internet can reach millions of smokers cost-effectively. Many cessation Web sites exist, but few have been evaluated, and of more than 300 Web sites, fewer than 10 met criteria for having content outlined as effective in the PHS guideline (Bock et al., 2004). In a European study, 3,501 purchasers of a nicotine patch who proactively logged on to use a free Internet program and then consented to participate in a research study (76%) were randomly assigned to a tailored or an untailored program (Strecher, Shiffman, & West, 2005). At 3-month follow-up, using ITT analysis of continuous abstinence for 10 weeks, the tailored condition (22.8%) outperformed the untailored condition (18.1%). A preliminary large-scale evaluation of a broadly disseminated smoking cessation Web site reported cessation at 3 months in the range of 7% (ITT) to 30% (responders only) (Cobb et al., 2005). It is noteworthy from a comprehensive systems perspective that approximately 30% of those surveyed indicated they had already quit smoking at registration and were using the Web site for relapse prevention. Collectively, these studies are a promising start in evaluating Internet-based smoking cessation programs.

Interventions that are translated from clinical to community settings to proactively reach more smokers in a cost-effective manner vary widely in outcome effectiveness. This is because of variability in the factors that are present in real-world settings; for example, target groups have more heterogeneous characteristics, and there are differences among programs, providers, delivery systems, and other contextual or setting factors. Channels of intervention delivery must also be factored in, such as whether the setting is a health care organization or a medical setting, from hospitals to private offices, a worksite, a school, a telephone quit lines, the Internet, or other print and electronic media.

Systems-level models are needed to address the diversity of channels and of populations of users. Models such as stepped care, the tailoring of interventions to motivational readiness to quit (e.g., stages-of-change model, Motivational Interviewing), and the targeting of interventions to channels of delivery (e.g., primary-care offices, managed-care organizations, worksites, schools, the Internet, telephone quit lines) or to population groups (e.g., younger or older smokers, underserved or uninsured groups, women and minorities) will need to be evaluated empirically to demonstrate their utility and cost-effectiveness.

The role of private payers (i.e., health plans, employers) must be considered in this discussion as well. State and local departments of health cannot be expected to bear the burden of providing accessible treatment services to all comers. Medicare and, in some states, Medicaid programs are setting the example in covering pharmacologic and counseling services for its beneficiaries, and private insurers are slowly increasing their coverage, as well (Centers for Disease Control and Prevention: Morbidity and Mortality Weekly Report, 2006; Curry & Orleans, 2005; Curry, Orleans, Keller, & Fiore, 2006).

Conclusion

The fact that there are still more than 40 million smokers in the United States alone in the early part of the 21st century points to the urgent need for a redoubling of efforts to adopt a nationwide comprehensive approach to addressing tobacco use. The most effective and efficient evidence-based interventions and

policies must be adopted and incorporated into a comprehensive plan of policy and practice. The political will is needed to adopt this comprehensive approach, as recommended by the prestigious National Academy of Sciences, because such a policy ought to be a part of the very fabric of quality public health and health care delivery systems in the United States (Institute of Medicine, 2007). While smoke-free laws and ordinances are increasing, media campaigns have decreased. The most dramatic recent declines in smoking rates have occurred in states where residents have easy access to medications and counseling (Centers for Disease Control and Prevention, 2007). Institutionalizing tobacco treatment within the health care system is one way to ensure that all smokers are aware of and have the ability make use of treatment services available. Programs such as QuitWorks offer a step in the right direction by providing treatment resources to the health care system and their patients.

The Institute of Medicine includes this compelling summary in the appendix entitled *Comprehensive Smoking Cessation Policy* (see D. Abrams in Institute of Medicine [2007]):

> *For a smoker it is a long and arduous journey from starting to smoke to enjoying smoking in one's carefree youth to wanting to stop to actually stopping for good. For much of that journey the smoker is not motivated to quit and does not make any quit attempts at all. Somewhere along the way the smoker may change, either suddenly or gradually over time. Smokers can move from being unmotivated and not making any quit attempts to wanting to quit (over 70% say they want to quit) and then to making serious quit attempts (about 45% try seriously to quit each year). If at first a smoker is not successful at quitting (over 90% are not), the arduous journey continues from cycles of trying to quit but relapsing to trying again. Some smokers may give up trying to quit and withdraw out of fear of failure, shame or embarrassment. Sometimes the smoker may use unproven treatments or will power to quit (over 75% do that) and perhaps the smoker may use an effective product or service. Finally the journey ends when the smoker either quits for good or suffers and dies from a smoking related cause (about a third to a half of lifetime smokers will die of a smoking related disease). A comprehensive approach must also provide aggressive, direct to consumer marketing and education campaigns to improve their health literacy about the dangers of smoking and the best tools for quitting (Cokkinides et al., 2005). An approach that covers the entire smoker's journey and provides interventions tailored to the smoker's needs. This can be achieved through cessation policies that support a comprehensive care management network with aligned financial incentives at federal state and local levels across both the health care industry and the public health system. (p. 373)*

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Promoting Dietary Change

11

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Bovbjerg

In the decade since the publication of the second edition of the *Handbook of Health Behavior Change*, it has become increasingly apparent that obesity is the single most important diet-related condition affecting the health of individuals in first world or industrialized countries. In the United States in 2003–2004, 17% of children and adolescents were overweight, and an astonishing 32% of adults were obese (Ogden et al., 2006). Obesity is a risk factor for many serious medical conditions, including cardiovascular disease, diabetes, certain types of cancer, gallbladder disease, and osteoarthritis (Field et al., 2002). Long-term studies of dietary interventions for weight loss show that modest weight loss can be achieved and is associated with reduced risk of diabetes and cardiovascular disease in at-risk individuals (Diabetes Prevention Program Research Group,

2002; Douketis, Macie, Thabane, & Williamson, 2005). For this reason, much of the following discussion of strategies for dietary change draws examples from the literature on weight loss.

Dietary interventions generally target the individual, with the intervention delivered in a variety of formats, including one-on-one, face-to-face delivery, delivery in groups or classes, and delivery through other formats, such as the Internet. Herein we refer to all such interventions as individual-level approaches to dietary change. Interventions may also target change at the level of the community, in which community may mean entire towns, schools, churches, or worksites. In this chapter, these interventions and perspectives are referred to as public health approaches to dietary change. While a review of all individual and public health intervention targets is beyond the scope of this chapter, we will attempt to highlight some of the more promising approaches to promoting dietary change in individuals and communities.

Individual-Level Approaches to Dietary Change

Clinical lore and research experience have repeatedly demonstrated that it is difficult for people to follow dietary recommendations. The problem of dietary adherence grows out of a wide range of biopsychosocial issues, including intra- and interpersonal factors, economic constraints (food insecurity), cultural preference, social influences, environmental conditions, and myriad psychological factors. Health delivery systems also impact patients' ability to follow health providers' dietary recommendations.

Barriers to Making Dietary Changes

All modifications in eating patterns for the purpose of losing weight require one or both of the following: decreasing the quantity of food consumed (e.g., smaller portions, fewer servings) and making less-preferred food choices on the basis of caloric density (e.g., choosing vegetables instead of cookies). A combination of these approaches reduces total daily caloric intake. Increased energy expenditure, often in the form of planned physical activity, is also helpful in facilitating weight loss. The problems associated with exercise adherence are addressed in chapter 12.

Barriers to dietary adherence may be a result of environmental factors, internal states, or social factors. A common environmental barrier is limited food selection. For example, grocery stores in low-income areas often have a more restricted range of products from which to choose than stores in more affluent areas, and this is reflected in poorer-quality diets among shoppers in those areas (Laraia, Siega-Riz, Kaufman, & Jones, 2004; Rose & Richards, 2004). The most common internal barrier to good dietary adherence is hunger, and the interplay between diet composition and satiety is complex (Hill, 2007). Emotional factors often contribute to poor adherence, with patients reporting that they ignore dietary guidelines in the face of emotional extremes. Social factors, such as holidays or other cultural influences, also pose barriers to people attempting to exert control over their intake (McCann, 2006).

Enhancing Dietary Adherence

Most approaches to individual-level dietary change incorporate several key components to achieve initial dietary change and long-term maintenance. We previously identified several common components used in dietary intervention programs to promote dietary change and maximize long-term maintenance (McCann & Bovbjerg, 1998). These include nutrition education, use of Motivational Interviewing and readiness to change, careful assessment of "baseline" diet practices, goal setting, self-monitoring, training in stimulus control, problem-solving training, enhancing social support for changes, enhancing self-efficacy through cognitive control strategies, relapse prevention training, and ongoing program contact to facilitate maintenance of changes. These treatment elements are grounded in principles of behavioral self-management (Kanfer, 1977; McFall, 1977; Watson & Tharp, 1997), social cognitive theory (Bandura, 1977), motivational interviewing (Miller & Rollnick, 2002), and the Transtheoretical Model of Change (Prochaska & Velicer, 1997). Several clinical trials of diet or lifestyle (diet plus exercise) interventions have used these treatment components to maximize weight loss (Diabetes Prevention Program Research Group, 2002; Funk et al., 2006; Lin et al., 2007; Pi-Sunyer et al., 2007) and to achieve reductions in sodium and alcohol intake (Funk et al., 2006; Lin et al., 2007). Specific examples of these components and their practical application have been described elsewhere (McCann, 2006). However, we will provide a brief update on the use of these components over the past decade.

Nutrition Education

Adequate nutrition information is an important ingredient for success in dietary interventions. Greater nutrition knowledge is associated with healthier diets (Wardle, Parmenter, & Waller, 2000). In a study of low-income mothers of young children, women in a weight-loss program who lost at least 2.27 kg over the course of 8 weeks had higher scores on a 25-item nutrition knowledge test than those who did not lose as much weight (Klohe-Lehman et al., 2006).

Motivational Interviewing and Readiness to Change

Motivational Interviewing (Miller & Rollnick, 2002) has emerged as an important component in both initiating and maintaining individuals' involvement in dietary interventions. Individuals vary in their willingness to accept recommendations to make dietary changes (McCann et al., 1996). Several studies have used Motivational Interviewing both at the initiation stage of dietary changes and at various points during treatment in order to enhance participants' involvement in lifestyle interventions (Carels et al., 2007; Diabetes Prevention Program Research Group, 2002; Funk et al., 2006).

Problem-Solving Training

Another important treatment component for improving the efficacy of individual-level interventions is training in problem solving. Problem-solving therapy

addresses patients' approaches to dealing with obstacles through the use of cognitive and behavioral techniques (D'Zurilla, 1999). Patients are trained to identify problems, generate alterative solutions to solving them, decide which solution to try, make plans for implementing the solution, and evaluate the outcome (Nezu, Nezu, & Perri, 2006). Problem-solving therapy has been shown to facilitate greater weight loss as a component of a stepped-care approach to treatment (Carels et al., 2005) and to be more effective than relapse prevention training during the maintenance phase of weight-loss treatment (Perri et al., 2001).

Goal Setting

Goal setting remains an important component of interventions designed to promote dietary adherence. Goal setting can refer to the setting of specific weight-loss goals. In the Diabetes Prevention Program and the Look AHEAD trial, the weight-loss goal was expressed in terms of a percentage of weight loss (7%) from each participant's starting weight (Diabetes Prevention Program Research Group, 2002; Pi-Sunyer et al., 2007). In the PREMIER study of blood pressure control, the weight-loss goal was expressed in terms of absolute pounds (15) for participants who entered the study with a body mass index of 25 kg/m^2 or greater (Lin et al., 2007).

Importantly, goal setting is not limited to establishing clear expectations for outcome goals. Participants in the Diabetes Prevention Program and the Look AHEAD trial were also provided with specific goals for daily intake of grams of fat or total calories, as well as goals for weekly amounts of exercise expressed in minutes per week (Diabetes Prevention Program Research Group, 2002; Pi-Sunyer et al., 2007). Likewise, participants in PREMIER were given specific goals regarding exercise minutes per week, daily sodium intake, and daily alcohol intake (Funk et al., 2006).

Self-Monitoring

Frequent self-monitoring of dietary intake has emerged as perhaps the single most important ingredient to successful dietary change efforts. Survey studies of people who have successfully lost weight find that regular self-monitoring of weight and food intake are common and appear to be critical to successful weight loss (Kruger et al., 2006; Wing & Phelan, 2005). Several studies have shown that weight gains typically associated with significant holidays can be avoided through careful self-monitoring during these periods (Baker & Kirschenbaum, 1998; Boutelle, Kirschenbaum, Baker, & Mitchell, 1999).

Ongoing Program Contact

Ongoing program contact is now recognized as a key component of maintenance of initial dietary changes—sometimes referred to as the continuing care model (Latner et al., 2000). Long-term maintenance of changes in obesity treatment appears to be best met by continued program contact (Perri & Corsica, 2002).

Social Support

Just as inadequate social support can be seen as a barrier to making and maintaining dietary changes, interventions that enhance social support among program participants or otherwise promote social support may have an advantage over those that do not (Latner et al., 2006). For example, participants encouraged to bring weight-loss partners with them to programs may have an overall advantage (Wing & Jeffery, 1999).

Stepped-Care Approaches to Dietary Change

Stepped-care approaches to the delivery of these interventions have become increasingly common (Carels et al., 2005; Carels et al., 2007). In the traditional stepped-care approach, all individuals receive a basic intervention considered to be of sufficient intensity to achieve reasonable gains in the majority of its recipients. Efforts are intensified for individuals who have difficulty making reasonable progress. These approaches are generally more successful than "one size fits all" programs where all participants receive the same treatment "package." The "toolbox" approaches employed in the Diabetes Prevention Program and the Look AHEAD study are stepped-care approaches in that participants who were not achieving weight-loss goals were offered additional tools, resources, and contacts with program staff in order to optimize their chances for success (Diabetes Prevention Program Research Group, 2002; Pi-Sunyer et al., 2007).

In summary, virtually all programs designed to produce dietary changes in individuals include nutrition education. The use of various self-monitoring and goal-setting tools is generally introduced early on. This is often sufficient for a significant number of individuals to make changes in their diet that produce sufficient significant improvements in health.

Additional assessment is often introduced if individuals are struggling to make significant changes in diet without success. This may include evaluation by a dietitian or by someone trained in more advanced behavioral issues, such as a psychologist. Intensification of efforts may include more frequent meetings between the patient and the health care provider, meetings with another specialist, use of new self-monitoring tools, or use of motivational enhancement strategies. Techniques and topics including stimulus control strategies, problem-solving training, cognitive strategies, and relapse prevention may be introduced.

Maintenance of initial dietary changes generally requires ongoing program contact. Longer treatment programs are associated with better maintenance of new dietary behaviors. Extended contact can be achieved via telephone contact, mail, or e-mail. In-person contact may be face-to-face or in groups, even in some instances having patients form their own support networks for ongoing monitoring of dietary changes.

Public Health Approaches to Dietary Change

The late psychologist George W. Albee often noted, "No mass disorder afflicting humankind is ever brought under control or eliminated by attempts at

treating the individual." While the "mass disorder" Albee was referring to is mental illness, his comment is relevant to the worldwide epidemic of diet- and activity-related disorders. Individual-level approaches to diet change will not by themselves stem the tide of overweight and obesity (Mann et al., 2007) and face an uphill struggle when attempted in "obesogenic" environments and societies (Caballero, 2007). Individual-level approaches to dietary change—very useful in clinical settings—have not focused on environmental factors promoting dietary choices, except to promote changes in the immediate environment of individuals (e.g., limiting household food options, promoting social support). Increasingly, there is recognition that a wide range of genetic, personal, interpersonal, and environmental factors influence dietary intake and that interventions at all levels may be needed to effectively change population-level health outcomes (Sallis & Owen, 2002). Clearly, approaches that take into account the traditional triad of person, behavior, and environment provide the greatest promise of success (Caballero, 2007; Glanz, 2002).

Community-Level Dietary Change

Community-level approaches to dietary change have incorporated elements of mass marketing and mass communication to spread the intended health-promoting messages. Some critical elements of mass-marketing approaches to health promotion have been enumerated. It is essential to obtain the means to disseminate the message—characterized as "pay for exposure" (buy airtime and print space), "beg for exposure" (ask for donations), and "earn exposure" (make the cause newsworthy in its own right) (Hornik & Kelly, 2007). Community members or target populations must be exposed to the relevant messages. In several well-known community-level health-promotion efforts, exposure to study-specific health-promotion measures was nearly as great in control as intervention communities (Hornik & Kelly, 2007). Diet interventions also face a challenge unlike other health-promotion campaigns (e.g. tobacco use), in that there is no simple, single message that can be communicated that implies an obvious course of action (e.g., don't smoke). Furthermore, it is not always clear through which pathway(s) mass-communication approaches may work to effect dietary behavior change: direct persuasion, changing social and community norms, or modifying institutional or policymaker behavior. No matter how well funded, mass-communication campaigns to promote dietary change also have the potential to be drowned out in an advertising and media environment that promotes behavior opposite to that encouraged by the campaign. Finally, like any other intervention, the message must be tailored to the target audience. Dietary-change messages may differ depending on whether the need is for information or motivation and on whether the message is simple or complex; decisions regarding whether to use a celebrity spokesperson or dietitian, whether to present information undermining competing messages, and whether to use fear of disease as a motivator can be important in presenting appealing and effective messages (Wilson, 2007). In tailoring strong behavior-change messages to target audiences, however, it is crucial that such messages not overstate their case and inadvertently reinforce the already strong stereotype that disease prevention is largely the result of individual behavior (Sankofa & Johnson-Taylor, 2007).

In addition to the large-scale community and mass-communication projects—which are difficult to mount, methodologically challenging, and open to substantial influences of secular trends external to the study—many smaller community interventions have been carried out in grocery stores, restaurants, schools, and worksites. Though many effective interventions combine population and individual approaches, the discussion that follows focuses on community-*level* interventions, in which a primary focus of the intervention is at the population level, separate from the conceptually distinct community-*based* but primarily individual-level interventions.

Community-Level Dietary Change in Organizations

Schools

Schools are natural venues for promoting healthful eating, but school interventions face several challenges. First, institutional resources may be constrained, making it difficult to institute school- or system-level changes in food purchases or vending-machine policy. Second, outcomes of school-based interventions may include changes in attitude, individual behavior, institutional behavior, the physical and social environment, and markers of excess weight and it may be difficult to demonstrate effects on BMI or disease risk (French, 2005). Third, many school-based studies use multicomponent approaches—a combination of individual, institutional, and sometimes family-level interventions, often incorporating additional interventions to increase physical activity. Such approaches gain synergy, but may not be of sufficient scope to disentangle the effects of the individual components (French, 2005). Fourth, school-based initiatives may not carry over outside school, where children get the majority of their food energy. Finally, if substantial external (e.g., school district or statewide) efforts are made to modify pupils' dietary behavior, the ability to detect treatment effects may be compromised by larger secular trends. Nonetheless, studies to date suggest that interventions at the school level can influence dietary intake, at least while children are at school.

Multicomponent approaches, combining individual-level behavioral interventions, family involvement, and changes in school environment or policy, are most likely to observe changes in both behavior and the environment (French, 2005; French & Wechsler, 2004). Such interventions are popular and have been successfully implemented and evaluated outside more controlled academic research activities (Stables et al., 2005).

Food availability has been examined in a number of settings. Making healthful choices available, through school meal programs or vending machines, may influence some students to select those options more frequently (French, 2005). For example, increasing low-fat and decreasing high-fat options in one school led purchasers to make low-fat selections 32% of the time, whereas low-fat options were picked only 14% of the time in a comparison school (Bartholomew & Jowers, 2006).

One attractive intervention may be to simply provide healthful food to children, rather than merely encourage their purchase or consumption. Providing a salad bar has been shown to increase consumption of fruits and vegetables among low-income children eligible for free or subsidized meals (Slusser,

Cumberland, Browdy, Lange, & Neumann, 2007). Recently, a school-level randomized trial in 98 schools demonstrated that offering a daily fruit or vegetable to young students increased intake during the program period and that the effect waned after program cessation (Ransley et al., 2007). Such interventions are likely to be modest, and ongoing support is needed to maintain changes long enough to develop lasting health benefits or substantial changes in school or community norms.

The influence of food pricing in schools has been relatively well documented. Adding low-fat snack items to school vending machines and pairing that with varying levels of discount for purchasing low-fat options can lead to large proportional (but small absolute) increases in low-fat snack purchases (French et al., 2001). Similar significant but small effects have been observed by subsidizing low-fat options and "taxing" high-fat options in school cafeterias (Hannan, French, Story, & Fulkerson, 2002). Even substantial discounts have modest effects on choice—adolescents cite price as important in food choices but cite taste substantially more often (Shannon, Story, Fulkerson, & French, 2002), so effective interventions must address acceptability and taste, in addition to cost.

Promoting healthful eating, either through broad or individually targeted methods, is effective in increasing consumption of health-promoting foods. General promotion activities, either school-wide or at the point of purchase (i.e., school cafeteria, vending machines), such as informational or motivational signs and posters, seem to have small but independent effects on food choices by students (French, 2005).

Worksites

Like schools, worksites offer a tempting venue for dietary change efforts but there are important differences between the two. Worksite interventions, though not reaching the entire population, have the potential to change not only individual behavior but social norms both in surrounding communities and other businesses. The physical and social variation in worksites that makes it difficult to say "what works" is compounded by the heterogeneity of interventions and outcomes in worksite research (Katz et al., 2005). Unlike school pupils, employees often have a say in working conditions. Like schools, worksites may be loath to introduce changes that divert time from business activities or decrease profits or wages. If there is substantial dropout or workforce turnover, as was common in many early worksite studies (French, 2005), generalizability and validity can suffer. Nonetheless, changes in dietary behavior can be promoted at worksites, using many of the same techniques that have been effective in school settings.

Many of the more successful efforts have employed multicomponent interventions (French, 2005), typically pairing individual educational efforts with some combination of mass media, labeling and other point-of-purchase information, product promotion, and, often, an employee advisory board. Worksite-level trials have generally shown modest but significant improvements in target behaviors, according to measures ranging from fruit and vegetable intake to intake of calories and fat calories. The Working Healthy Project (WHP), for example, combined individual-level dietary change education, changes to vending-machine signage,

modifications to catering policies, general promotional materials, incentives for participation, and the formation of an employee advisory board, and found small but significant increases in fruit and vegetable and fiber intake (Emmons, Linnan, Shadel, Marcus, & Abrams, 1999). It is difficult, however, to disentangle the effects of individual-level interventions from the collective and environmental interventions unless that is an explicit part of the study design. Multicomponent approaches will continue to be popular, in the hope that the synergy between individual and environmental approaches will result in greater, more robust effects.

Pricing influences purchases in worksites, as well. Discounts appear to promote selection of targeted items at worksites (Seymour, Yaroch, Serdula, Blanck, & Khan, 2004), hardly surprising given that cost is second only to taste in determining food purchases (Popkin, Duffey, & Gordon-Larsen, 2005). Pricing approaches, while promoting healthful food choices, must be implemented carefully to avoid unintended consequences. In the CHIPS project (French et al., 2001), 10% price reductions on low-fat vending snacks had little influence on purchases, but discounts of 25% and 50% showed not only strong associations with increased selection of low-fat snacks but increased purchases, suggesting that employees may have been using the discounts to buy extra snacks. Future investigations should determine whether eating habits modified by price changes generalize to other settings and whether sustained change requires sustained discounts.

Promotional approaches have had mixed success in apparently similar settings, with the pairing of promotional items and nutritional information reducing selection of higher-fat options and promoting lower-fat choices in some settings (Zifferblatt, Wilbur, & Pinsky, 1980) but not others (Mayer, Brown, Heins, & Bishop, 1987). Multiple promotional and informational approaches—for instance, posters, brochures, table-top information, inserts in paychecks, flyers, newsletters, tip sheets, and message cards—can be combined to reinforce a central interventional theme or message (Beresford et al., 2001).

The work climate is important in fostering success. Company leadership is important in carrying out and supporting interventions (Sorensen, Linnan, & Hunt, 2004). Advisory boards are a common way of involving both management and employees in worksite nutrition interventions. Such boards take responsibility for tailoring interventions to their specific worksites, for implementing intervention activities, and for involving other employees in intervention activities (Beresford et al., 2001) and are crucial to success and sustainability.

The Built Environment

Built environments are associated with overweight and obesity. There is evidence that body mass index may be associated with the density of fast-food outlets, the presence of convenience stores, a relative lack of supermarkets, and higher costs for fruits and vegetables (Papas et al., 2007), but the field is only now emerging, and both methods and results have been mixed. The growth of investigations on diet and environment, along with improving research methods, suggests that the field will contribute substantially to community-level dietary change efforts.

While neighborhood characteristics may be used to assess associations with eating patterns, they can also be used to identify barriers to healthful eating and to promote dietary change. For instance, community members have combined physical neighborhood surveys with previously published work to successfully identify barriers to healthful eating, such as relative lack of supermarkets in some areas, high fast-food outlet density, and relative paucity of produce markets (Jilcott, Laraia, Evenson, Lowenstein, & Ammerman, 2007). Using neighborhood assessments allows interventions to be tailored to specific settings and is compatible with both individual and community-level approaches. Two important sources of food and therefore potential venues for promoting community-level dietary change in every community are grocery stores and restaurants. Because grocery stores and restaurants are ubiquitous and similar, interventions developed locally have the potential to be relatively easily translatable across settings and populations.

Grocery Stores

The availability of healthful food items at grocery stores, and their placement within stores, may influence shopping and, in turn, eating habits and therefore affect our ability to prevent or control disease. If healthful items are not available, they cannot be purchased and consumed, and stores located in low SES settings have been shown to be less likely to stock healthful items (Horowitz, Colson, Hebert, & Lancaster, 2004). Grocery stores, while an attractive venue for interventions to promote more healthful eating, must balance commercial and marketing considerations against the desire to promote healthful items and provide nutrition education (Winett et al., 1992), and it will be difficult to mount successful efforts to promote health eating in commercial stores if they require staff or management time, interfere with the volume or variety of products on display, or discourage purchase of entire types of foods.

In general, diet change interventions in grocery stores employ point-of-purchase information; coupons or price reductions, increased access or availability, or promotions (Glanz & Yaroch, 2004). All grocery stores use information, advertisements, and product placement to promote items—the placement of energy dense confections near checkout stands to encourage impulse purchases is well documented (Dixon, Scully, & Parkinson, 2006). Despite this, there have been relatively few published results of such interventions specifically to promote healthful food choices. A recent review (Seymour et al., 2004) suggested that information strategies were the most common approach to promoting healthful items, while multiple avenues of information, incentives, and improved access and availability were used less frequently. Outcomes of grocery store interventions were mixed, however, with 5 of 10 studies showing no effect and the others showing modest effects on targeted foods. Price may be one of the most powerful incentives for modifying behavior but is based on the cost of production, storage, and transportation rather than on the healthfulness of the product. In many settings, this means that health-promoting foods are more expensive than less-healthful choices, and price has been shown to be second only to taste in the consideration of food purchases (Popkin et al., 2005). Providing free access to reduced-calorie foods has proven effective in experimental settings (Weststrate et al., 1998), but it

is not clear how such findings translate into environments with inexpensive high-calorie foods.

Overcoming some methodological challenges may also promote evaluation of grocery store interventions. For instance, the advent of extensive and identifiable purchase information makes it possible—with appropriate privacy safeguards—to examine individual-level purchasing over time (Ni Mhurchu et al., 2007), as a complement to established environmental methods of characterizing community shopping habits (Cheadle et al., 1993).

Restaurants

With approximately one-third of U.S. calories consumed in or prepared by restaurants, the potential for public health impact through changes in restaurant eating practices is great. However, like grocery stores, commercial restaurants may be reluctant to allow dietary change efforts that result in substantial management or employee effort, disruption to efficient operations or increased costs, and potential for diminished sales or dissatisfied customers. Diners are confronted with the fact that the same amount of money used to purchase a several-hundred-calorie salad at an upscale restaurant can buy a several-thousand-calorie meal at a fast-food outlet.

Restaurant interventions often use some combination of information, availability or access, pricing, and advertising and promotion (Glanz & Hoelscher, 2004). Restaurants often respond to perceived consumer demand by identifying health-promoting menu items. Unless these items are appealing and competitively priced, there will be little reason to eliminate the pricing incentives for larger portions of energy-dense foods (French, 2005). Health-promoting interventions to date in restaurant settings suggest that informational strategies—labeling certain menu items to suggest healthfulness within a general promotional campaign—are the most common approach (Seymour et al., 2004), though there is concern that labeling healthful foods connotes poorer taste quality (Seymour et al., 2004) or invokes unfavorable stereotypes of healthful eating (Fries & Croyle, 1993). Nevertheless, these informational approaches have proven generally successful in the short term, though their long-term influences have not been documented. Increasing availability or access to health-promoting items in restaurants—for instance, by offering side dishes that feature fruits and vegetables—is an understudied approach (Glanz & Hoelscher, 2004), and efforts to modify availability of healthful foods and to reduce portion sizes may have to overcome norms and standards in both the food service industry and among food service workers (Condrasky, Ledikwe, Flood, & Rolls, 2007).

Looking to the Future

It is clear at this point that the epidemic of diseases related to diet and energy imbalance will be solved only through concerted efforts at both the individual and the collective level. However, there have been relatively few demonstrated community-level and environmental interventions to modify dietary intake, in contrast to the wealth of documentation of individual-level interventions. Diet

change at the community, environmental, and organizational levels is likely to remain focused on multimodal approaches combining individual interventions with multiple environmental or organizational interventions. Researchers must focus on identifying those combinations of interventions that are most effective—and cost-effective—while at the same time identifying the individual contribution of each intervention component. Research to date suggests that point-of-purchase interventions hold a great deal of promise in communities, worksites, and schools, though the long-term effectiveness of such interventions has not been demonstrated (Matson-Koffman, Brownstein, Neiner, & Greaney, 2005). Translational research is needed to determine the settings in which economic incentives, information, and promotions not only have an impact on behavior but can do so in ways that are acceptable to consumers and businesses. Similarly, the role of the environment—whether community, worksite, or school—in shaping food choices is only now being fully explored, and this is reflected in the sometimes mixed results of studies to date. Research in the area is already moving away from merely associating physical aspects of the environment to characteristics of people in those environments and is exploring the dynamic person-environment interaction (Sallis & Owen, 2002). Both research and practice will continue to be improved by the involvement of interdisciplinary teams of researchers, clinicians, policymakers, business leaders, and citizens. Only such a widespread, concerted effort will be able to overcome the huge global challenge we face in combating diseases related to one of the most fundamental of all human behaviors—eating.

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Adherence to Physical Activity Recommendations and Interventions

12

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Understanding how to facilitate the maintenance of health-promoting behaviors represents a major challenge for health practitioners and researchers. Physical activity is particularly challenging to support as it takes more time and effort than most other preventive health behaviors. The difficulty of adhering to regular physical activity is reflected in the high proportion of individuals who are sedentary or irregularly active and thus not physically active at the level needed to achieve health benefits (Haskell et al., 2007). Difficulty adhering to a physical activity regimen also is reflected by the high relapse rates from physical activity programs, which have been estimated at approximately 50% (Castro & King, 2002). However, regular participation in physical activity yields tremendous benefits, and additional benefits continue to be discovered. Therefore, adherence to physical activity is a critical issue.

Adherence is difficult to define, as it can be discussed in very specific or very general terms and can apply to all phases of the physical activity continuum from the initiation of physical activity behavior to the early adoption of the physical activity habit to the maintenance phase and then periodically to the relapse phase and, one hopes, to recovery and the resumption of the physical activity habit. Thus, there is much inconsistency in the literature as to how physical activity adherence is defined. One definition of adherence that is often used is the fulfillment of predetermined goals (Dubbert, Rappaport, & Martin, 1987). This definition is a useful one, as it can be adapted to include goals set by public health initiatives such as *Healthy People 2010* (U.S. Department of Health and Human Services [USDHHS], 2000). In this chapter, adherence is considered more broadly to include the amount of physical activity one participates in relative to the amount that the participant was asked to perform. In this chapter we will typically use the phrase *physical activity,* rather than *exercise.* The American College of Sports Medicine (ACSM, 2000) defines exercise as "planned, structured and repetitive bodily movement done to improve or maintain one or more components of physical fitness" (p. 4), whereas physical activity is defined as "bodily movement that is produced by the contraction of skeletal muscle and that substantially increases energy expenditure" (ACSM, 2000, p. 4).

This chapter focuses on recent studies that examine the impact of various interventions on the physical activity patterns of healthy adults. Many of these studies utilize psychological theories as an organizing framework, and therefore, several of these theories are presented. Next, specific intervention studies organized by the channel utilized (i.e., provider, home-based, worksite, community) are discussed. It should be noted that the discussion of interventions is not an exhaustive review, which would go beyond the scope of this chapter (see Hillsdon, Foster, & Thorogood, 2005).

Physical Activity Recommendations

Despite the fact that it is now well known that regular participation in physical activity helps to reduce mortality rates (Schnohr, Lange, Scharling, & Jensen, 2006), approximately 70% of the U.S. population remain sedentary (USDHHS, 2006). Sedentary individuals are classified as those who do not consistently meet the minimum public health physical activity recommendations set forth by a joint recommendation from the American College of Sports Medicine and the American Heart Association (ACSM, 2000; Haskell et al., 2007). To maintain health, individuals should accumulate 30 minutes or more of at least moderate-intensity aerobic physical activity five or more days per week, or they should accumulate 20 minutes or more of vigorous-intensity aerobic physical activity, on three or more days per week. In addition, individuals should perform activities that maintain or increase muscular strength and endurance at least two days per week. Combinations of moderate and vigorous intensity physical activity can also be done to meet the recommendations (for more specific examples, see Haskell et al., 2007). These guidelines have important implications for adherence, as research has demonstrated that individuals are more likely to adopt and maintain moderate intensity physical activity than more vigorous activity (Perri et al., 2002).

Useful Psychological Frameworks

Understanding complex behavior, such as physical activity behavior, is facilitated through theories and models identifying important constructs. Theories such as learning theory (Skinner, 1953), social-cognitive theory (Bandura, 1977, 1986), the Transtheoretical Model (Prochaska & DiClemente, 1983) and the relapse prevention model (Marlatt & Gordon, 1980) are especially useful because of their inclusion of both personal and environmental factors and their explicit implications for interventions (Marcus & Sallis, 1997; USDHHS, 1996). Two additional frameworks that have become more popular recently include Motivational Interviewing (Miller & Rollnick, 2002) and ecological approaches (e.g., Spence & Lee, 2003) that explicitly change the environmental factors to increase physical activity.

Learning Theory

Applications of operant learning have been widely used in physical activity interventions. Physical activity is conceived as a response that can be acquired and maintained by controlling or modifying the antecedents and consequences associated with exercise participation. "Behavior modification" is a term used to denote strategies derived from learning theory, such as stimulus control and contingency management. Stimulus control involves increasing the cues for physical activity and/or decreasing the cues that prompt sedentary behavior. Contingency management utilizes reinforcements to increase physical activity adherence and may include strategies such as contracts, incentives, lotteries, and competitions. Behavior modification strategies have been found to increase physical activity adherence 10%–75% above that found in control groups that receive no treatment (e.g., Marcus et al., 2006). Overall, reviews of behavior modification strategies support their effectiveness in improving adherence; however, the particular strategy utilized does not appear important (e.g., Marcus et al., 2000).

Social-Cognitive Theory

Social-Cognitive Theory (SCT) (Bandura, 1977, 1986) focuses on the importance of the interaction between the person and her environment and stresses an individual's ability to control her behavior. Self-efficacy is a central concept within social-cognitive theory (Bandura, 1977, 1986) and involves individuals' degree of confidence that they can perform a particular behavior. Self-efficacy is one of the most frequently identified psychosocial determinants of adherence to physical activity among adults, and numerous studies demonstrate that high levels of self-efficacy prospectively predict physical activity behavior (e.g., Petosa, Suminski, & Hortz, 2003). In addition, recent exercise intervention studies have shown that increases in exercise self-efficacy mediate not only exercise behavior (Lubans & Sylva, 2006) but also health-related quality-of-life benefits (Anderson, King, Stewart, Camacho, & Rejeski, 2005). Another major component of SCT, self-regulation, includes many behavior modification strategies such as goal setting, planning, and self-monitoring and is frequently applied in exercise interventions (e.g., Hortz & Petosa, 2006).

Transtheoretical Model

The Transtheoretical or stage-of-change model integrates a person's current behavior with his intention to maintain or change this pattern of behavior (Prochaska & DiClemente, 1983). According to the model, individuals progress through a series of stages of readiness for change. As applied to physical activity, precontemplation includes individuals who do not participate in physical activity and do not intend to start. People in the contemplation stage do not participate in physical activity but intend to start. Those in preparation participate in some physical activity, but not regularly. The action stage includes individuals who currently participate in regular activity but have done so for less than six months, and the maintenance stage includes those who have been regularly active for 6 or more months (Marcus & Forsyth, 2003). Interventions based on the Transtheoretical Model utilize the concept of tailoring treatment to the individual's stage of readiness for change (e.g., Marcus et al., 2007b). A recent review concluded that stage-matched physical activity interventions appear effective at improving short- but not long-term physical activity adherence (Adams & White, 2003). However, more recently published studies show efficacy through 1 year (Marcus et al., 2007a; Marcus et al., 2007b). Additional research is needed, however, to determine how best to maintain physical activity among different populations.

Relapse Prevention

The relapse-prevention model (RPM) posits that maintenance of a new behavior is influenced by an individual's ability to cognitively and behaviorally cope with relapses to the undesirable behavior (Marlatt & Gordon, 1980). One concept from the RPM, the abstinence violation effect (AVE), applies to a broad range of behaviors and is a maladaptive belief that, once the abstinence rule has been broken, total relapse is inevitable. One goal of the model is to teach individuals to distinguish a lapse from a relapse in order to prevent a lapse from physical activity (e.g., missing a physical activity session) from escalating into a complete relapse (e.g., return to a sedentary lifestyle). The individual is encouraged to identify situations that are likely to lead to a lapse and then receives training in appropriate cognitive and behavioral skills to cope with the lapse. Data suggest that physical activity relapsers have fewer strategies for coping with high-risk situations than do physical activity maintainers (Simkin & Gross, 1994) and that relapse-prevention strategies are effective for increasing adherence to a physical activity program (Belisle, Roskies, & Levesque, 1987).

Motivational Interviewing

Motivational Interviewing (MI) is a client-centered approach to bringing about behavior change. According to Miller and Rollnick (2002), four general principles underlie this approach: expressing empathy, developing discrepancy, rolling with resistance, and supporting self-efficacy (for more information on this theory see chapter 8 of this book). A recent meta-analysis of MI-controlled clinical trials found that MI approaches were equivalent to other active treatments and superior to placebo or no-treatment controls in bringing about behavior change with regard to substance use and improvements in diet and exercise

(Burke, Arkowitz, & Menchola, 2003). More recently, Resnicow and colleagues found that MI did not add to the effectiveness of culturally tailored self-help materials designed to increase physical activity (Resnicow et al., 2005). Given the demonstrated effectiveness of MI for other behaviors and its initial promise with physical activity, more research is needed to determine the true value of MI for increasing physical activity.

Ecological Models

Ecological or social-ecological models add to social cognitive theory by recognizing that environments directly influence physical activity by promoting certain behaviors (e.g., commuting to work on bike paths) and restricting other behaviors (e.g., a lack of sidewalks discourages walking). Sallis and Owen (1996) define "ecological" activities as transactions between people and their physical and sociocultural environments. Ecological models take account of intra-individual factors such as physiology, self-efficacy, and attitudes, as well as extra-individual influences such as community, policy, and culture (McLeroy, Bibeau, Steckler, & Glanz, 1988). Ecological models conceive of these influences as interdependent and as exerting direct effects on each other (Kelly, 1990). A key feature of the ecological models is the belief that multiple levels of influence determine individual behavior. Thus, the most effective means of increasing physical activity would be to intervene on both the intra-individual and the extra-individual levels. Sallis and colleagues (2006) propose that the most powerful ecological interventions would include the provision of safe and attractive places to exercise, the introduction of strategies to increase motivation and self-efficacy, and the use of the mass media to bring about change in social norms for exercising. Because of its specification of numerous determinants of behavior, the ecological model provides a useful framework for understanding barriers to physical activity (e.g., Fleury & Lee, 2006).

Group-Based Interventions

Historically, physical activity adherence research focused on the identification of individual factors that were predictive of activity level (King, 1994). However, in light of the prevalence of a sedentary lifestyle and the time and effort required to deliver individualized treatments, more effective strategies need to be identified that can be applied at a group level. Some group interventions have merely tried to apply techniques obtained from research on individual behavior to a group setting. However, group interventions can differ from individual treatment on a number of dimensions. Group interventions can focus on social support, peer groups, or observational learning.

For example, Project Active was a randomized clinical trial comparing the efficacy of lifestyle and traditional structured group programs among 235 healthy, sedentary adults (Dunn et al., 1999). Participants received 6 months of intensive intervention based on Social-Cognitive Theory and the Transtheoretical Model. The structured group received an exercise prescription (50%–85% of maximal aerobic power for 20–60 minutes) and attended three exercise sessions per week with the goal of gradually increasing to five sessions. The lifestyle group received exercise prescriptions emphasizing 30 minutes of moderate

lifestyle activity on most (preferably all) days of the week, along with monthly stage-matched manuals and weekly homework assignments for behavioral skill building and problem solving. In addition, small groups on cognitive and behavioral strategies were held weekly for 16 weeks and then biweekly through month 6. After 6 months, an 18-month maintenance intervention began, which involved regular meetings, monthly activities calendars, and quarterly newsletters. Results show that both the lifestyle and the structured exercise group programs produced significant (and equivalent) increases in physical activity and cardiorespiratory fitness from baseline to 24 months, along with reductions in blood pressure and individuals' percentage of body fat. Thus, the results from Project Active support the efficacy of structured group-based interventions for increasing physical activity.

However, group-based programs can be costly, and researchers have now begun to reexamine lower-cost strategies to enhance the adoption and maintenance of physical activity. As such, the future of studies utilizing a group-based design for physical activity adherence research will require researchers to weigh the costs and benefits of using this particular strategy in comparison to other designs. It may be that healthy individuals can be appropriately treated with lower-cost interventions, such as printed materials, phone calls, and computerized prompts. Newer studies will ultimately determine how the results from group-based interventions can most effectively be applied or generalized to a larger audience.

Public Health Approaches to Physical Activity Promotion

Individual and small-group approaches to enhancing adherence to physical activity have met with some success. However, these approaches, while important, are unlikely to make a significant impact on the achievement of the national physical activity goals outlined in *Healthy People 2010* (USDHHS, 2000). A primary goal of these objectives is to increase the proportion of adults who engage in regular moderate or vigorous intensity physical activity. Individual and small-group approaches reach only a small segment of the population, particularly those who may be self-selected and somewhat motivated to change their behavior. Therefore, higher-level and more macro-level approaches may be needed to achieve these goals. Public health interventions extend their reach to the 20%–30% of the population who are most sedentary and are at greatest risk for diseases preventable by increases in physical activity. These more macro approaches utilize worksites, primary care settings, and communities as both the target of intervention and the unit of analysis and aim for environmental, organizational, and policy changes. Thus, public health approaches widen the scope of intervention delivery by proactively targeting at-risk groups, often through preexisting channels. In the following section, we discuss the role of public health interventions in enhancing adherence to physical activity in whole communities and in special subgroups within communities, such as in the home, at worksites, and in physician's offices. We also discuss the policy and environmental changes that can facilitate the adoption and maintenance of the behavior change.

Provider-Delivered Interventions

Physicians play an important role in the promotion of healthy lifestyle behaviors such as physical activity. The U.S. Preventive Services Task Force has recommended that physicians counsel all patients to engage in a program of regular physical activity (Task Force on Community Prevention Services, 2002). The Task Force noted that there remains uncertainty about the effectiveness of provider-delivered physical activity counseling since most studies have tested brief, minimal, and low-intensity interventions, such as three- to five-minute counseling sessions in the context of a routine clinical visit. However, multicomponent interventions that combine provider advice with behavioral interventions appear promising. Such interventions often include patient goal setting, written exercise prescriptions, individually tailored physical activity regimens, and mailed or telephone follow-up assistance. Linking primary care patients with community-based fitness programs may enhance the effectiveness of primary care clinician counseling.

Although physicians are likely to have a positive effect on patients' level of activity, the rate of physical activity counseling by physicians is generally low (Rogers et al., 2006). For example, in one study, only 34% of physicians surveyed reported that they usually counsel on physical activity during a preventive checkup (Wee, McCarthy, Davis, & Phillips, 1999.) However, there is growing evidence suggesting that physician-delivered counseling can change patients' activity levels. A review of studies in which physical activity counseling in family practice was evaluated among adults (Petrella & Lattanzio, 2002) concluded that exercise prescriptions in family practice can help patients initiate physical activity. Positive results also have been obtained in other studies.

For example, a recent 5-year, multicenter trial, the Activity Counseling Trial (ACT), showed that the addition of a 30-minute counseling session ("Assistance") and counseling plus telephone follow-up ("Counseling") did better than physician advice alone (Anderson et al., 2005). At the 24-month follow-up, fitness test results were significantly higher in the Assistance and Counseling groups than in the Advice group. Overall, both the Assistance and Counseling treatment approaches were equally effective, although the Assistance approach appeared more effective for men and the Counseling approach seemed more effective for women.

In summary, the efficacy of brief physician-delivered counseling interventions enhanced by interventions delivered by nonphysician interventionists in physical activity hold great promise from a public health perspective. Trials examining the minimal and optimal doses of physician and other allied health professionals' time that produce the desired behavior change in patients are extremely important at this time.

Home-Based Interventions

A large number of home-based physical activity interventions have been conducted, and many have been done with specialized populations, such as older adults or those with known disease. Describing the various types of interventions utilized and the populations targeted is beyond the scope of this chapter, however. We therefore focus on two very recent home-based interventions that

were done with a broad reach, utilizing mail and Internet-based interventions, and an apparently healthy population.

Recently, investigators tested the efficacy of a 1-year home-based individually tailored intervention using print and phone delivery channels and compared these to a contact control condition. At 6 months, results showed that the groups that received the print and the phone interventions showed significantly greater increases in number of weekly minutes of at least moderate intensity exercise than did the controls (Marcus et al., 2007a, 2007b). However, at 12 months, participants in the print condition continued to increase their exercise relative to those in the control group, while participants in the phone condition decreased to a level of exercise that was not significantly different from that of the control group. The print intervention was also shown to be more cost-effective than the phone intervention (Sevick et al., 2007).

The study just cited is an example of the recent advances in computer technology that have enabled health care delivery services to provide low-cost, yet highly individualized interventions. Computer "expert systems" have been developed to deliver professional-level counseling and interventions for the adoption of physical activity (e.g., Marcus et al., 2007a). An expert system is a computer program that mimics the reasoning or advice-giving capabilities of a human expert (Negotia, 1985). These systems can be used to supplement behavioral treatments and can enhance interventions delivered to the home. Expert systems can provide inexpensive, tailored interventions and are capable of modifying their intervention to match the needs and interests of the user (Slack, Safran, Kowaloff, Pearce, & Delbanco, 1995).

For example, a recent study randomized 249 sedentary adults to one of three physical activity interventions: (1) Internet intervention motivationally tailored to the individual (Tailored Internet); (2) print intervention motivationally tailored to the individual (Tailored Print; shown to be effective previously); and (3) six researcher-selected Web sites currently available to the public (Standard Internet). Results indicated that there were no significant differences among the three arms; however, all three arms significantly increased from baseline to 6 months and from baseline to 12 months (Marcus et al., 2007). Since the result for the group reached via the Internet was not different from that for the group reached via the print-based intervention, it appears that Internet-delivered physical activity interventions may provide a way to reach a larger proportion of sedentary adults in a more cost-effective way.

In sum, the utilization of computerized tailored reports that can be delivered to the home via the mail or the Internet has become an exciting new and important area for physical activity promotion and adoption (e.g., Marcus et al., 2007). With the increased number of home computers and the spread of Internet use in this country, home-based designs will likely continue to provide researchers with multiple opportunities to deliver effective physical activity interventions in the future.

Worksite-Based Interventions

One approach to increasing participation in physical activity has been to provide programs at the worksite. Worksites offer an accessible and often diverse population base, convenience, potential avenues for group support, and

existing communication and health care delivery channels (Bull, Gillette, & Glasgow, 2003). Companies that sponsor these programs often hope to reduce costs to their business, such as those associated with absenteeism, sick leave, and low productivity levels (Marshall, 2004).

Although some worksite-based physical activity programs have been successful in increasing rates of physical-activity participation among employees (Proper, Hildebrandt, Van der Beek, Twisk, & Van Mechelen, 2003), many programs offering onsite fitness facilities or referrals to worksite fitness programs have showed little efficacy and were attended mostly by those who were either already exercising or highly motivated to do so (Marshall, 2004). Across a number of studies, higher socioeconomic status, based on level of education and income level and type of job (white-collar), is positively associated with participation in leisure-time physical activity (Seefeldt, Malina, & Clark, 2002). For instance, a recent review described the imbalances that exist among worksite wellness programs, with white-collar employees tending to utilize these programs more frequently than blue-collar employees (Thompson, Smith, & Bybee, 2005) and men tending to utilize worksite programs more frequently than women (Dishman, Oldenburg, O'Neal, & Shephard, 1998). However, worksite physical activity programs that have specifically targeted traditionally hard-to-reach blue-collar workers have shown improvements in the targeted group's participation in physical activity (Campbell et al., 2002). For example, a New Zealand study of low-income, blue-collar men found that after, attending a 30-minute worksite workshop once a month for 6 months, the men showed a significant increase in physical activity behavior at 12 months and when compared to a control group (Cook, Simmons, Swinburn, & Stewart, 2001). Thus, future worksite physical activity interventions may be more successful if they are tailored to meet the specific needs of the employees (e.g., Griffin-Blake & DeJoy, 2006).

In conclusion, worksite health promotion and physical activity campaigns have been somewhat successful in promoting physical activity adoption among employees. However, additional work is needed to determine the most effective methods for increasing physical activity among employees. The future of effective worksite interventions will require innovative programs that can reach the largest number of employees. Thus far, the majority of studies in these settings have enrolled self-selected samples of people who volunteer to participate in a physical activity program. This does not reach the majority of individuals who are sedentary, and would stand to benefit most from these interventions. Finally, there is currently a lack of evidence regarding the impact of increased physical activity on absenteeism, job stress, turnover rates, productivity levels, and job satisfaction (Marshall, 2004), and future research is needed to assess these and other outcomes that are hypothesized to occur with physical activity worksite interventions.

Randomized Community Trials

Few large-scale national trials have focused exclusively on the promotion of physical activity. Rather, physical activity promotion has often been embedded within larger multiple risk-factor interventions. For example, previous community-based research such as the Stanford Five-City Multiple

Risk Reduction Project sought to reduce cardiovascular disease risk factors through community organizations. Residents in the treatment cities were encouraged to build physical activity into their daily routines (e.g., walk to the store, take stairs), to increase participation in recreational activities, and to enroll in exercise classes. Overall mortality and cardiovascular disease risk were significantly reduced in intervention communities (Farquhar et al., 1990); however, changes in knowledge, attitudes, and behavior regarding physical activity were only modest. While these results were encouraging at the time, research like this ultimately fell short of achieving national goals for levels of physical activity. One possible explanation may be that previous community-based studies utilized broad approaches and took little account of differences among individual segments of the population. For instance, it may be necessary to penetrate the population at a variety of different levels vertically (from micro-level face-to-face interventions to the macro level of mass-media interventions), as well as horizontally (using sociodemographic, psychosocial, and biobehavioral parameters).

More recent research addresses some of these issues. For example, Active for Life (Wilcox et al., 2006), an ongoing physical activity intervention, has been developed in order to determine whether previously established evidence-based physical activity programs can be successfully and effectively translated into a community setting. One of the primary goals of the program is to determine the impact these interventions have on specific quality-of-life outcomes related to physical activity. Currently, the first-year results are promising, with statistically significant increases in moderate-to-vigorous physical activity and total physical activity, decreases in depressive symptoms and stress, increases in satisfaction with body appearance and function, and decreases in body mass index (Wilcox et al., 2006).

As such, it appears that effective community-level physical activity campaigns may need to first utilize evidenced-based, theoretically grounded programs previously established as efficacious. Second, they may need to account for individual differences in sociodemographic and psychosocial variables. Third, they may need to segment populations according to these differences, and, fourth and finally, develop interventions that target these specific subgroups and accelerate the acceptance of behavior change.

Ecological Interventions

Recent reviews of ecological interventions (e.g., Badland & Schofield, 2005; Foster & Hillsdon, 2004) have found evidence to support a relationship between the physical environment and physical activity. For example, researchers have consistently found neighborhood design and recreational environment (i.e., quality of sidewalks, walking/cycling facilities) to be significantly associated with participation in moderate and vigorous physical activity (De Bourdeadhuij, Sallis, & Saelens, 2003). Other studies have focused on changing the environment in order to bring about a change in physical activity behavior. For instance, Peel and Booth (2001) assessed physical changes to the work environment (e.g., the installation of weight training equipment and treadmills) in the Royal Australian Air Force (RAAF). The authors found that the proportion of RAAF participants

reporting regular vigorous physical activity increased from 46% to 55% over a 6-year period, which was significantly greater than increases found in the control sample, whose activity increased from 44% to 48%.

Numerous other studies have examined the use of health education posters to increase physical activity (i.e., to prompt stair use; Boutelle, Jeffery, Murray, & Schmitz, 2001; Titze, Martin, Seiler, & Marti, 2001). While the settings (e.g., public transportation, commercial, worksite, and university) of these studies and the messages included on the posters varied widely, most of these interventions produced a short-term improvement in stair use that was maintained for up to 3 months, with one study demonstrating an effect lasting up to 6 months. Visible and cheerful reminder signs have also been used to promote the use of sidewalks and walking paths. For instance, Rhode Island is the first state in the United States to introduce the Paths to Health program. Paths to Health have already been established in 11 Rhode Island communities. The paths are generally in downtown areas near attractive historic sites, parks, or schools. A recent study (Napolitano, Lerch, Papandonatos, & Marcus, 2006) examined the impact of a 1-month promotional campaign on the use of paths in Providence, Rhode Island. The promotional materials included flyers, e-mail, Web site postings, and informational booths. Observations of path use revealed that the number of walkers tripled from baseline to postcampaign.

In a general review of the effectiveness of physical activity interventions, Kahn and colleagues (2002) located 10 studies involving ecological approaches to promoting physical activity, such as creating walking trails, building exercise facilities, or providing access to existing nearby facilities. These studies also typically offered training on how to use equipment, health behavior education, risk-factor screening, and referrals to physicians, fitness programs, and support systems. These studies suggest that ecological interventions produce a median 25% increase in the proportion of people who exercise at least three times per week. Thus, the Task Force on Community Prevention Services (2002) described the evidence in support of their effectiveness in increasing activity levels as "strong."

In sum, ecological interventions show promise as a public health intervention for promoting physical activity, but there have been few published studies in this area. Most of the research currently available is cross-sectional in design. Future researchers should consider prospective studies in settings other than the military and address methodological flaws (i.e., quasi-experimental design) common to this literature.

Targeting Underserved Populations

The term "underserved populations" typically refers to individuals with low incomes and/or minority racial or ethnic status. Despite their increased risk for sedentary behavior, there has been little physical activity research conducted among such groups. Early intervention studies in this area often lacked a theoretical background and were plagued with methodological flaws. However, recent studies with more rigorous designs have shown promising results among underserved populations.

For example, the Increasing Motivation for Physical ACTivity (IMPACT) Project (Albright et al., 2005) was designed to promote physical activity among low-income (73% had yearly incomes <$20,000) healthy Latinas in vocational training programs. The study began with eight weekly behavioral skills classes, which were run by Latina health educators and focused on local parks and community events and discussed barriers common to Latinas, such as family responsibilities. Participants were randomly assigned to receive stage-matched phone and mail counseling or standardized mail support materials. The phone and mail counseling group reported significantly greater increases in estimated total energy expenditure than did the mail support group at 10 months.

Another study, "Moms on the Move," also utilized a combination of provider and home-based approaches among low-income mothers enrolled in the Women, Infants, and Children (WIC) program. The intervention group received Transtheoretical Model (TTM)–based provider counseling supplemented by an interactive brochure and four telephone follow-ups over 8 weeks (Fahrenwald, Atwood, Walker, Johnson, & Berg, 2004). Two weeks after completing the program, the intervention group reported significantly greater increases in physical activity than the attention control group.

While results from these two studies support the use of combined (home and provider based) approaches among underserved populations, interventions have also been delivered entirely through mediated approaches (i.e., mail, telephone, Internet). Results from two studies suggest that theory-based (TTM) print materials produced short-term increases in physical activity among a sample of predominantly African American healthy female clerical staff (Cardinal & Sachs, 1996) and low-income primary care patients with high rates of chronic illnesses (Whitehead, Bodenlos, Cowles, Jones, & Brantley, 2007). However, rates of attrition were high and gains had attenuated by 6 months in one study (Whitehead et al., 2007).

Most efforts to promote physical activity among underserved populations have been combined with nutritional interventions. For example, the WISEWOMAN projects funded by the Centers for Disease Control provide culturally and regionally appropriate cardiovascular disease prevention services based upon social cognitive and socioecological theories to low-income, multiethnic, middle-aged women with no insurance. A total of 12 state and tribal health agencies currently operate WISEWOMAN projects, and approximately 8,164 participants were screened by 2002. Available results from three studies suggest that WISEWOMAN interventions produced significant increases in activity levels (Staten et al., 2004; Stoddard, Palombo, Troped, Sorensen, & Will, 2004).

Similar multicomponent interventions have also been delivered through churches. For example, the Healthy Body Healthy Spirit Trial was delivered through African American churches in an attempt to promote physical activity, along with the consumption of fruits and vegetables (Resnicow et al., 2005). A total of 16 churches (1,056 participants) were randomly assigned to three conditions: standard education materials (exercise videos, cookbooks, pamphlets), culturally targeted self-help materials, or culturally targeted self-help materials plus four telephone calls using Motivational Interviewing techniques. At the end of 1 year, participants who received the culturally targeted self-help materials reported significantly greater increases in physical activity than the

control group, but the additional telephone contacts did not enhance the impact of the intervention.

In sum, few studies have targeted or even included substantial numbers of those in underserved populations; however, the research available suggests that members of racial or ethnic minorities and low-income individuals do increase their physical activity levels in response to intervention. These groups can be hard to reach and often report more barriers to being active, such as child care problems and monetary costs. Future studies may wish to consider interventions delivered via mediated approaches, as they can be mass distributed and do not require clinic visits.

Discussion

While physical activity is positively associated with numerous physiological and psychological benefits, a large part of the population continues to be sedentary or irregularly active and therefore is at increased risk for morbidity and mortality. While research on the health benefits of physical activity was once concerned with vigorous exercise, current evidence shows that moderate intensity physical activity is also positively associated with improvements in health. The ACSM/AHA physical activity guidelines recommending moderate and/or vigorous activity are flexible, and, given that research suggests improved adherence to moderate activity, these guidelines may help to eventually increase the proportion of individuals who are regularly active.

Sedentary behavior is more characteristic of minorities, the elderly, and individuals with low levels of education and low income levels (USDHHS, 2006). Therefore, physical activity interventions need to accommodate the current needs of these individuals and address potential barriers to their participation in physical activity, recognizing that different individuals may have different needs and face different barriers to becoming physically active. For example, while certain barriers, such as time, money, and access to child care, are frequently cited by both genders (Seefeldt, Malina, & Clark, 2002), these barriers tend to have a greater impact among women and low-income individuals (Bennett, Wolin, Puleo, & Emmons, 2006; Weiss, O'Loughlin, Platt, & Paradis, 2007). Programs should be designed with these potential barriers in mind.

Worksite-based physical activity programs have the potential to reduce several common barriers to physical activity participation, such as inconvenience of facilities, financial costs, and both work and child care schedules. In addition, the most frequently cited barriers to participation, time and accessibility (Seefeldt, Malina, & Clark, 2002), may be most readily addressed by providing interventions in the workplace.

The issue of physical activity adherence, independent of initiation, has gained attention in large-scale community and public health studies. However, public health interventions need to deliver interventions at all levels of analysis (from micro individual to macro policy changes), while accounting for psychosocial and demographic factors within each level of analysis. In this way, matching treatments to specific patients does not have to lie exclusively within the realm of clinic-based programs.

In conclusion, research on physical activity interventions highlights the importance of increasing our understanding of the factors related to physical activity adherence so that more effective interventions can be developed. Research on behavior change has identified the importance of individual factors, and there is an increased interest in the environmental and policy factors. The Transtheoretical Model and Social-Cognitive Theory are particularly useful in matching treatments to individuals, as they provide a framework for tailoring interventions to the motivation level of the individual, as well as addressing the environmental and policy factors that may contribute to physical activity adherence.

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Adoption and Maintenance of Safer Sexual Practices

13

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Sexual risk behavior is a leading cause of morbidity in the United States and the world. Consequences of sexual risk behavior include exposure to and transmission of sexually transmitted infections (STIs), including HIV infection. Worldwide, more than 1 million people become infected with an STI each day. In the United States, 19 million new STIs occur each year, and about half of these infections occur in people ages 15–24 years.

HIV, which has multiple modes of transmission but most often is sexually transmitted (Heymann, 2005), continues its impact, with an estimated 40 million people living with HIV/AIDS worldwide, and 4.3 million people are newly infected each year. In the United States, an estimated 1 million people are living with HIV/AIDS currently, and 40,000 new infections occur each year (Centers for Disease Control and Prevention [CDC], 2006a). Rates

of HIV infection in the United States have been decreasing over the past decade, although the rate of HIV diagnosis among African Americans and Hispanics/Latinos remains disproportionately high compared to that for non-Hispanic/non-Latino Whites (CDC, 2005a). Approximately 50% of new HIV infections occur among 13–24-year-olds, usually through sexual behavior. Approximately 60% of new cases in youth occur in females, and 75% are in racial or ethnic minorities (CDC, 2003; Futterman, 2005).

Unintended pregnancy is another outcome of unsafe sexual behaviors. More than one-third of all pregnancies worldwide, 80 million each year, are unintended. In the United States, approximately 95% of the 1 million pregnancies each year among U.S. teenagers are unplanned (Finer, 2007; Klima, 1998). Recent changes in contraceptive and sexual behaviors have resulted in significant declines in adolescent pregnancy rates (Ventura, Abma, Mosher, & Henshaw, 2004), although it is estimated that up to one-third of teenagers experience a pregnancy by age 20 (Hillard, 2005).

Because of the profound impact of STIs, there is a need for further implementation of existing interventions to reduce sexual risk behaviors that lead to negative sexual health consequences. In addition, the further development and evaluation of innovative strategies to prevent STIs and HIV infection and re-infection among multiple populations and subgroups are needed. Barrier methods of contraception, particularly latex male condoms and polyurethane female condoms, have been shown to be effective in reducing the spread of STIs and in preventing unintended pregnancies (Anonymous, 2005; CDC, 2005b; Sheroff & Darney, 2005; Winer et al., 2006). Therefore, the majority of safer sex programs have been designed to increase condom use and to decrease high-risk sexual behaviors among persons who are sexually active. Among teenagers not yet sexually active, efforts have focused on delaying the initiation of sexual behaviors.

In this chapter, we present an overview of the epidemiology of sexual risk, its predictors, and safer sexual intervention strategies that have been used with men who have sex with men (MSM), adolescents and young adults, and women who have sex with women (WSW). We also recommend directions for future research that may be necessary to reduce the morbidity and mortality associated with STIs and HIV.

Men Who Have Sex With Men

Risk Among MSM

National and international studies have found rates of same-sex sexual behavior among men ranging from 2.7% to 9.8% (Analyse des Comportements Sexuels en France ACSF Investigators, 1992; Laumann, Gagnon, Michael, & Michaels, 1994; Rhodes, McCoy, Hergenrather, Omli, & DuRant, 2007). HIV continues to disproportionately affect gay men, with an estimated 365,000–535,000 men currently infected with HIV in the United States (Blair, Fleming, & Karon, 2002; Wolitski, Valdiserri, Denning, & Levine, 2001). A 1997 study of urban MSM found HIV prevalence of 17% overall, with the prevalence ranging from 29% among African American MSM to 40% among MSM who reported injecting drugs (Catania et al.,

2001). Although there has been a decline in the prevalence and incidence of HIV infection among MSM in the United States during the past 10–15 years, MSM still account for a significant proportion of new infections (Karon, Fleming, Steketee, & De Cock, 2001), and recent reports suggest that the rates of new HIV infections among MSM may be on the rise (CDC, 2001; Rhodes & Yee, 2006). Moreover, African American and Hispanic/Latino MSM made up 53% of all MSM diagnosed with AIDS in 1999 (CDC, 2001; Malebranche, 2003; Rhodes, Yee, & Hergenrather, 2006; Wolitski et al., 2001). HIV is important in the MSM community not only among young men but across many age groups of MSM. In a probability sample of 2,881 MSM over the age of 50 years from several urban centers in the United States (New York, Los Angeles, Chicago, and San Francisco), the prevalence of HIV observed was 19% for men in their 50s and 3% for men in their 60s (Dolcini, Catania, Stall, & Pollack, 2003).

In addition to HIV, recent trends suggest an increased incidence of gonorrhea and syphilis among MSM (CDC, 2002a; Fox et al., 2001), indicating that increased risk is eclipsing the safer sex practices promoted in the 1980s and early 1990s. Consistent condom use remains low among MSM. Studies have found use rates during anal intercourse to range from about 30% among MSM in U.S. urban centers (Koblin et al., 2006) up to 60% among a multiethnic sample of young self-identifying gay men in the rural southern United States (Rhodes et al., 2006). Condom use varies by sexual activity, too; it is much higher for anal sex than for oral sex (Hunt et al., 1993; Rhodes et al., 2006). Studies of condom use among international populations of MSM suggest even lower rates of condom use in less well-resourced communities and higher condom use in more well-resourced communities (Herbst et al., 2005).

Predictors of Risk and Condom Use

A lack of consensus about the predictors of condom use among MSM exists because of often contradictory results from various studies and the complexity of condom use behavior. Among the many variables that have been identified as predictive, consistent condom use has been found to be associated with higher levels of social support from informal sources of help, the perception that condom use is the community norm, expectations that condoms will have positive interpersonal and personal consequences, increased condom-use self-efficacy, and HIV-positive serostatus. Inconsistent condom use has been found to be associated with substance use, including use of alcohol, methamphetamines, and medications designed to treat sexual dysfunction (i.e., Viagra, Levitra, and Cialis) used recreationally to enhance sexual satisfaction; injecting-drug use, negative attitudes and expectations about condoms; sex in public venues; perceiving oneself or one's partner as "low risk," condoms as decreasing sensation, and condom use as an inconvenience and interruption of intimacy; indifference about condom use; lack of control over initiating or negotiating safer sex; commercial sex work; and meeting partners on vacation and online through the Internet (Bull, Piper, & Rietmeijer, 2002; Carballo-Dieguez & Dolezal, 1996; Koblin et al., 2006; Rhodes, 2004; Rhodes, DiClemente, Cecil, Hergenrather, & Yee, 2002; Rhodes et al., 2006; Whittier, Lawrence, & Seeley, 2005).

Although some studies indicate that alcohol use is associated with unsafe sexual behaviors (Semple, Patterson, & Grant, 2003; Stone et al., 1999;

Tawk, Simpson, & Mindel, 2004), other research has not found this association (Clutterbuck, Gorman, McMillan, Lewis, & Macintyre, 2001; Seage et al., 1998; Smith, Grierson, Pitts, & Pattison, 2006). Alcohol use may be associated with indiscriminate forms of sexual behavior or risk taking (e.g., having multiple partners or engaging in "casual" sexual intercourse) but is not negatively associated with protective behaviors such as condom use (Cooper, 2002; Rhodes et al., 2006; Vanable et al., 2004). This hypothesis, which requires further theoretical exploration and testing, suggests that the decision to engage in sexual intercourse is affected by alcohol use, but protective behaviors during sexual intercourse are not (Rhodes et al., 2006b). More research is needed to untangle the associations between substance use and risk behavior (e.g., having multiple partners) and prevention behaviors (e.g., condom use). These associations also may differ by population subgroup.

Cultural and social factors also affect condom use (Bajos, 1997; Bakeman & Peterson, 2007; Diaz, 1998; Rhodes & Yee, 2006). For example, Hispanic/Latino and African American MSM may have less social support, and therefore lower condom use, because of the stigma associated with same-sex behavior within some communities. Furthermore, sex holds different meanings. MSM who consistently have unprotected anal intercourse have been found to be less likely to approve of sex without love (Crosby, Stall, Paul, Barrett, & Midanik, 1996). Thus, for these men, sex may hold meanings associated with intimacy, trust, and commitment. Condom promotion contradicts these meanings.

Intervention Research

Because publicly funded risk reduction interventions were slow to address prevention among MSM (Miller, 1995), significant resources within the gay community enabled gay community-initiated and community-based interventions early on during the epidemic. These interventions concentrated on risk counseling with HIV testing, eroticizing safer sex among men, modeling social and behavior change through community organizing and peer leadership, and training in condom skills (Miller, 1995; Rhodes & Yee, 2006). Because of the urgency of the epidemic, little time was available for determining efficacy prior to the implementation of interventions (Valdiserri, Lyter, Leviton, Stoner, & Silvestre, 1987), and thorough evaluation of many interventions remains rare (Chesney et al., 2003; Gay and Lesbian Medical Association, 2001; Herbst et al., 2005; Rhodes, 2004; Rhodes, Hergenrather, Duncan, Ramsey, Yee, & Wilkin, 2007; Rhodes & Yee, 2006; Wolitski et al., 2001).

However, since the 1980s, much has been tried and learned about preventing HIV and STIs among MSM. Characteristics of effective interventions include the provision of facts and information to increase HIV and/or STI knowledge, as well as to change cognitive factors such as attitudes, perceptions, or beliefs of MSM about HIV, STDs, and protection (e.g., condoms). Effective interventions develop technical skills, including the correct use of condoms; personal skills, including safer sex eroticization; and interpersonal skills, including negotiating safer sex and assertiveness. Most effective interventions are delivered in small groups by trained peers or counselors during multiple sessions (Herbst et al., 2005).

Effective interventions for MSM also are based on scientifically derived theoretical models. For example, the Popular Opinion Leader (POL) intervention

(Kelly et al., 1992) is based on theories of peer influence (Hallinan, 1982), social support (House, 1981), and diffusion of innovations (Rogers, 1983). A bar-based, HIV-prevention intervention using natural helpers, POL intervention has been found to be effective in HIV risk behavior reduction, including decreasing un-protected anal intercourse among gay bar patrons (Kelly et al., 1992). As it was originally tested using the naturally occurring social network of the bar, natural helpers known as "popular opinion leaders" were selected on the basis of their popularity. They attended four weekly 90-minute sessions that led them through a process of exploring and thoroughly understanding HIV prevention, both facts and skills, and practicing effective communication and leadership strategies. The training of these popular opinion leaders covered basic epidemiology and transmission of HIV/AIDS, behavioral strategies for risk reduction, misconceptions about HIV/AIDS, characteristics of effective health promotion messages, and role plays of conversations endorsing safer sex. Community-level triggers such as posters within the bar and buttons worn by popular opinion leaders promoted the intervention and encouraged dialogue between bar patrons and opinion leaders; often, these popular opinion leaders were bartenders. Bartend-ers have been found to be successful as opinion leaders because they have more and less busy moments, are often casual yet well-trusted confidantes, and are "on-site" regularly.

The use of this type of a natural helper approach is especially appropriate for STI and HIV prevention because opinion leaders can reach populations not easily accessed by health professionals. For example, harnessing the Internet, Chat Room-Based Education and Referral/Men for Men (CyBER/M4M) is an ongoing intervention to increase STI and HIV knowledge and testing within local existing chat rooms designed to facilitate social and sexual networking among MSM (Rhodes et al., 2007). CyBER/M4M educators, who are trained in-dividuals from the MSM community and are familiar with the chat room cul-ture, participate in the development and distribution of culturally relevant chat room dialogue triggers and educational materials that use culturally relevant channels (i.e., chat rooms). They provide information and skills building around safer sex and risk reduction and affect the norms regarding sexual risk within online social networks. Implicit in this approach is the exchange of social sup-port (Eng & Parker, 2002). From a public health perspective, the empirical as-sociations found between social support and health (Berkman, Glass, Brissette, & Seeman, 2000; Broadhead et al., 1983; Cassel, 1976; Kaplan, Cassel, & Gore, 1977) hold substantial potential for translating the health-enhancing effects of social support into interventions (Heaney & Israel, 2002).

Adoption and adherence to safer sex behaviors among MSM, as among all populations, is complex. The diversity among MSM mirrors the expansive di-versity of society as a whole. Whether exploring needs through basic behavioral and epidemiologic research or planning, offering, providing, or evaluating one-on-one counseling or support services, referrals, clinical services, or group- or community-level interventions designed to affect sexual risk behavior, it is key to move beyond assumptions about MSM men. As with any population or sub-group, a comprehensive understanding of the individual as he exists within a variety of influencing contexts is key to successful intervention. These contexts include a variety of partnerships and family systems, spatial neighborhoods and social networks, institutions (schools, workplaces, and religious organizations),

racial and ethnic communities, and other influencing contexts from the larger society. These contexts have unique norms and cultures and impose expectations that create and interact with the individual's sense of self and identity. These influencing contexts vary in the messages, overtly and covertly, relayed about being MSM. These messages are internalized and affect each individual differently.

Adolescents and Young Adults

Risk Among Adolescents and Young Adults

In general, participation in sexual activity increases with age during adolescence and young adulthood. Adolescent males are likely to initiate sexual behaviors at younger ages than adolescent females, as African American males and females are more likely than Hispanic/Latino or non-Hispanic/Latino White males and females to do so (CDC, 2002b). From the 1970s until the mid-1990s, the initiation of sexual behaviors among teenagers occurred at increasingly younger ages (Forrest & Singh, 1990; Zelnick & Kantner, 1980). Between 1991 and 2003, however, the percentages of 9th-grade through 12th-grade students who had had sexual intercourse decreased from 54% to 47%, and there were corresponding decreases among African American, Hispanic/Latino, and non-Hispanic/Latino White adolescents (CDC, 2002b; Grunbaum et al., 2004). A 2003 study found that by 12th grade, 61.6% of males and females had had vaginal intercourse (Grunbaum et al., 2004). Between 1991 and 2003, the number of adolescents having had four or more sex partners in their lifetime decreased, and the number who had made use of a condom at last sexual intercourse increased (Biddlecom, 2004; CDC, 2002b; Grunbaum et al., 2004). These improvements in health outcomes are attributed to multiple efforts by parents, schools, community organizations, health care providers, religious organizations, the media, and governments agencies to reduce sexual risk among adolescents and young adults (CDC, 2005b).

Rates of participation in oral sexual activities were not assessed in adolescents and young adults until recently (Mosher, Chandra, & Jones, 2005). In 2002, cross-sectional data of males ages 15–24 years indicated that rates of participating in any oral sexual contact with a member of the opposite sex were approximately 25% at age 15, 63.5% at age 17, 74% at age 19, and 82% ages 22–24. Rates for females were comparable at 26% at age 15, 55.5% at age 17, 74% at age 19, and 85% at ages 22–24. STI prevention efforts have not always focused on safer sexual practices for those participating in oral sexual activities, either alone or in combination with other sexual behaviors, suggesting a need to enhance intervention strategies to include oral sexual acts among adolescents and young adults.

In general, those who initiate sexual intercourse at younger ages report a higher number of sexual partners in their lifetime and are at greater risk for an unintended pregnancy and/or sexually transmitted infection, largely due to higher rates of unprotected sexual encounters. Thus, safer sex interventions in adolescents and young adults are aimed primarily at delaying the initiation

of sexual activity for those not yet sexually active and, among those already sexually active, reducing the incidence of STIs and unplanned pregnancies. Although the behaviors to be initiated or sustained are somewhat similar for either the prevention of STIs or pregnancy (e.g., condom use, reduction in the number of sexual partners), the focus of the interventions and the information provided vary.

Barriers to Safer Sexual Practices

Many studies have investigated barriers to condom use among adolescents and young adults. Some of the most frequently mentioned barriers are the cost of condoms; their interference with pleasure and spontaneity; embarrassment about purchasing condoms; difficulty negotiating condom use with partners; and/or lack of partner support (Crosby et al, 2004; Kline & Van Landingham, 1994; Pulerwitz, Amaro, DeJong, Gortmaker, & Rudd, 2002; Smith, 2003); alcohol and other substance use (Chesson, Harrison, & Stall, 2003; Fortenberry, 1995; Kline & Van Landingham, 1994; Santelli et al., 2004); younger age (DiClemente et al., 2003; Santelli et al., 1999); greater number of sexual partners (DiClemente et al., 2003); and low perceived need (DiClemente, Wingood, & Crosby, 2003; Wendt & Solomon, 1995). Factors not predictive of condom use consistently are fears of contracting HIV, knowledge about STIs, and a prior history of STIs (Crosby et al., 2004; Diamond & Buskin, 2000; Fortenberry, Brizendine, Katz, & Orr, 2002). Sexual coercion may also play a more significant role in younger women's sexual behavior than has been thought previously (Shrier, Pierce, Emans, & DuRant, 1998). Incidents of rape, sexual assault, and emotional coercion place women at increased risk for negative health outcomes.

Among adolescents and college students, the consistent use of condoms, although increasing, is lower than desired. Condom use also appears to be higher in casual relationships or those of shorter duration than in long-term and/or exclusive sexual relationships (Doval, Duran, O'Donnell, & O'Donnell, 1995). The movement away from consistent use of condoms in long-term relationships may reflect the progression to a more stable, exclusive status, where there is perceived trust in the partner, as well as a decision to use an unobtrusive or more effective method of contraception, such as oral contraceptives. The higher use of nonbarrier methods of contraception, particularly oral or other hormonally based contraceptives, has increased the risk of acquiring a STI among young adults who are not in exclusive sexual relationships and do not also use condoms for the prevention of disease (Wendt & Solomon, 1995). These data suggest that condoms are viewed primarily as a means of contraception, not as protection against STIs.

Despite increasing knowledge of the transmission of STIs and HIV, many individuals underestimate their vulnerability to contracting a STI. Adolescents and young adults who are just becoming sexually active are particularly likely to believe they are invincible to these risks (DiClemente et al., 2003). The need for education and intervention with adolescents and young adults is particularly crucial during this period of life as patterns of sexual behavior are tried and adopted and may frame subsequent behavior and practices during adulthood.

Intervention Research

A variety of different interventions have been used with adolescents and young adults to encourage condom use, safer sex, and effective methods of contraception for those persons who are sexually active. Strategies that have been developed include peer education programs, didactic lectures, patient education in student health or community health centers, school-based clinics, school-based classroom educational programs, brochures, increasing condom availability, skills training, and presentations by print and broadcast media.

Informational programs have been the most widely used interventions in this population, with some varying degree of success. Education alone has not always been related to behavior change without also teaching skills training and modifications in attitudes or beliefs about sexual activity and STI contractions. Skills training aimed at addressing social interactions provides young adults with methods to increase interpersonal competencies to resist coercion and peer pressure and increase skills to manage and negotiate their preferences successfully (St. Lawrence et al., 1995).

In general, providing safer sex interventions to adolescents is a socially sensitive issue. Concerns have been expressed that providing explicit information or skills training may serve to condone or promote sexual activity. Others, however, have advocated a more explicit and interactive approach because of the high rates of sexual activity among adolescents and the fact that sexual activity is rarely followed by a return to abstinence once it has been initiated (DiClemente, 1993; DiClemente et al., 2003). In addition, federal funding for educational programs has largely been restricted to abstinence-only programs in the past decade, which has limited the range of acceptable prevention strategies in school-based interventions (Landry, Darroch, Singh, & Higgins, 2003). Such programs often focus on abstinence as the best or only option for pregnancy prevention, rather than presenting abstinence as the best among multiple contraceptive choices. Focusing on the ineffectiveness of contraceptive methods, except for abstinence, and not providing students with information on how to use methods effectively may contribute to sexually active adolescents' and young adults' poor use of contraceptive methods or failure to use any at all (Bearman & Bruckner, 2001; Jemmott et al., 1998). Abstinence-focused programs are also not as effective or practical among those youth who are already sexually active, so it is necessary that a range of information be included in effective prevention materials and programs (Aten, Siegel, Enaharo, & Auinger, 2002).

Although there has been some progress in recent years in delaying the onset of sexual activity in adolescents and in increasing condom use, the prevalence of STIs and unplanned pregnancy still necessitates the development and long-term evaluation of effective prevention strategies for adolescents and young adults. These programs should be tailored to address specific needs for information about pregnancy and STI prevention, as well as to take into account the specific needs of the subgroups to be addressed (e.g., minority populations, women, poor individuals, well-educated persons). Tailoring the information to the developmental stages and transitions that occur during adolescence and young adulthood has also been identified as an important component (Pedlow & Carey, 2004). In addition, sexual behavior is a social activity, and, thus, the

social context in which sexual behavior occurs and is negotiated and managed needs to be considered in effective prevention efforts.

Women Who Have Sex With Women (WSW)

Risk Among WSW

Research on STI rates and prevention strategies for women who have sex with women (WSW) and bisexual women is lacking. It is often assumed that WSW are at low risk for the contraction of STIs, which may lead to unsafe sexual practices. However, the actual lifetime rates of STIs between WSW have been found to be roughly equivalent to those of heterosexual women (10%–20%; Diamant, Lever, & Schuster, 2000; Skinner, Stokes, Kirlew, Kavanagh, & Forster, 1996).

Part of the difficulty in examining safer sexual practices among women who are not exclusively heterosexual is in how terms such as "lesbian" or "bisexual" are defined in research investigations or survey tools (McNair, 2005). In fact, in most behavioral and epidemiologic studies, including those studies that are population based, measures of sexual orientation are not included routinely (Gay and Lesbian Medical Association, 2001; Greenwood et al., 2005; Marrazzo, 2004; Rhodes & Yee, 2006; Sell & Becker, 2001). Research in this area is often based on very small sample sizes, such as convenience samples of clinic attendees or volunteers, and there is a lack of uniformity and clarity regarding women's sexual history and practices (Marrazzo, 2004).

Predictors of Risk

It has been reported that approximately 80% of women who may now engage in sexual activities exclusively with women have had sex with a man at some point in their lifetime (Diamant, Schuster, McGuigan, & Level, 1999). Thus, a women's sexual history regarding the sex of her partners can be an important determinant in establishing her lifetime STI and HIV risk.

In general, STI risk has been found to increase among WSW who have a higher number of female partners and independently among those with a higher number of male sexual partners (Diamant et al., 2000). Sexual practices involving digital-vaginal or digital-anal contact and the use of penetrative sex toys have been reported as a means for STI contraction (Bailey, Farquhar, Owen, & Whittaker, 2003; Fethers, Marks, Mindel, & Estcourt, 2000). Sexual practices that involve the transmission of cervicovaginal secretions may also be related to higher rates of bacterial vaginosis, which can be related to problems in the upper genital tract, such as pelvic inflammatory disease, as well as greater risks of acquiring other STIs, such as gonorrhea and HIV (Marrazzo, 2004; Marrazzo, Coffey, & Bingham, 2005; McNair, 2005). WSW and bisexual women have also been found to have higher rates of behavioral risk factors, such as alcohol and illicit drug use (Friedman et al., 2003; Hillier, De Visser, Kavanagh, & McNair, 2003), sexual risk tasking, sexual abuse (McNair, 2005), and lower levels of social support and self-esteem (Jordan and Deluty, 1998), all of which have been found to be negatively related to safer sexual practices. One of the more problematic factors, however, is the perception that WSW have lower rates of STIs.

This leads to an inaccurate perception that they have a low STI risk and that they therefore do not need knowledge about how to protect themselves in sexual activity with other women (Diamant et al., 2000; Morrow et al., 2000).

Intervention Research

Although it is clear that many WSW do not know how to engage in safer sex behaviors (Fishman & Anderson, 2003), at present, there is a lack of tested interventions that have been used with WSW populations to increase their knowledge of their STI risk and to teach them how to prevent risky sexual behaviors. Part of the difficulty has been the lack of knowledge about rates of STIs among exclusively female partners and how specific STIs are transmitted between women. Clinical screening guidelines for annual cervical cancer screening are meant to apply to all women, regardless of their sexual orientation, and can serve as a mechanism to detect and treat STIs among WSW (Marrazzo, 2004). The CDC has also provided brief STI/HIV prevention guidelines for WSW (CDC, 2006b). In addition, the CDC Web site regarding gay, lesbian, bisexual, and transsexual health issues is also updated on a periodic basis to provide information regarding preventive health behaviors (http://www.cdc.gov/lgbthealth). Other types of written materials are increasingly being developed for WSW (Booth, 2002), which can also serve as a guide for practicing preventive behaviors among WSW.

Information regarding effective interventions for the prevention of STIs among WSW has not been reported in the published literature to date. The development, implementation, and evaluation of interventions targeting WSW should be a priority in the coming years in order to reduce the incidence of STIs among these individuals.

Conceptual Considerations

The adoption and maintenance of safer sexual behaviors and STI prevention strategies is of critical importance. Intervention strategies must largely focus on the modification of very intimate behaviors between individuals, which in themselves are shaped by the larger interpersonal and social environment. Personal meanings attached to sex, societal norms and expectations for behavior, and attitudes strongly influence sexual behaviors and the adoption and maintenance of preventive strategies. In addition, the diverse population groups affected by unsafe sexual practices make devising effective strategies extremely challenging.

The majority of research regarding safer sex has been completed in the past several decades. Research across many subgroups is still focused on delineating predictors of safer sexual practices and developing and testing effective strategies to modify behavior. The state-of-the science has not progressed to where there are multiple, effective interventions that are being widely disseminated and used in the population.

Several cross-cutting themes exist that deserve consideration:

■ Sexual activities are often viewed as individual acts, rather than as social acts engaged in by two or more individuals. Interventions that have

focused on changing the behavior of individuals without regard to the social relationship inherent in sexual behavior have been relatively ineffective. Condom use should be viewed as an attribute of a relationship, rather than as an individual attribute.

■ Sexual behavior is often viewed as monosemic. However, sexual behavior has different meanings in different contexts, and, consequently, different codes of behavior apply in different situations. Attention should be focused on the type of relationship in which sex is shared (e.g., casual or primary partner; the exchange of sex for money, shelter, food, or drugs) and the factors that promote or reduce safer sexual practices in each of these contexts.

■ Power imbalances in relationships are often ignored. Across all categories, the less powerful, whether they be uneducated, young, women, or economically or psychologically dependent on their partners, seem to be the least successful in changing their behavior. These individuals are often at a disadvantage in negotiating safer sexual practices, because they have less power and control than their partners in their sexual relationships. These observations suggest the need for intervention efforts that target the empowered partner separately from, and in equal proportion to, the disempowered partner in the relationship.

■ Social norms and gender roles strongly influence the ability to implement and maintain safer sexual practices. Beliefs about appropriate behavior for males and females are strongly ingrained across subgroups of the population and need to be considered in intervention efforts. Gender-specific interventions may be required.

■ Ethnic and cultural differences influence the adoption of safer sexual practices. Ethnicity is a category that glosses a complex set of political, economic, and social interactions. Poverty is highly correlated with ethnicity and the increased risk of disease, but cultural or ethnic differences should not be confused with differences engendered by political and economic forces. For interventions to be effective, they must incorporate ethnic values and priorities, as well as specific attitudes and behaviors toward the adoption and maintenance of safer sexual practices.

■ Results from many of the studies suggest that greater success in adopting and maintaining safer sexual behaviors is obtained when action is taken early. It may be easier and more efficient to prevent unsafe sex than it is to attempt to modify existing patterns of unsafe behavior. For instance, middle-aged women who initiated sexual activity when the primary focus was on pregnancy prevention may have used oral contraceptives primarily. These women who are now in new sexual relationships at midlife have to reorient their view of "protected" intercourse to include not only contraception but also the prevention of STIs.

Research Needs

Future research needs and priorities include the following:

■ Because researchers have relied on cross-sectional data to infer trends in sexual behaviors and success in modifying and maintaining safer

sexual behaviors, more research is needed to follow cohorts of individuals in order to understand trends and evaluate the effectiveness of intervention programs over time.

■ More research regarding how the dynamic environment through changing social norms, medical advances, and technology, affect risk is needed. For instance, AIDS fatigue, methamphetamine use, medications used for sexual dysfunction and sexual satisfaction enhancement (i.e., Viagra, Levitra, and Cialis), barebacking, migration and immigration trends, and the Internet contribute to risk among various populations and subgroups in profound ways. Furthermore, emerging technologies such as microbicides hold promise and further challenges for pregnancy and disease prevention.

■ A thorough understanding and a comprehensive operationalization of masculinity are absent from much of the sexual health literature. Research utilizing constructs and measures that assess endorsement of beliefs and values about manhood are needed to test and build models that embed masculinity within a risk-reduction framework.

■ With the increase in oral sexual behaviors among adolescents and young adults, intervention strategies may need to be broadened and re-evaluated among heterosexual populations to include more specific information about sexual risks associated with these types of sexual activities.

■ Research that is authentic and explores the health and sexual well-being of women who have sex with women (WSW) is needed. WSW may in fact be one of the most understudied groups in the STI and HIV literature.

■ Studies of the sexual practices and intervention needs for middle-aged and older adults are necessary in order to reduce the sexual risk of these persons, who are often neglected in STI prevention efforts.

■ Studies focused on identifying effective strategies to change the negative attitudes toward condoms, particularly among males, may prove to increase condom use across people in all age and ethnic groups.

Conclusion

Research designed to increase and promote the maintenance of safer sexual behaviors is of paramount importance but is extremely challenging to complete. Research efforts in recent decades have provided needed information that can be used to guide the development, implementation, evaluation, and refinement of intervention efforts. Targeted future research that builds on what is currently known and understood will serve to enhance public health efforts to reduce the spread of undesirable health consequences associated with unsafe sexual practices.

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Intervention Elements Promoting Adherence to Mindfulness-Based Stress Reduction (MBSR) Programs in a Clinical Behavioral Medicine Setting

14

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This chapter describes recent applications of *mindfulness meditation* in clinical health care settings centered on the Mindfulness-Based Stress Reduction (MBSR) program established at the Stress Reduction Clinic and its umbrella institute, the Center for Mindfulness in Medicine, Health Care, and Society (CFM) at the University of Massachusetts Medical School (UMMS). Since the previous edition of this chapter, there has been an explosion of interest in mindfulness, evident in the proliferation of programs in mindfulness-based stress reduction (MBSR) and close derivatives involving cognitive and other forms of psychotherapy (Germer, Siegel, & Fulton, 2005; Teasdale et al., 2000), eating awareness training, art therapy for cancer patients, and childbirth and parenting education. It is also evident in the range of conceptual and construct analyses (Bishop, 2002; Brown & Ryan, 2003), operational definitions (Kabat-Zinn, 2003; Bishop et

al., 2004), and empirical investigations of mindfulness-based interventions reviewed by Baer (2003) and Salmon et al. (2004). This literature underscores not only the increasing number and sophistication of clinical outcome studies but also the increasing breadth of applications in medicine, health care, and psychology (Walsh and Shapiro, 2006). Mindfulness- and acceptance-based therapy models are referred to as the "third wave" of Cognitive-Behavior Therapy (Hayes, Follette, & Linehan, 2004). Moreover, mindfulness-based approaches are now cited in medical journals as empirically validated health care interventions in their own right (Astin, Shapiro, Eisenberg, & Forys, 2003).

The growing interest in mindfulness in clinical medicine itself, the context in which MBSR developed, is related to the fact that medical practice is by necessity rapidly becoming far more participatory than its 20th-century counterpart (Epstein, Alper, & Quill, 2004; Kabat-Zinn, 2000). While medical care has always been participatory to some degree because of the primacy of the doctor-patient relationship within the Hippocratic calling, it is also true that in large measure, most 20th-century medicine has been characterized by authoritarian, paternalistic physician-patient relationships. In this context, the patient's point of view has historically been less relevant to treatment than that of the physician or even unacknowledged (Toombs, 1993) because of the tacit habits and dictates of medicine itself (Epstein, 1999).

While the biopsychosocial perspective (Engel, 1977) and increased understanding of suffering and illness (Cassell, 1999) in patients seeking medical treatment have improved patient-practitioner relationships, mindfulness-based approaches offer an even broader entrée and perspective into these relational dynamics. When patients *and* practitioners practice mindfulness, *both* may begin to experience more directly their own suffering *from the inside out.* Often overlooked or undervalued, the process of learning to "own" these inborn, archetypal dimensions of humanness can alter the physician-patient relationship and the entire healing enterprise. Adherence may be affected by the mutually shared honoring of these interpenetrating realities and set the stage for a more authentic patient-practitioner relationship (Santorelli, 1999).

The process of caring for people in times of both health and illness increasingly involves active listening to the patient's experience, collaborative problem solving, and negotiated decision making. This entails recognizing and respecting the patient as a person, rather than just an interesting problem or case. In turn, this necessitates sensitivity to the actual *lived experience* (Toombs, 1993) of the patient and an appreciation for its first-person manifestations, embodiment, and meaning. Connecting with people in this way is a powerful stimulus for mobilizing inner resources to promote healing and coping with chronic medical conditions and other life-altering stressors. Making this connection is fundamental to the MBSR program, a factor we believe is directly relevant to high-level adherence (Santorelli, 1999; Kabat-Zinn, 2005).

One early manifestation of the trend toward greater participatory health and medical care was the rapid proliferation of hospital- and clinic-based MBSR programs. Currently, more than 240 hospitals and clinics nationwide and abroad offer MBSR programs, in which compliance rates are typically high (Kabat-Zinn and Chapman-Waldrop 1988). The program originated with the founding of the Stress Reduction Clinic at the University of Massachusetts Medical Center in 1979. Since 1995, it has been embedded within the larger

Center for Mindfulness (CFM) in Medicine, Health Care, and Society, within the Department of Medicine, Division of Preventive and Behavioral Medicine. As originally conceived, MBSR was an outpatient service, based on a patient education model emphasizing self-care as a complement to traditional medical treatment (Kabat-Zinn, 1990; Kabat-Zinn, 1993). Since its inception, more than 17,000 medical patients and other participants have completed the program, consisting of weekly sessions based on intensive training in mindfulness meditation. Between 1979 and 2000, more than 90% of all referrals to the program were from physicians, with the remainder coming from other health professionals. However, in recent years, there has been a steady increase in self-referrals to the Stress Reduction Program, to the point that over the 4-year period 2002–2006, the majority of enrollments (51%) were self-referrals, with only 49% from within the medical system (S. Santorelli, 2007, personal communication).

Despite changes in referral sources at UMMS and modification of the pre- and post-program assessment procedures described in this chapter, program completion rates remained unchanged (S. Santorelli, 2007, personal communication). Overall completion rates for a one-year period in 2002, based on 1,254 program participants, remains high (median completion rate > 80%). Data for enrolled participants for the period 2002–2006 (N = 1,520) revealed a comparable 85% completion rate. This pattern of high adherence is consistent with results of early outcome studies (Kabat-Zinn, 1982; Kabat-Zinn, Lipworth, & Burney 1985; Kabat-Zinn, Lipworth, Burney, & Sellers, 1987; Kabat-Zinn & Chapman-Waldrop, 1988; Kabat-Zinn et al., 1992; Miller, Fletcher, & Kabat-Zinn, 1995). The UMMS-based MBSR program is the prototype for clinically oriented mindfulness-based group interventions that have been widely adapted for use in other clinical settings. In this chapter, we focus on elements of the UMMS program that, on the basis of 29 years of clinical experience, we believe are particularly potent in both engaging and sustaining active participant involvement.

Mindfulness–Based Stress Reduction (MBSR)

MBSR is based on intensive training in mindfulness meditation, the systematic cultivation of nonjudgmental, moment-to-moment attention (Kabat-Zinn, 2003).

The following description and discussion are based on the MBSR Program at UMMS. Following orientation and enrollment in the program, participants are immersed in eight weekly 2.5–3.5 hour-long, instructor-taught classes for approximately 30 individuals with a wide range of medical and psychological conditions. This heterogeneity is deliberate, for several reasons. First, it is a practical acknowledgment that stress and suffering accompany all forms of medical and psychiatric maladies. Second, it bypasses the inherent tendency of groups sharing a particular diagnosis to focus primarily on specifics of the disease burden itself. Third, being surrounded by fellow participants with a wide range of diagnoses encourages perspective taking and an immediate shift of focus onto what is "right" with them, rather than what is "wrong." Finally, the program encourages an investigation and sharing of basic life experiences that individually and collectively contribute to a sense of integrity and wholeness,

akin to the salutatory perspective on health (Antonovsky, 1987). This sense of shared humanity is underscored by a day-long retreat held on the weekend following the sixth session and attended by all participants in the current program cycle (four per year), and prior program graduates, as well. As many as 150 participants attend these day-long retreats, which reinforce and deepen mindfulness through extended practice. They also serve as "booster sessions" for graduates to help sustain, deepen, and further integrate mindfulness into their everyday lives. Current participants benefit from seeing program graduates return to engage in a day of "non-doing" that may at first seem daunting and from hearing others speak and share their experiences toward the end of the day (Kabat-Zinn, 1990; Santorelli, 1999).

Prior to 2001, extended individual interviews were conducted with virtually all potential participants referred to the Stress Reduction Clinic to evaluate their suitability and to provide an overview of the program (Kabat-Zinn and Chapman-Waldrop, 1988; Santorelli & Kabat-Zinn, 2002). Since then, group-based orientation sessions have replaced the original individual interview model. During these sessions, baseline assessment questionnaires are administered, and essential information about the 8-week program and an introduction to mindfulness are presented to groups of 15–40 individuals. An additional brief screening interview is also conducted to further ensure the appropriateness of each candidate, augmented by further assessment if warranted. This format is highly cost-effective, resulting in a 30% saving in operating expenses (S. Santorelli, 2007, personal communication) while ensuring that participants are appropriately screened and well informed about the program. These orientation sessions were phased in over time, making it possible to compare the impact of both pre-admission formats on program outcome. Between 2001 and 2006, symptoms and global measures of distress using the Medical Symptom Checklist (MSCL) and SCL-90-R inventories showed comparable and significant reductions in these outcome measures for both models (S. Santorelli, 2007, personal communication).

During the program itself, participants are exposed to four primary mindfulness practices: (1) the Body Scan Meditation; (2) Sitting Meditation; (3) Mindful Hatha Yoga; and (4) Mindful Walking. These formal mindfulness practices and the rationale for their use are described in detail elsewhere (Kabat-Zinn, 1990, 1994b, 2005; Santorelli, 1999). Other structural elements of the program include (a) home practice (45–60 minutes per day, 6 days per week) using CDs; (b) a workbook with daily awareness exercises; (c) the all-day retreat; and (d) a post-program assessment.

Home practice, an integral element of the program (Kabat-Zinn, 1990; Santorelli, 1999) is structured using CDs to guide participants through the Body Scan, Sitting Meditation, and two Mindful Hatha Yoga sequences, each approximately 45 minutes in duration. These sessions emphasize noticing (without becoming preoccupied with) sensations associated with the body in stillness and in movement, as well as transient thoughts and emotions that inevitably come and go. In addition, "informal" mindfulness practices are also assigned each week involving aspects of daily living, such as breathing, walking, driving, cooking, eating, cleaning, showering, talking, listening, working, parenting, and playing. This aspect of the practice emphasizes and builds on (1) awareness of body sensations and carriage of the body cultivated in formal practice; (2) awareness

of emotional states, thoughts, and perceptions that arise during daily activities; and (3) awareness of stressful situations, the events that trigger them, and possible responses that might serve as alternatives to habitual, automated reactions. Because informal practice is woven into the fabric of daily life, it requires little extra time and is viewed as highly useful by a majority of responders in follow-up studies (Miller, Fletcher, & Kabat-Zinn, 1995).

In addition to practicing formal meditation during class sessions, participants spend considerable time in dialogue with course instructors and with each other about their personal experiences with meditation practice. These interactions constitute another means of integrating mindfulness into common aspects of everyday life (e.g., mindfulness of speech). The dialogue can be extremely animated, cogent, sensitive, and emotionally moving, while reinforcing the sense that participants and instructors alike share in common expertise and creativity in facing life's challenges.

MBSR and Adherence: Descriptive Factors

Outcome studies noted earlier assessing the impact of the MBSR program tend to report high rates of program completion and substantial participant engagement in the formal and informal class- and home-based mediation practices. We believe the following characteristics of MBSR contribute to this pattern of strong commitment:

1. A time-limited, group format of sufficient duration to foster lifestyle changes
2. An educational orientation to elicit active participation and self-inquiry
3. A range of mindfulness practices to accommodate individual temperaments
4. Highly developed instructor competencies, including a personal meditation practice
5. Recognition of how suffering and wholeness unite participants and instructors
6. Meditation practices that foster sensitivity to mind-body interactions
7. Heterogeneous group composition
8. An all-day silent retreat
9. Emphasis on growth and learning via coping, sharing with others, and even unwanted distress.

We now consider adherence in relation to (1) entry into the MBSR program; (2) initial, intermediate, and end-stage sessions; and (3) post-program assessment and relapse.

Referral Procedures and Pre-Program Orientation

The intention of the original MBSR individualized screening interview was to provide outpatient clinical services with minimal exclusionary criteria—primarily active suicidality, severe psychopathology, or both (Santorelli & Kabat-Zinn, 2002). It also introduced participants to mindfulness, as taught

in the program. The current procedure streamlines this procedure, via group orientations and briefer personal interviews.

Historically, a network of referral sources was developed throughout the medical center and surrounding community. Various referring physicians even participated in the MBSR program themselves, attended in-service programs, or developed a feeling for referrals based on patients they had referred in the past and from periodic updates sent by the clinic. Since the original focus of the program was on medical patients, the incidence of severe psychiatric symptomatology was relatively low and remains so, although symptomatic anxiety and depression were (and continue to be) common.

Referral procedures always exert some degree of influence on program adherence by selecting potential candidates likely to do well in the program. However, since 2001, entry has shifted from being primarily physician-based to self-referrals (S. Santorelli, 2007, personal communication). Although this eliminates one screening level, it capitalizes on the heightened motivation of those who actively seek out the program. This shift appears to reflect several factors, including the momentum that has developed over years of operation, with thousands of participants from the immediate geographic region who serve as a potent word-of-mouth referral source. Second, the program increasingly appeals to clients facing a broader range of challenging life circumstances, not just those of a medical nature. Third, this trend reflects a broader social movement toward a participatory model of health care, health maintenance, and disease prevention to which MBSR has contributed. Fourth, meditation has become a more common and accepted aspect of experience in contemporary society. Finally, and perhaps most important, the philosophical basis of this intervention model extends beyond medicine to other facets and strata of society.

Orientation sessions address this increasing diversity by providing a broad overview of factors that create stress and emphasize the importance of taking personal responsibility for one's behavior. This helps distinguish the program from traditional medicine, which emphasizes predictable diagnostic and treatment procedures.

The fact that prospective participants are provided with a detailed explanation of the program may have at least two potential effects on adherence. First, it discourages enrollment by individuals who are not up to the challenges posed by the program. Second, some may decline to participate at a particular point in time because they are not able or willing to make the necessary commitment of time and energy.

Participants are exposed from the very start to an orientation that explicitly and somewhat paradoxically emphasizes nondoing and nonstriving, consistent with the nondualistic meditative approach underlying mindfulness (Kabat-Zinn, 1994b, 2003, 2005). Participants are cautioned from the start against becoming overly invested in setting goals or obtaining "results," such as an end to pain or relief from anxiety. Instead, emphasis is placed on simply doing what is required from day to day in keeping with the present moment orientation of mindfulness. It is further recommended that one suspend judgment about the program until the very end.

In keeping with this orientation, the various aspects of mindfulness are practiced in a manner that slows things down, minimizes extraneous stimulation, and encourages an increasingly intimate relationship with whatever is

encountered internally or externally. The purpose of this is to enhance percep-
tual clarity ("bare attention"), regardless of what one may experience in a given
moment: relaxation, tension, or any other state.

The typical emphasis on behavior change characteristic of most cognitive-
behavioral interventions is absent. Rather, careful self-observation and appre-
ciation for the experience of one's life from moment to moment is encouraged.
Somewhat paradoxically, such acceptance constitutes a positive attitudinal shift
for those who struggle constantly with the desire for things to be somehow
different than they are (Hayes, Follette, & Linehan, 2004; Hayes, Strosahl, &
Wilson, 1999; Williams, Teasdale, Segal, & Kabat-Zinn, 2007).

Initial Program Stage and Adherence

During the first 20 years of the MBSR program, the use of preliminary indi-
vidual interviews resulted in an enrollment rate of approximately 90% and a
subsequent 85% program completion rate among those who attended the first
class (Kabat-Zinn & Chapman-Waldrop, 1988). Nine percent of those who en-
rolled did not attend any classes (no shows), and 15% dropped out before the
program was over. "Completers" were those who attended at least five classes
and were present for the final class, the post-program interview, or both. As
already noted, switching to group-based orientations and brief screening inter-
views has not significantly affected completion rates.

During the program, participants are expected to notify their course in-
structor or administrative support personnel if they miss a class and to make it
up if possible in a concurrent group. Participants who do not call are contacted
within a day by the instructor as an immediate expression of concern. Moreover,
since 2001, group members have had the option of communicating with instruc-
tors via e-mail.

The first class frequently progresses spontaneously to a substantial and
striking level of self-disclosure, as participants are invited to share their rea-
sons for entering the program. Importantly, this is not intentionally elicited by
the instructor but appears to emerge out of the collective sense of affirming
one's commitment to doing something for oneself in a supportive therapeu-
tic and social context. The willingness of most participants to openly express
grief, fear, and pain has several effects. First, it highlights the broad range of
human suffering represented within the room, counterbalanced by the courage
embodied by participants in the face of such suffering. At the very least, this is
inspiring to other class members; at best, it illuminates the possibility inherent
within each individual to bring full-hearted attention to stress, pain, and ill-
ness. In turn, this places any one person's story or problems in a broader con-
text. Some people, no matter how severe their own problems, feel they do not
belong because others' problems seem more serious, a reaction addressed by
emphasizing the unique qualities of each individual's situation. Second, pow-
erful emotional forces are often generated as people begin to share with each
other—many for the first time ever—burdens that may have accumulated for
years, along with more recent stressors that may have catalyzed referral to the
program. One participant, who could speak in class and feel accepted and sup-
ported subsequently remarked that, while riding the subway, he came to see the
entire world was "a community of the afflicted" (Kabat-Zinn, 1994a).

In the first class, participants are provided with a more detailed context and framework for the program, based on the preliminary orientation session. The cultivation of a nongoal orientation and nonjudgmental, moment-to-moment attention to experience is emphasized. Common misconceptions about meditation as an esoteric or mysterious practice are addressed early on. To help counter such views, the first meditation typically involves eating one or two raisins mindfully over a period of several minutes. The sheer novelty and intensity of the experience, coupled with highly focused attention directed at so seemingly mundane a task, typically evokes a range of responses from astonishment to insightful laughter. This simple exercise helps illustrate the nature of mindfulness meditation as a systematic form of attention training, a way of learning to consciously attend to even the most mundane aspects of everyday life. It helps emphasize the pervasive range of opportunities to practice mindfulness. Instructors describe their role as guides or coaches and do not assume an authoritarian stance or tone.

Ongoing Participation and Adherence

As suggested in a qualitative study of participants in an MBSR class (Santorelli, 1992), as well as in our clinical experience with MBSR over almost 30 years, one of the most powerful elements promoting strong engagement in home practice is the deep sense of well-being that can arise from regular exposure to the various "formal" mindfulness practices. This is related to an intentional willingness to reside in stillness and silence, observing the unfolding of one's experience from moment to moment, while assuming a nonreactive, nonjudgmental stance through even difficult and troubling experiences. Sitting meditation in particular emphasizes nonjudgmental, open awareness of whatever arises in body or mind as a natural part of the landscape of consciousness. Such unrestricted awareness is related to feelings of ease, calmness, and perhaps self-efficacy that can develop within the observational process.

It should be noted that meditation and its effects are neither romanticized nor idealized in MBSR. Rather, the emphasis is simply on nondoing and being and *resting in awareness* of whatever arises in the present moment, rather than trying to achieve any particular mind state that might seem desirable. This novel feature of mindfulness training may contribute to long-term engagement, since the core message is that one is already *whole* in the most fundamental way and possessed of inner resources to draw upon even when facing aversive experiences, thoughts, and feelings.

As the program continues, new factors potentially related to adherence come into play as well. The required daily home practice becomes embedded in daily life, drawing on the body scan, sitting meditation, and mindful yoga (using guided-practice CDs), and teaching members to treat life circumstances as opportunities to cultivate focused attention and skillful response patterns. The constant repetition of these elements all emphasizes the same thing: cultivating and sustaining focused attention and familiarity with awareness *itself*. Elements of Western cognitive psychotherapy, including "self-monitoring" and "nonreinforced exposure" (Linehan, 1994), are clearly evident within this orientation, both of which involve selectively directed attention: "self-monitoring" helps clients track thoughts, emotions, and behaviors associated with negative

emotions, whereas "'nonreinforced exposure" encourages confronting anxiety-provoking circumstances as a means of reducing their impact. However, both forms of awareness are intended to enact change in emotions or behavior. "Being mindful" offers an alternative: rather than attempting to fix or alter, deny or subdue unwanted mental or behavioral events, it advocates cultivating *hospitality*—sometimes referred to as generosity or basic warmth—toward whatever arises in the field of awareness. Paradoxically, this more acceptance-oriented stance experience seems to slowly and radically dismantle strong, conditioned behaviors associated with fight, flight, or denial. Simply acknowledging, rather than attempting to change, unwanted thoughts or feelings appears to have positive implications for living one's life more fully (Santorelli, 1999).

Nonjudgmental attention is key to this process, the foundation of an attitudinal framework that makes it less likely that doubts or feelings of inadequacy about how one is doing in the program will adversely impact adherence. "Being mindful" not only makes it more likely that thoughts and feelings that could adversely affect practice motivation will be detected but also provides a conceptual framework and practical strategy for limiting the impact of such thoughts and feelings on adherence when they occur.

This capacity to dispassionately notice and track potentially stressful, anxiety-provoking, or depressive thoughts has been fruitfully incorporated in other recent clinical applications. For example, Teasdale and colleagues (Teasdale, Segal, & Williams, 1995) proposed employing attention regulation (mindfulness) as a method for preventing relapse from clinical depression by teaching participants to detect and respond nonjudgmentally to recurring depressive thoughts or emotions that, if left unacknowledged, might result in full-blown relapse. The positive impact of this theorizing was documented in a large-scale study (Teasdale et al., 2002) in which patients with three or more lifetime episodes of major depression showed a significantly reduced rate of relapse. These results were replicated in a second trial (Ma and Teasdale, 2004), providing further empirical validation of what is now termed mindfulness-based cognitive therapy (MBCT) (Segal, Williams, & Teasdale, 2002; Williams, Teasdale, Segal, & Kabat-Zinn, 2007).

In addition to formal mindfulness practice, participants are encouraged to take advantage of episodic practice opportunities in the context of daily life that provide a means of generalizing treatment effects in a manner consistent with psychotherapeutic "exposure" or "inoculation" (Santorelli, 1992). Both formal and informal mindfulness practices are intended to foster nonattachment, self-acceptance, compassion for others and for oneself, and deepening insight into the nature of "self" and self-in-relationship (Gunaratana, 1991; Kabat-Zinn, 1990; Santorelli 1999; Thera, 1962). Informal practice is especially noteworthy, because it encompasses experiences that may be more challenging than those encountered in the classroom or during quiet practice at home. Teaching basic skills in the context of formal meditation and encouraging their development through daily practice helps bridge the gap between in-class and real-life experiences (Kabat-Zinn and Chapman-Waldrop, 1988; Santorelli, 1992). The time between classes serves as an *in-vivo* laboratory for practicing *a way of being,* not just reducing stress.

Yet another factor potentially related to high program completion rates is a progressive shift from prescriptive adherence to the program to gradually "making the practice your own." Self-exploration and self-responsibility are

increasingly encouraged to help translate program requirements into personal terms concerning both formal and informal practice. For example, participants are encouraged to "mix and match" home practice elements (body scan, sitting meditation, yoga) in personally meaningful ways as the program progresses, within a 45-minute daily practice framework.

Overall, this process-oriented approach to education, growth, and change contrasts markedly with more goal or "end-oriented" models, with important implications for adherence. In essence, participants learn to cultivate an awareness of what they are already doing, thinking, or experiencing in any particular moment, whatever it may be, rather than focusing on trying to change things. Given a willingness to cultivate nonjudgmental awareness in the present moment, there is really little else that one might do or say or think that would somehow *not* reflect inherent adherence. The invitation to simply "pay attention" creates a relatively permissive context within which change can occur, a characteristic now embodied in emerging acceptance-based psychotherapy (Germer, Siegel, & Fulton, 2005; Hayes, Strosahl, & Wilson, 1999; Linehan, 1994). Mindfulness reduces potential resistance because it can be directed toward resistance itself, thereby narrowing the range of what would otherwise be considered nonadherent behaviors.

Finally, the all-day meditation retreat certainly stands out as a key element affecting adherence. The challenge of an entire day (approximately 8 hours) of predominantly silent practice guided by teachers in the presence of other current and past participants provides a rich experiential laboratory for sustained practice of the principal components of MBSR training. It might be described as "quasi *in vivo*," because it entails the shared experience of an environment that is less intimate than the regular classes because of the size (up to 150 people) but is at the same time very different from one's day-to-day living environment. There is a strong sense of a shared community ("*sangha*") common to both the classes themselves and the larger all-day meditation session (Santorelli, 1999).

Prior participants in the MBSR program also benefit from the all-day sessions, which serve as booster sessions to deepen mindfulness practice. They also offer an opportunity to reconnect with teachers and other participants in a setting that may evoke recollections of their reasons for taking the program and of the internal resources they developed at that time. As best we can determine, combining current and former participants in a large practice setting is unique to mindfulness-based interventions. Current participants benefit in part simply from seeing people come back to practice intensively after finishing the program, as well as from reflections that graduates often share during a group dialogue near the day's end (Kabat-Zinn, 1990; Santorelli, 1999).

Adherence and Concluding Weeks of the MBSR Program

As noted, participants are encouraged to devise their own home meditation practice as the program progresses. This feature of MBSR may positively affect end-stage adherence in several ways. First, the element of choice reinforces the importance of personal responsibility emphasized throughout the course.

Second, many participants develop strong preferences for specific techniques by this time (Kabat-Zinn, Chapman, & Salmon, 1997) and are motivated to continue practicing. Finally, this phase serves a preparatory function with respect to closure at a time when participants still have the benefit of contact with each other and their instructors. The last 2 weeks provide opportunities for participants to explore and reinforce individual inclinations and initiatives, and to tailor the program to their own present and anticipated needs. The eighth week (following the eighth and final class) is characteristically termed "the rest of your life," implying that as people prepare to leave the security and structure of the program, the momentum they have developed can continue indefinitely if they make a commitment to maintain the practice.

Post–Program Assessment and Advanced Training

The original MBSR program concluded with participants completing assessment measures and a personal interview with the course instructor at post-program interviews following the last class. Since initiation of the Group Orientation Model, the post-program assessment is now conducted during the final (8th class) session itself. In both models, the purpose of the assessment serves two functions: First, it provides participants with an opportunity to reflect on their experience in the program in terms of meeting their needs and intentions. Second, repeating the assessment measures administered prior to the program provides data for program outcome studies.

Currently, all participants continue to be assessed pre- and post-intervention using the Medical Symptom Checklist (MSCL) and the General Severity Index (GSI) of the SCL-90-R. In the first teaching cycle using the group assessment model, the mean reduction on the MSCL was 30.2% (N = 134), and the mean reduction in the GSI was 51.6% (N = 118) (S. Santorelli, 2007, personal communication). These findings are comparable to those obtained using the individual interview model. Similar reductions were also found for a larger sample of consecutive program participants enrolled in the period 2002–2006; the mean MSCL reduction was 28.7% (N = 724) and the mean GSI reduction, 42.3% (N = 674). Thus, symptom reductions have been sustained despite changes in the intake and post-program assessment procedures, while completion rates across the two models have remained virtually identical (Individual Interview Model = 86%; Group Orientation Model = 85%), using data collected between 2002–2006. Significantly, in the period 1979–2001, virtually all program referrals came from the medical system. Since initiation of the group orientation and assessment model, medical referrals now constitute 49% of the program participants, and self-referrals make up the other 51%. Of those who actually enroll, 38% are medically referred, while the majority (62%) are self-referred. Thus, while referral patterns and assessment procedures have changed, adherence and outcome figures have remained consistently high over 28 years of continuous operation of the MBSR program.

In addition to ongoing all-day retreats, participants may attend "graduate programs" offered periodically to further deepen their meditation practice by applying skills learned during the initial MBSR experience. Focusing on various program themes such as interpersonal mindfulness, coping with holiday

stress, mindfulness and cinema themes, or mindful aging, these sessions meet weekly, biweekly, or bimonthly for several months and incorporate extended periods of meditation practice using methods taught in the basic course, with an overarching focus on application of mindfulness not only to stress and illness but also to health and well-being. Home practice is augmented with additional materials and assignments mailed to participants midway between sessions to encourage ongoing engagement and to help keep the focus on continuously bringing mindfulness to the unfolding of daily life experience. Also, these programs offer those whose practice has relapsed an opportunity to recommit to it, and encourages those who have maintained the practice to explore deeper implications of mindfulness.

Relapse

Relapse to pretreatment mind-states or behavior constitutes a significant impediment to long-term adherence, even following "successful" behavior change interventions. The MBSR program addresses relapse (faltering engagement in and implementation of what one has learned in the program) in several ways. First, the nonjudgmental, nonstriving orientation tends to reframe ideas of "relapse" (and other comparably judgmental terms) in a more benign way that emphasizes acceptance. This idea is increasingly prominent in contemporary cognitive therapies that view acceptance as a fundamental starting point for meaningful change (Germer, Siegel, & Fulton, 2005; Hayes, Follette, & Linehan, 2004). Periodic relapses—ceasing to sustain the meditation practices in one form or another—are treated as a natural part of learning, worthy of attention and curiosity. It is also remediable in any moment simply by re-establishing mindfulness. Thus, one is always only one breath, one moment, one thought away from being fully in the practice, especially if this shift in attention is sustained over time.

Second, meditation practice emphasizes that the present moment is continuously unfolding, presenting itself in new and unique configurations. One comes to appreciate that no two moments are identical, and that there is always the potential to see a new opening, a new choice, and to allow change to occur out of one's deliberately cultivated awareness. A common self-statement describing relapse, such as "I've fallen back into my old patterns again," implies that one is at the mercy of old behaviors, simply repeated without variation. However, this is not only improbable but virtually impossible, owing to the dynamic and fluid nature of experience itself. The words "I" "have fallen back" "into my old patterns" "again" are linguistic labels describing a unique experience that cannot duplicate the past. Attending systematically to present-moment experience, rather than merely thinking about an experience or a moment, loosens "the dominance of evaluative languaging" (Hayes, 1994; Hayes, Barnes-Holmes, & Roche, 2001).

Third, within this framework, a relapse incident can be viewed with generosity and compassion, rather than as a setback. Missing daily practice sessions or feelings of panic, anxiety, or depression can all be seen as simply new opportunities for practice. By framing events in this manner, mindfulness, along with contemporary contextualist thought (Hayes, 1994; Hayes, Strosahl, & Wilson,

1999), cognitive and constructivist psychotherapies (Meichenbaum, 1993), and relapse prevention models (Marlatt, 1985) emphasizes taking a "fresh look" at linguistically driven interpretive biases. In a general sense, this encourages getting beyond linguistic terms like "relapse" used to describe experience (Hayes, 1994; Hayes, Strosahl, & Wilson, 1999; Hayes, Barnes-Holmes, & Roche, 2001) because they embody unconscious, habitual, reflexive, and often idiosyncratic associations that tend to inhibit seeing new possibilities for adaptation, growth, and change. By inviting participants to become more observant of the ebb and flow of beliefs and experiences and less attached to thoughts and self-statements, both voiced and silent, the program encourages moving beyond emotional-laden concepts capable of triggering distressful reactions commonly associated with the "slippery slope" of relapse.

Finally, of crucial importance with respect to relapse is the "phasic," nonlinear nature of human development and learning. Whereas relapse is commonly viewed as a discontinuity in a linear process of change, growth and change are dynamic, nonlinear processes that involve cycles of regression, restructuring, and reintegration. This cyclic progression, documented in a studies of meditation practitioners (Kornfield, 1979) and MBSR participants (Santorelli, 1992), suggests that what might be termed "relapse" or "regression" actually represents an inevitable aspect of learning and personal growth.

Summary and Conclusions

The MBSR program has stimulated considerable research in clinical, health, and experimental psychology. It has paved the way for the development of acceptance-based forms of psychotherapy that have been characterized as the "third wave" of cognitive behavior therapy (Hayes, Follette, & Linehan, 2004)—a clear testament to its impact. Mindfulness-based treatment protocols for depression (Segal, Williams, & Teasdale, 2002), anxiety (Orsillo & Roemer, 2005), and other conditions are becoming more prominent in clinical practice. Many, if not most, of these interventions show the influence of mindfulness meditation as initially conceptualized and developed at the University of Massachusetts Medical Center (Kabat-Zinn, 1990, 2005; Santorelli, 1999).

MBSR teaches participants to pay attention and be present with whatever arises in the field of experience, a message that is easily remembered and applicable in a variety of contexts, through both formal and informal mindfulness practices. The behavioral changes associated with MBSR are equally simple and direct, emphasizing being reflective and responsive rather than reactive, and focusing more on "being" and less on "doing." The orientation is attractive in its simplicity. Although maintaining the practice is both challenging and arduous, MBSR skills can be practiced with many degrees of persistence and awareness. Sitting quietly for a time or lying down and resting in awareness moment by moment with whatever arises in the domain of inner and outer experience is a capability native to all human beings and virtually universally accessible, even though internal associative mind and body states vary widely from person to person. Such mind-body patterns are observable by and profoundly amenable to nonreactive mindful attending (Goldstein & Kornfield, 1987; Gunaratana, 1991; Siegel, 2007; Thera, 1962; Wallace, 2006). MBSR may help provide access

to a new dimension of one's own experience associated with nourishment and growth and stemming from the commitment to bring intentional awareness to the unfolding of one's life. It has been described as an "orthogonal rotation of consciousness" (Kabat-Zinn, 2005). In essence, mindfulness fosters both familiarity and intimacy with body and mind, with self and other, and with the world itself. As this intimacy becomes more fully integrated and embodied, the willingness to inhabit—to live fully inside—one's life becomes increasingly possible and palpably real. If what we are most drawn to as human beings is a direct, fully embodied experience of being alive, regardless of our circumstances, it may be that the connection with such aliveness is the most compelling motive for cultivating a mindful way of being.

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Multiple Risk Behavior Change: What Most Individuals Need

15

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The co-occurrence of risk behaviors—such as tobacco and other substance use, poor quality diet, physical inactivity, stress, and distress—predicts a heightened risk of morbidity and mortality, as well as increased health care costs (Edington, Yen, & Witting, 1997). The majority of U.S. adults meets criteria for two or more behavioral risk factors (Fine, Philogene, Gramling, Coups, & Sinha, 2004; Pronk et al., 2004); yet, to date, most health promotion research has addressed risk factors as categorically separate entities.

Given a window of intervention opportunity, a higher impact paradigm is to target multiple behaviors. Growing evidence suggests the potential for multiple risk behavior change (MRBC) interventions to have much greater impact on public health than single-behavior interventions. In this chapter, we discuss

the need for and evidence base of interventions that target multiple risk behaviors. Recent innovative studies are presented, and methodological, analytic, and theoretical issues unique to MRBC interventions are discussed. We close with consideration of dissemination issues and our vision for this growing area of research.

Background and Rationale for Multiple Risk Behavior Change

Background and Rationale

The major causes of morbidity and premature mortality in the United States—heart disease, cancer, and stroke—are influenced by multiple health behaviors, including smoking, alcohol abuse, physical inactivity, and poor diet. The 52-nation INTERHEART study identified tobacco use, obesity, high lipids, and psychosocial factors as accounting for about 90% of the population-attributable risks for myocardial infarction; fruit and vegetable consumption and exercise were identified as protective (Lanas et al., 2007; Yusuf et al., 2004). Mental illness, or stress and distress more broadly, also place a significant burden on health and productivity in the United States and globally (U.S. Department of Health & Human Services, 1999).

Individuals often struggle with multiple unhealthful behaviors, and there is evidence of co-occurrence among the risk factors. Analysis of data from the 2001 National Health Interview Study indicated that the majority of adults in the United States met criteria for two or more risk behaviors (Fine et al., 2004; Pronk et al., 2004). Tobacco users, in particular, tended to have poor behavioral profiles, with about 92% of smokers having at least one additional risk behavior (Fine et al., 2004; Klesges, Eck, Isbell, Fulliton, & Hanson, 1990; Pronk et al., 2004). In the United States, only 3% of adults met all four health behavior goals of being a nonsmoker, having a healthy weight, being physically active, and eating five or more fruits and vegetables a day (Reeves & Rafferty, 2005).

Among youth, there is evidence of a clustering of dietary patterns and physical activity (Sallis, Prochaska, & Taylor, 2000); tobacco use increases the likelihood of experimentation with illicit drug use (Lai, Lai, Page, & McCoy, 2000), and tobacco and other substance use is highly predictive markers for youth engagement in multiple risk behaviors, including bicycling without a helmet, perpetrating violence and carrying a weapon, not using a seat belt, and having suicidal ideation (DuRant, Smith, Kreiter, & Krowchuk, 1999).

The health care burden is believed to multiply with an increasing number of risk factors in terms of both medical consequences and costs (Edington et al., 1997). Put simply, excess risks lead to excess costs. Figures 15.1 and 15.2 at the end of this chapter show the incremental gain in pharmaceutical and disability costs due to excess risks. Longitudinal data indicate that effectively treating two behaviors reduces medical costs by about $2,000 per year (Edington, 2001). Targeting multiple risk behaviors for change offers the potential of greater health benefits, maximized health promotion opportunities, and reduced health care costs.

Lifestyle behaviors also may serve as a gateway to intervention on behaviors for which individuals have low motivation to change. Confidence or self-efficacy

gained from making changes in one behavior may serve to support changes in additional risks. In a 3-year prospective study, individuals who quit smoking significantly increased their physical activity, whereas continued smokers did not (Perkins et al., 1993). Similar changes were not observed for diet or alcohol use. The change process appears to be similar for different health behaviors, and it may be efficient to work on multiple behaviors at the same time in a single intervention.

Given limited opportunity for health promotion contacts, interventions would ideally address all behaviors relevant to an individual's health profile. Researchers have emphasized that opportunities for intervening on multiple behaviors abound in the applied setting and have reasoned that specifically targeted interventions, even if effective, will be limited in their impact (Hayes, Barlow, & Nelson-Gray, 1999). A science of multibehavioral change is needed.

Definitions

MRBC interventions can be defined as efforts to treat two or more risk behaviors effectively within a limited time period simultaneously or sequentially. By risk behaviors, we mean actions in which individuals engage that impact health. The impact can be negative, as with tobacco and other drug use and risky sexual behaviors, or positive, as with physical activity, fruit and vegetable consumption, and the wearing of helmets or seatbelts. Medical screening behaviors, such as mammography, colonoscopy, cholesterol testing, blood pressure screening, HIV tests, and glucose screening, also are clearly relevant to health and disease prevention and may be included as behavioral targets in MRBC interventions.

The field of MRBC research is at an early stage, with its boundaries still being defined. Historically, much of the research has focused on changing multiple risk behaviors within populations; fewer studies have targeted multiple risks within individuals; and the distinction is meaningful. When MRBC interventions are focused on populations, a program of interventions is offered to a community and community members receive intervention only on the behaviors for which they are identified as at risk. For example, only smokers in a community would receive the quit-smoking program, while individuals with high-fat diets would receive the nutrition intervention and individuals at risk for both smoking and high fat-diet would receive both intervention components. Changes are reported at the population level as a change in means or prevalence rates (e.g., smoking rates). With greater behavioral targets, the relevance of the intervention to the community and systems being served is increased as all members are likely to be at risk for at least one of the targeted behaviors.

When MRBC interventions target multiple risks in individuals, all individuals receive intervention on all targeted behaviors. The potential impact on an individual's health is increased, as are the behavior change demands. MRBC interventions within individuals may be relevant to only a select high-risk group, since participants need to be at risk for all targeted behaviors, though this may be less of an issue with behaviors that co-occur at high rates, such as alcohol and tobacco use or physical inactivity and poor diet. If the intervention promotes concurrent immediate action in multiple behaviors, it may be overwhelming and result in poor adherence. Sequencing change goals or matching

intervention strategies to individuals' readiness to change may facilitate greater adherence and overall change.

To summarize, the main difference between MRBC interventions at the population level and similar interventions at the individual level is that the former matches the intervention strategies to the risk needs of the participants within the community, whereas the latter delivers all interventions to all participants. The former provides interventions more broadly to everyone in the community, while the latter focuses on a more select high-risk group.

Reviews of Multiple Risk Behavior Change Intervention Studies

Studies of MRBC Interventions in Populations

The concept of intervening on multiple risk behaviors concurrently became a focus of attention in the early 1970s and was targeted at preventing cardiovascular disease (CVD) (Labarthe, 1998). One early proposal was a factorial design to evaluate the independent contributions and the joint effects of targeting diet, physical activity, and smoking habits in a single trial, named "Jumbo." The proposal was deemed too costly, however, and the trial was never conducted. Large-scale multifactorial CVD risk factor interventions that were conducted include the Multiple Risk Factor Intervention Trial (MRFIT), the North Karelia Project, the Stanford Three-City and Five-City Projects, and the Pawtucket and Minnesota Heart Health Programs. Youth multifactor interventions also were developed, with a movement toward comprehensive school health programs.

The multibehavioral studies conducted over the past 30 years have had a range of outcomes, from favorable to unfavorable. The interventions have focused almost entirely on practitioner-based modalities such as health advice and counseling from a physician, dietician, or nurse; home visits; and group health education. Community-level promotional materials also have been incorporated. Significant changes were often seen in some but not all targeted behaviors (Emmons, Marcus, Linnan, Rossi, & Abrams, 1994; Sorensen et al., 1996). A Cochrane review of these large multifactor interventions estimated the net reduction in smoking prevalence at 20% (Ebrahim, Beswick, Burke, & Davey Smith, 2006). Changes in dietary and physical activity behaviors, unfortunately, were not reported in the review. The pooled effects suggested that the MRBC interventions had no effect on mortality.

Findings from 14 youth obesity prevention studies that targeted physical activity and dietary change were summarized in another Cochrane review (Summerbell et al., 2005). The studies were conducted in schools and communities, with children and adolescents, in the United States and Europe, representing a diversity of ethnic groups and socioeconomic levels. Most of the studies followed a social learning or environmental theoretical framework. Only 1 of the 14 studies achieved significant changes in both dietary and physical activity behaviors, with the finding significant only for girls and not for boys (Gortmaker et al., 1999). This same study was the only one to report significant reductions in youth body mass index; again, however, the finding was specific to girls.

A recent Dutch, school-based, obesity prevention intervention used individual and environmental components (Singh, Paw, Brug, & van Mechelen, 2007). The intervention yielded significant reductions in waist-to-hip ratio for girls and boys and in the sum of skin fold measurements for girls. Changes in body mass index and fitness, however, were not statistically significant, and changes in physical activity and dietary behaviors were not reported.

Recent Successes in Population-Based MRBC Interventions

While many of the attempts at achieving change in multiple risk behaviors within populations have met with limited success, the story does not end there. Here we describe several recent examples of innovative interventions that have succeeded in stimulating change in multiple risk behaviors and discuss some of the potential reasons for their successes.

Historically, researchers and practitioners have used an action paradigm, prescribing immediate action in a risk behavior. Pushing individuals to make behavioral changes in more than one area, however, can have negative effects. For example, less than 10% of smokers are prepared to take action on more than one risk behavior (Prochaska, Velicer, Prochaska, Delucchi, & Hall, 2006). When instructed to change multiple behavioral risks, individuals can become over-whelmed, disillusioned, and ineffective at making any behavior changes.

In contrast to action-oriented paradigms, which promote immediate action among all participants, the Transtheoretical Model (TTM) recommends tailor-ing of strategies to an individual's intention and readiness to change (Prochaska, DiClemente, & Norcross, 1992). Briefly, the TTM has identified five stages of change defined as *precontemplation,* not intending to change; *contemplation,* intending to change within the next 6 months; *preparation,* actively planning change within the next 30 days; *action,* overtly making changes; and *mainte-nance,* taking steps to sustain change and resist temptation to relapse. To be in action, individuals are required to meet some behavioral criterion for some minimal amount of time (e.g., quit smoking for 24 hours). With most behaviors, the action stage has been defined as lasting up to 6 months, at which time the in-dividual enters maintenance. Other key TTM constructs are decisional balance, or the pros and cons of change, and self-efficacy, operationalized as situational confidence in changing a behavior and situational temptations to engage in a problem behavior. Using the TTM or stage-of-change paradigm, there is con-sistent evidence supporting multiple risk behavior change (e.g., Johnson et al., 2006; Jones et al., 2003; Prochaska et al., 2004; Prochaska et al., 2005).

Three parallel TTM population-based MRBC studies targeted smoking, high-fat diet, and high-risk sun exposure (Prochaska et al., 2005; Prochaska et al., 2004; Velicer et al., 2004). The studies were conducted with employees in worksites, parents of high school students, and patients in primary care. The interventions used computerized expert system interventions delivering tai-lored individualized feedback based on participants' responses to measures of the key TTM constructs. The expert system was repeated at three time points over a 6-month period, and feedback was provided on the basis of both norma-tive data and participants' earlier responses. Combined, the studies included nearly 10,000 participants. Participants assigned to the TTM intervention

group received treatment for the behavior(s) for which they were identified as being at risk on the basis of their baseline stage of change. In all three studies, across all three behaviors, treatment effects were significant at 12- and 24-month follow-up, with the exception of smoking in the worksite study, which had a relatively small number of smokers. Importantly, the smoking cessation effects obtained in these TTM-based MRBC studies were comparable to previously reported intervention effects for TTM studies focused on smoking alone (Prochaska et al., 2006). Further, among smokers in the three trials, treatment of one or two coexisting risk factors (diet and/or sun exposure) did not decrease the effectiveness of smoking cessation treatment, and treatment for the coexisting factors was effective, as well.

Targeting individuals with high cholesterol, another population-based TTM intervention reported significant effects on lipid medication adherence, physical activity, and dietary fat reduction. The treatment group was 50% more likely than the control group to make changes to reach the criterion for action on all three behaviors (Johnson et al., 2006).

The unique advantage of TTM interventions for multiple risk behavior change is that the likelihood of overwhelming participants is greatly reduced and the proportion of the at-risk population participating is likely to be greatly increased, since immediate action is not demanded. With proactive recruitment strategies such as random digit dialing, TTM studies have consistently reported participation rates of 80% or greater (Prochaska et al., 2004; Velicer et al., 2004). Importantly, strategies are matched to participants' readiness to change, and all participants at risk are supported through the change process.

Social cognitive theory, which focuses on the interaction of personal factors, behavior, and the environment, also has been applied to multiple risk behaviors with some success (Bandura, 1986). PREVENT, a telephone-delivered intervention plus tailored materials, based on motivation to change and social-cognitive theory, targeted six behavioral factors in determining colon cancer risk: red meat consumption, fruit and vegetable intake, multivitamin intake, alcohol, smoking, and physical inactivity (Emmons et al., 2005). Participants were 1,247 adults with recent diagnoses of adenomatous colorectal polyps. Intervention participants were more likely to change two or more risk behaviors than were those in the standard care condition. For the individual behaviors, intervention effects were significant for improved multivitamin intake and reduced red meat consumption, and there was less regression in physical activity levels among those receiving intervention over the course of the study. There were no between-condition differences in smoking, alcohol, or fruit and vegetable consumption.

The Mediterranean Lifestyle Program is another successful example of a population-level MRBC intervention (Toobert et al., 2007). This randomized clinical trial for postmenopausal women with type 2 diabetes employed social learning theory to guide intervention strategies to address healthful eating, physical activity, stress management, smoking cessation, and social support. At 12 and 24 months, intervention participants demonstrated improvements in all targeted lifestyle behaviors except smoking (there were too few smokers to analyze effects of the intervention on tobacco use). Additionally, significant treatment effects were seen in psychosocial measures of use of supportive resources, problem solving, self-efficacy, and quality of life.

Studies of MRBC Interventions in Individuals

Few studies have directly compared the effectiveness of multifactor interventions within individuals to that of single-factor interventions, and findings have been inconsistent. A recent review of MRBC interventions in primary care identified large gaps in the field's knowledge base (Goldstein, Whitlock, & DePue, 2004). The review emphasized the successes of interventions targeted on single risks, such as tobacco use, alcohol use, poor diet, and, to a lesser extent, physical inactivity, but acknowledged the dearth of studies in primary care aimed at treating multiple risks.

The strongest evidence for MRBC interventions in individuals has aimed at secondary rather than primary prevention, specifically interventions focused on individuals at high risk for or already diagnosed with CVD (Ketola, Sipila, & Makela, 2002) or diabetes (Norris, Engelgau, & Narayan, 2001). These interventions have targeted tobacco use, physical inactivity, and poor diet, as well as more specific disease management care, for example, adherence to lipid-lowering drugs and hypertensives for those with CVD and blood glucose monitoring and foot exams for those with diabetes. Even in these studies, while the evidence generally has been strong for short-term effects, sustained effects have been difficult to achieve.

A notable exception is the Lifestyle Heart Trial for patients with moderate to severe CVD. The intensive intervention promotes a 10% fat whole foods vegetarian diet, aerobic exercise, stress management, and smoking cessation and provides group psychosocial support. In a small efficacy trial (N = 48), program adherence was reported as excellent and significant intervention effects were seen at 1 and 5 years for reductions in weight and LDL cholesterol, as well as reduction in arterial diameter stenosis and cardiac events (Ornish et al., 1998).

Individuals with drug and alcohol problems are another high-risk patient group of interest for multibehavioral change. In particular, rates of tobacco use are high, and tobacco is a primary cause of death among individuals treated for substance abuse (Hser, McCarthy, & Anglin, 1994; Hurt et al., 1996). The health effects of tobacco and other substance use appear synergistic, 50% greater than the sum of each individually (Bien & Burge, 1990). Historically, clinical lore has discouraged smoking cessation efforts during addictions treatment out of concern that sobriety would be compromised. Tobacco has been viewed as the last remaining vice among those in recovery and a necessary behavioral crutch. A recent meta-analysis examined this issue in 12 randomized controlled smoking cessation interventions delivered to individuals in substance abuse treatment (Prochaska, Delucchi, & Hall, 2004). The interventions were built on a variety of theoretical frameworks, including stage-based or motivational enhancement, cognitive-behavioral therapy, relapse prevention, and pharmacological treatments. Smoking cessation effects were significant at post-treatment but were not sustained at long-term follow-up. Importantly, exposure to the smoking cessation interventions was associated with a 25% increased likelihood of long-term abstinence from alcohol and illicit drugs. The study concluded that, contrary to previous concerns, smoking cessation interventions delivered during addictions treatment appeared to enhance rather than compromise long-term sobriety.

Tobacco treatment studies also have examined the impact of incorporating strategies to prevent weight gain, a common side effect and a potential deterrent to quitting smoking. Efforts to integrate dietary restraint components within tobacco treatment interventions, however, have raised concerns about their potential deleterious effects on motivation to quit smoking (Hall, Tunstall, Vila, & Duffy, 1992). Clinical tobacco treatment guidelines even discourage weight control efforts through dieting so as not to detract from motivations to quit smoking (Fiore et al., 2000). As with tobacco cessation among substance users, the concern is with multiple intervention interference—that change in one behavior may negatively impact change in another.

When there is concern about multiple intervention interference, a sequential treatment approach may be undertaken. A recent study compared the effect of a dietary intervention implemented early in the quit attempt to those of an after-cessation effort and a no-diet control program (Spring et al., 2004). The study reported no difference in smoking cessation rates among the three groups, with some advantage in weight gain prevention among participants in the delayed diet group. Similarly, a recent study evaluating immediate and delayed smoking cessation among veterans in substance abuse treatment reported comparable quit smoking rates, with some apparent benefit to sobriety among participants treated for tobacco use in the delayed-treatment group (Joseph, Willenbring, Nugent, & Nelson, 2004).

Another study examining the impact of simultaneous and sequential targeting of multiple risks concluded that sequential targeting was not superior to, and may be inferior to, a simultaneous approach (Hyman, Pavlik, Taylor, Goodrick, & Moye, 2007). The intervention used stage-based counseling and promoted changes in physical activity, dietary sodium intake, and tobacco use. The theoretical model employed and the types of behaviors targeted certainly may influence the efficacy of a simultaneous and a sequential approach. More research is needed to address this key intervention design issue.

Health behaviors also may be used as a treatment strategy. For example, the effect of exercise for supporting smoking cessation has been tested. A Cochrane review concluded that while exercise promotion did not appear to harm smoking cessation efforts, there was limited evidence that it helped (Ussher, 2005). Only 1 of the 11 identified trials found evidence for exercise aiding smoking cessation at long-term follow-up (Marcus et al., 1999). Unfortunately, only two of the studies reported changes in physical activity, limiting our understanding of the feasibility of efforts to help smokers make changes in their tobacco use and exercise patterns concurrently. Of note, the one study that had significant effects for both quitting smoking and increasing fitness was based on the TTM and matched exercise and smoking cessation strategies to participants' readiness to quit, rather than prescribing immediate action (Marcus et al., 1999).

Co-occurring mental illness often is an exclusionary criterion for clinical trials, and, as a result, the field knows very little about intervening on multiple risks with those with mental problems. Two recent innovative studies, by separate research teams, evaluated tobacco treatments among smokers with current mental illness—one focused on clinically depressed outpatients (Hall et al., 2006) and the other on veterans with posttraumatic stress disorder (McFall et al., 2006). Both reported significant intervention effects for long-term

smoking cessation with no adverse effects on mental health functioning (Prochaska, Hall, et al., 2008). The study with veterans demonstrated the value of integrating tobacco treatment into mental health services, rather than referring out to a separate system of care.

Two other trials examined exercise as a treatment for clinical depression and reported significant changes in physical activity with significant reductions in depressive symptoms (Blumenthal et al., 1999; Dunn, Trivedi, Kampert, Clark, & Chambliss, 2005). The immediate effects of exercise in treating depression were comparable to those of antidepressant medication, with a significantly lower likelihood of depression relapse over time (Babyak et al., 2000). Further, individuals with clinical depression rank exercise among the most commonly tried and effective self-help strategy for managing depression (Parker & Crawford, 2007).

Methodological Issues

Methodological challenges with multibehavioral interventions include the increased time and participant demands for intervention and evaluation components and the lack of direction in the field on how best to conceptualize and analyze multiple risk behavior change.

Measuring Changes in Multiple Risk Behaviors

Approaches taken to minimize assessment and participant burden include efforts to simplify assessment tools, while maintaining rigorous psychometrics, and movement toward more technologically sophisticated and, one hopes, more objective, assessment tools that ideally reduce the burden on participants for data collection. Health risk appraisals are one option for quickly assessing engagement in a wide range of risk behaviors (Smith, McKinlay, & McKinlay, 1989).

More objective behavioral measures include biochemical measures of dietary changes (e.g., plasma carotenoid concentrations), tobacco (e.g., cotinine, anabasine), and other drug use; biometric measures of physical activity (pedometers, accelerometers) and fitness (VO2max); and computerized innovations to assess medication adherence (e.g., MEMScaps). All measures, of course, have their limitations. With biometrics, a metabolite's half-life may be too short to detect sustained behavioral changes, research costs can be high, and participants may not adhere to assessment protocols. In the tobacco arena, consensus guidelines have been developed recommending when bio-information is and is not necessary (Society for Research on Nicotine and Tobacco, 2002).

Alternatively, rather than measuring changes separately for each targeted behavior, measures may be incorporated to conceptualize and assess overall health outcomes due to changes in multiple risks. Examples include changes in weight, blood pressure, cholesterol, or blood glucose due to changes in diet, exercise, and/or tobacco use. Self-report measures of overarching change may include health-related quality of life (Rasanen et al., 2006). The Mediterranean Life Program, for example, reported changes in behavioral, psychological, and quality of life measures (Toobert et al., 2007). Economic measures may include

medical, pharmaceutical, and disability costs (see Figures 15.1 and 15.2). If MRBC interventions ultimately aim to maximize health outcomes, then measures should assess these gains. Longer follow-up periods, however, will likely be necessary to detect changes in these more distal outcomes.

15.1

Excess pharmaceutical costs due to excess risks, age and gender adjusted.
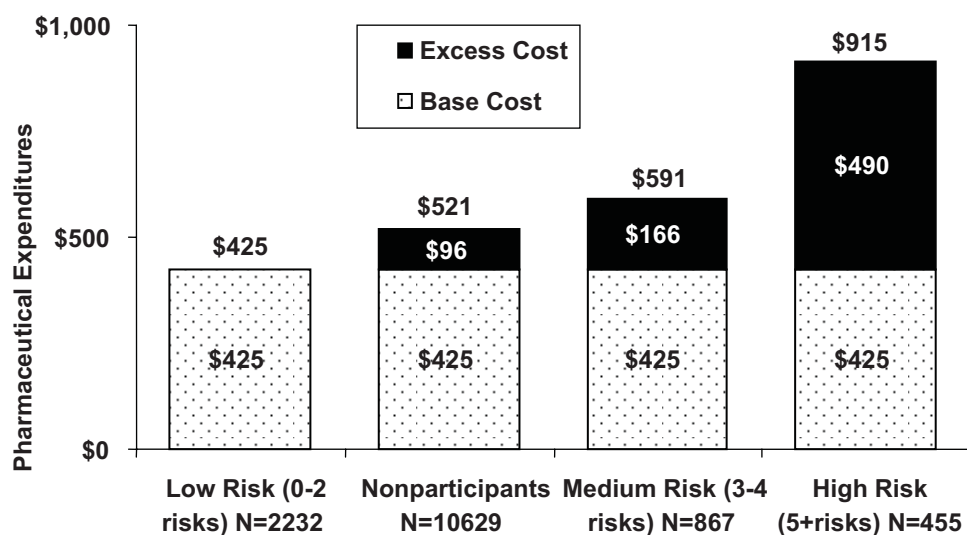
15.2

Excess disability costs due to excess risks.
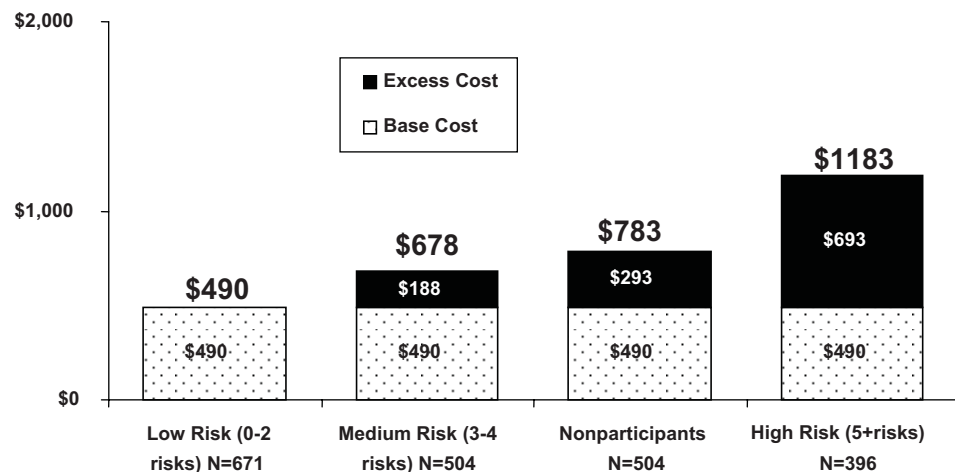
Analyzing Changes in Multiple Risk Behaviors

Use of overarching, integrative measures also would serve to simplify analysis of outcomes in MRBC interventions. Historically, MRBC interventions have included separate measures for each risk behavior targeted, sometimes incorporating multiple measures for each behavior. The consequence is multiple significance testing with the potential for inflating the type I error rate, as well as creating confusion by describing inconsistent findings across the different outcomes.

Indices of MRBC have been proposed as a way of combining changes in separate risk behaviors, although no standard exists and questions remain about whether behaviors should be weighted with respect to mortality risk. Examples include the Framingham Heart Study risk score; the Cooper Clinic mortality risk index; cancer risk indices; dietary quality indices; and an index of early problem behaviors (Janssen, Katzmarzyk, Church, & Blair, 2005; McGue, Iacono, & Krueger, 2006; Patterson, Haines, & Popkin, 1994; Wilson et al., 1998).

Another alternative is creating an index of behavior change scores. If the behavioral measures to be combined are on different scales—for example, minutes of physical activity and servings of fruits and vegetables—a statistical transformation will be necessary. Standardized change scores can be created by subtracting baseline scores from the follow-up scores and then dividing by the standard deviation of the difference (i.e., z-score). The scores can then be summed into a combined behavioral index, which indicates the amount of increase or decrease in the combined behaviors from baseline to follow-up. Alternatively, standardized residuals from linear regressions of follow-up scores on baseline measures provide a simple change score adjusted for baseline variance. Residualized change scores are referred to as "base-free" measures of change (Tucker, Damarin, & Messick, 1966) and are viewed as superior to simple pretest-posttest differences in scores (Veldman & Brophy, 1974).

Impact Factor

The significance of intervention effects is moderated by the generalizability of the individuals willing to participate. An important outcome measure that incorporates intervention efficacy and participation rates is impact. Impact is increased by greater intervention efficacy and greater participation among individuals in the target population. For interventions targeting single-risk behaviors, impact has been measured as intervention efficacy (E) times participation (P) or $I = E \times P$. In MRBC interventions, measures for assessing impact need to account for the number of behaviors treated effectively. In MRBC interventions, impact may be considered as intervention efficacy times participation summed over the multiple behavioral targets, $I = \Sigma_{\text{\# of behaviors}(n)} (E_n \times P_n)$. Here, P is the proportion of at-risk individuals participating in the intervention for each behavior. E is the estimate of efficacy for each behavior. Use of a common metric, such as the percentage no longer at risk (i.e., the percent reaching Action or Maintenance), allows for summation across behaviors. This revised-impact equation provides a measure for assessing the impact of interventions for treating individuals and populations with multiple behavior risks.

Theory Testing Across Behaviors

Theories of behavior and behavior change have been applied across a wide variety of risk factors, demonstrating that the same skills can be applied to multiple behaviors. A model of lifestyle behavior change has suggested that with behaviors that co-occur (e.g., alcohol abuse and smoking), change in one may support change in the other (Wankel & Sefton, 1994). At this time, however, no theory of behavior change directly addresses the issue of how to intervene on more than one behavior simultaneously.

The Transtheoretical Model (TTM) of behavior change, discussed earlier, was developed in the area of smoking cessation and has demonstrated relevance to over 20 problem or target behaviors (Hall & Rossi, 2005; Prochaska et al., 1994). Across multiple health behaviors, significant cross-sectional associations have been found with the TTM mediators of change. Among adults, the pros and cons for smoking were inversely associated with the pros and cons of exercising (King, Marcus, Pinto, Emmons, & Abrams, 1996). That is, individuals rating the benefits of smoking highly were less likely to endorse the benefits of physical activity as self-important. Self-efficacy for smoking cessation also was significantly related to self-efficacy for exercise. While the data were cross-sectional in nature, the authors concluded that the associations provide preliminary evidence for how change in one behavior may be related to change in another. Individuals working on increasing their physical activity seem motivated and confident about decreasing their smoking and vice versa. Similarly, Unger (1996) observed that adults in the later stages of change for smoking cessation had more healthful levels of alcohol use and exercised more than subjects in the earlier stages of change, suggesting people changing on their own may make improvements in several health behaviors concurrently.

The PREVENT trial, which utilized social cognitive theory, broadened intervention goals to include raising participants' self-efficacy for changing multiple risks by helping them recognize the natural intersections among their risky health habits. General cognitive and behavioral skills also were taught for application in changing any of their risk behaviors (Emmons et al., 2005).

The National Institutes of Health, the American Heart Association, and the Robert Wood Johnson Foundation jointly funded a Behavior Change Consortium (BCC) focused on multiple risk behavior change. The BCC studies include assessment of the utility of different theoretical models for changing two or more health risk behaviors (Nigg, Allegrante, & Ory, 2002). The field looks forward to the findings from these theory-comparison and MRBC research studies.

Considerations for Dissemination

Most of the early successes in MRBC interventions were achieved in research clinics or specialty settings, and serious considerations need to be taken into account when planning for dissemination. From the practitioner's perspective, there are legitimate concerns about addressing more than one behavioral risk at a time. It can be very challenging for health care professionals to try to impact behavioral changes through counseling or other forms of intervention within short medical appointments. One recent clever health message for promoting

changes in multiple risk behaviors is 0–5–10–25, indicating 0 cigarettes, 5 servings of fruits and vegetables, 10,000 steps, and a body mass index of less than 25 (Reeves & Rafferty, 2005).

In designing programs for dissemination, key considerations include: (1) involving the target population and organizations in intervention design and development; (2) reducing individual and organizational barriers to participation; and (3) being mindful of feasibility issues and the breadth of appeal of the intervention to the target system (Nigg et al., 2002).

Experts in the field have concluded that using interactive behavior change technologies and tailored feedback are the current best practices for addressing multiple risks in primary care (Glasgow, Bull, Piette, & Steiner, 2004; Goldstein et al., 2004). Interactive behavior change technologies have been praised for offering a viable solution to the otherwise overwhelming problem of addressing prevention effectively in primary care. Computer-delivered expert system interventions are self-directed, generate tailored feedback to participants, maintain treatment fidelity, and are an important dissemination option.

Moving beyond the clinic, schools and worksites are becoming important channels for distribution of multiple risk behavior changes. Expert systems can reside on a school's Web server with multimedia components provided on a CD-ROM to minimize download time. Teachers do not require additional training, as their main responsibility is to assist students in starting and completing the program. The programs provide a private interaction for youth to address sensitive issues such as experiences with bullying and experimentation with substance use. Because the programs are tailored to individuals' readiness to adopt or cease a risk behavior, they are broadly relevant to the populations served. Within a worksite, employees can take a comprehensive health risk appraisal online and then be guided to work on their identified risk behaviors. In addition to computer-tailored feedback, participants can be referred to a self-help interactive workbook with activities to increase engagement in effective change processes.

As one example of success with disseminating MRBC interventions to clinics, schools, and worksites, Pro-Change Behavior Systems, with funding from the National Institutes of Health, has focused on developing and disseminating evidence-based behavior change programs. The programs utilize stage-based expert system interventions to target multiple risk behaviors, including weight gain (physical inactivity and poor diet), substance use, tobacco use, bullying, interpersonal violence, and high cholesterol. The programs have been disseminated nationally to more than 500 schools, 100 worksites, and 200,000 adults and youths. The programs have been well received and well used and have delivered significant impacts on multiple behavioral risks (Evers, Prochaska, Van Marter, Johnson, & Prochaska, 2007; Mauriello et al., 2006; Mauriello, Sherman, Driskell, & Prochaska, 2007).

The Internet provides a convenient option for dissemination, but it still can be difficult to engage individuals. In the research literature, Internet-delivered intervention trials have reported participation rates as low as 2% to 10% and retention rates as low as 20% (Glasgow et al., 2007; Rothert et al., 2006). Through our research and dissemination practices, we have found that participation rates range greatly based on the types of incentives employed (see Table 15.1).

15.1 Recruitment Incentives and Participation Rates		
Recruitment incentives	**Mechanism**	**Participation rate**
Persuasive messages in letter or e-mails with or without a token incentive (e.g., T-shirt or $15 coupon)	social influence	20%–30%
Positive reinforcement in the form of $150 to $300	social influence	40%–50%
Personal outreach through face-to-face or phone call contact	social influence	60%–70%
Negative reinforcement by requiring all nonparticipants to face some increase in financial payment for their health care plan for not participating	social control	80%–90% (but do get negative reactions)

Vision for the Future

The need for multiple risk, transbehavioral research models and paradigms has been identified (Orleans, 2004). Specific research questions include "whether, or in which situations, multiple risk factor interventions are *more* effective or efficient at reducing risk than targeted single interventions" (Atkins & Clancy, 2004). For example, some attribute the success of tobacco-cessation initiatives to a narrowly focused research and policy agenda. Research is needed to determine under what conditions multiple risks can be targeted without diminishing the effectiveness on any single behavior (Atkins & Clancy, 2004). Other areas in need of greater research are interventions that integrate efforts to change multiple risk behaviors, as well as interventions that teach change strategies that can be generalized to multiple behavior change goals. With increased interest in MRBC interventions, the field will need ways to conceptualize and analyze the issue of overall behavior change (Prochaska, Velicer, et al., 2008).

If the challenge of MRBC intervention is met, health promotion and disease management programs will significantly effect entire populations. Such impacts require scientific and professional shifts from:

1. An action paradigm to a stage paradigm;
2. Reactive recruitment to a public health approach of proactive recruitment (that is, reaching out proactively to individuals and populations to engage them in MRBC interventions, rather than waiting passively in the clinic to react to the small proportion of patients who will seek services);
3. The expectation that participants must match the needs of programs to the understanding that programs must match their needs;

4. Clinic-based to population-based programs that are able to apply the field's most powerful individualized and interactive intervention strategies;

5. Single-behavior-change programs to MRBC programs for entire populations.

If the health behavior change field makes these paradigm shifts, a behavior health delivery system could be developed to reach many more people with behaviors that are the major killers and cost drivers in the United States.

How can population approaches to health promotion be funded? Longitudinal data indicate that effectively treating two behaviors reduces health care costs by about $2,000 per year (Edington, 2001). For worksites, the return on investment (ROI) for employee participation in MRBC programs is estimated at 1.98 over 3 years' time, on the basis of reductions in absenteeism and workers compensation hours, nearly a two-fold return on investment (Schultz et al., 2002). Population-based behavioral medicine is one of the few opportunities for health care systems to increase services that improve health and reduce health care costs. Over time, population-based prevention programs could pay for themselves.

We can envision a health care system in the near future where interactive MRBC interventions will be to behavioral medicine what pharmaceuticals are to biological medicine: one of the most cost-effective methods to bring optimal amounts of science to bear on multiple behavior problems, in entire populations, in a relatively user-friendly manner, without many of the side effects seen with pharmaceuticals.

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Section
3

Measurement

Kristin A. Riekert
Editor

Section III is new to this edition of the handbook and represents the growing attention given to the importance of reliable and valid measures of health behavior as well as appropriate analysis of behavioral data within clinical trials. If a clinician feels it is important to recommend a regimen, be it diet, exercise, or medication, it should be just as important to the clinician to know the extent to which the patient followed that recommendation. Unfortunately, few clinicians routinely incorporate valid protocols for assessing regimen adherence into their practice. Similarly, the measurement of participants' adherence to study protocols is a critical component of clinical trials research. If a trial is focused on drug development, then it is important to know if and how participants are using the

drug to assess its efficacy and to understand the occurrence of adverse events. If the focus of the study is lifestyle change, then to appropriately evaluate the efficacy of the intervention, accurate and valid measures are needed that not only assess what behavior was performed and how often but one that is also sensitive to change over time. Unfortunately, the measurement of health behaviors is challenging.

Otsuki and colleagues (chapter 16, Medication Regimens), Wilcox and Ainsworth (chapter 17, Physical Activity) and Dougherty, Dawes, and Nouvion (chapter 18, Substance Use) discuss the various types of assessment methodologies for their respective behaviors and compare and contrast content of measures and their psychometric properties, as well as costs and benefits of each approach. The similarities of the measurement issues and limitations are quite notable considering the very different behaviors the chapters address. A take-home message is that no one measure is ideal for every purpose, so it is essential to carefully consider the trade-off between accuracy and comprehensiveness, as well as the ease and cost of administration. Often the optimal solution is to use multiple measures.

Finally, chapter 19 focuses on missing data and statistical methods. Even the best-designed and -managed studies will encounter missing data and, as Conway and colleagues discuss, if missing data are ignored, this can lead to biased estimates. The authors offer recommendations for selecting the optimal statistical approach for handling different types of missing data and incorporating strategies to minimize the occurrence of missing data.

Measuring Adherence to Medication Regimens in Clinical Care and Research

16

Michiko Otsuki,
Emmanuelle
Clerisme-Beaty,
Cynthia S. Rand, and
Kristin A. Riekert

When patients' therapies do not work, clinicians often adjust dosages, order more diagnostic tests, or switch to different, sometimes riskier treatments. When a clinical trial does not find a significant treatment effect for a promising investigative drug, that therapy may be judged inefficacious and abandoned as a possible treatment option. All too often, however, the cause of the ineffective therapy lies not with the drug or treatment but rather with patient or provider behavior. Clinicians and researchers who do not measure patient adherence appropriately are at risk of misjudging the causes of treatment ineffectiveness.

Patient adherence is the necessary intermediary between efficacious therapies and treatment effectiveness. Studies that have measured patient adherence to medication regimens have repeatedly documented the magnitude of medication nonadherence across all diseases and therapies. Estimates are that

50%–65% of all outpatients do not adhere appropriately to their medication regimens (DiMatteo, 2004b; Melnikow & Kiefe, 1994; Schaub, Steiner, & Vetter, 1993).

Nonadherence to prescribed treatment has implications for clinicians in several critical areas. Most obviously, a patient who does not adhere to a short- or long-term medical regimen may not get the complete therapeutic benefits (DiMatteo, Giordani, Lepper, & Croghan, 2002). A physician can often be misled by patient nonadherence to conclude that the prescribed treatment is inadequate or inappropriate. This, in turn, can lead to costly diagnostic procedures or even dangerous intensification of therapy, when the patient would have been served best by accurately following the originally prescribed regimen.

Another serious consequence of patient nonadherence is the compromise of clinical drug trials. A new treatment can easily be judged ineffective if participants do not adhere adequately to the treatment protocol. So critical is the issue of adherence to the evaluation of drug efficacy that some researchers have suggested that clinical studies are of only limited value without the inclusion of valid measures of adherence (Besch, 1995; Granger et al., 2005; Melnikow & Kiefe, 1994).

Defining and Classifying Adherence

"Adherence" or "compliance" may be broadly defined as the degree to which patient behaviors coincide with the clinical recommendations of health care providers. Despite the fact that clinicians and researchers alike categorize patients as being either complaint or noncompliant, such adherence is not inherently a dichotomous variable. There is no gold standard for what defines "satisfactory" or "poor" adherence across all health behaviors. Factors such as the dosage necessary for therapeutic effectiveness, the risks of nonadherence, and the clinical or research goals will all influence the criteria for good adherence. Appropriate adherence must be situationally defined, with parameters of good adherence explicitly delineated and appropriate to the medication regimen or health behavior under study. How one chooses to define good adherence is integrally related to the way in which adherence will best be measured. A broadly defined, flexible criterion of acceptable adherence may not need precise measurement methodology. In contrast, when detailed and exact adherence data are necessary, the measurement instruments should be comparably precise. Assessment of adherence in a clinical trial, for example, must be as rigorous as possible in order to ensure the fundamental integrity of the study's conclusions.

In both clinical care and research settings, measuring and classifying patients' patterns of medication uses is as necessary as assessing overall adherence level. Understanding patterns of medication use is important in the evaluation of treatment response and efficacy and in developing strategies to enhance adherence. The expected patient behavior is "appropriate adherence"—that is, using medications exactly as prescribed and consistently over time. The most obvious form of noncompliance is chronic "underuse," where a patient regularly uses less medication than is prescribed. Although underuse is most often considered a risk for poor disease control, for some patients, underuse may be an effective self-management or self-titration strategy when treatment has

been overprescribed (Diette et al., 1999; Sale, Gignac, & Hawker, 2006). Patients also may have "erratic adherence," in which medication use alternates between adherent use (usually when symptomatic) and underuse or total nonuse (when asymptomatic). Patients with erratic adherence may present for treatment during symptom exacerbations with apparent complete adherence to their prescribed regimen. Erratic adherence may also reflect forgetfulness, stress, changed schedules, running out of medication, or other barriers to full adherence. The term "drug holiday" is sometimes used to describe multiday lapses in medication use. Finally, some patients using pain or symptom-relieving drugs on an as-needed basis (i.e., PRN), may be prone to "overuse" during exacerbations. This may cause a patient to delay seeking care or lead to complications associated with excessive medication use (Diette et al., 1999; Rand, Nides, Cowles, Wise, & Connett, 1995; Spitzer et al., 1992).

Methods for Measuring Medication Adherence

Several investigators have published excellent reviews of medication adherence measurement research, and the reader is referred to them for greater detail (Berg, Dischler, Wagner, Raia, & Palmer-Shevlin, 1993; Melnikow & Kiefe, 1994; Rand, 2002). As these reviewers have noted, various methods for assessing adherence have both strengths and weaknesses that must be considered in their use. Adherence measures can be divided into "indirect methods" (presumed used) and "direct methods" (confirmed use).

Indirect Measures

Clinician Judgment

In everyday clinical care, health care providers form thumbnail impressions of how well each of their patients is following their prescribed regimens. These judgments necessarily shape the patient-provider interaction, the selected therapy, and the follow-up plan. Results from the majority of published studies show that physicians generally greatly overestimate the degree to which their patients comply with their recommendations (Davis, 1966; Kasl, 1975; Paulson, Krause, & Iber, 1977; Sherman, Hutson, Baumstein, & Hendeles, 2000). Sherman et al. (2000) showed that, measured against a pharmacy database, physicians were able to accurately identify only 49% of subjects who obtained less than 50% of the refills of the medication prescribed for children with asthma. Another study by Miller et al. (2002) looking at the accuracy of clinicians' judgment regarding patients adherence to antiretroviral therapy, found that clinicians overestimated measured adherence using electronic monitors by 8.9% (86.2% vs. 77.3%).

Hamilton (2003) showed that although physician judgment and electronic monitoring had comparable rates of adherence, they were not correlated. Physicians not only overestimate patient adherence but are also poor predictors of which specific patients will be good or poor adherers. Steele, Jackson, and Gutmann (1990) found that physicians identified only 53% of the adherence problems in 38 critical-case encounters. Physicians who used indirect

approaches to assessment (e.g., "have you noticed any changes since you started taking your medicine?") were the least successful in identifying adherence problems (0/9 correct); simple, direct questioning (e.g., "You've been taking your medications?") was moderately successful (8/13 correct); and information-intensive strategies (open-ended queries about patterns of medication use) was the most successful approach (8/10 correct). The investigators conclude that a "nonaccusatory, open-ended, information-intensive approach can be a sensitive and productive tool for the diagnosis of patient's adherence status" (Steele et al., 1990, p. 299). The lack of physician skill in identifying patients with adherence difficulties has been attributed to a medical education focus that neglects communication skills and attention to psychosocial issues. A study by Steiner and colleagues (1991), however, found that even nurse-practitioners (members of a profession that emphasizes patient education and communication) were poor judges of patient adherence, identifying only 23.1% of the poorly adherent patients and misclassifying 22.5% of the more adherent patients as partial compliers. Clinical judgments based on preconceived beliefs about the attributes of the "typical" compliant patient are destined to fail. Patient characteristics such as race, education, gender, socioeconomic status, and personality have not been found to be reliable predictors of adherence (see chapter 20). Physician interviewing skills and the qualities of the patient-provider interaction are more important in both measuring and facilitating adherence than stereotypical beliefs about adherence (DiMatteo et al., 1993; Dunbar-Jacob, 1993; Heszen-Klemens & Lapinska, 1984; Sackett & Haynes, 1976).

Self-Report

Self-report of medication use is a common measure of adherence in both clinical trials and behavioral intervention studies. Patient self-reports may be collected by interview, diaries, and questionnaires. No cross-disease, validated adherence-specific questionnaire is currently in common use, in part because most self-report questionnaires of adherence have been designed for specific diseases and studies or because they are often embedded in more general disease self-management measures (Dolce et al., 1991; Rand & Wise, 1994). Self-report is an inexpensive, simple measurement strategy that is applicable to different regimens, is generally brief, and has face validity (see Rand, 2000, for a review). In addition, self-report (particularly in the clinical setting) is the best measure for collecting information about patient beliefs, attitudes, and experiences with medication regimens. For example, the patient who misunderstands a dosing regimen or who has altered her regimen because of fear of side effects will not be identified by objective adherence assessments (Britten, 1994; Donovan & Blake, 1992).

Self-report is the most appropriate means for evaluating reasons for nonadherence, including health and attitudes as well as cultural variations that affect adherence to prescribed therapy (Rand, 2000). Several studies have shown that patients' dissatisfaction with therapy, their perceptions of treatment efficacy, inconvenience, fear of side effects, and self-efficacy are associated with nonadherence (Apter et al., 2003; Bosworth et al., 2006; Brown, Rehmus, & Kimball, 2006). As a quantitative measure of medication use, self-report has been found to have a highly variable degree of accuracy (Coutts, Gibson, & Paton, 1992;

Mason, Matsuyama, & Jue, 1995; Waterhouse, Calzone, Mele, & Brenner, 1993). Specifically, self-report has been shown to consistently overestimate medication adherence relative to objective measures in hypertension (Wang et al., 2004), HIV (Liu et al., 2001), asthma (Krishnan et al., 2004), cancer (Waterhouse et al., 1993), epilepsy (Cramer, Mattson, Prevey, Scheyer, & Oullette, 1989), and arthritis medications (Kraag, Gordon, Menard, Russell, & Kalish, 1994).

Self-reports of adherence are influenced by the demand characteristics on the setting in which the information is collected. The desire to please the physician or investigator can lead patients to exaggerate reports of medication use. Patients with memory impairment (related to illness, age, concurrent medications, or stress) may not be able to accurately self-report their usage pattern of any one medication (Levine et al., 2006). Patients' report regarding long-term medication use may be less reliable the longer the recall period becomes. Physicians' and investigators' sensitivity and skill in eliciting patients' self-reports will certainly influence the reliability and usefulness of the information they receive.

While self-report may not be a sufficient measure of adherence in many settings (particularly in research), it is probably a necessary measure in all settings. For, when carefully collected, this information can provide invaluable insight into the nature of patients' problems with adherence. Additionally, because there is no evidence to suggest that adhering patients will misrepresent themselves as nonadherers, when the patients report that they are non-adherent to the prescribed therapy, the information can be considered to be reliable and valid (Rand et al., 1995).

Medication Measurement

Medication measurement has frequently been used as a relatively simple, yet objective measure of adherence. Counting pills and weighing inhaler canisters or liquid mediation are examples of measures that allow researchers to infer the degree of medication adherence. This method requires that the clinician or investigator know exactly how much medication the patient began the measurement period with and how much medication should have been used during this period.

Medication measurement has been used to provide objective data on the relationship between adherence with therapy and disease exacerbations. Hilbrands and colleagues (1995) used pill counts to evaluate adherence with immunosuppressive and antihypertensive drugs among adult patients who had received a renal transplant in the previous year. They found that overall adherence was generally good (87% to 64% of patients were fully adherent); however, there was considerable variability, both within patients for different drugs, and among patients. Patients who experienced a subsequent rejection episode had lower adherence with immunosuppressive drugs than did patients without a rejection episode, and adherence appeared to improve in these patients after the rejection month.

In some settings, medication measurement can serve as both an adherence intervention tool and an outcome measure. Koch and colleagues (1993) contracted with 23 pediatric patients with thalassemia to improve adherence to desferrioxamine iron chelation therapy. Patients were asked to increase the

number of days they used the subcutaneous pump delivery system, and the number of empty desferrioxamine vials served as a basis for reinforcement and adherence documentation. By the end of the 6-month program, patients' use of the pump had climbed from 4.5 to approximately 5.5 days per week. Koch and colleagues note that because of the need for parental supervision during therapy and the high cost of desferrioxamine, it was unlikely that patients would deceptively empty vials.

Medication measurement need not be confined to clinic visits. Cromer and colleagues (1989) studied adherence with therapy for iron deficiency among 71 adolescents using a home pill count (conducted by research staff), serum ferritin levels, and urinary assays for tracer riboflavin. Pill counts in this setting were found to be highly correlated with biochemical indices of compliance, suggesting that this measurement strategy is an accurate method for measuring adherence. Moss and colleagues (2004) examined adherence to highly active antiretroviral therapy (HAART) in the homeless population, a high-risk population for poor adherence to therapy and for developing drug-resistant HIV strains. In this special population, pill count was found to be a more feasible method of adherence monitoring than electronic measures.

While these adherence data are both objective and reasonably simple to collect, they are limited by several factors. Medication measures can easily be influenced by a patient's efforts to deceive the investigator. As discussed, some patients may discard medication to appear adherent. Participants' knowledge that medication will be measured may negatively affect its accuracy. For example, DuBard and colleagues (1993) evaluated adherence with low-dose aspirin therapy for the prevention of pre-eclampsia. They compared pill-count estimations of adherence with biochemical measure (serum thromboxane 2) and found that women with a pill count greater than 100% had lower biochemical levels of drug than did women with pill counts <95%, suggesting that pills may have been discarded. This phenomenon of medication "dumping" has been described by a number of investigators (Mawhinney et al., 1991; Rand et al., 1992; Urquhart, 1991) and appears to be a common occurrence when medication measurement is used in a clinical trial setting to confirm compliance. Medications are often shared within households, particularly when family members are on the same medication (i.e., tranquilizers, antibiotics, sleeping pills). Additionally, medication measures give no indication of the accuracy of dosages or the timing of medication. However, in situations where patients are unthreatened by the consequences of reporting nonadherence, the pattern of medication use is not critical, and where the likelihood of medication-sharing is low, medication measurement is a useful, objective, and valid means of assessing adherence.

Automated Pharmacy Database Review

As managed care has expanded and the technology for health care utilization data tracking and management has become more sophisticated, it has become increasingly feasible to monitor patients' medication adherence by examining insurance pharmacy databases. Pharmacy databases can provide information regarding prescription practices, the amount of medication dispensed, and the timing of refills. This data can be used to calculate roughly the average dose per day. In some health care data management systems, prescriptions written

but never filled can also be monitored. Dispensing data also can be matched with medical record and health care utilization databases to provide integrated analyses of the antecedents and consequences of patient adherence behaviors.

Studies using this methodology have examined patient adherence across a wide range of regimens and diseases, including depression (Stein, Cantrell, Sokol, Eaddy, & Shah, 2006), glaucoma (Gurwitz et al., 1993), hypertension (Grant, Singer, & Meigs, 2005) hyperlipidemia (Parris, Lawrence, Mohn, & Long, 2005; Schectman, Hiatt, & Hartz, 1994), HIV (Laine et al., 2000), and asthma (Bender, Pedan, & Varasteh, 2006; Stempel et al., 2005). Review of automated pharmacy records also can allow large-scale population studies of patient adherence with medications. Nachega and colleagues (2006) used pharmacy claims to evaluate the association between HAART adherence and HIV-1 survival in South Africa and showed a relationship between medication adherence and survival. Another study by Spitzer and colleagues (1992) examined the relationship between beta-agonist use in pulmonary patients and the risk of death and near-death from asthma by examining computerized prescription-refill records. Their study, based on refill patterns, suggested that regular use or overuse of beta-agonist medications was associated with an increased risk of death or near-death. Although this provocative study could not determine if this increased risk results directly from toxic properties of the pharmacological agent itself or indirectly from the patient's delayed treatment, its publication sparked intense debate on the relationship between patient adherence patterns and asthma mortality.

Pharmacy data review can reveal refill-based adherence patterns for different classes of medication or dosing regimens (Dolder, Lacro, & Jeste, 2003). Using data from a pharmacy database, Marceau, Lemiere, Berbiche, Perreault, and Blais (2006) found that, although treatment adherence to inhaled corticosteroids (ICS) and long-acting beta-agonist (LABA) medication was overall poor, patients on a combination therapy were more persistent and adherent than those treated with ICSs and LABAs taken in two different inhalers. Review of pharmacy and medical records can also determine the risks associated with nonadherence. Maronde and colleagues (1989) reviewed records of patients being treated for hypertension after having been admitted to an acute-care hospital with a diagnosis of hypertension in the previous 6 months and found that poor compliance was associated with a higher risk of rehospitalization within a year. In contrast, Steiner and colleagues (1991) reviewed the automated pharmacy records of hypertensive patients enrolled in a medication step-down program in a VA hospital and found that patients with histories of partial compliance were more likely to be successful in reducing their antihypertensive medication regimens, suggesting that some patients may have been successfully self-regulating their medication doses. They note that the review of centralized pharmacy records to identify partial compliers with normal blood pressure would allow reductions in unnecessarily high doses of medication.

Pharmacy database review to identify nonadherence has several limitations. First, adherence estimates can be calculated only for patients who exclusively rely on the target pharmacy system for all prescriptions and refills. Patients who use "out-of-network" pharmacies will have incomplete refill data. Second, pharmacy data can determine when a prescription was filled; however, it provides no confirmation of consumption or appropriate consumption patterns. Pharmacy

database review cannot determine if medications sit unused, are hoarded for future use, are shared or given to family and friends, or are taken inappropriately. However, Tamblyn and colleagues (1995), in a study of the accuracy and comprehensiveness of the prescription claims database in Quebec, found pharmacy databases to be an accurate measure of medication dispenses. As more pharmacy data go online, this adherence-measuring strategy has great potential to "be applied comprehensively, inexpensively and unobtrusively to a large number of individuals" (Steiner, Fihn, Blair, & Inui, 1991).

Electronic Medication Monitors

In the past 15 years, the increased availability of computer-based technology has introduced a new strategy for adherence monitoring. Electronic monitoring devices record and store the date (and, in the case of some devices, the time) of each medication use. Devices have been developed to monitor medication adherence behaviors including, but not restricted to, opening a pill bottle, releasing a blister-pak pill, discharging inhaled medications, and releasing eyedrops. Behaviors important to medical outcomes, such as home apnea monitoring for premature infants (Cordero, Morehead, & Miller, 1993), self-monitoring of blood glucose for patients with diabetes (Wysocki, Green, & Huxtable, 1989), and the use of removable appliance wear in orthodontic patients (Bartsch, Witt, Sahm, & Schneider, 1993), also have been targeted for electronic monitoring.

Three electronic devices that have been widely investigated are the Medication Event Monitoring System (MEMS-AARDEX, LTD, Switzerland), the Doser (Meditrack Products, Hudson, MA) and the MDILog (Westmed Technologies, Englewood, CO). The MEMS can be used in conjunction with any regimen that includes the use of pills or tablets. A microprocessor in the MEMS cap electronically records each time the bottle is opened and stores the date, time, and duration of opening for subsequent downloading and retrieval via computer. The Doser is made of a pressure-activated cap that is attached to the most commercially available Metered Dose Inhalers (MDIs). The Doser has a pre-programmable liquid crystal display that shows the number of remaining doses in the canister and the number of actuations for each day. The MDILog is a more recent model of Nebulizer Chronolog (NC-Medtrac Technologies, Lakewood, CO) that is attached to MDIs. The MDILog has an embedded computer chip that records the date and time of each actuation. Additionally, the MDILog evaluates whether the canister was shaken before use and an inhalation actually took place (see Riekert & Rand, 2002, for a detailed description of each medication monitor). Last, there is emerging technology concerning remote download of adherence data. This will enable clinicians to assess patients' adherence between clinic visits, as well as allow researchers the opportunity to minimize missing data in clinical studies.

These devices provide a unique opportunity to investigate long-term patterns of presumptive adherence that were heretofore unavailable in such detail. For example, using electronic monitors, Rand et al. (2007) were able to examine the effect of dosing frequency and mode of therapy delivery on both adherence and clinical outcome. The study consisted of 389 patients with mild intermittent asthma randomized to either a once-a-day oral medication (montelukast) or a twice-a-day inhaler (fluticasone). The authors found that although subjects

were more likely to use their inhalers at least once a day, they were more likely to take the once-daily medication as prescribed. However, they failed to demonstrate any benefits of increased adherence on the clinical outcomes measured in the study.

Mason and colleagues (1995) used several measures of adherence in addition to the MEMS to determine which most closely assessed metabolic control in patients with noninsulin-dependent diabetes mellitus. Assessment of medication adherence by provider, patient, and pill count did not explain metabolic control as closely or as accurately as assessment by the MEMS. Adherence studies conducted as a part of the Lung Health Study (Rand et al., 1992) using the Nebulizer Chronolog also have demonstrated the limitations of self-report and medication measurement seen with many of the studies using the MEMS. However, the NC was better able to capture a phenomenon called "dumping." In the Lung Health Study, participant self-report and canister weighing overestimated participant adherence by more than 30%. In addition, this study indicated that there was a subset of participants who appeared to discard medication deliberately before follow-up visits. Dumping is nearly impossible to detect by traditional methods of adherence assessment, and inclusion of dumping data in a dose-response analysis can yield counterintuitive results; highly adherent subjects show poorer response than moderately adherent subjects.

In recent years, the number of published studies using electronic adherence-monitoring devices has increased dramatically. The primary benefit of this type of monitoring is clear: electronic monitoring methods can provide a continuous record of timing of presumptive doses over periods of months. Assessments of adherence made by provider, self-report, pill counts, or canister weights can be inaccurate because of recall, demand characteristics, deception, and provider biases. These methods, usually the "gold standards" of adherence, reveal medication ingestion but do not reveal the timing of doses.

While this trend toward high-tech computer-based monitoring devices continues, these systems are not without their limitations. The cost for wide-scale use can be prohibitive for a small practice and may be feasible only in a clinical trial setting. The up-front cost can be thousands of dollars. Additionally, there is a failure rate associated with the use of any type of electronic device. The failure rate in electronic devices can be caused by patient misuse, device failure, or computer hardware or software problems. In a study by Cramer and colleagues (1995), participants at 8 out of 10 sites did not use MEMS properly, thereby voiding their data for analyses. It also may be argued that the monitoring devices themselves, or the awareness that one is being monitored electronically, may alter adherence behavior. A detailed discussion of the benefits, issues, and precautions for using electronic medication monitors is found in Riekert and Rand (2002).

Direct Measures

Biochemical Analysis

Clinical analysis of blood, urine, or other bodily excretions has frequently been used to objectively measure medication or byproduct levels (Berg et al.,

1993; Gordis, 1976; Schaub et al., 1993). This is the only method of adherence measurement that confirms that medications have actually been taken by a patient, and for this reason biochemical analysis is one of the most valuable techniques available for assessing adherence. Unfortunately, this strategy is available for only a few drugs, and individual variations in absorption patterns may limit interpretation. Investigators can sometimes measure adherence with drugs that are not directly evaluable by biochemical assays by adding tracer substances that can be monitored. Riboflavin (Dubbert et al., 1985), digoxin (Maenpaa, Manninen, & Heinonen, 1992), phenobarbitone (Hatton, Allen, Vathenen, Feely, & Cooke, 1996), and deuterium oxide (Rodewald & Pichichero, 1993) have all been used as added biochemical adherence markers.

While biochemical analysis allows a very direct assessment of drug use, it also has some limitations. In order for the excretion pattern of the drug, tracer, or byproduct to be clearly understood, drug adherence is best assessed by repeated measures and analyses. This type of repeated assessment is probably clinically practical only when the monitoring is also necessary for determining appropriate therapeutic levels of medication (i.e., dilantin levels). Repeated measures solely for confirming adherence are usually impractical, particularly when biochemical analysis requires the use of an invasive procedure to collect a sample. Even when biochemical monitoring is feasible, not all medications can be easily detected or tagged with tracer substances. Biochemical analysis can provide a measure of adherence for a single test or for multiple tests, but it cannot realistically be used to measure day-to-day adherence with long-term medication. And, finally, even this technique can be compromised if a patient deliberately or inadvertently begins taking his or her medication just prior to the clinical analysis.

Directly Observed Therapy (DOT)

Other than biochemical analysis, observing therapy is the only direct measure of patient adherence to therapy. Directly observed therapy (DOT) requires that patients be monitored for each dose or treatment to confirm adherence. DOT was pioneered in the treatment of tuberculosis because (1) poor patient adherence had been identified as the major barrier to effective treatment; (2) as a highly infectious disease, TB posed a major public health threat, and (3) those populations with the highest incidence of TB (I.V. drug abusers, recent immigrants, homeless people) were historically the most transient and difficult to retain in conventional therapy (Volmink & Garner, 2000).

In addition to tuberculosis, recent data have shown DOT to be feasible and sustainable intervention to significantly improve patient adherence with treatment for active diseases like HIV (Jayaweera et al, 2004; Lucas, Weidle, Hader, & Moore, 2004), as well as prophylactic therapy for communicable diseases like pertussis (Purcell, Dooley, Gray, Hill, & Oliverson, 2004). Results of a clinical trial by Lucas et al. (2006) showed that directly administered antiretroviral therapy (DAART) was more effective at achieving viral suppression (74%) than medication self-administration (33%) in 82 subjects with HIV on methadone therapy. However, DOT is a potentially coercive strategy, particularly when used for society's most indigent, disenfranchised members, and, as such, it raises important issues of public health policy, medical ethics, and civil liberties (Bayer & Dupuis, 1995).

Issues in Adherence Measurement

No one measure of adherence is appropriate for all settings. When considering the most appropriate strategy to apply, the following issues should be considered.

Reactivity

When adherence behavior is monitored by methods that are known by both the clinician and the patient to be both accurate and revealing, there is a strong possibility that the patient's adherence behavior will meet the demand characteristics of the monitoring situation. Few existing studies have evaluated this concern, and the findings in this area have been mixed. In the aforementioned Lung Health Study, Rand et al. (1992) found no difference in adherence rates (as measured with canister weights) between those using a Nebulizer Chronolog and those without it. Similarly, Matsui et al. (1994) found no significant changes in adherence before and after the explanation of the purpose of MEMS. In contrast, other studies have shown that there can be a direct relationship between the detail and precision of any measurement strategy and its impact on adherence (Nides, Tashkin, Simmons, Wise, Li, & Rand, 1993). How troublesome reactivity is depends upon the goals of the study or clinical interaction. When the focus of a study is on the ability to generalize the study's conclusions (i.e., will most patients use enough bronchodilator to achieve therapeutic goals?) or clinical purposes, then the use of reactive measurement techniques may be desirable. It is therefore important to clarify the goals of adherence assessment in each research or clinical application and then to select the most appropriate measurement strategies.

Measuring Children's Adherence

Assessing medication adherence in children presents unique challenges that require evaluating and considering both the family context in which medication use occurs and the level of communication between the health care provider and the family (see DiMatteo, 2004b, for a review).

This communication starts with identifying the family member responsible for delivering medications to the child and who is the most reliable source of adherence information. Responsibility for medication administration generally shifts as a child grows, from total parent management for a young child, to shared medication management for the school-age child, to complete self-management for the adolescent. Caregivers' reports of medication adherence on behalf of their children are often discrepant from objective measures of adherence as obtained by pill counts and electronic medication monitor (e.g., Steele et al., 2001). As parents transfer responsibility for medication management, they generally become less accurate reporters of the child's medication adherence.

There can be great diversity among families in how medication management is implemented. Day care providers, grandparents, and siblings may assume responsibility for regular medication delivery in some households. Because of the highly variable and often shifting family responsibility for a child's medication use, it is necessary for the health care provider to review medication-use habits with both the caregiver and the child in order to develop an adherence profile.

Multiple Measures of Adherence

Because of the relative strengths and weaknesses of each of the adherence measures discussed, the optimal strategy for assessing adherence usually involves the use of multiple measures (DiMatteo, 2004b; Liu, Kaplan, & Wenger, 2002). In a longitudinal study of medication adherence to HAART using MEMS, pill count, and self-report, Golin and colleagues (2002) found that although all three measures tracked over time, they each had shortcomings that could be minimized by combining the different methods of assessment. Llabre et al. (2006) found that using at least two different methods of adherence measurement assessed at multiple times enhances reliability and validity of adherence measures.

Nevertheless, patient contacts in both clinical and research settings should almost certainly include eliciting self-report information. Skillfully collected, these data not only identify adherence difficulties and barriers but also provide the investigator with information about the circumstances of nonadherence. The correction of adherence difficulties may well depend upon the investigator understanding the "whys of nonadherence" and working with the patient toward a solution. The inclusion of one or more objective measures when assessing adherence will confirm patients' self-reports, but the potential reactive effect of the measures should be weighed. Self-report and an unannounced biochemical analysis of a urine sample are unlikely to have any impact on patients' adherence behavior, while self-report and electronic medication monitoring and repeated drug-screening urinalysis probably will alter the patient's adherence behavior, the self-report, or both.

The Use of Adherence Data

Clinicians interested in assessing patient adherence should clarify to themselves and then, in turn, to their patients why this information is being collected and how the information will be used. In a research context, where the value of a drug or therapeutic regimen is being evaluated, the purpose of adherence assessment may be well defined for the investigator but unclear to the participant. In clinical care, adherence assessment can easily be interpreted by patients as paternalistic intrusion, the doctor checking for who's been "naughty" or "nice." Unfortunately, for some clinicians, that is exactly the intent and tone of their adherence assessment, with patients categorized as "good" adherers or "bad" adherers. Such classifications fail to consider the barriers to patient adherence (Dunbar-Jacob, 1993; Ross, 1991; Waitzkin, 1984). If the goal of adherence determination is to evaluate a treatment's efficacy, rather than to judge the patient's reliability or trustworthiness, then this goal should be both explicit and implicit in the patient-physician interaction.

Future Directions for Adherence Research

The better a behavior can be observed, the more complete will be our understanding of that behavior. The recent explosion in microcomputer technology has opened up remarkable new opportunities to incorporate adherence-monitoring

technology into everyday patient care. Similar opportunities are possible with the increased access to sophisticated, integrated pharmacy and health care databases. The possibility now exists for both the clinicians and the investigator to examine real-life adherence behavior and to directly correlate this behavior with patient response to therapy. While automated health care databases and specialized electronic adherence monitors are hardly a panacea for patient adherence difficulties, incorporating their use in both clinical and research settings would not only improve measurement precision but also offer increased opportunities for adherence-promoting interventions.

Whether sophisticated new technology or a simple clinical interview is used to measure and promote adherence, the patient or subject should be recognized as an active partner in the patient-provider exchange. No technology, now or in the future, will replace the good listening and the sincere concern of a first-rate therapeutic relationship.

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The Measurement of Physical Activity

17

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A growing body of work has focused on examining and improving the measurement of physical activity. In the past decade, several conferences and resources have focused on the assessment of physical activity with the goal of gaining insight into ways to increase precision within various measurement settings (Table 17.1). Within the health-related disciplines, there are at least four major reasons to measure physical activity: (1) to examine the role of physical activity as a risk or protective factor in the development of a particular disease such as cardiovascular disease or cancer, (2) to monitor changes in physical activity in a population over time (surveillance), (3) to examine the associations between physical activity and individual, social, and environmental factors for the purpose of informing interventions and identifying populations to target in interventions, and (4) to determine whether interventions at the individual and

| **17.1** | **Useful Resources for the Measurement of Physical Activity** |

Topic	Resource
Assessment of physical activity in specific populations and with specific methods	Proceedings of the October 1999 Cooper Institute Conference, *Measurement of Physical Activity.*
	Published in the June 2000 issue of *Research Quarterly for Exercise and Sport, 71,* Supplement to No. 2
Reproduction of commonly used self-report measures and reliability and validity references	Issue of *Medicine and Science in Sports and Exercise, 29(6)* (1997, Supplement)
Use of accelerometers in different settings and populations	Proceedings of the December 2004 conference *Objective Measurement of Physical Activity: Closing the Gaps in the Science of Accelerometery.*
	Published in *Medicine and Science in Sports and Exercise, 37*(11, Supplement) (November 2005)

population levels are effective. This chapter identifies definitions of terms used in physical activity assessment and reviews self-report and objective measures of physical activity. In each section, considerations that must be made when selecting measures for population subgroups (e.g., women, people of color, older adults, and children) are discussed where relevant.

Definitions

It is important to differentiate among physical activity, exercise, and energy expenditure. Physical activity is a complex behavior defined as any bodily movement produced by skeletal muscles that results in increased energy expenditure (Caspersen, Powell, & Christenson, 1985). This broad definition includes activities such as housework, yard work, child care, transportation, occupational activity, sport and exercise, and leisure-time activity. Exercise is a type of physical activity and is more narrowly defined as planned, structured, and repetitive bodily movements done to improve or maintain one or more components of physical fitness (Caspersen et al., 1985). Energy expenditure is the outcome of physical activity and is defined as the exchange of energy required to perform biological work. Components of total energy expenditure include basal metabolic rate (encompassing 50%–70% of total energy), the thermic effect of food (encompassing another 7%–10% of total energy), and physical activity (encompassing the remaining percentage of total energy) (Ravussin & Swinburn, 1992). Physical activity is the most variable component of total

energy expenditure and makes up a greater proportion of energy expenditure in active than inactive individuals. This chapter focuses on the measurement of physical activity.

Physical activity can be measured using direct methods such motion detectors and by indirect methods such as questionnaires, records, and logs. Several dimensions of physical activity are typically measured, including frequency, duration, intensity, and type to assess the volume of activity performed and to estimate the energy expenditure if desired. Frequency is generally defined as the number of sessions or days per week or per month an activity is performed. Duration usually refers to the time (minutes or hours) spent in one bout of a specific activity. Intensity refers to the level of effort required to perform a specific activity and is often expressed in terms of metabolic equivalents (METs). METs are defined as the ratio of the energy cost of an activity divided by the energy cost of the resting metabolic rate (1 MET). One MET is roughly equivalent to expending 1 kcal per kilogram body weight per hour (1 kcal/kg/hr) (Taylor et al., 1978). Public health programs encourage participation in moderate intensity physical activity to reduce disease risks and enhance health. Moderate intensity physical activity is defined as three to six METs (Pate et al., 1995). Vigorous intensity physical activity is defined as more than six METs and is associated with improvement of cardiorespiratory fitness. Total physical activity is often reported as hours or minutes per week and is a function of the frequency, duration, and intensity of activity performed. As a weighted estimate of intensity, MET-hr/wk (or MET-min/wk) is computed by multiplying the appropriate weight metabolic equivalent value for each activity by the amount of time spent performing that specific activity in a given week (Ainsworth et al., 2000). Finally, comprehensive measures of physical activity also measure the type or mode of the activity performed (e.g., walking, vacuuming, jogging) to allow for understanding the context in which physical activity occurs.

Key Issues to Consider When Selecting a Measure

There are many issues to consider when choosing a physical activity measure. The measure should reflect the dimension(s) of greatest interest to the study or program. For example, if an intervention targets walking, walking should be a primary activity assessed in the measure. If, however, the intervention targets lifestyle activity (e.g., building more activity into one's daily routine), then a broader and more comprehensive assessment of physical activity is likely needed. Beyond the match between measure and purpose of the assessment, other issues to consider include reliability, validity, sensitivity to change, feasibility, reactivity, and potential sources of bias (Table 17.2).

Reliability indicates the degree to which a measure consistently produces the same results with repeated administration, or test-retest reliability. Inter-rater reliability, or the degree of agreement between two independent raters, is also relevant for interview-administered measures and direct observation of physical activity. It is important to remember that a measure can be reliable but not valid. That is, the measure might consistently yield the same score but not measure the underlying construct of physical activity. Validity indicates how well the measure assesses what it is purported to measure, typically referred to

17.2 Issues to Consider When Selecting a Physical Activity Measure	
Measurement concerns	**Definitions**
Test–retest reliability	Degree to which a measure consistently produces the same results with repeated administration
Interrater reliability	Degree of agreement between two independent raters
Construct validity	How well the measure assesses what it is purported to measure
Criterion validity	Accuracy of a measure by comparing it with another measure which has been demonstrated to be valid
Convergent validity	How well two measures of the same construct correlate with each other
Sensitivity to change	Ability to detect a change when true behavior change occurs
Feasibility	Relates to the setting that measures will be used, the number of individuals measured, the cost of the measures, and the acceptability of the measures to the target population
Reactivity	Degree to which the simple act of measurement changes a person's behavior
Social desirability	The tendency for people to present themselves in an overly positive manner
Demand characteristics	The participant's tendency to respond in a manner consistent with what he/she perceives as the study hypotheses

as construct validity (Shadish, Cook, & Campbell, 2002). For example, an occupational questionnaire that accurately identifies the amount of physical activity performed in an occupational setting would have acceptable construct validity. Criterion-related validity is used to demonstrate the accuracy of a measure or procedure by comparing it with another measure or procedure that has been demonstrated to be valid. Assessing a measure's criterion-related validity is problematic for physical activity. Patterson (2000) notes that even objective measures, such as doubly labeled water, accelerometers, heart rate, and direct observation, are not likely true "gold standard measures" of physical activity as they singly do not assess the breadth of movement by type and intensity. Instead, she suggests that comparing a measure of interest to these more objective measures provides convergent validity, which is only one component of construct validity and reflects the degree that construct measures are related.

A measure's sensitivity to change is another important but sometimes overlooked issue to consider in the assessment of physical activity. A measure that is sensitive to change is one that detects a true change when it occurs. Sensitivity to change is most relevant in prospective and intervention (quasi-experimental and experimental) studies that rely on physical activity assessment tools to

determine the effects of the intervention strategies on changing physical activity behaviors.

Feasibility issues often drive the selection of study measures. Some measures are more feasible than others depending on the setting in which they will be used, the number of individuals measured, the cost of the measures, and the acceptability of the measures to the target population. For example, expensive objective measures (i.e., accelerometers) are not very feasible for use in surveillance systems where large numbers of individuals are typically assessed via telephone. Some may feel the measures pose too much of a participant burden, are perceived as intrusive, or are too expensive to administer. It is interesting to note, however, that physical activity was recently measured with accelerometers in the National Health and Nutrition Examination Survey and found to be acceptable by the study participants (Troiano, 2005). Finally, potential sources of bias (often called threats to construct validity) (Shadish et al., 2002) must be considered when selecting a measure and interpreting study findings. Reactivity, social desirability, and demand characteristics are some of the most likely sources of bias in physical activity measurement. Reactivity refers to the idea that the simple act of measurement may change a person's behavior. For example, keeping a diary of activity or wearing a pedometer may cause a person to alter his activity level. Social desirability refers to the tendency for people to present themselves in an overly positive manner—for example, as more physically active than they actually are. Demand characteristics refer to participants' tendency to respond in a manner consistent with what they perceive as the study hypotheses. For example, participants may over report physical activity after an intervention if they know the purpose of the study is to increase physical activity. Social desirability and demand characteristic biases are of particular concern with self-report measures. For more details regarding these and other sources of bias, the reader is referred elsewhere (Shadish et al., 2002). Each of these issues is highlighted in the review of physical activity measurement approaches.

It is important to keep in mind that there is no "perfect" measure of physical activity. Typically, one must weigh the pros and cons relative to the issues just described. Wherever possible, it is advisable to use more than one method of measuring physical activity to help balance different sources of bias.

Types of Physical Activity Measures

Indirect Measures—Self-Report of Physical Activity

Self-report measures are the most frequently used method of assessing physical activity due in large part to their low cost and ease of use. Self-administered measures (e.g., paper-and-pencil questionnaires), interview-administered measures, and physical activity records and logs are described in this section.

Self- and Interview-Administered Self-Report Measures

A large number of self-report measures are available for use in general as well as specific populations, and they vary greatly in complexity and length, assessment time frame, domain of activity assessed, and expression of physical activity

(e.g., unitless value, MET hrs/wk, minutes/week). Examples of self-report measures are presented in Table 17.3. Global measures tend to be very brief and typically ask participants to rate their physical activity level on a Likert-type scale. Participation in specific types of activities is not assessed, and often the participant is asked to respond relative to a "usual" or "typical" day. These measures tend to be used to measure physical activity when it is not the primary behavior of interest, for example, to control for physical activity in a study of dietary behavior.

Self-report recall measures can range from very short questionnaires or interviews that are used in surveillance studies to more lengthy questionnaires. Surveillance measures are typically used to categorize people into groups (e.g., percentage meeting physical activity recommendations) rather than to provide a precise estimate of physical activity. Longer, more comprehensive measures ask participants to report their participation in specific types of activities, as well as the frequency and duration of the activities. There is some variation in the time frame assessed in recall measures, although the time frame generally ranges from the preceding 24 hours to the previous month.

Finally, historical self-report questionnaires most commonly assess physical activity patterns over the past 12 months or one's lifetime. These measures are useful for assessing typical patterns of physical activity and for relating long-term physical activity or inactivity to various health outcomes.

Overall, when deciding on what time frame is most appropriate for the assessment of physical activity, it is important to consider how well the assessment method fits with the study purpose. In addition, the advantage of shorter time frames is that recall bias is likely to be reduced as people aren't required to think back over a long period of time, whereas the disadvantage is that the previous 24 hours or week may not be typical of the person's physical activity due to illness, a stressful life event, or other factors. Measures that assess longer time frames, such as the past year, are more likely to assess an individual's usual pattern of behavior but are more susceptible to recall errors.

Finally, self-report measures vary in the domains of physical activity they capture. Examples of domains included on many self-report questionnaires include leisure-time physical activity, sport, exercise, household activities, yard work, transportation-related activity, and child-care-related activities. Measures that contain domains related to the primary purpose of the study should be chosen.

Self- and Interview-Administered Self-Report Measures—Reliability, Validity, Sensitivity, Feasibility, and Bias

Self-report measures typically have fairly high test-retest reliability in adult samples (Sallis & Saelens, 2000). It is important to keep in mind that reliability correlations can be attenuated due to actual variability in physical activity levels over time. Validity of self-report measures is more difficult to assess because of the lack of appropriate criterion measures discussed earlier. When researchers compared objective measures such as doubly labeled water, accelerometers, and heart rate monitoring to commonly used measures, validity correlations were found to be lower than reliability correlations, ranging from $r = .14$ to $.36$, although the Seven-Day Physical Activity Recall (PAR) had higher correlations

17.3 — Examples of Self-Report Physical Activity Measures for Adults

Measure	Reference	Number of items	Recall time frame	Domains assessed
Brief, global				
Lipid Research Clinics Physical Activity Questionnaire	Ainsworth, Jacobs, & Leon, 1993	4	Usual day	Occupational exercise
Stanford Usual Activity Questionnaire	Sallis et al., 1985	2	Usual activity unspecified & usual activity in the last 3 months	Moderate-intensity and vigorous-intensity activity
Recall questionnaires or interviews				
Baecke Questionnaire of Habitual Physical Activity	Baecke, Burema, & Frijters, 1982	16	Usual activity	Sport, leisure, occupational
Behavioral Risk Factor Surveillance System (BRFSS)	Centers for Disease Control, 2005	6	Usual week	Moderate-intensity and vigorous-intensity lifestyle physical activity
Community Healthy Activities Model Programs for Seniors (CHAMPS)	Stewart et al., 2001	42	Typical week in the past 4 weeks	Exercise, sport, leisure, occupational, transportation
Physical Activity Scale for the Elderly (interview- or self-administered)	Washburn et al., 1999; Washburn et al., 1993	10	Past 7 days	Leisure, household, occupational
Seven-Day Physical Activity Recall (interview-administered)	Blair et al., 1985	Not applicable (guided recall of activity in morning, afternoon, and evening in past 7 days)	Past 7 days	Exercise, leisure, occupational

17.3	Examples of Self-Report Physical Activity Measures for Adults (*Continued*)			
Measure	Reference	Number of items	Recall time frame	Domains assessed
Historical questionnaires				
CARDIA Physical Activity History	Jacobs et al., 1989	60 (if all questions are answered yes)	Past 12 months	Leisure, occupational, household
Historical Leisure Activity Questionnaire	Kriska et al., 1990	List of 39 activities is read (plus "other") and for those done >10 times, participant reports on 4 periods in life	Lifetime	Exercise, sports
Lifetime Total Physical Activity Questionnaire	Friedenreich et al., 1998	Open-ended question for each domain	Lifetime	Exercise/ sports, occupational, household
Minnesota Leisure-Time Physical Activity Questionnaire	Taylor et al., 1978	63	Past 12 months	Exercise, sports, recreation, yard, household

with accelerometers (range of r = .50 to .53) (Sallis & Saelens, 2000). Higher-intensity physical activities are more accurately reported than lower-intensity activities, likely because they are more memorable and time-limited than light- and moderate-intensity activities (Sallis et al., 1985; Sallis & Saelens, 2000).

Self-report measures are often selected because of their feasibility. They are inexpensive and generally easy for participants to complete, therefore presenting relatively low participant burden, and can be used in a wide variety of settings. Data regarding sensitivity of measures to change are often not reported to the extent that validity and reliability data are. The potential for bias is the most substantial concern with self-report measures. While reactivity is not a concern, social desirability biases and demand characteristics are among the most commonly voiced concerns with self-report measures. The reader is also referred to an excellent paper by Choi and Pak (2005), which outlines a number of additional biases in self-report measures and ways to minimize these biases.

Several approaches have been used to try to identify and minimize bias in questionnaire development. Durante and Ainsworth (1996) discuss a cognitive model that can be used to identify potential sources of bias in questionnaires.

They propose four stages of cognitive processing that influence how respondents answer questions: (1) comprehension, (2) retrieval, (3) decision making, and (4) response generation. Ambiguities in the question impact comprehension. For example, if respondents are left to define critical terms (e.g., "a city block," "moderate-intensity"), biases are likely in this first stage of comprehension. Challenges related to mental operations required in the decision-making stage (e.g., summing time walked over a one- to seven-day period) could produce errors in this stage. Further, errors in translating information from the decision-making stage to the response generation stage could result in errors. Several ways to reduce such sources of error have been recommended. First, questions are often subjected to cognitive testing. Respondents are asked, for example, to rephrase what they think the question means or to state how confident they are in the accuracy of their response. Another approach that enhances accuracy is to provide contextual cues and recall calendars. For example, in the Seven Day Physical Activity Recall (Sallis et al., 1985), participants are asked to think about the activities they did in a given day (e.g., when did they wake up? Did they work that day? Did they have class that day?) in order to give greater context to their day and thus enable them to report physical activity more accurately. Recall calendars (e.g., focused on educational and occupational activities and life events) are used in the Lifetime Total Physical Activity Questionnaire (Friedenreich, Courneya, & Bryant, 1998) to help serve as memory aids for the participant. Another approach to minimizing self-report errors has been used to attempt to reduce social desirability. The Community Healthy Activities Model Program for Seniors (CHAMPS) physical activity questionnaire (Stewart et al., 2001) asks about activities that are not physical in nature (e.g., visiting with friends, reading, working on a computer) in addition to physical activities. The rationale is that individuals will be more likely to truly respond negatively to items if there are some activities included to which they can respond positively. Finally, in the area of dietary assessment, some used a social desirability measure as a way to estimate bias and control for it in analyses (Hebert, Clemow, Pbert, Ockene, & Ockene, 1995). A similar approach could be used in physical activity assessment. Additional techniques to minimize reporting errors are discussed elsewhere (Choi & Pak, 2005; Durante & Ainsworth, 1996).

Self- and Interview-Administered Measures in Population Subgroups

There are several factors that must be considered when using self-report measures in children, older adults, women, and persons of color. Sallis and colleagues reviewed self-report measures used in the 1990s for children, adults, and older adults (Sallis & Saelens, 2000). Children, particularly those under the age of 9 years, are more limited in their cognitive functioning than adults, translating into less accurate recall of physical activity and an inability to accurately estimate time on self-report measures (Welk, Corbin, & Dale, 2000). Therefore, self-report measures are not recommended for children under the age of 9 years. In a review of self-report measures for children age 9 years and older (Sallis & Saelens, 2000), test-retest reliability correlations for self-report measures were generally acceptable (range: r = .60 to .98), but validity correlations were variable, ranging from r = .07 to r = .88 for self-administered surveys and from r = .17 to r = .72 for interview-administered measures. However, they noted that approximately half of the measures assessed

had validity correlation coefficients of r = .50 or higher. In an effort to reduce cognitive demands, the Previous Day Physical Activity Recall (PDPAR) was developed for use with children and validated (Weston, Petosa, & Pate, 1997). Children are asked to recall the dominant activity engaged in during a series of 30-minute time increments and the intensity of the activity. A MET value is assigned to each activity corresponding to the activity type and intensity. Multiple days of recalls must be collected, as is the case in the 3-Day Physical Activity Recall (3DPAR) (Pate, Ross, Dowda, Trost, & Sirard, 2003).

Women and persons of color are less likely than men and non-Hispanic whites to participate in structured, vigorous-intensity physical activity. Instead, they are more likely to participate in activities that are less structured and of light- to moderate-intensity, such occupational, household, and family-care activities (Ainsworth, 2000b). Many self-report measures do not assess these types of activities, and thus the physical activity levels of women and ethnic minority adults are likely underestimated (Ainsworth, 2000a; Kriska, 2000; Mâsse et al., 1998). Indeed, Brownson and colleagues (Brownson et al., 2000) found that when a broader definition of physical activity was used that included occupational activity and housework, nearly three-fourths of women in the U.S. Women's Determinants Study were classified as regularly active. Ainsworth and colleagues (Ainsworth, Irwin, Addy, Whitt, & Stolarczyk, 1999) reported similar findings in that 63% to 70% of African American and Native American women over the age of 40 years were classified as regularly active when activities such as household chores, occupation activity, and child care were assessed. Related, most available questionnaires have not been critically evaluated as to the extent that they are culturally and gender sensitive (Mâsse et al., 1998). Terms such as "moderate intensity," "vigorous," "exercise," "leisure-time," and "physical activity" may not be interpreted the same way across study populations (Tortolero, Mâsse, Fulton, Torres, & Kohl, 1999). Furthermore, as was noted earlier, lower-intensity activities are recalled with poorer accuracy than higher-intensity activities, posing challenges for valid and reliable physical activity assessment in women and persons of color.

Mâsse and colleagues (Mâsse et al., 1998) outlined a number of recommendations for assessing physical activity in midlife, older, and minority women. These include being sensitive to the characteristics of the study population, accounting for various dimensions of physical activity performed, measuring moderate and intermittent activities as well as vigorous and continuous activities, and designing and administering surveys that are culturally inviting to the study population. In response to a number of these concerns and consistent with Mâsse and colleague's recommendations, Ainsworth and colleagues developed a self-report survey to assess physical activity among White, African American, and Native American women (Ainsworth et al., 1999). Survey items were generated based on detailed physical activity records kept by women that characterized types and patterns of physical activity in which they participated. The resulting questionnaire is one of the few developed specifically for ethnic minority women.

Finally, there are unique considerations in the measurement of physical activity in older adults. Some of the same challenges that affect the assessment of physical activity in women and persons of color apply to older adults. Although there is a great deal of diversity within the older population, low- and

moderate-intensity physical activities are much more common than vigorous-intensity physical activities, potentially creating problems in accurate recall as well as in the appropriate inclusion of activities on surveys (Mâsse et al., 1998). Thus, prevalence studies likely underestimate physical activity participation among older adults because of the types of questions that are included in most self-report surveys. Another challenge in assessing physical activity in older adults relates to cognitive and sensory impairments. Cognitive impairments and age-related sensory declines in vision and hearing, which increase with age, may attenuate the accuracy of self-report measures. Thus, when considering which measure to use with an older population, the time frame and types of activities assessed are important considerations. Ideally, measures should ask about the past week or a usual week and should include household, yard, and caregiving activities. Older adults should be reminded to bring visual and hearing aids as needed, the interviewer should avoid speaking softly or in a high-pitched tone, and a larger font size (14 point) and matte rather than glossy paper should be used.

Several physical activity questionnaires have been developed specifically for older adults. Washburn (2000) reviewed four measures and reported adequate test-retest reliability correlations (range: r = .42 to .75) and validity correlations (range: r = .42 to .75). As noted by Washburn, validity studies were relatively rare and consisted of small samples. The four surveys were the Modified Baecke Questionnaire for Older Adults (Voorrips, Ravelli, Dongelmans, Deurenberg, & Van Staveren, 1991), the Zutphen Physical Activity Survey (Caspersen, Bloemberg, Saris, Merritt, & Kromhout, 1991), the Yale Physical Activity Survey (Dipietro, Caspersen, Ostfeld, & Nadel, 1993), and the Physical Activity Scale for the Elderly (Washburn, McAuley, Katula, Mihalko, & Boileau, 1999; Washburn, Smith, Jette, & Janney, 1993). Since that publication, Stewart and colleagues (Stewart et al., 2001) reported on the development of the Community Healthy Activities Model Program for Seniors (CHAMPS) physical activity questionnaire. This measure has comparably high reliability and validity correlations and has been shown to be sensitive to change in a number of intervention studies. Although the Zutphen Physical Activity measure only assesses leisure activity, the other measures assess broader domains, including household and occupational activity.

Physical Activity Records and Logs

Another type of self-report measure is a physical activity record or log. Physical activity records are typically detailed accounts of the types of activity in which participants engaged over the course of days or weeks. More detailed records might ask participants to report all activities in which they engaged, the duration of the activities, and perceived effort, whereas other, somewhat less detailed records might have participants record their activity at specified time intervals. This approach is similar to a food diary and can be completed as the person is going about her day. More detailed records can be used to validate other physical activity measures, since issues of recall bias are greatly minimized due to near-real-time recording (Ainsworth et al., 1999).

Physical activity logs are similar to records but are generally less burdensome. Typically, a checklist of activities and intensity levels is included for the

participant to complete at specified time intervals (e.g., every 15 minutes). The logs are completed at the end of the day, and intensity values from the Compendium of Physical Activity (Ainsworth et al., 2000) are assigned to each activity. Examples of physical activity logs include the Bouchard Physical Activity Log (Bouchard et al., 1983) and the Ainsworth Physical Activity Log (LaMonte, Ainsworth, & Tudor-Locke, 2003). Finally, in the context of intervention studies, very simple logs are often used to record bouts of physical activity. For example, in a walking study, participants could record the total minutes they walked each day for exercise on a calendar and return this log to staff on a monthly basis.

Physical Activity Records and Logs—Reliability, Validity, Sensitivity, Feasibility, and Bias

The psychometric properties of physical activity records and logs have not been studied as extensively as self- and interview-administered self-report questionnaires. However, because these records or logs are typically completed during the course of the day or at the end of the day, it is assumed that the degree of recall bias is considerably less than with questionnaires, thus enhancing reliability and validity. As noted earlier, detailed physical activity records are sometimes used to validate self-report measures. When compared to accelerometer counts, physical activity records have relatively high validity correlations (Richardson, Leon, Jacobs, Ainsworth, & Serfass, 1995). When records are completed over short periods of time, participant burden is relatively low. Similarly, physical activity logs, especially brief ones, impose very little participant burden. However, detailed records kept over longer periods of time can pose more substantial participant burden and can require substantial research staff time to code behavior, enter data, and synthesize data. Thus, feasibility is dependent on the level of detail required and the length of the reporting period. While reactivity is of minimal concern with questionnaires as the mere act of completing them is unlikely to change behavior, reactivity is of greater concern with physical activity records and logs. That is, the act of recording activities could change actual behavior patterns. The effects of social desirability and demand pressures are more worrisome with physical activity questionnaires and logs than with objective measures but are of less concern than when self- and interview-administered questionnaires are used. However, these biases may still operate, as participants may overestimate duration or intensity due to social desirability and demand characteristic biases.

Direct Measures of Physical Activity

Accelerometers

Accelerometers are increasingly being used to measure physical activity as availability and improvements in technology continue. While the Caltrac (Muscle Dynamics, Torrence, CA) was the first accelerometer to be widely used in research, there are currently a number of accelerometers available for use, including Tritrac-R3D, RT3, Actigraph, Actical, ActiTrac, Actiwatch, BioTrainer, Tracmor, and SenseWear PRO_2. Accelerometers are small, battery-operated

devices, typically worn at the hip (although arm and ankle placements are also used), that measure movement and velocity of movement. Most use piezoelectric sensors that detect movement in one to three planes. Accelerometers can be programmed to assess movement at different intervals or epochs (e.g., every minute) and store data for extended periods (up to 28 days of minute-by-minute recording). Data stored on the device are later downloaded, and regression equations based on laboratory calibration studies can be applied to classify physical activity into intensity categories using various cutpoints (Freedson, Melanson, & Sirard, 1998; Freedson, Pober, & Janz, 2005; Matthew, 2005).

Both uniaxial and triaxial accelerometers have been used to assess physical activity in various settings. Uniaxial accelerometers measure movement in one plane, typically the number and velocity of vertical movements. A commonly used uniaxial accelerometer is the Actigraph (formerly called the Computer Science Application or CSA; Actigraph, LLC, Fort Walton Beach, FL). Triaxial accelerometers measure movement in three dimensions. A commonly used triaxial accelerometer is the RT3 Triaxial Research Tracker (StayHealthy, Inc., Monrovia, CA). The Actical (Mini Mitter Co., Inc., Bend, OR) is an example of a newer triaxial accelerometer that is becoming widely used. It can record physical activity counts for up to 45 days (using minute-by-minute recording). In addition to the uniaxial and triaxial accelerometers, emerging technologies in accelerometers are described by Chen and Bassett (2005). These include accelerometers that take multiple measurements at different body segments, devices that combined accelerometery with other physiological measurements (e.g., heart rate, temperature), and shoe- and ankle-mounted accelerometers. Multisensor accelerometers such as the Intelligent Device for Energy Expenditure and Activity (IDEEA, MiniSun LLC, Fresno, CA) hold promise for enhancing prediction accuracy.

Reliability, Validity, Sensitivity, Feasibility, and Bias

Accelerometers are often selected because they remove the need for participant recall and thus eliminate self-report biases that limit reliability and validity. When compared to oxygen consumption and similar measures in controlled laboratory settings, accelerometers have high validity and reliability, particularly for dynamic activities such as walking and running, which are among the more common activities adults undertake (Matthew, 2005). Theoretically, triaxial accelerometers should be more accurate than uniaxial accelerometers because they should better characterize human movement and reflect movement in all geometric planes (e.g., forward, back, sideways, uphill, and downhill), but data reduction programs do not fully capitalize on this potential strength (Chen & Bassett, 2005), and validity coefficients have tended to be only marginally higher in triaxial models than in uniaxial models (Trost, McIver, & Pate, 2005). Accelerometers are not as valid for activities that require upper-body movement, strength training, water activities, or more complex activities. There is also evidence from validation studies. that accelerometers tend to underestimate energy expenditure, particularly for lifestyle activities, with triaxial accelerometers performing only slightly better than uniaxial accelerometers (Trost et al., 2005). In addition, while an appeal of accelerometers is that they measure both time and intensity, there

are some instances where intensity is not properly assessed, such as walking or hiking on an incline.

With regard to feasibility, accelerometers typically impose only a modest participant burden. However, accuracy is threatened if the monitor is not worn properly, if the participant forgets to wear it or wears it for only part of a day, or if the monitor is not returned to the researcher. Thus, participant compliance is essential. Because of day-to-day variability in physical activity, it is recommended that the accelerometer be worn for 3 to 5 days in adults and 7 days in children to obtain adequate reliability coefficients (Trost et al., 2005). The cost of accelerometers ($300–$600) limits their feasibility in some contexts, such as population-based studies, and, because the monitor must be distributed and then collected some period of time later, its use is limited in some settings. Reactivity is a potential bias with the accelerometer because people may alter their behavior if they know it is being measured. However, the accelerometer does not provide feedback to the participant, thus minimizing this bias. An appeal of the accelerometer is that, because it eliminates the need for self-report, it is not subject to recall biases, social desirability, or demand characteristics.

Pedometers

The pedometer is another measure of physical activity that has grown in popularity in part because of its low cost and small size. Pedometers are worn at the waist and are triggered by the vertical accelerations of the hip that cause a horizontal spring-suspended level arm to move up and down, resulting in counted "steps." Pedometers are typically used to obtain a step count over a specified period, typically over the course of a day. They are used both as a measurement tool, particularly to assess walking, and as a self-monitoring and self-motivation tool in intervention studies. With regard to typical step counts one can expect, a systematic review of 32 empirical studies reported that 12,000–16,000 steps/day for 8–10-year-old children, 7,000–13,000 steps/day for relatively healthy, younger adults, 6,000–8,500 steps/day for healthy older adults, and 3,500–5,500 steps/day for individuals living with disabilities and chronic illnesses is typical (Tudor-Locke & Myers, 2001). Counts are lower in girls and women than in boys and men. The pedometer also has been used to assess population levels of physical activity (Tudor-Locke, 2002; Tudor-Locke et al., 2004). Tudor-Locke (2002) provides a comprehensive description of the use of pedometers for surveillance and research and in practice settings.

Reliability, Validity, Sensitivity, Feasibility, and Bias

In many settings the pedometer is a feasible alternative to the accelerometer because of its substantially lower cost ($20–$30). When walking is the primary activity of interest, a number of pedometers are available that are valid and reliable (Schneider, Crouter, & Bassett, 2004; Schneider, Crouter, Lukajic, & Bassett, 2003). Three days of measurement are considered necessary to obtain acceptable reliability coefficients with a pedometer (Tudor-Locke et al., 2005). The pedometer does not perform as well for very slow walking speeds and does not assess some types of physical activity, including upper-body exercises, strength training, and water activities. Placement and type of pedometer may

be particularly important issues to attend to in obese individuals, especially when assessing very slow walking speeds (Crouter et al., 2005). Pedometers also provide no information regarding intensity of activity, duration of activity bouts, type of activity, or when the activity was performed.

As with the accelerometer, the participant burden imposed by the pedometer tends to be low, and participant compliance is important for accurate measurement. The participant must wear the pedometer correctly and consistently, record steps on a log at the end of the day, and zero it out every day. When it is used as a measurement tool, the pedometer does create a potential for reactivity. Because the participant gets feedback on number of steps taken, he can modify (increase) physical activity behavior as a result of assessment. One way to lessen reactivity is to have the participant wear the pedometer for a longer period of time than needed and to use only data acquired after several days of wearing. The novelty of the pedometer is likely to decrease after a few days of measurement. Also like the accelerometer, the pedometer eliminates recall biases. Assuming that the participant properly records his steps in a log, the biases imposed by social desirability and demand characteristic are minimal with pedometers.

Accelerometers and Pedometers in Population Subgroups

Because self-report measures have more limited reliability and validity in children, particularly young children, than in adults, accelerometers and pedometers are appealing. The reliability and validity of pedometers have not been examined extensively in children, but there is concern that children tend to react to the monitor and manipulate it and therefore reduce its validity (Ward, Saunders, & Pate, 2007). Nonetheless, Rowlands and colleagues reported a high correlation between pedometer and Tritrac accelerometer counts (r = .90) in a sample of children ages 8–10 years (Rowlands & Eston, 2005), and Eston and colleagues reported a high correlation (r = .78) between pedometer steps and oxygen uptake for treadmill walking and an even higher correlation with unregulated play activities (r = .92) (Eston, Rowlands, & Ingledew, 1998). Another study, however, found that pedometers did not fare well in a comparison with a direct observation system in younger children (Oliver, Schofield, Kolt, & Schluter, 2006).

Accelerometers, on the other hand, have been widely used in studies of children, and acceptable reliability and validity have been shown in both laboratory and field conditions (Trost et al., 2005; Welk et al., 2000). The Actigraph, Actical, and RT3 Triaxial Research Tracker have been studied most extensively. A key issue in assessing physical activity with children through accelerometers is that children tend to have more intermittent bursts of behavior. Thus, using time intervals or epochs of 1 minute, as is common in adults, is too long for children. Shorter time epochs should be used (e.g., 15 or 30 seconds). More days of monitoring (five to nine) are needed for children than for adults, and 7 days are recommended (Trost et al., 2005).

While the use of objective monitors in older adults is appealing as a way to avoid recall biases, few data are available regarding the reliability and validity of accelerometers in this population. There is some evidence, however, that pedometers underestimate steps taken by older adults with a slow walking speed and those with gait disorders, thus limiting their utility with frail individuals

(Cyarto, Myers, & Tudor-Locke, 2004). However, pedometers can be used with a high degree of reliability and validity with healthy older adult populations.

Direct Observation

The final direct approach to the measurement of physical activity is direct observation. Because of some of the limitations inherent in the measurement of physical activity in children via self-report measures, direct observation has been used almost exclusively in the context of assessing physical activity in children. Examples of observational systems include the Children's Activity Rating Scale (CARS) (Puhl, Greaves, Hoyt, & Baranowski, 1990), the System of Observing Play and Leisure Activity in Youth (SOPLAY) (McKenzie, Marshall, Sallis, & Conway, 2000), the System for Observing Fitness Instruction Time (SOFIT) (McKenzie, Sallis, & Nader, 1991), BEACHES (McKenzie et al., 1991), and the Observational System for Recording Physical Activity in Children-Preschool Version (OSRAC-P) (Brown et al., 2006). For example, SOPLAY is based on momentary time sampling and is used to obtain observational data on activity levels among children during play and leisure opportunities. During a scan, the physical activity of each child in the study is coded as sedentary, walking, or very active. Additional contextual information is also noted, including accessibility, usability, and availability of equipment. The type of activity in which the child is engaged is also recorded. For the activity measures, counts are tallied for sedentary, walking and very active behavior, and counts are transformed into estimates of energy expenditure. The system requires extensive training to ensure that observers reach acceptable criteria for reliable assessment.

Reliability, Validity, Sensitivity, Feasibility, and Bias

Observational systems have been shown to be reliable and valid and are often used to validate other measures. However, proper training and assessment are necessary to ensure adequate interrater reliability and to prevent coder drift over time. Ideally, multiple raters code behavior and interrater reliability is assessed, at least for a sample of observations. While this approach eliminates participant burden, it can be a time-intensive and thus expensive approach for the investigator. This approach is not feasible for population-based studies. In addition, the information learned is restricted to a narrow time window and to a limited setting or context (e.g., physical education class, playground). Direct observation can be very informative for understanding the contextual factors that influence physical activity and for quantifying physical activity in specific situations (e.g., physical education classes). It is a less useful method for estimating total physical activity.

Summary and Conclusions

A number of options exist for assessing physical activity in children and adults, but these options vary in their level of precision. Ideally, where possible, multiple measures (i.e., direct and indirect measures concurrently) should be used to adequately capture frequency, intensity, type, duration, and context of this complex behavior. All measurement methods have limitations to some degree

in their reliability, validity, sensitivity, feasibility, reactivity, and potential sources of bias. Thus, these issues must be considered when selecting a measure for the specific study population. Indirect methods used to assess physical activity, such as self-report measures, are commonly used because of their low cost, low participant burden, ease of use, and limited reactivity. However, depending on the measure, reliability and validity can be limited due to recall and other self-report biases. Direct methods used to assess physical activity, such as objective monitoring devices (accelerometers and pedometers), are appealing because they eliminate recall biases and are generally reliable and valid, although some types of activity may not be captured and some types of activity (slow walking, lifestyle activities) are less accurately measured. In addition, the type of activity performed and the context in which it is performed are not recorded. Accelerometers are expensive, require high participant compliance, and require up to a week of wearing to gather reliable data, thus limiting their use in some settings. Pedometers are inexpensive but do not store data and thus require participant logging of steps. In addition, pedometers do not capture the dimensions of type, duration, or intensity of activity bouts. Finally, direct observation is an objective approach that is used to measure physical activity in children in specific settings such as physical education class or recess. This approach eliminates participant recall bias and participant burden and is considered high in validity and reliability, but substantial training of observers is required to obtain high interrater reliability. This approach can also be expensive in terms of staffing and data reduction.

While there is no perfect measure of physical activity, the study purpose, setting, and resources must be considered to identify the optimal method to assess physical activity. Prior to adopting a method to assess physical activity, investigators must carefully evaluate the method for its measurement properties and for its suitability for the study population.

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Changes in Substance Use Behavior

18

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This chapter describes a number of techniques and tools available for the measurement of substance use behaviors, changes in these behaviors, and risk and factors that predict changes in substance use behavior. Measurement of substance use behavior requires repeated use of multiple measures and informants to capture the patterns and changes in substance use that occur over time. The chapter includes definitions of substance use behavior and describes the developmental patterning of substance use behavior. Also included are sections and tables on questionnaires and biological measures that assess substance use behavior in adolescents and adults. We review risk and protective factors that are associated with the onset, progression, and continuation of substance use behavior and measures that assess these factors. Finally, we discuss challenges

related to current methods of assessment and measurement, as well as future directions.

Substance Use Behavior

Substance use is the use of any substance that acts on the central nervous system in a manner other than prescribed and often features impaired control related to substance intake and difficulty in self-regulation of substance intake, despite negative outcomes (Martin, Fillmore, Chung, Easdon, & Miczek, 2006). Substance use disorders (abuse and dependence) are maladaptive patterns of substance use that include clinically significant impairment or distress, as manifested by occurrence of specific symptoms that have occurred within a year (American Psychiatric Association, 2000).

Substance use behaviors are pervasive among adolescents and young adults in the United States and present a significant burden to both the user and society. The National Survey on Drug Use and Health (Substance Abuse & Mental Health Services Administration, 2006) found that 19.7 million individuals over the age of 12 had used an illicit drug in the past month, representing approximately 8% of the population 12 years or older. Marijuana was the most widely used illicit substance, although "harder" drugs such as cocaine and other stimulants, including methamphetamine, were also prevalent.

An important developmental model of substance use is the "gateway" theory (Kandel, 1975), which describes sequential stages of *onset* of drug use (Kandel, Yamaguchi, & Klein, 2006). The first stage involves use of beer or wine; the user then progresses to use of hard liquor and cigarettes (stage 2), marijuana (stage 3), and, ultimately, other illicit drugs (stage 4). These transitions occur *across* classes of drugs, as progression from less severe drugs (e.g., marijuana) toward more severe drugs (e.g., cocaine, heroin). However, the gateway theory does not adequately explain the behaviors involved in the progression of substance use *within* classes (e.g., maintenance of use, increasing use). Although gateway effects may exist, a common factor (drug use propensity) may also predispose the initiation and continuation of drug use (Dawes et al., 2000; Morral, McCaffrey, & Paddock, 2002).

Theories explaining onset of substance use must be viewed in a broader context that includes transitions *within* stages. For example, the development of substance use disorders has been described as transitioning through five stages: (1) Initiation, (2) Continuation, (3) Maintenance and progression within a drug class, (4) Progression across drug classes, and (5) Regression, cessation, and relapse cycles (Clayton, 1992). Initiation is the phase when a nonuser begins to use a particular substance. Continuation is the transition of drug use just beyond initiation, when first exposure leads to increased use. Maintenance of use includes persistence of both moderate and excessive usage. Progression within a drug class refers to increased consumption of the substance, as well as progression in route of administration of the substance (e.g., from snorting cocaine to smoking it). Progression across drug classes is the transition from use of one substance to polysubstance use. Finally, regression, cessation, and relapse cycles are transitions from use to nonuse and back to use.

Assessment of Substance Use Behavior

Substance Use Severity

Substance use behaviors are more accurately measured along a continuum of severity of involvement: experimental use, early abuse, abuse, dependence, and recovery. Experimental use coincides with the initiation and continuation stages and involves minimal, often recreational, use. Early abuse is present early in the maintenance stage and involves more established use, with adverse consequences beginning to emerge. Abuse occurs later in the maintenance stage and involves regular use over an extended period with several adverse consequences. Dependence is present toward the end of the continuum and involves repeated use, severe consequences, signs of tolerance, and schedule accommodation for drug seeking (Winters, Latimer, & Stinchfeld, 2001). Abstinence is cessation of use after a period of abuse or dependence. The optimal assessment of substance use involvement should assess changes severity and consequences of substance use over time (Clark & Winters, 2002).

Measurement and Validity

In order to accurately assess substance use behavior, it is essential to use sensitive, reliable, and valid methods of measurement. Available measures fall into two general categories: questionnaires and laboratory tests. Questionnaires include self-report and parent-report measures. Structured and semistructured interviews assess substance use severity, psychopathology, presence of risk and protective factors, and cognitive domains of substance use. Laboratory measures include testing blood samples, urine samples, breath samples, and other biological samples.

Clearly, questionnaires and interviews require the cooperation of the individual being assessed. Furthermore, the individual should demonstrate some degree of insight into the condition, willingness to accept the existence of problems, and motivation to seek assessment and treatment. Assessment can be hindered because substance-using individuals may have impairments in cognitive and decision-making abilities that can affect their willingness to address problems (Noam & Houlihan, 1990). For adolescents, assessments and corroborating parental reports require honesty and accurate insight, as well as objective reporting concerning their child and knowledge of their child's substance use behaviors. Often, parents cannot provide meaningful information concerning the substance use behaviors of their children (Winters et al., 2001). Self-report measures have received considerable scrutiny, with support both for and against validity (Winters et al., 2001). To increase validity, standardized instruments should include response bias scales and interviewing techniques that help the individual feel comfortable and therefore more likely to disclose substance use (Winters et al., 2001).

Comprehensive Assessment

Comprehensive assessment of the severity of current substance use is a multifaceted process that utilizes questionnaires, interviews, and laboratory

measures. The first step, screening, should address multiple domains of functioning, using instruments with high reliability, validity, and predictive ability. The screening assessment should focus both on severity of use and the effects of use on everyday functioning across many domains (e.g., school, home). If indicated (i.e., signs of poor functioning across several domains due to substance use), further assessment should be undertaken by a trained professional.

The second step, diagnostic assessment, requires use of multiple measures and multiple informants. Structured or semistructured interviews and drug monitoring in urine samples provide information about the severity of substance abuse, psychiatric comorbidity, and medical and health status to determine what level of intervention and/or treatment is indicated (Substance Abuse and Mental Health Services Administration [SAMHSA], 1999). The purposes of the diagnostic assessment are to (1) identify if a substance use disorder and a psychiatric comorbidity exist, (2) determine those individuals in need of treatment, (3) determine to what extent the individual's environment affects substance use behavior, and (4) develop a plan for treatment (SAMHSA, 1999).

Questionnaire Measures

"Questionnaire measures" describe the tools (typically pen-and-paper measures) used to gather nonbiological information related to substance use behaviors. Measures used in adolescents and adults all differ, although some have been altered to be compatible with broader populations. In adolescents, a critical measurement issue is the necessity of corroborating information (e.g., from parents or teachers). Information gathered from adolescents and informants includes, but is not limited to, history of use, current patterns of use, presence of risk/protective factors, and cognitive beliefs concerning substance use (Winters et al., 2001).

Adolescent Measures—Screening Instruments

Screening instruments should be used to estimate where an individual stands on the continuum of severity of substance use. Generally, screening instruments provide a brief estimation of substance use severity and indications that further assessment is needed. Many screening tools are available for use in adolescents and are appropriate for different situations. Some cover items strictly related to substance use, while others provide a more multidimensional screening. Screening instruments include the Drug Use Screening Inventory—Revised (DUSI-R; Kirisci, Mezzich, & Tarter, 1995), the Problem Oriented Screening Instrument for Teenagers (POSIT; Rahdert, 1991), and screening instruments to assess adolescent alcohol and drug use in primary care (CRAFFT; Knight, Sherritt, Shrier, Harris, & Chang, 2002), alcohol use (Adolescent Alcohol Involvement Scale, AAIS; Mayer & Filstead, 1979), drug use and dependence (Adolescent Drug Involvement Scale, ADIS; Moberg & Hahn, 1991) and problems arising from alcohol use (Rutgers Alcohol Problem Index, RAPI; White & Labouvie, 1989). For a comparison of the properties of these adolescent screening measures, please see items 1 through 6 in Table 18.1.

TABLE					
18.1	**Substance Use Screening Measures, Questionnaires, and Structured and Semistructured Interviews**				

Instrument/ Measure	Items; Administra-tion Time	Age Range	Use	Key Features	Citation
1. *Drug Use Screening Inventory—Revised* (DUSI-R)	159 items; 20–40 minutes	Adolescent to adult	Evaluate suspected drug using individu-als; quantify severity of consequences of drug use	Can be used in adolescents and adults; Lie Scale included; Spanish version available; self-administered	Tarter, 1990
2. *Problem Oriented Screening Instru-ment for Teenagers* (POSIT)	139 items; 20–30 minutes	12–19	Identify potential prob-lems requiring fur-ther assessment in 10 areas	Assesses multiple domains; modified form for repeatability available; can be used by school, juvenile, and family court personnel; follow-up can be used as a measure of change; self-administered	Rahdert, 1991
3. *CRAFFT Substance Abuse Screening Test* (CRAFFT)	6 items; 5 minutes	Adolescents	Drug use screening in adolescents	Specific for adolescents; very brief; screens for drugs and alcohol; self- or interviewer-administered	Knight et al., 2002
4. *Adolescent Alcohol Involvement Scale* (AAIS)	14 items; 5 minutes	Adolescents	Brief standardized mea-sure for detecting adolescents' use and misuse of alcohol	Assesses quantitative use and psychosocial consequences in three domains: psychological functioning, social relations and family living; self-administered	Mayer and Filstead, 1979

(*Continued*)

Instrument/ Measure	Items; Administration Time	Age Range	Use	Key Features	Citation
5. *Adolescent Drug Involvement Scale* (ADIS)	12 items; 5 minutes	Adolescents	Distinguish heavier problematic users from less involved users	Used for both research and screening; drug involvement defined in terms of consequences, motivations, and sense of control; self-administered	Moberg and Hahn, 1991
6. *Rutgers Alcohol Problem Index* (RAPI)	23 items; 10 minutes	Adolescents	Screening tool for assessing adolescent problem drinking	Easily administered; no training required; usable in clinical and nonclinical samples; self-administered	White and Labouvie, 1989
7. *Diagnostic Interview for Children and Adolescents* (DICA)	416 items; 60–90 minutes	6–18	Semistructured interview assessing 19 DSM-IV disorders, including substance use disorders	Detailed substance abuse section; separate versions for children 6–12 and adolescents 13–18; computerized version available; interviewer-administered or self-administered on computer	Reich et al., 1982
8. *Diagnostic Interview Schedule for Children* (DISC-C)	358 "stem" questions; 70–120 minutes	6–17	Highly structured interview designed to assess DSM-IV psychiatric disorders, including substance use disorders	Separate parent and child versions; designed for epidemiological research; generates symptom counts and diagnoses; interviewer-administered	Shaffer et al., 1996
9. *Kiddie Schedule for Affective Disorders and Schizophrenia* (K-SADS)	300 items; 90–120 minutes	6–18	Semistructured interview covering a broad spectrum of child psychiatric diagnoses, including substance use disorders	Used primarily in research settings, not ordinary clinical settings; administered by a trained clinician	Endicott and Spitzer, 1978

10.	Modified Structured Clinical Interview for the DSM-IV (mSCID)	92 items; 45–60 minutes	Adolescents	Structured interview assessing age of substance use onset and frequency of use	Assess developmentally appropriate drug problems; should be administered to the adolescent and the parent; interviewer-administered	First et al. 1997; Martin et al., 1995
11.	Adolescent Diagnostic Interview (ADI)	213 items; 30–90 minutes	12–18	Structured interview assessing psychoactive substance use disorders	Screens for accompanying mental/behavioral problems; Based on DSM-III and IV criteria; Interviewer-administered	Winters and Henly, 1993
12.	Adolescent Self-Assessment Profile (ASAP)	225 items; 25–50 minutes	Adolescents	Assessment of psychosocial adjustment and substance use involvement	May be used for, during, and after treatment to determine changes in perception of adolescents' psychosocial and substance use problems; self-administered	Leccese and Waldron, 1994
13.	Adolescent Drug Abuse Diagnosis (ADAD)	150 items; 45–55 minutes	Adolescents	Structured interview assessing substance use and other life problems	Comprehensive evaluation yielding 10-point severity ratings in nine life problem areas; 83 items are used for measuring change; interviewer-administered	Leccese and Waldron, 1994
14.	Comprehensive Addiction Severity Index for Adolescents (CASI-A)	10 modules; 45–90 minutes	Adolescents	Semistructured clinical interview for evaluating adolescents in many domains, including substance use	Can be used in many provider settings and repeated at follow-up; assesses many domains; incorporates urine drug screen results; interviewer-administered	Meyers, 1991
15.	American Drug and Alcohol Survey (ADAS)	55 items; 30–50 minutes	4th–12th grade	Self-report inventory of drug use and related behaviors	Administered at school; child (4th–6th grade) and adolescent (6th–12th grade) versions; provides information to help school districts understand extent of local substance use; self-administered	Conoley and Impara, 1995

Instrument/ Measure	Items; Administration Time	Age Range	Use	Key Features	Citation
16. *Personal Experience Inventory* (PEI)	276 items; 60–90 minutes	12–18	Self-report inventory documenting onset, nature, degree, and duration of chemical involvement	Screening includes possible family problems, sexual abuse, physical abuse, eating disorder, and suicide potential; self-administered	Winters and Henly, 1989
17. *Alcohol Expectancy Questionnaire—Adolescent Version* (AEQ)	100 items; 10–15 minutes	12–19	Assess individual's expectancy of effects of alcohol use	Assists in identifying factors in the process of transition to, or persistence of, problem drinking; self-administered	Brown et al., 1987
18. *Problem Recognition Questionnaire* (PRQ)	25 items; 5 minutes	Adolescents over 16 years	Assess user's recognition of problem drug use and readiness for treatment	Evaluates degree of problem recognition and willingness to change; self-administered	Cady et al., 1996
19. *Stages of Change Readiness and Treatment Eagerness Scale* (SOCRATES)	19 items; 3 minutes	12–18	Assess readiness for change in alcohol abusers	Three scales: problem recognition, ambivalence, and taking steps; can assist clinicians in treatment plans; self-administered	Maisto et al., 2003
20. *CAGE Questionnaire* (CAGE)	4 items; 1 minute	Adolescents 16 or over; Adults	Screening for problem alcohol use	Single positive answer has 90% detection rate for alcohol use disorder; computerized version available; self-administered	Mayfield et al., 1974

21.	*Drug Abuse Screening Test* (DAST)	28 items; 5 minutes	Adolescents Adults	Brief method for identifying individuals who are abusing psychoactive drugs	Shortened versions of 10 and 20 items available; identifies individuals needing further assessment; self-administered	Skinner, 1982
22.	*Alcohol Use Disorders Identification Test* (AUDIT)	10 items; 2 minutes	Adults	Screen to identify persons whose alcohol consumption has become hazardous or harmful to their health	Optional Clinical Screening Procedure includes a blood test; self-administered	Allen et al., 1997
23.	*Michigan Alcohol Screening Test* (MAST)	25 items; 8 minutes	Adolescents Adults	Provide rapid screening for lifetime alcohol-related problems	Shortened versions of 9, 10, and 13 items available; widely used measure for assessing alcohol abuse; self-administered	Allen and Columbus, 1995
24.	*TWEAK* (TWEAK)	5 items; 1–2 minutes	Adult women	Screen for risk drinking during pregnancy	Specific to pregnant women; self-administered	Russell et al., 1991
25.	*Structured Clinical Interview for the DSM-IV* (SCID)	4 abuse items, 9 dependence items; 10-45 minutes	Adults	Structured interview to diagnose DSM-IV substance use disorders for all major drugs of abuse	Very commonly utilized; interviewer-administered	Spitzer et al., 1987
26.	*Timeline Follow-Back* (TLFB)	30–360 items; 10–30 minutes	Adolescents Adults	Obtains estimates of daily drinking up to the past 12 months	Evaluated in clinical and non-clinical populations; allows several dimensions of drinking to be examined: variability, pattern, and extent; interviewer-administered	Sobell and Sobell, 1992

Instrument/ Measure	Items; Administration Time	Age Range	Use	Key Features	Citation
27. *Addiction Severity Index* (ASI)	200 items; 50–60 minutes	Adults	Semistructured interview providing an overview of problems related to substance use	Assesses problems in medical status, employment, drug and alcohol use, legal/family/social status, and psychiatric status; interviewer-administered	McLellan et al., 1992
28. *Drinker Inventory of Consequences* (DrInC)	50 items; 10 minutes	Adults	Measure adverse consequences of alcohol abuse in five areas	Areas assessed: interpersonal, physical, social, impulsive, and intrapersonal; can be used for treatment planning and evaluation; self-administered	Miller et al., 1995
29. *Alcohol Expectancy Questionnaire— Adult Version* (AEQ)	120 items (90 scored); 10–15 minutes	Adults	Assess domain of alcohol reinforcement expectancies on six subscales	Six subscales: positive global changes, sexual enhancement, social and physical pleasure, assertiveness, relaxation/tension reduction, and arousal/interpersonal power; self-administered	Brown et al., 1987

Adolescent Measures—Psychiatric Interviews/Instruments Assessing Substance Use Disorders

Similarly, there are a number of structured and semistructured psychiatric interviews available for assessing substance use in adolescents. These include the Diagnostic Interview for Children and Adolescents (DICA; Reich, Herjanic, Welner, & Gandhy, 1982), the Diagnostic Interview Schedule for Children (DISC-C; Shaffer, Fisher, & Dulcan, 1996), the Kiddie Schedule for Affective Disorders and Schizophrenia (K-SADS; Endicott & Spitzer, 1978), the modified Structured Clinical Interview for the DSM-IV (mSCID; First, Spitzer, & Gibbon, 1997; Martin, Kaczynski, Maisto, Bukstein, & Moss, 1995; Spitzer, Williams, & Gibbon, 1987), the Adolescent Diagnostic Interview (ADI; Winters & Henly, 1993), the Adolescent Self-Assessment Profile (ASAP; Leccese & Waldron, 1994) and the Adolescent Drug Abuse Diagnosis (ADAD; Leccese & Waldron, 1994). As with the screening instruments, these interviews branch into other areas of functioning to help determine not only whether substance use is present but also the extent of the impact of substance use in the lives of adolescents. (See items 7 through 13 in Table 18.1 for specific information regarding these interviews.)

Additional Interviews Available

The Comprehensive Addiction Severity Index for Adolescents (CASI-A; Meyers, 1991) addresses many domains and incorporates urine drug screen results and assessor observations. The American Drug and Alcohol Survey (ADAS; Conoley & Impara, 1995) is administered to youth while at school and is used by school districts to gauge substance use among students in an effort to create awareness of use and to develop effective prevention strategies. The Personal Experience Inventory (PEI; Winters and Henly, 1989) assesses use of all substances and problems associated with substance use. (See items 14 through 16 in Table 18.1 for details.)

Adolescent Measures—Substance Use Expectancy and Behavior Change Readiness

The following measures are useful in determining the expected effects of substance use (e.g., expectation of positive outcomes of use) and the ability to self-report problem drug use. Additionally, the following provide measures of the user's readiness to change substance-using behaviors. The Alcohol Expectancy Questionnaire—Adolescent Version (AEQ; Brown, Christiansen, & Goldman, 1987) assesses an individual's expectancy of effects of alcohol use and can be used in adolescent and adult populations. The Problem Recognition Questionnaire (PRQ; Cady, Winters, Jordan, & Solheim, 1996) assesses the user's recognition of problem drug use and their readiness for treatment, and the Stages of Change Readiness and Treatment Eagerness Scale (SOCRATES; Maisto, Chung, Cornelius, & Martin, 2003) assesses two factors: taking steps and recognition. Please see items 17 through 19 in Table 18.1 for information regarding these measures.

Summary of Adolescent Measures: Stability and Changes in Substance Use Behaviors

Screening Measures

The POSIT has been used as a repeated measure to screen for substance abuse and related problems. In a sample of adolescents 12–16 years olds, the POSIT was administered twice, 30 weeks apart. Results indicated that scores on the substance use component of the POSIT were not statistically different after 30 weeks (Tuttle, Campbell-Heider, & David, 2006). In another study (Dembo, Schmeidler, Borden, Turner, Sue, & Manning, 1996), the POSIT was found to be a useful tool to determine which youths were in need of intervention and treatment services. Finally, Knight, Goodman, Pulerwitz, and DuRant (2001) demonstrated that the substance use/abuse scales of the POSIT have favorable test-retest reliability when administered to teenage patients a week apart.

Diagnostic Interviews

The modified SCID has been used in a longitudinal study following participants from the age of 10–12 up to 25 (Cornelius, Clark, Reynolds, Kirisci, & Tarter, 2006). Participants completed the SCID at age of intake, and at ages 14, 16, 19, 22, and 25 years, demonstrating the ability to use this diagnostic instrument repeatedly and to detect stability and change in substance use behavior. Tarter, Vanyukov, Kirisci, Reynolds, and Clark (2006), using some of the same cohort as the Cornelius et al. (2006) study, administered the modified SCID to participants at ages 12–14, 16, 19, and 22. Together, these studies support the predictive validity of the modified SCID and the ability of this measure to assess transitions in substance use behavior during adolescence and young adulthood.

Substance Abuse and Expectancy Changes

The Alcohol Expectancy Questionnaire-Adolescent Version (AEQ-A) has been administered to a group of 924 seventh graders at three time points over a 2-year period (Natvig Aas, Leigh, Anderssen, & Jakobsen, 1998). The authors reported that among those adolescents who were drinkers at the start of the study, there were expectations of positive social effects for drinking across the 2-year period.

Adult Measures—Screening Instruments

Screening instruments available for adult populations include the CAGE Questionnaire (CAGE; Mayfield, McLeod, & Hall, 1974), the Drug Abuse Screening Test (DAST; Skinner, 1982), and screening instruments used to assess harmful alcohol use (Alcohol Use Disorders Identification Test, AUDIT; Allen, Litten, & Fertig, 1997), lifetime alcohol use (Michigan Alcohol Screening Test, MAST; Allen & Columbus, 1995), and alcohol use during pregnancy (TWEAK; Russell, Czarnecki, & Cowan, 1991). (See items 20 through 24 of Table 18.1 for a comparison of these screening tools.)

Adult Measures—Psychiatric Interviews/Instruments Assessing Substance Use Disorders

The Structured Clinical Interview for the DSM-IV (SCID; First et al., 1997; Martin et al., 1995; Spitzer et al., 1987) is one of the most commonly used structured interviews to assess substance use disorders (Item 25, Table 18.1). It provides psychiatric diagnoses from the Diagnostic and Statistical Manual, Fourth Edition (DSM-IV; APA, 2000). The Timeline Follow-Back (Item 26, Table 18.1) (TLFB; Sobell & Sobell, 1992) reconstructs the individual's type, quantity, and frequency of substance use during the past 3 months up to the last year (Brandon, Copeland, & Saper, 1995). The Addiction Severity Index (Item 27, Table 18.1) (ASI; McLellan, Kushner, & Metzger, 1992) is a structured interview designed to assess problems in seven areas that frequently influence substance use disorders. The Drinker Inventory of Consequences (Item 28, Table 18.1) (DrInC; Miller, Tonigan, & Longabaugh, 1995) measures recent and lifetime negative consequences related to alcohol use.

Adult Measures—Measures of Substance Use Expectancy and Behavior Change Readiness

The Alcohol Expectancy Questionnaire—Adult Version (Item 29, Table 18.1) (AEQ; Brown et al., 1987) consists of 90 scored items regarding an individual's expectancy of effects of alcohol use and has been used in adolescent and adult populations.

Laboratory Measures—Urine Samples for Drug Testing

Laboratory measures of biological specimens provide complementary methods to self-report methodology for the determination of recent substance use. The presence of drugs, their metabolites, or both is most commonly determined from urine tests, which can be performed rapidly and inexpensively. A disadvantage of urine testing for recent substance use is that drug metabolites vary in detection times, and this can lead to inaccurate results. For example, metabolites of marijuana may be detectable in urine for several weeks in a chronic user, regardless of whether the user has abstained for several days, in which case a positive test for current use would be incorrect (Cone, 1997). Furthermore, detection can vary by other factors, including dose, frequency of administration, and metabolism (Cone, 1997). (For an overview of laboratory methods for drug screening, see Table 18.2.)

It is critical that laboratory measures of drug use be both precise and accurate because results can have a negative impact on those individuals being tested, especially if the result is a false positive. A valid method must be able to detect the drug and/or its metabolites (Gorodetzky, 1972). Valid laboratory assessment of drug use is ensured by first using a screening measure, which when positive should be followed by a more specific analytical method (Goldberger & Jenkins, 1999). Techniques to detect drugs in urine fall into two categories: immunological and chromatographic. Immunological tests include radioimmunoassay, enzyme immunoassay, fluorescence polarization immunoassay, and

18.2 Laboratory Measures of Substance Use

Test	Time frame	Drugs tested	Key features	Citation
Urine Samples—Enzyme Immunoassay	Mostly recent use (12–96 hours); Longer for chronic marijuana use	Amphetamines; Benzodi-azepines; Cocaine; GHB; LSD; MDMA; Marijuana; Opiates	Fast; simple; sensitive; inexpensive; on-site test-ing; covers most common substances of abuse; semiquantitative	Verstraete, 2004
Urine Samples—Chroma-tography/Mass Spec-troscopy	Mostly recent use (12–96 hours); Longer for chronic marijuana use	Amphetamines; Benzodi-azepines; Cocaine; GHB; LSD; MDMA; Marijuana; Opiates	Commonly used to confirm presumptive samples; can detect quantities down to 0.1–5 ng/ml	Verstraete, 2004
Breath Samples	Recent use (minutes to hours)	Alcohol	Fast; noninvasive; inexpen-sive; high sensitivity and specificity	
Blood/Serum/Plasma Samples	Recent use (5–48 hours); Chronic use for alcohol	Alcohol; Amphetamines; Benzodiazepines; Cocaine; GHB MDMA; Marijuana; Opiates	Chronic alcohol use de-termined by increase in mean corpuscular volume and increased liver en-zymes	Verstraete, 2004; Kolodziej et al., 2002
Saliva Samples	Recent use (5–50 hours)	Alcohol; Amphetamines; Benzodiazepines; Cocaine; GHB; MDMA; Marijuana; Opiates	Noninvasive; inexpensive	Verstraete, 2004

Sweat Samples	Recent and chronic use (minutes to 1 week or longer)	Amphetamines; Cocaine; MDMA; Marijuana; Opiates	Hampered by contamination and large variability	Kintz et al., 2000; Samyn and van Haeren, 2000; Samyn et al., 2002
Hair Samples	Chronic use (months)	Amphetamines; Cocaine; MDMA; Opiates	Noninvasive; low potential for sample manipulation	Cone, 1997; Musshoff and Madea, 2007
Emerging Biomarkers—Alcohol	Recent and chronic use	Alcohol	Biomarkers: ethyl glucuronide; phosphatidyl ethanol; fatty acid ethyl esters; sialic acid index of plasma apolipoprotein J	Wurst et al., 2005
Quantitative Urine Test Marijuana	Recent and chronic use	Marijuana	Biomarkers: THC/Creatinine ratio; 11-nor-9-carboxy-Δ9-tetrahydrocannabinal	Huestis and Cone, 1998
Quantitative Urine Test Benzoylecgonine	Recent use	Cocaine	Urine Benzoylecgonine	Delucchi et al., 1997

particle immunoassay. Chromatographic tests include thin-layer chromatography, high-performance liquid chromatography, and gas chromatography.

Immunoassay techniques are based on competitive binding of both a labeled and an unlabeled antigen to a specific antibody. In the most commonly used technique (enzyme immunoassay), the competition occurs between the unlabeled drug and the drug covalently bound to a specific enzyme. When the drug binds to the antibody, enzyme activity is decreased, but when the unlabeled drug displaces the drug-labeled enzyme, the free enzyme catalyzes a reaction that can be used to quantify drug presence in the sample (Goldberger & Jenkins, 1999). Advantages of the immunoassay techniques include speed, sensitivity, availability for all common substances of abuse, simplicity, qualitative and semiquantitative results, and the ability to test onsite (eliminating the need for expensive equipment and skilled operators). Disadvantages (mainly for radioimmunoassay methods) include a short shelf life and the extra safety precautions required with the use of radioisotopes.

Chromatographic and mass spectroscopy techniques are often used by laboratories to confirm a positive test. Chromatographic techniques separate liquid solutions into component parts through interaction with mobile and stationary phases (Bowers, Ullman, & Burtis, 1994). In gas chromatography, liquid extracts are vaporized and the remaining solid components are resuspended in a buffered solution and then transferred to a column in which components become separated. Components are identified and quantified by a detector as they elute from the column. Detection is by mass spectroscopy, which can detect quantities as small as 0.1–5 ng/ml (Bowers et al., 1994).

Laboratory Measures—Recent Drug Use

Alternate methods to test for substance use include analysis of samples of breath, blood, saliva, sweat, and hair (see Table 18.2). Breath samples are used primarily to detect alcohol use and have high sensitivity and specificity. Breath testing is rapid, noninvasive, and inexpensive. The primary disadvantage is that breath sampling has a narrow window of assessment (i.e., minutes to hours). Blood samples detect recent heavy drug use or consequences of chronic alcohol use. Chronic alcohol use may be determined by an increase in red blood cell mean corpuscular volume (MCV) and increased levels of glycoprotein carbohydrate-deficient transferrin (CDT), γ-glutamyl transferase (GGT), or other liver enzymes, which can indicate hepatic disease such as hepatitis or cirrhosis (Kolodziej, Greenfield, & Weiss, 2002). Saliva testing is noninvasive and cost-effective.

Laboratory Measures—Chronic Drug Use

Testing of sweat provides information on both current and cumulative drug use, with detection times of minutes to 1 week or longer (see Table 18.2). Sweat testing is hampered by possible environmental contamination and large variability among subjects. Hair testing provides an additional long-term measure of drug use, with a detection time of months. Hair testing is noninvasive and has a low potential for manipulation by the individual being tested, although it cannot measure current drug use (Cone, 1997).

Laboratory Measures—Emerging Biomarkers

Sensitive and specific biomarkers for alcohol and other drug use are needed for assessment and treatment of substance use disorders. Recently, several potential biomarkers of alcohol consumption have been identified. These include direct ethanol metabolites, such as ethyl glucuronide (EtG), phosphatidyl ethanol (PEth), fatty acid ethyl esters (FAEEs), and sialic acid index of plasma apolipoprotein J (SIJ) (Wurst et al., 2005). Overall, PEth appears to be the best candidate for a stand-alone marker for ethanol consumption.

Quantitative Urine Measures to Detect Changes in Drug Use

The use of quantitative urine tests to detect changes in drug use is an area of active research. One example is the use of the THC/Creatinine Ratio. Abstinence from cannabis use can be verified by daily quantitative (e.g., continuous outcome measure) urine tests. To detect changes in cannabis use or relapse, gas chromatographic-mass spectroscopic levels of 11-nor-9-carboxy-Δ 9-tetrahydrocannabinal (THCCOOH), the primary cannabis metabolite, are normalized to urine creatinine concentration to obtain a metabolite-creatinine ratio (THC/Cr). The recommended standard to confirm abstinence from recent cannabis use is a THC/Cr ratio greater than 50% from the previous visit to indicate recent cannabis use, and changes of <50% indicate abstinence (Huestis & Cone, 1998). Quantitative urine screening (THC/Cr) is the benchmark for monitoring abstinence in cannabis withdrawal studies. A second example of a quantitative urine test is the determination of the concentration of benzoylecgonine, a major metabolite of cocaine, in studies of cocaine treatment. Findings from placebo-control trials of fluoxetine as an adjunct to treatment cocaine abuse have shown that urine benzylecgonine level is related to self-reports of recent drug use and is independent of anxiety, and depression (Delucchi, Jones, & Batki, 1997). Together, these findings suggest that quantitative urine tests can be used for monitoring abstinence from cannabis use and cocaine use in clinical research studies.

Multiple Repeated Measures of Substance Use Behaviors

In addition to screening and diagnostic assessment of psychiatric and substance use disorders, a thorough history should include assessment of developmental, family, social, and environmental factors. During the assessment, it may also be necessary to use some of the laboratory measures described earlier, to determine the recency of substance use. Particularly for the assessment of adolescents, corroborating information from multiple informants increases accuracy. The assessment should then be used as a guide for a biopsychosocial formulation of a treatment plan for the particular individual. For treatment or prospective follow-up, substance use behaviors should be monitored regularly via the laboratory measures and self-report measures described earlier.

In addition to measuring and monitoring substance use behaviors during treatment and/or follow-up, it is beneficial to determine what risk and protective factors for substance use are present. Assessment of risk and protective factors can provide invaluable information to help predict the developmental course and/or treatment course of substance use and related disorders.

Biopsychosocial Risk and Protective Factors

As with all neurobehavioral disorders, a multifactorial model of inheritance (Falconer, 1965; Lander & Schork, 1994) provides a broad enough theoretical framework to encompass specific gene-gene and gene-environment interactions that predict stages of substance use involvement. From this model, characterization of the clinical phenotype (e.g., clinical characteristics, severity, family history, age of onset), along with specific risk and protective factors, are likely to be particularly useful in identifying groups of individuals at risk for developing substance use disorders (Falconer, 1965; Lander & Schork, 1994). Risk factors for substance use increase the probability of use, while protective factors decrease the probability of use. Specific genetic and environmental risk factors may predispose an individual to behaviors leading to substance use, abuse, and dependence. For example, children of substance-using parents, school dropouts, delinquent youth, and youth with mental health problems are all at high risk for the development of substance use disorders by young adulthood. Among college students, high-risk drinking and related consequences appears to be problematic within fraternities and sororities, as well as among student athletes (Turrisi, Mallett, Mastroleo, & Larimer, 2006). Throughout adulthood, the physical and social consequences of chronic alcohol and drug use can become severe, especially for individuals with risk factors such as poor health and pain (Christensen, Low, & Anstey, 2006). Risk status for drug use and related problems among adolescents and young adults can be screened using the DUSI-R, POSIT, ADI, ASAP and ADAD, whereas for adults, measures such as the ASI are recommended (see Table 18.1 for details). The incidence of drug use initiation generally increases to the age of 18 years, whereupon a rapid decline in the onset of drug use occurs throughout young adulthood (Kandel & Logan, 1984; Yamaguchi & Kandel, 1984a; Yamaguchi & Kandel, 1984b). However, the prevalence of substance abuse and related problems can continue throughout adulthood and lead to increased impairment in older adults who are heavy users (Christensen et al., 2006).

Measurement Issues for Assessment of Risk

For research purposes, it is necessary to demonstrate interrater reliability throughout each study that assesses changes in risk, since interrater indices evaluate both the instruments and the performance of the raters themselves. Reliability should be assessed by the scoring of recorded interviews by several raters, joint interviews, and use of test-retest methodology. One measure of interrater agreement is the kappa statistic, which corrects for chance agreement (Shrout, Spitzer, & Fleiss, 1987). Interrater agreement should be checked periodically, to prevent rater drift (Sanson-Fisher & Martin, 1981).

    Research participants may also provide inconsistent or discrepant information, requiring use of multiple sources of information to establish the best estimate for psychiatric diagnoses and other measures of risk. The best estimate method uses multiple sources of information to establish diagnoses, based on all available information, by expert clinicians (Leckman, Sholomskas, Thompson,

Belanger, & Weissmain, 1982). Use of best-estimate methods helps to establish accurate diagnoses and minimizes the chance of missed diagnoses (Kosten & Rounsaville, 1992).

Domains

Three general domains encompass the majority of factors that predict substance use behavior throughout the life span: (1) genetic, (2) individual characteristics, and (3) social-environmental (Bry, McKeon, & Pandina, 1982; Hawkins & Catalano, 1989; Labouvie, Pandina, White, & Johnson, 1986; Newcomb, Maddahian, & Bentler, 1986). Before discussing specific factors in these domains, some general principles should be noted. First, risk factors are either present or not, and presence of a risk factor increases likelihood of drug use. Second, the presence of a protective factor does not guarantee abstinence. Third, as the number of risk factors increase, the likelihood of drug use increases. Fourth, risk and protective factors can be categorical or dimensional constructs. Finally, preventive interventions aim to decrease the likelihood of developing a disorder but do not necessarily eliminate all risk factors (Clayton, 1992).

Genetic Factors

Substance use disorders, like other neuropsychiatric disorders, are complex and multifactorially inherited (Falconer, 1965; Lander & Schork, 1994). Evidence for multifactorial inheritance is supported by both animal and human studies (Cadoret, O'Gorman, Troughton, & Heywood, 1986; Falconer, 1965; Lander & Schork, 1994; Li, Lumeg, McBride, & Murphy, 1987). Twin studies have demonstrated that identical (i.e., monozygotic) twins are more likely to be concordant for alcoholism than fraternal (i.e., dyzygotic) twins (Cloninger, Bohman, & Sigvardsson, 1981; Hrubec & Omenn, 1981). Some (Goodwin, Schulsinger, Hermansen, Guze, & Winokur, 1973) but not all (Clifford, Fulker, Gurling, & Murray, 1981) adoption studies have demonstrated that children of alcoholics (especially boys), when reared apart from biological parents, are more likely to develop alcohol problems than children of nonalcoholic parents. Children of alcoholic parents (Hill & Hruska, 1992) and of polysubstance-dependent fathers also appear to be at increased risk for substance use involvement (Cadoret, 1992). Linkage-based genome scans now provide converging evidence that specific chromosomal regions contain common allelic variants that confer human vulnerability to addiction across multiple classes of drugs (Uhl, 2004, 2006).

Individual Characteristics

A number of personal characteristics may predispose an individual to substance use. For example, sensation seeking (a need for varied, novel, and complex sensations and experiences, Zuckerman, 1979; Cloninger, 1987), impulsivity, and deficits in information processing have been associated with alcohol and drug use. Males are at greater risk to develop substance use (Coffey, Lynskey, Wolfe, & Patton, 2000; Kosterman, Hawkins, Guo, Catalano, & Abbott, 2000; Von Sydow, Lieb, Pfister, Hofler, Sonntag, & Wittchen, 2001), although girls with an early onset of puberty have greater alcohol and substance use than those with typical

or late-onset puberty (Lanza & Collins, 2002). A particularly robust predictor of substance use is antisocial behavior. For instance, conduct problems (Coffey et al., 2000), deviance (Wills, Vaccaro, McNamara, & Hirky, 1996), rebelliousness (Hawkins, Catalano, & Miller, 1992), delinquency (Flory, Lynam, Milich, Leukefeld, & Clayton, 2004), and violence (Van den Bree & Pickworth, 2005) have all been associated with substance use development, particularly if present before middle adolescence; such individuals are more likely to escalate from use to abuse by young adulthood (Dishion & Loeber, 1985). For those individuals who continue to use drugs throughout adulthood, chronic alcohol and drug use can produce severe consequences and additional risk factors for continued drug use, such as poor health and pain (Christensen et al., 2006). All of these individual factors may play a role in the development of substance use initiation and progression through the stages of use, and it is very likely that these factors interact with social and environmental domains to produce substance use and substance use disorders.

Social and Environmental Factors

Family, peer, and dyadic relationships are strongly related to social environment (Dishion, Capaldi, & Yoerger, 1999), and reciprocal influences among social and environmental factors occur throughout childhood and adolescence (Stice & Barrera, 1995; Stice, Barrera, & Chassin, 1993). Parental influence in the initiation of drug use is more powerful in boys in early adolescence (Moss, Clark, & Kirisci, 1997), and parental influence continues to be a major risk factor for both genders throughout adolescence (Kandel, 1985). Dishion, Patterson, Stoolmiller, & Skinner (1991) and Patterson, Reid, & Dishion (1992) have shown that family influences precede the choice of, and direct the child toward, deviant peer groups.

The influence of the family structure has been studied as a risk factor for the initiation of substance use. For example, Kellam, Simon, & Ensminger (1983) found that the two-parent stable family is no longer the norm and that adolescents' solitude after the divorce of parents predicts drug use more in boys than in girls. In contrast, remarriage of the custodial parent is more related to drug use in girls than boys (Needle, Su, & Doherty, 1990). Additional familial risk factors for the development of substance use include the availability of alcohol or drugs in the home and the use of drugs or alcohol by parents or older siblings (Baumrind, 1983; Brook, Kessler, & Cohen, 1999); sexual or physical abuse (Dembo, Dertke, La Voie, Borders, Washburn, & Schmeidler, 1987), lack of closeness to parents (Kandel, 1982); and poor role modeling by parents or older siblings (Kaminer, 1994).

Peer affiliation is a key social factor in predicting the initiation and progression of substance abuse in adolescents and young adults (Swadi, 1999). Strong peer influence, peer pressure, and peer affiliation all predict more severe behavioral undercontrol and substance use (Fergusson, Linskey, Howard, 1995; Kandel, Kessler, & Margulies, 1978; Krohn, Lizotte, Thornberry, Smith, & McDowell, 1996; Swadi, 1999). Fergusson and colleagues (1995) found that hazardous alcohol use is best predicted by the extent of affiliation with substance-using peers. Best friends' smoking behavior consistently predicts adolescent smoking progression (Wang, Fitzhungh, Eddy, Fu, & Turner, 1997). Deviant peer

influence strongly predicts marijuana use (Kandel et al., 1975). Krohn and colleagues (1996) have shown reciprocal causal effects between adolescent and peer drug use, with the influence of peer drug use on progression of adolescent drug use increasing over time. Peer encouragement to use drugs predicts escalated alcohol, cigarette, and marijuana use (Duncan, Tildesley, Duncan, & Hops, 1995). Other social risk factors for substance use related to school include low grades, poor school performance, and dropping out (Clayton, 1992; Mensch & Kandel, 1988). Among college students, high-risk drinking and related consequences are especially prevalent within fraternities and sororities, as well as among student athletes (Turrisi et al., 2006). For college students in these environments, there appears to be strongly ingrained traditions to drink and low concern about the consequences of drinking (Turrisi et al., 2006).

Measures of Social and Environmental Factors

Two instruments of particular use in assessing the social environment are the ADAD and ASAP. Both thoroughly assess social and family factors, and both can be administered repeatedly to gauge changes in family dynamics and substance use involvement over time. To assess peer relations and peer substance use during adolescence and young adulthood, the DUSI-R is a good screening instrument. For more thorough assessment of peer environment during adolescence, the DICA covers school and peer functioning more extensively. School performance can be assessed using the ASAP, ADAD, or CASI-A. For adults, the ASI provides measures of employment and legal, family, and social functioning. Additional details on measures of social and environmental factors are in Table 18.1.

Conclusions

Problems With Current Diagnostic Nosology

In the United States, substance use disorders are diagnosed by DSM-IV-TR criteria. Unfortunately, there is controversy because of the lack of clarity and questions about the developmental appropriateness of the specific DSM criteria for diagnosing substance use disorders in adolescents (Harrison, Fulkerson, & Beebe, 1998; Martin et al., 1995; Pollock & Martin, 1999). For example, defining any amount of substance use as a substance use disorder in adolescents limits the usefulness of the term, because the classification is too inclusive (Harrison et al., 1998). The categorical nature of the DSM-IV-TR can lead to diagnostic uncertainty for the case of substance-using adolescents. For example, an adolescent may meet one or two dependence criteria while meeting no abuse criteria, which would leave the adolescent being undiagnosed according to DSM-IV-TR, despite the presence of dependence criteria and impairment. These adolescents who do not fit neatly into the current DSM criteria are termed "diagnostic orphans" and have included up to 30% of adolescents in some studies (Winters, Latimer, & Stinchfeld, 2001). Clearly, this is an issue for concern that remains to be resolved. This example is another illustration of our previous recommendation that it is often useful to include a multidimensional assessment for psychiatric diagnoses and other risk factors, especially in the case of

adolescents. Finally, it is also important to remember that "experimentation" with substances during adolescence and young adulthood may be a normative aspect of development, and the developmental outcomes may not necessarily be a substance use disorder. Many adolescents experiment with early "gateway" drugs, but most do not progress by young adulthood to use of more severe substances (Winters et al., 2001).

Future Directions

The measurement of substance use behavior and of changes in substance use behavior requires appropriate screening and comprehensive assessment. The specific screening and assessment tools depend on the purpose of the evaluation. Future studies on measurement of substance use behavior will need to determine which diagnostic criteria apply, especially for adolescent populations. Additional research will be needed to determine the most effective use and combinations of genotyping and biomarkers to further refine the behavioral phenotypes that define substance use behavior. Future longitudinal studies should include assessment using multiple measures of behavioral undercontrol, psychiatric comorbidity, substance use severity, and the severity, timing, and duration of environmental stressors. Future work in adolescent and young-adult populations should more effectively define and assess the social and environmental processes that increase or decrease the risk of substance use initiation and progression to substance use disorders. For adults with chronic use, prospective studies should examine the consequences and risk factors of continued use, examining how poor health and pain contribute to continued drug use.

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Statistical Issues in Measuring Adherence: Methods for Incomplete Longitudinal Data

19

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In randomized controlled trials (RCTs) of drug therapy or other behavior change interventions, an inevitable methodological conundrum is nonadherence to treatment (Meichenbaum & Turk, 1987). From a design and data analytic perspective, there are three distinct issues that surface around the topic of nonadherence. First, how can one design behavior change interventions to better promote adherence? Second, given that nonadherence to treatment is an inevitable feature of behavioral interventions, how does one proceed with analysis of adherence data, when those who are not adherent are often those with missing data? And, third, what can be done to promote the collection of data related to

treatment adherence? Although some of our own research has been directed at designing theoretically driven interventions that directly address the promotion of adherence to treatment in RCTs (Rejeski et al., 2003), the primary goal of this chapter is to examine various statistical approaches to handling missing adherence data. In addition, because the collection of adherence data is an issue that is distinct from promoting adherence itself, consideration is given to methodological factors that can enhance data acquisition.

Measuring and Analyzing Adherence

An analysis of patient adherence can be crucial to understanding the results of an intervention study or for planning a subsequent study. For example, not long ago, journal publications ignored dropouts, masking the potential negative effects that interventions may have had on specific subgroups. In our research with physical activity programming for older adults who have arthritis (Rejeski, Brawley, Ettinger, Morgan, & Thompson, 1997), we found that that it was not necessary for participants to exercise at the level that we originally set (40 minutes of continuous work each session) to derive benefit from treatment. In fact, those who were the most compliant did not benefit at all! In our future research on arthritis, this finding led us to promote multiple bouts of activity that were shorter in duration. This example illustrates the benefits of doing adherence analyses. There are also a number of well-cited examples of studies in which attention to dropout is a key part of the inference. Molenberghs and Kenward (2007) cite three trials for treating depression in which there is a substantial amount of dropout and in which failure to account for this during analyses could lead to inappropriate conclusions from the trial.

In investigations of pharmaceutical compounds, adherence may be measured in terms of actual pill counts, whereas, for behavioral studies trials that involve dietary or physical activity interventions, self-reported data may be essential for quantifying adherence. For example, dietary studies often rely on 24-hour food recalls or food frequency questionnaires administered at set intervals to validate the degree to which participants complied with intervention objectives (Crumb-Johnson, Smith-Bands, Hatcher, & Hagan, 1993; Van Horn, Dolecek, Grandits, & Skweres, 1997). Physical activity interventions may be measured by attendance at scheduled educational or activity intervention clinic sessions or by self-reported physical activity as was done in the Activity Counseling Trial (Blair et al., 1998). This illustrates that adherence can be measured either objectively or subjectively and can be assessed continuously or at set intervals. It is important to keep in mind that success in collection of subjective measures of adherence such as the self-report of physical activity can be influenced by social desirability, particularly when these data are collected by interventionists. When this type of adherence data is collected at set intervals by staff members who are blind to treatment assignment to reduce the influence of social desirability, then recall bias may be an issue of concern.

To obtain valid inferences from incomplete data, the mechanism (probability model) producing the missing observations must be considered when choosing an analysis technique. Different analysis techniques operate under different assumptions about the missing-data mechanism. The focus of this

chapter is on methods for analyzing adherence data to obtain valid inference regarding adherence during follow-up when it is possible that missing adherence information may be related to patient characteristics or even the unobserved level of adherence. We have attempted to limit technical details and to concentrate on concepts related to what assumptions are made by various analytical methods so that analysts can make informed decisions when performing analyses of adherence data.

Two examples will serve to illustrate the methods. The first example is the Lifestyle Interventions and Independence for Elders (LIFE) pilot study, reported in Rejeski et al. (2005) and Pahor et al. (2006). A sample of 424 sedentary persons from four clinical sites were randomized to either a physical activity intervention or a successful-aging educational intervention. The primary outcome, measured at 6 and 12 months post-randomization, was the incidence of major mobility disability, defined as the inability to walk 400 meters within 15 minutes. The objectives of this pilot trial included obtaining data to be used in the sample-size calculations for a subsequent trial but also to assess adherence to the physical activity intervention as measured by self-report home exercise logs and the CHAMPS physical activity measure (Stewart et al., 2001).

A second example is the Leading the Way in Exercise and Diet (LEAD) study (Demark-Wahnefried et al., 2006). The goal of this study was to assess the effect of a 6-month home-based diet and exercise intervention on physical function in breast or prostate cancer survivors age 65 and older. A total of 182 subjects were randomized to either a diet and exercise intervention arm or a control arm that received general health information. The primary outcome of this trial is physical function as measured by the SF-36 Physical Function Subscale, augmented with four questions from Satariano, Ragheb, Branch, and Swanson (1990) at 6 and 12 months postrandomization. As in the previous example, physical activity was measured with the CHAMPS instrument.

In each of these examples, patient adherence to the intervention protocol is a key component of the evaluation of the trial. In the LIFE pilot study, an evaluation of adherence has implications for the design of the subsequent trial, both in terms of the sample size calculations and in terms of structuring the intervention protocol. The subjects in the LEAD study who were given the diet and activity intervention showed an improvement in physical function over those given the education-only intervention, but this difference was not statistically significant. By examining patient adherence to the protocol, researchers might be able to discover whether the next study would need a different type of intervention or whether the same intervention, with improved patient adherence, might be shown to be effective.

We note that other authors (Angrist, Imbens, & Rubin, 1996; Fischer-Lapp & Goetghebeur, 1999; Frangakis & Rubin, 1999, 2002) consider methods to account for nonadherence in analyzing the primary outcome variable. For example, these methods could be used in the LEAD study to compare the post-baseline physical function between the two arms, adjusting for patient adherence to the intervention protocol in the diet and exercise group, as well as for patients in the intervention group who adopt off-study diet and exercise changes (so-called drop-ins). Our focus is on methods for analyzing the adherence data alone, without regard to the outcome, in order to understand the level of adherence to the intervention.

Analyses of patient adherence are frequently complicated by subject drop-out or missing data. Statistical methods for analyzing incomplete data are needed to obtain valid estimates of the degree of adherence. Extensive discussion of methods for incomplete data are given by a number of authors, such as Schafer and Graham (2002), Fitzmaurice, Laird, and Ware (2004), Little (1995), Hedeker and Gibbons (2006), and Molenberghs and Kenward (2007).

For adherence data, the analyses are made more challenging by the fact that rates of dropout or missing data may be related to subject characteristics or to the underlying unobserved degree of adherence. For example, subjects who are not adhering to the intervention protocol could be more likely to miss regular assessments or to not turn in the self-reported adherence information. This chapter begins with a discussion of "missing-data mechanisms," which give a formal framework for assumptions about how the probability of missing responses is related to subject characteristics or the underlying degree of adherence. This is followed by an overview of general classes of statistical methods for analyzing incomplete data, with a particular application to measuring adherence. The general classes include (1) analysis of only the observed data, often called the "complete-case" analysis, (2) imputation methods, (3) weighting, and (4) likelihood-based and Bayesian methods.

Missing-Data Mechanisms

Most discussions of missing data follow the terminology of Rubin (1976). The terminology distinguishes among studies where the data are "missing completely at random (MCAR)," those where the data are "missing at random (MAR)," and those where data are "missing not at random (MNAR)." The distinctions are important for a number of technical reasons, as described by Rubin (1976), but also for the practical reason that the type of mechanism determines which analysis method is appropriate. More detailed and mathematically precise discussions of this terminology are given later in this chapter, but we begin with a less technical discussion of why these cases are distinguished from one another and why data that are MCAR or MAR present much less of a challenge than data that are MNAR.

Roughly speaking, the difficulty with missing data is that the set of observed outcomes may no longer constitute a representative sample from the population. In principle, if it were known how the observed cases deviated from a representative sample, one could adjust the analyses in a way that could overcome the biases induced by having a nonrepresentative sample. To illustrate, suppose an investigator planned to take a random sample of 100 subjects from a population. Of the 100 subjects, outcomes are missing on 30 subjects for reasons unrelated to the outcome of interest or any characteristics of the subjects (MCAR). The remaining 70 subjects would still constitute a random sample from the population, and standard methods could be used on data from the 70 subjects.

Suppose, instead, that study participants who score below 25% adherence on a certain measure during follow-up have a high probability of not returning to provide adherence data at the next scheduled visit; whereas those who score above 25% always return. Further, assume that adherence information is collected on all participants at this prior visit. This is a simple illustration of a

case where data are MAR because if we stratify on the basis of those that fall above and below 25% adherence at the antecedent visit, then for those with prior adherence <25%, "missingness" can be considered a random process with a specific probability of observing the follow-up measurement. Knowing the association between the probability of missing and the prior adherence measure would allow the researcher to adjust the results in the nonrepresentative sample to reduce bias.

Finally, suppose that, during follow-up, the research team is unable to obtain adherence measurements when participants have poor adherence. Further assume that there are no known covariates or prior observations collected that would permit formation of strata within which "missingness" is a result of chance alone. This would be considered a MNAR missing-data situation. Here, it is less clear how we should adjust the results in the sample to get accurate estimates for the population.

In order to be more precise about different forms of nonresponse, Rubin (1976) provides mathematical definition of the concepts. We will illustrate these definitions in the context of the LIFE and LEAD study examples mentioned earlier. Let $A = (A_0, A_6, A_{12})$ denote the measures of adherence from a subject at baseline (time 0) and at 6 and 12 months post-baseline. The values for (A_0, A_6, A_{12}) may be observed or unobserved, and we use indicators $R = (R_0, R_6, R_{12})$ to denote whether the adherence data at each time point for a particular subject is missing or observed. We assign $R_t = 1$ if the adherence data at time t is observed and $R_t = 0$ if the adherence data at time t is missing, for t = 0, 6, 12. Rubin (1976) partitions the adherence variables A into the missing and observed parts, $A = (A_{obs}, A_{mis})$. For example, if the adherence for a subject is observed at times 0 and 6 months but missing at 12 months, we have $A_{obs} = (A_0, A_6)$, $A_{mis} = (A_{12})$ and R = (1, 1, 0).

Rubin's (1976) terminology classifies how the probability distribution of the set of missing data indicators, R, given the adherence variables A, depends on the missing and observed components of A. If the probability that the adherence is missing depends only on the observed components, $P(R \mid A_{obs}, A_{mis}) = P(R \mid A_{obs})$, Rubin (1976) denoted this as "missing at random," usually abbreviated "MAR." A special case of this, called "missing completely at random" (MCAR), occurs when the distribution of R does not depend on either A_{obs} or A_{mis}. If the distribution of R depends on A_{mis} alone or both A_{mis} and A_{obs}, then the mechanism is termed "missing not at random (MNAR)."

The terminology can be confusing, mainly, we believe, because the technical definition of the phrase "missing at random" does not coincide with how most people would interpret the phrase if used in a nontechnical context. In our experience, the term "missing at random" is taken to mean "missing completely at random." Since the majority of statistical methods for incomplete data are derived for the MAR case, they are applicable more generally than most practitioners would initially suppose.

For example, suppose that in a study like the LEAD or LIFE trials, with assessments at 0, 6, and 12 months following randomization, the data are missing only because of patient attrition. A fraction of subjects may fail to complete the study but are fully observed up to the last time they are observed. Table 19.1 contains an illustration of this pattern, often called "monotone missing data." In this pattern, a subject observed at 12 months is known to have been

19.1 A Monotone-Nonresponse Pattern

Number of subjects	Baseline	6 months	12 months
n1	Observed	Observed	Observed
n2	Observed	Observed	Missing
n3	Observed	Missing	Missing

observed at both the baseline and the 6-month assessment; subjects observed at the 6-month assessment are known to be observed at baseline.

The corresponding R vectors for the n1 subjects are (1, 1, 1), for the n2 subjects the R vector is (1, 1, 0) and for the n3 subjects the R vector is (1, 0, 0). If the probability of missing does not depend on adherence at all, the mechanism is MCAR. If the probability that an adherence measure is missing at time t depends only on the degree of adherence at the last observed time, then the missing data mechanism is MAR. If the probability that an adherence measure is missing at time t depends on the adherence value at time t, then the mechanism is MNAR.

The discussion in the previous paragraph leaves out the important case where the probability of missing depends on covariates, such as patient characteristics or the intervention to which the patient is assigned. For the following description, we assume that covariates are always fully observed and not subject to missing values. When the probability of missing depends only on the covariates, Fitzmaurice, Laird, and Ware (2004) and Little (2005) use the term "covariate-dependent missingness" and note some subtle distinctions between this and MCAR. In this situation, by including important covariates in a model, one can obtain valid inference using estimation techniques that do not rely on maximum likelihood, such as generalized estimating equations (GEE) (Liang & Zeger, 1986). Data are said to be MAR if the probability of missing data depends on observed adherence and/or on covariates. Standard mixed-effects regression techniques based on maximum likelihood or Bayesian estimation or multiple imputation-based analyses can be used to obtain valid inference for MAR data. This again illustrates the generality of statistical methods derived under the assumption of MAR; the probability of missing can depend on observed adherence values and patient characteristics but still be "missing at random."

While the MCAR, MAR, and MNAR terminology is most commonly used to describe missing-data mechanisms, maximum likelihood and Bayesian methods for analyzing data containing missing outcomes tend to be described in terms of being applicable under assumptions of "ignorable" and "nonignorable" nonresponse mechanisms (Little & Rubin, 1987). In many cases, although not all, ignorable nonresponse mechanisms correspond to MCAR and MAR and nonignorable mechanisms correspond to NMAR cases. The importance of the distinction between ignorable and nonignorable mechanisms is that, for maximum likelihood methods, the same inference about the adherence measures is obtained under any ignorable model for nonresponse. For example, the probability of missing might depend on a patient's age, on gender, or on both age and

gender. As long as the nonresponse model is ignorable in each of these cases, it does not matter which one of these models is "correct"; identical inference about the adherence parameters would be obtained. The technical details are given in Little and Rubin (1987).

Standard maximum likelihood analyses estimation techniques like those provided in PROC MIXED of SAS (SAS 9.1, Cary, NC) allow for valid inference of ignorable nonresponse if both the model for the mean and the covariance between repeated adherence measurements are correctly specified. In contrast, when the model for the nonresponse mechanism is not ignorable (i.e., the data are MNAR), one must make explicit assumptions and specify a model for nonresponse. Here, estimation can also be carried out through the use of maximum-likelihood techniques; however, these algorithms must incorporate these assumptions about the missing-data mechanism.

Methods for Analyzing Longitudinal Adherence Data

Complete-Case and Available-Case Methods

One of the most common methods of analyzing data subject to dropout or missing data is to do "complete-case analysis" in which only the subset of subjects observed on all measures is included. In the example displayed in Table 19.1, analysis would be based on the n1 subjects observed at all times. A similar method is termed " available-case" analysis by Schafer and Graham (2002) and uses different sets of subjects in different analyses depending on whether or not adherence is observed. For example, a summary of the change from baseline at 6 months would use data from n1 + n2 subjects; a summary of the change from baseline to 12 months would use data from n1 subjects. The main advantage of these methods is simplicity (i.e., standard least squares or maximum likelihood estimation can be used), but the methods can be highly biased when the data are not MCAR. Even when the data are MCAR, estimates from these procedures can be inefficient. As a result of these statistical properties, these methods have largely been discarded in the statistical literature.

Imputation Methods

There are many procedures for "imputing" or "filling in" missing observations in order to complete the dataset. One of the advantages of the various imputation methods is simplicity, in that once the data have been imputed, standard analysis methods can then be applied to the completed dataset. Imputation methods can be broadly classified as "single" or "multiple" imputation procedures. In single imputation, a single value is generated for each missing observation to complete the dataset. Once the dataset is completed, standard analyses are applied.

Methods for single imputation include "carried forward" analyses, as well as mean and regression imputation. Little and Rubin (1987) describe a number of other imputation procedures not discussed here, including "hot deck" and "cold deck" imputation procedures.

For longitudinal data, one of the most popular methods is "last-value-carried-forward" (LVCF). In LVCF, the last observed value is filled in for all subsequent

time points for which the data are missing. For example, a subject observed to have values A0 and A6 for the baseline and 6-month follow-up but who is missing the 12-month observation would be assigned the A6 value at the 12-month follow-up. A subject missing both the 6- and 12-month follow-ups would be assigned the value A0 for the 6- and 12-month follow-ups. A number of authors have investigated the statistical properties of this procedure, including Shao and Zhong (2003). Fitzmaurice and colleagues. (2004, p. 393) and Molenberghs and Kenward (2007, p. 47) discuss the use of LVCF and describe how there are very few situations where the strong assumption that all observations following drop-out remain constant is valid. They do not recommend the use of this procedure.

Other imputation procedures include "mean" imputation and "regression" imputation. To illustrate these methods, consider a subject in the LIFE or LEAD trials who is observed on the baseline and 6-month follow-up but for whom adherence data are missing for the 12-month follow-up. In regression imputation, the fully observed cases would be used to develop a regression model for predicting 12-month data from the baseline and 6-month adherence. "Mean" imputation is a special case where only an intercept is fit within the regression equation; thus, the missing 12-month values are replaced by the average of the observed 12-month adherence outcomes. To obtain proper inference, an element of randomness is often added to this procedure.

In multiple imputation, several values are generated for each missing value and standard analyses applied to each of the completed datasets. The final analysis accounts for the variability of the estimates within each completed dataset, as well as the variability across the completed datasets. Rubin (1987) gives an extensive treatment of procedures for multiple imputation. He argues that "proper" multiple imputation procedures should also account for the variability in the estimation of the parameters and provides a Bayesian solution for doing this.

Rubin (1987) also discusses multiple imputation methods when the data are MNAR. He notes that there are differences in the distribution of outcomes between a subject who completes the study, and one who drops out, even if the subjects have identical values on the outcomes observed up to the point of drop-out. The data do not provide a way of estimating this difference directly, and the conclusions can be sensitive to the assumptions used in modeling how the probability of dropout is related to missing outcomes. Rubin (1987) suggests some simple models for creating imputed values for MNAR cases from imputed values created under the assumption of MAR. One such model is to multiply the imputed value under MAR by a fixed factor, f, to obtain Y (imputed under MNAR) = f * Y (imputed under MAR). Rubin cautions on the use of these models, noting that the results can be sensitive to assumptions that cannot be verified directly.

Weighting

Weighting has long been used in the analysis of sample surveys to account for nonresponse or missing data. For analyzing missing data or dropouts in longitudinal data studies, the basic idea is to estimate the probability of remaining in the study and to weight the observed responses inversely proportional to this probability. For example, if we estimate that a subject has a 20% chance of

remaining in the study, this person's responses are assigned weight 5. The probability can depend on subject characteristics or previously observed responses. Consequently, weighting provides a method that can be used in many different situations and in cases where the full likelihood is not completely specified, such as in generalized estimating equation (GEE) methods. Thus, through proper weighting of a GEE procedure, it is possible to extend this approach to handle data that are MAR. Examples of the use of weighting as a technique for analyzing incomplete data include Robins, Rotnitzky, and Scarfstein (1998) and Miller, Ten Have, Reboussin, Lohman, and Rejeski (2001).

Likelihood–Based Methods

Little and Rubin (1987) describe likelihood-based methods using the joint distribution of the adherence measures, A, and the missing data indicators, R. It is assumed that this joint distribution depends on a set of parameters θ, and estimates of θ can be obtained by maximum-likelihood or Bayesian methods. The methods are broad enough in scope that they can handle missing data mechanisms that are MCAR, MA R, or MNAR.

Two broad classes of models that have been developed to handle data that are MNAR include "pattern-mixture models" and "selection models" (Little & Rubin, 1987). "Pattern-mixture models" postulate assumptions about the distribution of adherence measures given particular patterns of the missing data indicators and the distribution of the missing data indicators without regard to adherence. Different nonresponse mechanisms can be modeled by specifying how the distribution of adherence depends on the pattern of observed or unobserved values. To illustrate, a pattern-mixture model in the LIFE study could state the assumptions that (1) mean adherence at each follow-up time is greater among those who complete the study than among those who dropped out, and (2) the probability of dropout is different at the 6-month and 12-month assessment times. Selection models specify (1) how the probability of nonresponse depends on the underlying adherence and (2) how adherence changes over the follow-up period. To illustrate a selection model for the LIFE study, one could assume that (1) the probability of nonresponse at the 6-month or 12-month assessments differs between those with high levels of adherence and those with low levels of adherence, and (2) adherence changes linearly over the follow-up period.

One specific type of selection model is termed a shared-parameter model (e.g., Ten Have, Kunselman, Pulkstenis, & Landis, 1998). This model specifies a mixed-effects model for the longitudinal adherence data and links this model to a model for the missing-data process by sharing a random effect between the two models. In its simplest form, the shared random effect allows the probability of missing response to be dependent on a random trend that characterizes the participant's adherence through time.

Each model has advantages in terms of interpretation. The pattern-mixture model provides an estimate of how the adherence variables differ across different patterns of nonresponse. On the other hand, the selection model explicitly states assumptions about the level of adherence over the follow-up period, which would be the quantity of interest if there were no missing data. Little (1995) provides an overview of the two types of models.

In either case, estimates of the parameters can be obtained by maximum-likelihood or Bayesian methods. It can be computationally difficult to maximize the likelihood directly, and methods based on procedures such as the EM algorithm (Dempster, Laird, & Rubin, 1977) have been suggested as a way of obtaining maximum-likelihood estimates.

Example From the Life Study

The LIFE pilot study randomized 213 participants to a comprehensive physical activity intervention with participants followed from between 12 and 18 months. The intervention had three defined phases: adoption (initial 8 weeks), transition (subsequent 15 weeks), and maintenance (week 24 through close-out). During maintenance, adherence to recommended levels of physical activity was measured using self-report home-based activity logs, which were collected monthly. These logs measured the number of times a participant was physically active and the number of minutes that the participant walked during the month. Exercise logs were received from 72% of the 213 participants during the maintenance period. The number of logs received in each month, the mean minutes of exercise per month, and the number of participants who turned in their last exercise log during each month are contained in Table 19.2.

We focus our analysis on those 154 participants who turned in at least one log during this time period, recognizing that those who never turned in a home-exercise log quite possibly had lower activity levels than those who returned at least one log. We explored whether having missing logs at subsequent months was related to the previously reported level of physical activity. We found that the odds of turning in future logs increased by 8.3% (p = 0.006) for each additional hour of reported physical activity. Thus, missing responses at subsequent visits were related to the observed responses at previous visits. Note that this relationship would violate the assumption of MCAR, where the probability of response cannot depend on previously observed responses.

To explore the longitudinal trend in physical activity, we fit a linear trend using three different longitudinal data analysis methods: GEE, a mixed-effects model, and a shared-parameter model. Because of skewness in the minutes/month outcome variable, a log transformation of the recorded minutes ($\log(\min + 1)$)

19.2	LIFE Home–Based Physical Activity Logs Collected During Maintenance		
Month	*N*	Mean (min/mo)	Last measurement
6	111	483	8
7	123	537	5
8	122	564	5
9	120	580	8
10	117	534	16
11	103	586	29
12	83	587	83

was applied prior to analysis. Thus, those recording 0 minutes received a value of 0 in the transformed distribution. The adherence model fit within GEE was:

$$A_i = \mu + \beta^* \, month_i + \varepsilon_i$$

with an unstructured covariance matrix. For the mixed-effects analysis, this adherence model was augmented with random intercept and slope terms (ν)

$$A_i = \mu + \beta^* \, month_i + \nu_1 + \nu_2 \, month_i + \varepsilon_i.$$

An unstructured covariance matrix was used for the random-effects parameters. Finally, the shared-parameter model contained the random effects specified in the adherence model described earlier within both a model for adherence and a model for dropout. The dropout model took the form

$$\log(-\log(1 - P(D_i = j \mid D_i \geq j))) = \alpha_1 \nu_1 + \alpha_2 \nu_2$$

where D_i is an indicator variable that identifies if a participant discontinued handing in physical activity logs at time j. The left side of the equation represents the complementary log-log transformation, which is widely used to model binary observations. If α_1 and α_2 are zero, then the shared-parameter model reduces to the mixed-effects model.

The GEE approach provides inference under an assumption that the missing data are MCAR. The mixed-effects model provides inference under an assumption of MAR. The shared-parameter model operates under one specific alternative to MAR, namely that the missing data mechanism can be explained by a person-specific random trajectory that is shared between the model for adherence and that for dropout.

Results from these three approaches are presented in Table 19.3 and Figure 19.1. All methods indicate an increasing level of physical activity with increased follow-up; however, the slope relating the month of follow-up to adherence levels becomes nonsignificant ($p = 0.13$) when methods that account for MAR (mixed-effects) or NMAR (shared-parameter model) nonresponse are used. The estimates of α_1 ($p = 0.08$) and α_2 ($p = 0.85$) were not significantly different from zero in the dropout portion of the shared-parameter model, thus resulting in the similarity between estimates from this and the mixed-effects model. All three results permit an interpretation that the amount of physical activity was at least constant through the maintenance phase of the intervention. Had analyses

19.3	Estimated Intercepts and Slopes for Log Minutes of Physical Activity	
Method	**Intercept**	**Slope**
GEE	5.29	0.072 ($p = 0.033$)
Mixed-effects	5.23	0.043 ($p = 0.134$)
Shared-parameter	5.23	0.046 ($p = 0.137$)

19.1

Plot of actual and predicted values at each month of follow-up.
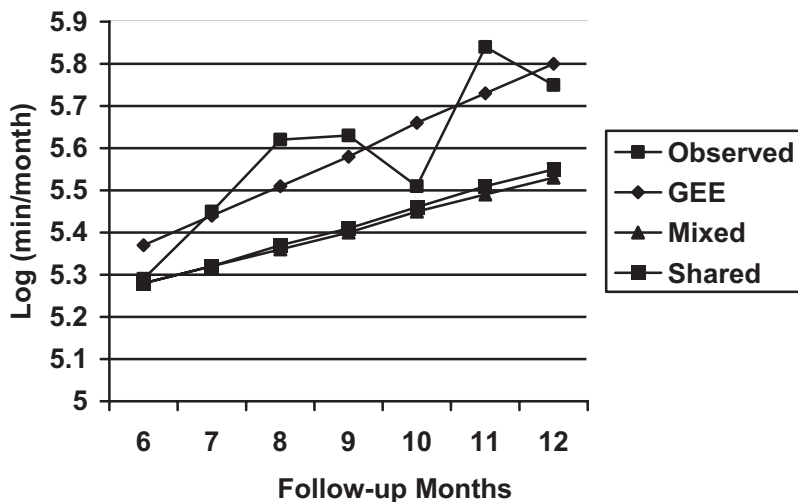
only been performed using the GEE approach, we might have concluded that activity levels increased.

In summary, our analyses showing that future missing data were dependent on previous observations led us to be suspicious of the MCAR assumption. The results from the mixed-effects analyses confirmed that different conclusions were obtained using an analysis technique applicable to data with MAR "missingness." Because it is very difficult to determine whether data may be NMAR, we explored the sensitivity of the conclusions to one form of NMAR and found that the conclusions were unchanged. By exploring the sensitivity of conclusions to different NMAR assumptions, one can have added confidence in the robustness of conclusions.

Avoiding Missing Data and Subject Dropout

The past 20–30 years have seen a rapid growth in the development of statistical methods for analyzing incomplete data, as well as a greater understanding of the statistical properties of older methods such as complete-case, available-case, and LVCF methods. While it is recognized that no statistical method is as good as having the actual data, a certain amount of missing data in clinical studies typically is unavoidable, as subjects either miss scheduled visits or drop out of the study. In addition, the collection of information on adherence to interventions is often complicated by the fact that participants are required to complete daily or weekly logs in order to track behavior in a continuous manner. In light of these challenges, investigators should take specific steps to retain participants in RCTs despite level of adherence to treatment and to devise strategies to facilitate data completeness when collecting data on a continuous schedule.

One of the strategies that has been advocated for reducing dropout is the use of pre-randomization screening for adherence. This screen can consist of a "placebo run-in" phase in which subjects are given a placebo and are monitored for compliance with the regimen. Subjects who do not comply are deemed ineligible for the trial. The perceived advantage of using the placebo run-in is statistical power. It is generally recognized that "noncompliers" tend to shrink the observed difference between treatment groups and consequently reduce power. By eliminating noncompliers, it is hoped that the statistical power is preserved. On the other hand, the use of these designs may reduce the generalizability of the findings.

The use of placebo run-ins is controversial. Senn (1997) raises objections on the basis of both ethical and statistical grounds. In a commentary on this article, Ramsey (1997) agreed that the statistical arguments supporting these designs are weak but notes that there are advantages to having pre-treatment information on subjects. For this reason, Ramsey (1997) argues that placebo run-ins should not be abandoned entirely. Pablos-Mendez, Barr, and Shea (1998) discuss placebo and active treatment run-ins as part of the design and conclude that these can either "dilute or enhance" the clinical applicability of a study, depending on the patient population to whom the results are applied. In a letter, Glynn, Buring, and Hennekens (1998) challenge these conclusions, arguing that the article overstates the generalizability of studies that remove subjects after the run-in period.

The retention of participants in RCTs for scheduled visits despite level of adherence is an area that has received particular attention at our own institutions. In general, the following steps are recommended. First, upon entry to a study, it is important to inform participants that the intervention and assessment visits represent distinct commitments. Thus, even if they are unable to participate in the intervention as intended, the hope is that they will still complete all assessment visits. We emphasize that their commitment to testing is critical to ensuring the scientific validity of study results. We ask participants to sign a form indicating that they understand the distinction between the intervention and assessment visits and agree to be contacted for assessments irrespective of their involvement in the intervention. Second, each time participants attend scheduled assessment visits, they are reimbursed for gas and given some small incentive as an appreciation for their attendance, and their names are placed in a lottery drawing that occurs at the end of each assessment cycle. Winners are announced by way of a newsletter that follows each cycle of assessment visits. We also provide feedback on several key variables that have significance for participants' health, such as levels of cholesterol and blood glucose. Third, assessment staff members are not involved in the interventions and never discuss participants' progress or level of participation in the intervention. At each assessment visit, staff members reinforce the importance of assessments visits to participants and thank them for their participation. And, fourth, we anticipate that participants who are ill around the time of assessments, those who have expressed a dislike for certain assessments, or those who are known dropout risks are less likely to attend assessment visits. Thus, assessment staff members are taught how to listen in a compassionate manner to participants concerns, to underscore the fact that partial data collection is extremely valuable even if participants cannot or do not want to complete specific assessments, and to be

flexible with scheduling. Elapsed time from the target date for specific assessment visits can be recorded and adjusted for during analyses.

In addition to completion of scheduled assessments, evaluation of adherence can require that patients self-monitor and record behavior on a continued basis. For example, in weight loss interventions, it is informative to have patients track caloric intake along with minutes of physical activity. There are a number of strategies that can be useful when collecting this information. First, patients need to be educated on the need for and the value of such data. For example, it is well known that self-monitoring is a key strategy for successful behavior change. Hence, making this an integral part of treatment as opposed to apologizing to patients for having to collect such data dramatically influences patients' willingness to do so. We also recommend using these data to provide systematic feedback to patients so that their utility is emphasized. Second, it makes sense to reduce the burden of collecting these data as much as possible. Thus, while daily monitoring makes sense in the early phases of a trial, we have found that it is more tolerable to eventually switch to a schedule in which patients are asked to report data from 1 week of each month, ensuring that the week of recording is a typical week for each patient. And, third, when there are breaks in the intervention due to illness, caregiving, or other responsibilities, it is important to document nonadherence. This process is facilitated by normalizing gaps in treatment and renegotiating goals during transition periods.

As mentioned, it is impossible to have complete data related to adherence and to prevent every instance of early termination by patients in RCTs; however, we do find that an unwillingness to report on adherence and eventual dropping out often result from participants feeling that that they failed to meet the expectations of interventionists. A key to successful data acquisition and retention is to consistently communicate to patients that goals and expectations related to both treatment and assessment are established collaboratively. In addition, success can be defined in many different ways. For example, participants may not meet intervention goals, yet improve their health status. Also, we have had participants in weight loss trials who fail to lose weight but feel that they benefited from group interactions and education on how to eat healthy. It is important to identify and underscore progress of participants in intervention research even if the outcomes are unrelated to study objectives, since retention and the collection of adherence data are as important to the success of a trial as maximizing adherence.

Summary

In this chapter, we have reviewed some of the methods that could be used to analyze incomplete adherence data. When the probability of response depends on the unobserved outcome, the missing-data process is nonignorable, and using complete-case, available-case, or LVCF method can lead to biased estimates. Most model-based approaches for analyzing incomplete data can be summarized as a process whereby the analyst makes assumptions about the distribution of the missing data in an attempt to obtain unbiased estimates based on

functions of the observed data. Unbiased estimates can be obtained if correct assumptions regarding the missing data process are made and incorporated into the analysis. To select an optimal statistical approach, the analyst must consider the underlying process that may have led to the missing observations, possibly using external data or expert knowledge from behavioral interventionists. In the face of uncertainty about the underlying missing data mechanism, we suggest that sensitivity analyses accompany most analyses of adherence data containing missing observations. When results from these analyses are similar, regardless of the nonresponse mechanism that is assumed, then the analyst can take comfort in knowing that conclusions made in the face of missing observations are robust to many assumptions regarding the missing-data process. When confronted by missing data, it is our view that the words of McCullough and Nelder (1999) that pertain in general to statistical models are quite applicable. They stated:

> *Modelling in science remains, partly at least, an art. Some principles do exist, however, to guide the modeler. A first, though at first sight, not a very helpful principle, is that all models are wrong; some, though are more useful than others and we should seek those. At the same time we must recognize that eternal truth is not within our grasp. (p. 8)*

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Obstacles and Predictors of Lifestyle Change and Adherence

Section 4

Sally A. Shumaker
Editor

A number of complex factors influence whether people are able to change and maintain healthier behavior patterns. In Section IV authors explore these factors from the biological through the psychological, social, and policy levels of analysis. A significant change in this section from the prior edition of this book resides in the increased attention by all of the authors to the multiple and interrelated determinants of health behaviors. Together, these chapters provide critical insights into the relationships among various levels of influence on adherence and the challenges faced by individuals and health providers in trying to promote healthier lifestyles within a context that often thwarts such efforts.

In the first chapter, "Predictors of Patient Adherence: Patient Characteristics," Dunbar-Jacob, Gemmell, and Schlenk review a set of predictors of adherence that are specific to the individual. These authors provide an updated and detailed review of the studies that have looked at the degree to which psychological characteristics and cognitive and motivational factors influence adherence. In addition, they explore how the prior adherent behavior of an individual—either to a similar health regimen or to a new regimen—is predictive of future adherence. There is a long history of data on the influence of adverse side effects of medications on adherence. In this chapter, these data are updated and additional information is provided on the effects of symptoms benefits and adherence. Finally, the authors explore the world of health literacy—a major issue in the population today and one that often goes unacknowledged and thereby not addressed in the health provider–patient interaction.

In "Biopsychological Obstacles to Adoption and Maintenance of a Healthy Lifestyle," Grunberg and Klein retain the important and unique contribution to this field of their previous chapter (Grunberg & Klein, 1998) by fully exploring the biological aspects of health behavior including the absence or misinterpretation of biological cues, and physical and behavioral limitations. In addition, however, they expand on this biology-based perspective by considering the degree to which biological variables that influence healthy behaviors are, in turn, influenced by psychological and social factors. By applying this more systems-oriented analysis and considering the biopsychosocial aspects of adherence, Grunberg and Klein build an important bridge to understanding the interconnected influence of variables from the biological to the social that impact adherence, health behavior change, and maintenance.

Using adolescent tobacco exposure as the focus of the health behavior concern, Holub, Altman, and Jackson explore in "Adolescent Tobacco Use and the Social Context" the complex world embodied within the broad social context in this updated version of their previous chapter (Altman & Jackson, 1998). As noted by the authors, tobacco use remains the most preventable cause of morbidity and mortality in the United States despite significant strides made in the reduction of its use among adults and adolescents. However, recent trends in adolescent smoking behavior are of particular concern. Although there was a decline in smoking in the 1990s among adolescents, the trajectory of this decline began to slow in the 21st century. The authors tackle the challenge of understanding this persistent health concern by applying an ecological approach to the question. As noted by the authors, adolescent tobacco use is a complex behavior rooted in biological, social, environmental, historical, and cultural contexts. Their systems approach to this issue is similar to that considered by Grunberg and Klein—although the current authors focus more attention on the cultural and health policy aspects of the system.

In "Psychosocial Barriers to Adherence and Lifestyle Change," Williams, DiMatteo, and Haskard note that despite decades of research on patient adherence, questions continue about its causes and treatment. Approaching the issue from a systems perspective, with a focus on psychological and social factors, these authors explore what is known today about the complex factors that determine the ability and willingness of individuals to adhere to medical regimens and adopt and maintain health behaviors. In particular, they consider

adherence as an ongoing process and describe the steps that individuals take throughout this process while considering the role of various psychosocial factors that contribute to a person's success or failure along the way.

In the final chapter in this section, "Changing Clinical Behavior: Implementing Guidelines to Improve Primary Care Practice," Dugan, Dodd, and Ellis consider the health provider, rather than the patient, and present a critical analysis of the world of evidence-based medicine and its relationship to adherence and health behaviors. The authors discuss the degree to which health care providers "adhere" to best practices as the health provider represents one of the key influences on the health behaviors of the general population. As noted by the authors, this area of research has grown substantially since the prior chapter on this topic (Dugan & Cohen, 1998), and these authors take full advantage of this growing field of inquiry by reviewing the complex, and sometimes dysfunctional, health care system in which clinical behavior occurs. Again, taking a systems approach and considering the components of that system (e.g., provider, practice setting, state or region, health maintenance organization, insurance providers, medical profession, and the United States) these authors consider why it is challenging for physicians to follow best practices and review the results of several interventions designed to improve primary care practices.

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Predictors of Patient Adherence: Patient Characteristics

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Jacqueline Dunbar-Jacob,
Leigh A. Gemmell,
and Elizabeth A.
Schlenk

With nonadherence rates ranging from 20% to 80% in practice and research settings, considerable health care resources are utilized in either remediating nonadherence or in addressing the consequences of inadequately treated diseases or risk factors. In the clinical research arena, further resources may be expended in the recruitment and management of additional participants to compensate for the loss of power due to dropouts or poor adherers. Resources might be better utilized at the outset of treatment or subject recruitment if individuals likely to have difficulty adhering could be identified. And, indeed, investigations have been undertaken directed toward the prediction of adherence.

A number of studies examined factors under the control of the provider that are likely to lead to nonadherence, such as prescription of multiple and/or complex regimens, lack of consistency in care providers, care provider behavior

toward patients, adequacy of instructions, and convenience. Other sets of predictors are those that are more specific to the person than to the regimen, provider, or clinical setting. It is this latter set of factors that is addressed in this review. That is, what characteristics of the individual are likely to influence subsequent adherence to a health care regimen? We examine a number of areas, including psychological characteristics, cognitive-motivational factors, behavior itself, somatic and cognitive factors, and health literacy.

Psychological Characteristics as Predictors of Adherence

Several studies examined *personality traits* as predictors of adherence, and many use the Five Factor model of personality. For example, Stilley, Sereika, Muldoon, Ryan, and Dunbar-Jacob (2004) found that conscientiousness predicted medication adherence to cholesterol-lowering medications, but that neuroticism, extroversion, openness, and agreeableness did not. Extroversion predicted exercise adherence in an intervention group of cancer survivors but not in the control group (Courneya, Friedenreich, Sela, Quinney, & Rhodes, 2002). Neuroticism, conscientiousness, openness, and agreeableness did not predict adherence to exercise in either group. Finally, Hershberger, Robertson, and Markert (1999) found that appointment keeping was correlated with the personality factors of well-being, socialization, and communality in a sample of men in cardiac rehabilitation. The literature is too scant to permit us to draw any conclusions about the role of personality factors in adherence. However, the literature that exists suggests that different behaviors may be influenced by different factors.

Mood has also been examined as potential predictor of adherence. Overall, it appears that *depression* is often associated with poorer adherence. For example, measures of depression or depressive symptoms were related to poorer adherence to antihypertensive medications (Morris, Li, Kroenke, Bruner-England, Young, & Murray, 2006; Siegel, Lopez, & Meier, 2007), antiretroviral medications (Gordillo, del Amo, Soriano, & Gonzalez-Lahoz, 1999; Reynolds et al., 2004), cholesterol-lowering medications (Stilley et al., 2004), and medical appointment keeping (Mackin & Arean, 2007). Other studies have found that measures of depression or depressive symptoms are not related to adherence (Schweitzer, Head, & Dwyer, 2007; Shemesh et al., 2004). In these studies, depression or depressive symptoms were either measured through self-report questionnaires (Morris et al., 2006; Reynolds et al., 2004; Stilley et al., 2004; Gordillo et al., 1999; Schweitzer et al., 2007; Shemesh et al., 2004; Mackin & Arean, 2007) or by reviews of participants' medical records (Siegel et al., 2007). Adherence was assessed a number of different ways in these studies, including self-report questionnaires (Gordillo et al., 1999; Schweitzer et al., 2007; Morris et al., 2006; Reynolds et al., 2004), electronic monitoring (Stilley et al., 2004), pharmacy refill databases (Morris et al., 2006; Siegel et al., 2007), pill counts (Gordillo et al., 1999), missed appointments (Mackin & Arean, 2007) and biological data (Shemesh et al., 2004). No consistent patterns of associations between depressive symptoms and adherence emerged on the basis of the measurement methods used.

The Medical Outcomes Study reported that emotional distress over one's health predicted adherence (DiMatteo et al., 1993). Similarly, Dobkin, Sita, and Sewitch (2006) found that lower psychological distress was associated with better medication adherence in women with fibromyalgia. Naar-King and colleagues (2006) found that psychological distress predicted better self-reported adherence to HIV medication in youths.

Data are mixed regarding whether or not *anxiety* is related to adherence. Higher levels of anxiety were related to poorer adherence to taking cholesterol-lowering drugs (Stilley et al., 2004), overuse of medications among patients with asthma (Mawhinney et al., 1993), and poorer adherence to smoking and alcohol cessation guidelines in patients with chronic heart failure (Schweitzer et al., 2007). Lower levels of anxiety predicted greater exercise behavior among older adults (Emery, Hauck, & Blumenthal, 1992). In contrast to these findings, anxiety did not predict adherence to prenatal class attendance among primagravidas (Michie, Marteau, & Kidd, 1990), exercise adherence among healthy women (Welsh, Labbe, & Delaney, 1991), or older adults' adherence to medical appointment attendance (Mackin & Arean, 2007). One study found that the presence of anxiety symptoms was associated with *better* adherence to antiretroviral medications (Ingersoll, 2004). Thus, the relationship of anxiety to adherence is complex and not easily predicted. This suggests that efforts to raise anxiety in an attempt to raise adherence are unlikely to be successful, at best, and may lower adherence.

Investigators have also studied *coping styles* as potential predictors of adherence. Avoidant coping predicted better adherence to prenatal class attendance (Michie et al., 1990) and adherence in the Medical Outcomes Study as well (Sherbourne, Hays, Ordway, DiMatteo, & Kravitz, 1992). Instrumental coping was related to better medication adherence in women with fibromyalgia (Dobkin et al., 2006). Weaver et al. (2005) found that avoidance-oriented coping was related to poorer medication adherence to antiretroviral medications, but greater approach-oriented coping was not significantly associated with adherence. Finally, Heckman, Catz, Heckman, Miller, and Kalichman (2004) found that active coping with HIV-related stressors was associated with better adherence to antiretroviral therapy.

Hostility has been examined also in the context of adherence. Lee et al. (1992) found that participants who reported greater hostility skipped more doses of medication, although they did not report any greater difficulty in remembering to take medications. In contrast, Irvine et al. (1999) found that hostility was not associated with medication adherence in survivors of acute myocardial infarctions. Asthma patients who reported anger and irritation about their disease were more likely to attend an asthma education program (Yoon, McKenzie, Miles, & Bauman, 1991). Welsh et al. (1991) found that *Type A* and *Type H* (hard-driving) behavior was related to attendance in an exercise program designed for healthy women.

Other characteristics related to personality style have been examined, but limited evidence is available. For example, *self-motivation* is considered a possible characteristic that might influence adherence. Typically, however, self-motivation is inferred, not directly measured. Welsh et al. (1991) reported that self-motivation was not associated with exercise program attendance, but it was

associated with exercise frequency. *Optimism* has also been associated with adherence to follow-up recommendations following detection of a suspicious skin lesion (Friedman, Webb, Bruce, Weinberg, & Cooper, 1995) and to adherence to attending a cardiac rehabilitation program (Glazer, Emery, Frid, & Banyasz, 2002).

Summary

The question arises as to why psychological states might predict adherence. It may be that psychological states directly influence adherence or that certain psychological states mediate the relationship between motivation and behavior. Certain psychological states may also be barriers to adherence. Although many studies have examined the relationships between psychological states and adherence, no clear patterns emerge.

Cognitive-Motivational Predictors of Adherence

Investigators have also examined beliefs and other cognitions as potential predictors of patient adherence, and it is in this area that much of the research on patient characteristics as an influence on adherence has focused. The principal models include health beliefs, intentions, self-efficacy, and stages of change.

The *Health Belief Model* is a cognitive-motivational model that states that recommended health actions will be taken if individuals believe that they are susceptible to the illness (perceived susceptibility), the consequences of the illness or of noncompliance are serious (perceived severity), the recommended action is beneficial or efficacious in reducing risk or severity (perceived benefits), and the barriers or costs of action do not exceed the benefits (perceived barriers). In addition to these beliefs, general health motivation is, at times, included in the model. General health motivation consists of both positive factors (e.g., engaging in healthy behaviors) and negative factors (e.g., worry or concern over health).

Perceived susceptibility has been the most commonly studied component of the Health Belief Model in studies examining predictors of patient adherence, but studies over the past 20 years have not supported its utility as a predictor of adherence. Perceived susceptibility did not predict adolescents' adherence to dental appointments (West, DuRant, & Pendergrast, 1993), follow-up appointment keeping in adults and children with otitis media (Jones, Jones, & Katz, 1989), medical follow-up for suspicious lesions in a skin cancer detection program (Friedman et al., 1995), participation in fecal occult blood testing among adults (Myers et al., 1994; Sandler, DeVellis, Blalock, & Holland, 1989), or mammography utilization in a community sample (Bastani, Marcus, Maxwell, Das, & Yan, 1994).

Perceived severity is a second component of the Health Belief Model. Lower ratings of perceived severity were related to poorer adherence to malaria medications in participants in a travel medicine clinic (Farquharson, Noble, Barker, & Behrens, 2004). Perceived severity has also been associated with appointment keeping among children and adults with otitis media (Jones et al., 1989) and participation in colorectal cancer screening in an HMO population (Myers

et al., 1994). Perceived severity did not predict dental follow-up for adolescents (West et al., 1993) or medication adherence in chronically ill adults (Lorenc & Branthwaite, 1993).

Perceived benefits or efficacy of health behaviors as a modifier of disease is a third component of the Health Belief Model. A positive relationship has been demonstrated between perceived benefits and adherence to malaria medication (Farquharson et al., 2004), in myocardial infarction (MI) patients (Miller, Wikoff, McMahon, Garrett, & Ringel, 1988), as well as colorectal cancer (Myers et al., 1994), and mammography screening (Bastani et al., 1994). Perceived benefits did not predict follow-up appointment keeping in adults and children with otitis media (Jones et al., 1989) and medication adherence among adults with chronic conditions (Lorenc & Branthwaite, 1993).

Perceived barriers to health behavior are a fourth component of the Health Belief Model. There are mixed findings in studies that examine the relationship between perceived barriers and patient adherence. Perceived barriers have been predictive of medication adherence in adults with chronic conditions (Lorenc & Branthwaite, 1993) and mammography utilization (Bastani et al., 1994). Participants who perceived fewer barriers to obtaining mammography screenings were more likely to obtain repeated screenings (Russell, Champion, & Skinner, 2006) and adults in an anticoagulation clinic who obtained higher scores on measures of perceived barriers were less likely to refill their medication (Orensky & Holdford, 2005). In contrast, researchers found that perceived barriers were not associated with adolescents' appointment keeping for dental follow-up (West et al., 1993).

The predictive ability of health beliefs may vary among populations and behaviors. The number of studies in each of the areas mentioned is small, but those that have been undertaken suggest that an important direction in the study of health beliefs is an examination of the interaction of specific beliefs with types of health behaviors. A complicating factor in evaluating the effects of health beliefs on adherence is the time at which the assessment of health beliefs is undertaken in relation to diagnosis. Health beliefs may be modified with experience with a particular regimen (Beck, 1981). The ability of health beliefs to predict behavior may be related to whether or not individuals have experienced the behavior and adjusted their beliefs accordingly.

Several studies examined the associations between *behavioral intentions* and adherence. Courneya et al. (2004) examined intention to exercise as a predictor of behavior in a randomized-controlled trial of an exercise intervention for colorectal cancer survivors. They found that intentions predicted exercise behavior in the control group, but not in the treatment group. Blanchard et al. (2003) also found that intention predicted exercise adherence in patients attending a cardiac rehabilitation program. Other studies have also found a relationship between intentions and behavior (e.g., Myers et al., 1994). No association was found between intentions during hospitalization and adherence to activity, stress management, medication, or diet prescriptions 2 years later in post-MI patients (Miller, Wikoff, Garrett, McMahon, & Smith, 1990), suggesting that any relationship between intentions and behavior does not persist over the course of treatment.

A second theoretical model, *Self-Efficacy Theory* (Bandura, 1977), postulates that individuals will engage in or persist with a behavior to the extent that

they believe themselves capable of carrying out that behavior (efficacy expectancy) and to the extent that they believe that the behavior will lead to a desired outcome (outcome expectancy). Overall, studies that examine the relationship between efficacy expectancy and self-efficacy support the notion that higher self-efficacy is associated with better adherence to HIV medications (Safren et al., 2001), and lower self-efficacy is associated with poorer adherence to HIV medications among younger, but not among older, participants (Barclay et al., 2007). Self-efficacy was also related to medication adherence in patients with rheumatoid arthritis (Brus, van de Laar, Taal, Rasker, & Wiegman, 1999) and multiple sclerosis (Fraser, Hadjimichael, & Vollmer, 2003; Fraser, Morgante, Hadjimichael, & Vollmer, 2004). In addition to being associated with medication adherence, self-efficacy has been found to be related to adherence to health behaviors including exercise regimen (McAuley, Courneya, Rudolph, & Lox, 1994) and preventive screening recommendations (Friedman et al., 1995; Myers et al., 1994). Conversely, self-efficacy was not related to exercise adherence in HIV-positive participants enrolled in an exercise intervention study (Pavone, Burnett, LaPerriere, & Perna, 1998). Finally, self-efficacy has been found to be related to adherence to diabetes self-management (Kavanagh, Gooley, & Wilson, 1993; Glasgow et al., 1989).

Few investigators have examined outcome expectancy either alone or in conjunction with self-efficacy. McCaul, Glasgow, and Schafer (1987) found that both self-efficacy and outcome expectancies were the strongest predictors of adherence for both the concurrent and prospective analyses in their study of patients with insulin-dependent diabetes mellitus. These findings held up among both adults and adolescents and across regimen: glucose monitoring, insulin administration, diet, and exercise. Researchers have also examined efficacy and outcome expectancies as determinants of adherence to exercise (Desharnais, Boullon, & Godin, 1986), medication-taking for rheumatoid arthritis (Dunbar-Jacob et al., 1993), and a cholesterol-lowering diet (Burke, Dunbar-Jacob, Sereika, & Rohay, 1996). Dunbar-Jacob et al. (1993) found that outcome expectancy was related to self-reported medication-taking but not to electronic monitoring of medication-taking. At least one study noted that self-efficacy is a stronger predictor of adherence than outcome expectancy. Desharnais et al. (1986) reported that at the outset of an exercise program, participants who became dropouts displayed lower self-efficacy related to attendance, even while expressing positive outcome expectancy.

A fourth cognitive-motivational meta-theoretical model, the *Transtheoretical Model* (DiClemente et al., 1991; Prochaska & DiClemente, 1983; Prochaska, DiClemente, & Norcross, 1992) addresses intentional behavior change. This model states that individuals move through five stages of change—precontemplation, contemplation, preparation, action, and maintenance—as they attempt to modify their behavior. This model states that progression through these stages is often nonlinear; rather, people tend to recycle through these stages. In general, people in the action and maintenance stages of change have the best adherence. Heapy et al. (2005) examined the relationship between stage of change and adherence in patients with chronic pain and found that the stage of change predicted adherence to coping skills practice. While this theory is promising, empirical reports to date tend to address clinical outcomes rather than adherence to treatment regimens. Also, the current literature tends to focus on the

effects of stage-based interventions on adherence, not necessarily the relationship between the specific stage-of-change variables and adherence.

Summary

Cognitive-motivational models contribute to our understanding of patient adherence to health care regimens. Each proposes a slightly different schema for understanding the relationship between motivational cognitions and subsequent behavior. In most cases, studies find that these models account for a small proportion of the variance observed in adherence behavior. Further, studies in the health belief area suggest that the effect of beliefs on behavior may vary with the health behavior, as well as with the timing of the assessment of beliefs. Intentions and self-efficacy seem particularly promising as predictors of adherence. Aspects of health beliefs may also have a role, particularly perceived barriers, benefits, and severity. Both self-efficacy and health beliefs appear to be influenced by experience. As self-efficacy and health beliefs appear to change in the direction of the behavior change, however, one wonders if behavior itself is predictive of future behavior.

Health Behaviors as Predictors of Subsequent Adherence

Health behavior as a predictor of subsequent adherence can be examined along two dimensions. The first is whether adherence to a specific behavior predicts adherence to that same behavior in the future. The second is whether adherence to a specific behavior or set of behaviors predicts adherence to a different health behavior.

If individuals adhere to a health care regimen at one time, they may be more likely to do so at a later time. Indeed, the few studies that have examined the effect of adherence to a specific regimen on subsequent adherence to the same regimen do support such a hypothesis. This has been particularly evident with screening behaviors. Lechner, de Vries, and Offermans (1997) found that participants who had had breast cancer screening in the past were most likely to seek future screening. Previous mammography has been shown to be the best predictor of participation in mammography screening (Bastani et al., 1994), and the best predictor of follow-up on suspicious skin lesions was frequency of skin self-examination (Friedman et al., 1995). Interestingly, Myers et al. (1994) found that while past colorectal screening was predictive of screening in univariate analyses, in regression analyses past screening predicted intentions only and not actual screening, although intentions and screening behaviors were correlated. Studies of an adolescent population found that those who have visited dentists in the past were most likely to utilize preventive practices (West et al., 1993).

Several studies support the idea that past adherence is a predictor of subsequent adherence. For example, Ascher-Svanum, Zhu, Faries, Lacro, and Dolder (2006) found that past nonadherence to antipsychotic medications predicted future nonadherence in a sample of patients with schizophrenia. In the Lipid Research Clinics Coronary Primary Prevention Trial, a 10-year study

of the cholesterol hypothesis, adherence to the study medication during the first month postrandomization accounted for 34.5% of the variance in adherence in the first year and approximately 24% in the seventh year (Dunbar & Knoke, 1986). Dubanoski (1988) also found that first-month adherence to tuberculosis preventive therapy was the strongest predictor of adherence at 6 months. Kribbs and colleagues (1993) found that adherence to nasal continuous positive airway pressure in the first month predicted usage at 3 months among patients with sleep apnea. The Medical Outcomes Study also reported that baseline adherence was associated with adherence 2 years later (DiMatteo et al., 1993). The ability of initial adherence to predict subsequent adherence over a 3-month to 7-year duration suggests certain stability to adherence based upon a pattern established early within a specific regimen. This growing body of evidence suggests interesting and valuable directions for the continued study of adherence to health regimens, in efforts to both understand and promote adherence.

Health behaviors other than early adherence to an intervention do not necessarily predict subsequent adherence to a specific regimen. For example, past exercise behaviors did not predict adherence to an exercise intervention for participants randomized to an exercise intervention group, but it did predict adherence in the control group (Courneya et al., 2002). This suggests that intervention may interrupt the early patterns. These studies suggest that behavior can predict behavior. The more similar the initial behavior is to the behavior to be predicted, the greater the ability to predict. However, there does not appear to be a set of behaviors that would allow prediction of individuals' adherence to a specific health regimen; that is, investigators could not predict that a health-oriented individual, as defined by the practice of a set of health behaviors, would necessarily adhere to a regimen solely on the basis of that earlier behavior. The studies do suggest that a history of adherence to a specific regimen predicts subsequent adherence to that regimen. Further study of the ability of behavior to predict subsequent adherence would be of interest and would be most useful in the selection of participants for clinical research efforts where maximal adherence to protocol regimen is desired.

Somatic and Cognitive Factors as Predictors of Adherence

Several studies examined aversive effects, as well as relief of symptoms due to treatment, as predictors of adherence. For example, physical discomfort during running predicted dropping out of a marathon training program (Heiby, Onorato, & Sato, 1985). Indeed, the amount of running done by the dropouts was a function of the number of injuries experienced. Other researchers similarly reported that adverse side effects, especially their number, nature, and perceived intensity, were inversely related to adherence in adolescents receiving iron supplements (Cromer, Steinberg, Gardner, Thornton, & Shannon, 1989) and in women prescribed ethinylestradiol (Kruse, Eggert-Kruse, Rampmaier, Runnebaum, & Weber, 1993). Ascher-Svanum et al. (2006) found that people with schizophrenia who were nonadherent to antipsychotic medication were more likely to report averse effects from the medication. Ickovics et al. (2006)

found that individuals living with HIV and on a highly active antiretroviral therapy regimen who reported fewer adverse events were more likely to adhere to treatment.

Adherence to self-management procedures for adults with chronic disease was related to fewer disease-related symptoms (Kravitz et al., 1993). Similarly, patients with chronic obstructive pulmonary disease who reported less shortness of breath were more likely to adhere to meter-dose inhaler regiments (Rand, Nides, Cowles, Wise, & Connett, 1995), and those with more severe dyspnea were more adherent to nebulizer therapy (Turner, Wright, Mendella, & Anthonisen, 1995). Two randomized clinical trials found that symptoms were not predictive of adherence (Jones et al., 1989; Yoon et al., 1991). The severity of disease among asthma patients did not affect their rate of attendance at an asthma education program after discharge from the hospital (Yoon et al., 1991). Duration and intensity of otitis media symptoms did not predict follow-up appointment keeping in adults and children presenting to an emergency department (Jones et al., 1989). Where an effect was found, fewer symptoms were associated with better adherence. The nature of the studies does not permit a clarification of the direction of the effect (e.g., whether fewer symptoms predict adherence or whether adherence leads to fewer symptoms).

Health Literacy as a Predictor of Adherence

Ratzan and Parker (2000) define health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (as cited in Institute of Medicine, 2004, p. 32). In 2003, the U.S. Department of Education conducted a National Assessment of Adult Literacy (NAAL), which included measures of health literacy. A separate report on the health literacy data suggested that higher levels of health literacy are associated with better overall self-reported health (Kutner, Greenberg, Jin, & Carlson, 2006), and, given this relationship, several researchers are beginning to examine the relationships between health literacy and patient adherence.

Several studies have examined the associations between health literacy and adherence and have obtained mixed results. Poor literacy was associated with poor adherence to HIV medications (Wolf et al., 2007), fewer medication refills in patients with glaucoma (Muir et al., 2006), and nonadherence to preoperative medications in patients who were preparing to undergo ambulatory surgery (Chew, Bradley, Flum, Cornia, & Koepsell, 2004). Although the majority of studies found that lower health literacy was related to poorer adherence, Paasche-Orlow et al. (2006) found that lower literacy was associated with better adherence to antiretroviral medications in HIV-positive participants.

Some researchers have not found an association between health literacy and patient adherence. Gazmararian et al. (2006) found that health literacy was not associated with medication refill adherence after controlling for several demographic variables and regimen complexity. Fang, Machtinger, Wang, and Schillinger (2006) also found that health literacy was not a predictor of adherence to warfarin therapy in patients attending an anticoagulation clinic. Data on health literacy and adherence are relatively recent, and, although there is some

evidence to support a relationship, there are insufficient data to determine the nature, strength, or consistency of the relationship.

Summary

A variety of factors specific to the individual predict adherence. Among these are psychological characteristics; cognitive-motivational factors drawn from theories and models regarding health beliefs, intentions and behavior, self-efficacy, and stages of change; health behaviors; somatic and cognitive factors; and health literacy. Although each of these areas has something to contribute to our understanding of predictors of adherence, the power tends to be modest at best for any single factor. The most promising of these are self-efficacy, intentions, and prior adherence behavior. Not to be lost, however, is the role of depressive symptoms and emotional distress, perceptions about the illness or its consequences, and the experience or perceived experience of somatic complaints. Of more recent interest is the potential influence of health literacy in predicting adherence to treatment. Few of the areas have a sufficient number of studies to allow us to draw firm conclusions, but, as noted, the role of psychological and motivational factors are promising in our effort to understand adherence. Many questions still arise in the area of predictions of adherence. How do these individual factors function in different populations and health care settings, and how does the type of prescribed behavior influence adherence? Also, how do these multiple factors interact, if at all, to lead to adherence or nonadherence? None of the studies examined the influence of multiple factors. Although more is becoming known about individual factors that predict adherence, the relatively modest associations obtained in the research to date suggest that there is still much to be learned.

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Biopsychological Obstacles to Adoption and Maintenance of a Healthy Lifestyle

21

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Decades of research have made clear what we should do (e.g., eat in moderation; eat fruits, vegetables, and grains; exercise regularly; nurture social support; take our medicines) and what we should not do (e.g., not smoke cigarettes; not consume alcohol or other drugs in excess; not eat high-fat foods in excess; not experience too much chronic stress) to enjoy good health. Although we know what to do, it is often difficult to adopt and to maintain a healthy lifestyle

because of economic, social, psychological, and biological obstacles. This chapter discusses the biopsychological obstacles to adoption and maintenance of a healthy lifestyle.

Biological obstacles relevant to a healthy lifestyle received little attention before the 1990s. Grunberg and Lord (1990) first highlighted this category of variables and offered a framework to categorize biological barriers to the adoption and maintenance of health-promoting behaviors. Since then, the broad topic of compliance with health-related behaviors has received increased attention and has become a part of some medical and health care curricula. A computer literature search of *PubMed* for "compliance" or "adherence" lists more than 5,000 titles in 2007 alone, and, of these many reports, hundreds now consider biologically relevant aspects of compliance across many different scientific disciplines and domains. This chapter updates our previous report on this topic (Grunberg & Klein, 1998a) in light of recent scientific advances across many health-related disciplines, including psychology, medicine, and biobehavioral health.

Much of the information we discussed in 1998 regarding biological variables and compliance remains true today and is reiterated in this chapter. One of the marked and purposeful changes that we have made in this chapter is the revision of the title from "biological" to "biopsychological" obstacles. Another purposeful semantic change is from "health-promoting behaviors" to "healthy lifestyle." These changes reflect our opinion that (1) the biological variables that dissuade individuals from complying with medical and health-promoting behaviors are influenced by psychological factors and vice versa, and (2) health and the obstacles to maintaining health are affected by how individuals go about living their daily lives. Another important change in this revised chapter is the expansion of the types of biopsychological obstacles and a recategorization of these variables across several biopsychological domains, including physical, behavioral, cognitive, and motivational limitations. This expansion acknowledges the contributions of each of these domains to a healthy lifestyle, and it is our hope that readers will conceptualize practical and research issues with all four of these domains in mind. A final update is the change from strictly addressing "adherence" and "compliance" to the inclusion of "adoption" and "maintenance" because we believe that it is important to emphasize the collaborative role that patients should have with their health care provider to establish and to practice a healthy lifestyle.

As with our previous chapter, we continue to believe that marked technological advances in the biological and behavioral sciences, substantial expansion of interdisciplinary and multidisciplinary consideration of health issues, and incorporation of multilevel analyses in behavior and health work together to sustain a renewed mind-body monism. Advances in behavioral and cognitive neuroscience, genetics, molecular biology, and behavioral science all point to the effects of the mind on the body and the body on the mind. In the context of the present chapter and the present volume, biological variables are part of the biopsychological and environmental milieu that affects adoption and maintenance of healthy lifestyles and compliance and adherence to healthful behaviors and treatments.

Types of Biological Obstacles

The biological obstacles that affect adoption and maintenance of a healthy lifestyle can be organized across eight domains: (1) absence or misinterpretation

of biological cues; (2) physical and behavioral limitations; (3) cognitive limitations; (4) motivational limitations; (5) interference of healthful behaviors with quality of life; (6) unpleasant side effects of treatments to enhance a healthy lifestyle; (7) common biopsychological obstacles; and (8) individual differences. Each major category is addressed in order.

Absence or Misinterpretation of Biological Cues

An important factor that may affect adoption and maintenance of a healthy lifestyle but that receives limited research attention is the patient's failure to experience or correctly interpret symptoms of underlying disorders. Basically, patients may feel fine and conclude that they are fine. As a result, they believe that they do not need bed rest, medications, restricted activities, or dietary changes. Premature discontinuation of therapy can be dangerous. For example, a patient typically feels better (e.g., no fever, weakness, pain, cough) before a course of antibiotic treatment is finished. If the antibiotic regimen is not completed, then drug-resistant strains of microorganisms can multiply and create a more serious health risk to the individual and to the general public. This serious scenario is playing out today in the development of drug-resistant and extensively drug resistant (XDR) strains of tuberculosis. Symptomless diseases such as hypertension or type II diabetes also require treatments (e.g., medication, regular medical tests and checkups, dietary changes, exercise) with physical effects that will not be felt by the patient. Preventive treatment for asthma with daily regimens of nonsteroidal (e.g., cromolyn sodium or Intal®) and leukotriene receptor antagonists (e.g., montelukast or Singulair®), along with peak flow meter evaluation, is not directly or immediately felt by the patient, and prevention efficacy is measured by decreased number of asthma attacks weeks later. In addition, misinterpretation of symptoms (e.g., "I get headaches whenever my blood pressure is high" or "I feel anxious right before I have an asthma attack") may lead to inappropriate self-dosing or inappropriate abstinence (e.g., "I don't have a headache, so I don't need to take my pills" or "My chest doesn't feel tight, so I don't need to use my inhaler").

A variant of this misinterpretation obstacle to promotion of a healthy lifestyle occurs when people feel fine and, therefore, believe that they do not need to do anything special to promote or improve health. For example, when people feel fine, they may assume that it is unnecessary to exercise, be careful about cholesterol intake, quit smoking, or avoid excess sun exposure.

Adoption and maintenance of a healthy lifestyle also are reduced when a given healthful behavior has no noticeable positive effects that are obvious to the individual. For example: "I've been exercising for weeks, but I don't feel any better (in fact, I feel worse because my muscles and back hurt); I've given up smoking for 3 months now, but I don't feel better (in fact, I've gained weight); I take my pills regularly, but I don't feel any different—I bet the doctor gave me sugar pills because he thinks I'm not sick or to stop me from bugging him; I've been getting allergy shots twice a week for over a year and I still sneeze around cats." These experiences and lack of awareness of bodily states, therapeutic effects, or preventive effects should be addressed and explained to patients.

Patient expectations about treatments and illnesses can be wrong. It is these expectations, however, that affect the confidence in a given healthful behavior, the credibility of a health care provider, and the likelihood that patients will adhere to and comply with healthy behaviors.

Physical and Behavioral Limitations

Another category of biological obstacles to adoption and maintenance of a healthy lifestyle involves problems or deficiencies in physical and behaviorally based abilities of patients. Impairment of a sensory system, such as hearing or vision, can interfere with the ability to gather or interpret information from the health care provider. These impairments also may make a patient more reluctant to ask questions of the health care provider. For example, impaired vision interferes with the processing of written instructions about prescribed health behaviors, and impaired hearing can make it difficult to understand oral instructions from the health care provider. Difficulties in visual acuity, myopia, and hyperopia all can act to make objectively clearly written instructions inaccessible to patients. Color deficiencies in an individual patient also can interfere with that patient's ability to adhere to medication regimens that require taking different colored pills on different days or at different times of the day.

Physical barriers to adoption and maintenance of a healthy lifestyle also include a variety of allergies and physical handicaps. For example, food allergies may interfere with nutrition or the ability to adopt a healthy diet (e.g., celiac disease or a gluten allergy prohibits consumption of wheat products), drug allergies may prevent the administration of effective pharmacologic agents, and contact dermatologic reactions may interfere with the use of some medications and some medicinal soaps and may prevent safe-sex practices. Respiratory allergic responses, such as extrinsic asthma or allergic rhinitis, can inhibit an individual from performing exercise activities, eating certain foods, and complying with immunotherapy (e.g., allergy shots).

Further, individuals with physical and hidden disabilities such as orthopedic, neuromuscular, cardiovascular, and pulmonary disorders (e.g., injury, muscular dystrophy, multiple sclerosis, cerebral palsy, amputation, heart disease, pulmonary disease) must rely on assistive devices such as wheelchairs, crutches, canes, prosthetic devices (artificial limbs), and oxygen to obtain mobility. These disabilities and physical challenges may require specialized attention to develop an individualized health adoption and maintenance plan across psychological and physical domains.

Cognitive Limitations

There are biologically based cognitive impairments that interfere with adoption and maintenance of a healthy lifestyle. These impairments include mental retardation, senile dementias, Alzheimer's Disease, Traumatic Brain Injury, acute illness-induced cognitive impairments, HIV-induced cognitive impairments, AIDS dementia, drug-induced dementias, and attentional

disorders. As we enjoy the benefits of modern medicine and live well into our 80s, the likelihood that people will experience various cognitive limitations and the proportion of people so affected increases because of unhealthy aging, chronic diseases, and, for some people, reduced daily intellectual challenges. The aging demographics of today's society means that more people will (1) need help to maintain healthy lifestyles, (2) need continued medical attention, and (3) have some difficulty understanding that they need help, how and where to get this help, and how to put sound health-promoting advice into practice. An increasing source of cognitive limitations is the result of traumatic brain injuries (Wood & Rutterford, 2006). Traumatic brain injuries result from automotive accidents, falls, athletic collisions, and exposure to improvised explosive devices (IEDs). These injuries often have deleterious cognitive effects, including effects on executive function, organization skills, and memory. In the clinical realm, we need to screen for cognitive limitations to optimize the likelihood that people can understand what they need to do to engage in healthy lifestyles.

Motivational Limitations

It is relevant to consider how motivation may affect the adoption and maintenance of healthy lifestyles. Knowledge about nutrition, weight, exercise, long-term health, and the positive effects of taking various medications have little or no value for people who are apathetic or do not care about their current or long-term health status. Misunderstanding the importance of developing healthy lifestyles can undermine attempts by health care professionals and significant others to encourage the adoption and maintenance of a healthy lifestyle. Biopsychological conditions (fatigue, pain, depression, anxiety) can weaken motivations to practice a healthy lifestyle. Motivations are separate from behaviors and cognitions, which is an important distinction to make in order to understand how to increase motivations relevant to positive goals and to decrease motivations that interfere with positive goals.

Interestingly, the study of motivation was central to the discipline of psychology in the late 19th and early 20th centuries but was replaced in the mid-20th century with a focus on behavior per se. In the mid- to late 20th century, cognition slipped back in to psychology, but motivation still was largely set aside. In the late 20th century, behavior and cognition came together as cognitive-behavioral therapy, a surprising "marriage" for scholars and practitioners who had long considered these two approaches to be opposing and mutually exclusive. In the late 20th century and early 21st century, motivation has made a small comeback as a topic of study and construct for therapeutic intervention. Further, brain imaging studies have sought to determine which areas of the brain are active with particular emotions and motivations related to health, such as drug addiction, pain, and depression (Bär et al., 2007; Peyron, Laurent, & García-Larrea, 2000; Yücel et al., 2007). However, we believe that motivation remains a sleeping giant that must be awakened in the present biopsychological era of study and practice. With regard to healthy lifestyles, motivation is the engine that drives the relevant behaviors and cognitions and, therefore, deserves center stage for study.

Interference of Healthful Behaviors With Quality of Life

Restrictive diets designed to improve cardiovascular function (e.g., low-cholesterol diets), decrease the likelihood of cancer or diabetes (e.g., high-fiber or low-glycemic diet), or to help lose weight (e.g., diet with few sweet, high-caloric foods) promote health (Grunberg, 1987) but often are not enjoyable and may cause discomfort in some individuals who suffer from diet-related diseases such as celiac disease (i.e., gluten intolerance), lactose intolerance, or irritable bowel syndrome. Daily rituals (e.g., morning coffee, high-fat or high-cholesterol breakfast) may have biological actions to which we adapt, come to need, and enjoy. Undoubtedly, we miss such daily pleasures when they become unavailable. Perhaps the enjoyment associated with specific foods, such as salty or sweet foods, involves biologically driven hedonic preferences to consume foodstuffs needed by the body (Cabanac, 1971; Richter, 1943; Young, 1936, 1955). In this context, it is interesting to note that cigarette smokers prefer and consume more sweets after cessation of smoking (Grunberg, 1985, 1986a). Anecdotal reports indicate that similar phenomena accompany abstinence from habitual use of alcohol or narcotics. It has been hypothesized that the enjoyment derived from eating specific foods taps similar biological processes involved in the self-administration of some drugs of dependence (Grunberg & Baum, 1985; Grunberg & Klein, 1998b). Specifically, the unpleasantness associated with withdrawal from habitual drug use can be attenuated by the consumption of sweets and carbohydrates (Grunberg, 1986b; Grunberg & Baum, 1985). Whether or not this hypothesis linking drugs of dependence to food preferences is correct, it is clear that consumption of specific foods is enjoyable, that restricted diets are not, and that people often cheat on their diets.

In addition to eating, people enjoy drinking, smoking, and using "recreational" drugs. Consumption of alcohol, nicotine, marijuana, cocaine, Ecstasy, amphetamines, and other psychoactive drugs is reportedly enjoyable. These drugs have various effects and become desired by the users. Even when the health messages for these substances are well known (e.g., cigarette smoking is responsible for 400,000 deaths annually in the United States; driving while intoxicated can be lethal), individuals are motivated by the pleasurable effects of psychoactive drugs or by the discomfort of abstinence or withdrawal and, therefore, continue to self-administer rather than adopt more healthful behaviors.

Cigarette smoking is the single most preventable cause of premature death and illness (Centers for Disease Control and Prevention, 1993, 2006; U.S. Department of Health & Human Services, 1988). The health message is clear: do not smoke. Quitting smoking, however, is far more difficult than this simple health message leads us to believe. Use of tobacco products is an addictive behavior that involves powerful psychological and biological reinforcers. Consequently, asking habitual smokers to abstain from smoking requires the cessation of self-administration of an addictive pharmacological agent, namely nicotine. Smoking cessation results in irritability, anxiety, sleep disturbances, difficulty concentrating, and body weight gains (Grunberg & Bowen, 1985; Shiffman, 1979). These biologically based abstinence effects are powerful obstacles to adopting and maintaining a healthy lifestyle. In addition, abstinence means that the ex-smoker no longer will receive the effects of nicotine that

are considered positive, such as decreased body weight, focused attention, and stress modulation.

Other abused substances, including alcohol, opiates, and sympathomimetics (e.g., cocaine, methamphetamine), similarly have biological effects that are reinforcing and abstinence effects that are unpleasant. Therefore, abstinence from use and abuse of these substances is hindered by biological obstacles, and it is important that health care providers and significant others become aware of the consequences of abstinence.

Moreover, some substances (e.g., alcohol, some tranquilizers), when used in excess, reduce motivation or competence to comply with instructions involving other healthful behaviors. Prodding, coercion, scare tactics, and hinting are minimally effective in changing a dazed, addicted individual into someone who exercises, eats right, and takes medications on the appropriate dosing schedule.

Safe-sex practices are another example of healthy behaviors that interfere with biologically based enjoyment. Sexual intercourse with condoms and abstinence from sexual intercourse are recommended to decrease the likelihood of transmission of HIV and sexually transmitted diseases (STDs). Safe-sex practices, however, may decrease or prevent sensuality and pleasures of sexual intimacy. They also take time and planning, which can interfere with intimate, arousing moments.

Medication schedules also can interfere with biologically based enjoyable behaviors. Some medications require administration during the night or during a sleep period. Other medications require administration either an hour before or 2 hours after a meal. These modifications or inconveniences pit the health-promoting behavior against a biologically necessary state. In addition to medication dosing schedules, some drugs are associated with behavioral restrictions that many people find enjoyable or necessary. For example, medications that are accompanied by the instruction "Do not operate a motor vehicle or other large equipment" can be a nuisance that interferes with pleasures and conveniences, or this instruction can interfere with one's livelihood. Instructions to avoid strenuous activities (e.g., physical activity, exercise, lifting, sexual activity) can interfere with jobs, hobbies, and general enjoyment. The development of long-acting drugs to enhance patient adherence are coming into the forefront of preventive medicine. For example, there have been tremendous advances in medications to treat osteoporosis, ranging from sodium alendronate (Fosamax®) and risedronate (Actonel®), taken once a week, to ibandronate (Boniva®), taken once a month, to the newly available bisphosphonate zoledronic acid (Reclast®), administered as a single, 15-minute, intravenous infusion once a year. Medications that are taken less frequently may help improve adoption and maintenance of a healthy lifestyle by minimizing the impact on quality of life.

In all of these cases, the interference of healthful behaviors with enjoyable behaviors is not insurmountable. However, the incompatible relationship of these behaviors and the intensity of the pleasures that are lost must be addressed by the health care provider and cannot be ignored. For example, most people agree that safe-sex practices are important. However, the decreased pleasure and inconveniences associated with abstinence or condom use may offset concerns about STDs or AIDS, especially when the likelihood

of contracting these infections is viewed as being minimal. In order to optimize adherence to healthful behaviors, the balance between biological and psychological aspects of the healthful behaviors, with their impact on quality of life, needs to be addressed.

Unpleasant Side Effects of Treatments to Enhance a Healthy Lifestyle

When a healthful behavior is physically unpleasant or painful or causes discomfort, people are less likely to adhere to the healthful behavior. This category includes unpleasant biological side effects of nonmedicinal treatments; prescription medications; over-the-counter (OTC) medications; drug interactions with alcohol; and drug-drug interactions.

Nonmedicinal Treatments

Rehabilitation medicine has expanded dramatically in the United States over the past 25 years, and the role of physical and alternative therapies in medical treatment has earned respect. Unfortunately, physical therapy has a variety of effects that can be considered to be unpleasant biological effects (or psychobiological actions) that deter compliance. For example, an individual who was rear-ended in rush hour traffic and suffered whiplash and minor apparent bruises now receives muscle relaxants, analgesics, and several months to several years of physical therapy. This therapy may include traction, muscular and neural electrical stimulation, heat and cold packs, specific exercise routines, deep-muscle manipulation, muscular ultrasound, stretching exercises, and spinal disc manipulation. Although this therapeutic adjunct to pharmacotherapy is valuable and effective, it may hurt and has effects that can be characterized as biopsychological obstacles that may deter patients from compliance. Specifically, physical therapy can result in: headaches, numbness, nausea, muscle aches, muscle fatigue, pain, sleep disturbances, and a cascade of other physical discomforts, as physical therapy and manipulation has a domino effect on other, presumably uninjured, parts of the body. As with other aspects of compliance, predictability, identification of the cause of problems, understanding of the time course or duration of discomfort, and communication among the health care team of physicians, other health care specialists, and patients all are likely to encourage maintenance of the behaviors that will help to restore or to optimize health.

In addition to physical therapy, there are other nonmedical treatments that result in discomfort and may act as biopsychological obstacles to compliance with a particular treatment or lifestyle change. For example, surgeries that are not required for survival are, indeed, unpleasant and frightening episodes that we all would prefer to avoid. Even when we become convinced that the benefits of surgery outweigh the risks, we also become aware of the impact of surgery on our comfort and regular routines. When we know someone who has gone through a similar experience and who reports being bedridden for weeks or who reports the resultant pain and discomfort, we often can come up with reasons to put off that procedure just a bit longer. Communication from health care providers that is credible in reporting the unpleasant side effects, yet that

presents a convincing rationale for the benefits of the procedure can go a long way to surmount the biopsychological obstacles. Perhaps health care providers who are faced with such obstacles that obstruct the best treatment procedures should consider the value of adopting a convincing and concerned advocacy position, rather than an authoritarian posture or a seemingly disinterested style. Moreover, the involvement of supportive significant others may help people to make sound decisions that will optimize long-term health.

Even rather innocuous changes, such as exercise and healthful dietary changes, may result in discomfort for individuals and, thereby, act as biopsychological obstacles. In these cases, anything that can be done to make the healthful behaviors accessible, positive, and rewarding would help. Enhancement of motivation is likely to help with compliance, particularly when the consequences may be uncomfortable.

Prescription Medications

Pharmaceutical houses certainly aim to develop and market drugs with the widest possible therapeutic range and the fewest and weakest unpleasant side effects. Unfortunately, many therapeutically effective and lifesaving drugs have unpleasant biopsychological effects that deter people from taking their medicine. These side effects range from mildly irritating to almost debilitating.

Unpleasant biopsychological effects of drugs that could interfere with adherence to drug-taking therapies become clear when one consults the *Physicians' Desk Reference* (2007) or reference books about pharmacotherapeutics (e.g., Brunton, Lazo, & Parker, 2006; Julien, 2005; Katzung, 2007; Melmon, Morrelli, Hoffman, & Nierenberg, 1992). There are many unpleasant side effects associated with a variety of drugs. For example, tricyclic antidepressants can cause hallucinations, disorientation, delusions, anxiety, restlessness, numbness and tingling in the extremities, lack of coordination, muscle spasms or tremors, seizures, confusion, convulsions, dry mouth, blurred vision, constipation, inability to urinate, rash, itching, sensitivity to bright light or sunlight, retention of fluids, fever, allergy, nausea, vomiting, loss of appetite, stomach upset, diarrhea, sleep disturbances, panic, black coloration of the tongue, yellowing of the eyes or skin, perspiration, frequent urination, dizziness, weakness, headache, and loss of hair. No wonder that a patient might not comply with this medication regimen.

Lifesaving antineoplastic drugs can cause many unpleasant side effects that can interfere with a patient's willingness to undergo cancer chemotherapy, including nausea and vomiting, peripheral neuropathies, cerebral blindness, loss of taste and hearing, and seizures (e.g., cisplatin or Platinol®); leukopenia, anemia, anorexia, nausea, vomiting, and diarrhea (e.g., cyclophosphamide or Cytoxan®); pain, scarring, diarrhea, anorexia, nausea, vomiting, and contact dermatitis (e.g., fluorouracil or Efudex®); or hepatotoxicity, cirrhosis, fetal death, anemia, leukopenia, thrombocytopenia, diarrhea, ulcerative stomatitis, nausea, vomiting and anorexia (e.g., methotrexate, formerly Amethopterin®). No wonder a patient might fail to completely follow a regimen of even a lifesaving drug.

Drugs taken to improve cardiovascular function can manifest a variety of unpleasant effects. For example, digitalis can cause abdominal discomfort, pain, and headaches; hydralazine can cause headaches, angina, myalgia, or chest pain;

methyldopa can cause diarrhea, blurred vision, dizziness, impaired concentration, and nightmares; propranolol can cause insomnia or sexual impairment; and metoprolol can cause fatigue and dizziness. These side effects can become obstacles to adherence to prescribed pharmaceutical regimens, especially in individuals whose condition is asymptomatic (e.g., hypertension).

Anti-HIV medications, such as nucleoside reverse transcriptase inhibitors (e.g., Truvada® [emtricitabine and tenofovir disoproxil fumarate]) and synthetic nucleoside analogues (e.g., Retrovir® [azidothymidine, AZT], Hivid® [zalcitabine, ddC], Videx® [didanosine, ddI], Zerit® [stavudine, d4T], and Epivir® [lamivudine, 3TC]), slow the progression of HIV disease but do not cure AIDS. Long-term use of several of these drugs can result in debilitating peripheral neuropathies, severe pain, and general toxicity (Berger et al., 1993; Border & Arcane, 1990; Cherry et al., 2006; Dubinsky, Arcane, Dalakas, & Border, 1989; Merigan Skowron, & ddC Study Group, 1990; Nolan & Mallal, 2004; Simpson, 2002; Youle, Osio, & ALCAR Study Group, 2007).

Over-the-Counter (OTC) Medications

The over-the-counter (OTC) pharmacopeia is becoming more and more impressive every day. This development helps keep prices down and makes medications more available but often makes the medicines seem like nonmedicines and the condition seem like a nonmedical condition. These medications, including bronchodilators, cough suppressants, antihistamines, painkillers, sleep aids, mild sympathomimetics, and treatments for yeast and fungal infections, can mask biological symptoms that otherwise would motivate individuals to seek medical attention. This desirable effect of treatment, therefore, can have the paradoxical effect of deterring patients from seeking and adopting health-promoting actions. Conversely, these medications, in some cases, can have side effects (e.g., gastrointestinal irritation, dermatologic irritation, sleep disturbances, tachycardia) that can be categorized as biological or biopsychological obstacles to compliance.

Drug Interactions With Alcohol

In addition to nonprescription medications, alcohol must be considered as a nonprescription drug that can interact with other drugs and medications to cause untoward side effects. It is noteworthy that negative interactions can occur with the use, not necessarily abuse, of alcohol. For example, many drugs that otherwise have a wide therapeutic range with few side effects cause serious problems when taken along with alcohol. Alcohol with antianginal drugs (e.g., nitroglycerin) results in hypertension, dizziness, and syncope; alcohol with anticoagulants (e.g., Coumadin®, dicumarol, Panwarfin®) alters the anticoagulant action depending on whether there is acute or chronic alcohol ingestion. Alcohol with antidiabetic drugs (e.g., Glucophage® [metformin], Prandin® [repaglinide], Orinase® [tolbutamide]) results in unpredictable blood sugar, disulfiram-like reactions, and angina pectoris; alcohol with antihypertensives has an additive hypotensive effect; alcohol with antitubercular drugs (e.g., Isoniazid, rifampin) decreases the therapeutic response and increases the likelihood of hepatotoxicity; alcohol with salicylates (e.g., aspirin) leads to gastrointestinal

bleeding. Alcohol plus some antibiotics (e.g., cephalosporins, furazolidone) produces disulfiram-like reactions. Alcohol self-administration with benzodiazepines can contribute to adverse side effects such as vomiting and nausea.

Drug–Drug Interactions

Drug-drug interactions (involving substances besides alcohol) can be dangerous or unpleasant. Administration of OTC nonsteroidal anti-inflammatory drugs (NSAIDs) like ibuprofen (Advil®) with concomitant administration of certain antineoplastics (e.g., methotrexate) can cause unexpected, sometimes fatal, bone marrow suppression and gastrointestinal toxicity. Even simple antacids can potentiate the effects of anticholinergics; inhibit the actions of anticoagulants; and potentiate the effects of antihistamines, antimalarials, and bronchodilators (e.g., albuterol or Proventil®, beclomethasone dipropionate or Vanceril®). Nicotine (other than that derived from tobacco products) now is a prescription and OTC medication that can interact with other drugs. Nicotine is the active pharmacological agent in several smoking cessation aids (e.g., nicotine polacrilex gum, nicotine patch, nicotine nasal spray, nicotine lozenge) and is being tested as a medical agent for the treatment of several disorders (e.g., Parkinson's Disease, Gilles de la Tourette's Syndrome, Attention Deficit Disorder With and Without Hyperactivity, Parkinson's Disease, Alzheimer's Disease). Nicotine is a powerful sympathomimetic that affects catecholamines, indoleamines (including serotonin), sex hormones, pro-opiomelanocorticotropin hormones (including the endogenous opioid peptides), insulin, and other neurochemicals and hormones. There can be drug-drug interactions between nicotine and other medications that can result in uncomfortable effects and affect compliance.

There are many other undesirable side effects of drugs. This list is meant to provide an illustrative rather than a comprehensive review of biological and biopsychological effects that are unpleasant enough to become obstacles to compliance and adherence, particularly when weighed against the salience to the individual of the benefits of the given drugs.

Common Biopsychological Obstacles

This chapter purposely focuses on biopsychological obstacles to healthy lifestyle that may not be obvious and that, in our opinion, receive too little research, clinical, and public health attention. A discussion of biopsychological obstacles to a healthy lifestyle also must emphasize the most common health-relevant behaviors that involve biopsychological mechanisms: tobacco use and eating.

Despite the well-documented and well-publicized health hazards of tobacco use, roughly 20% of American adults continue to smoke tobacco cigarettes and even more use other tobacco products. It is clear that tobacco use involves biopsychological mechanisms, including nicotine addiction and reinforcement of behaviors, cognitions, and situations associated with tobacco use (Chaudhri et al., 2006; USDHHS, 1988; Wonnacott, Sidhpura, & Balfour, 2005). Tobacco use remains the single most important preventable cause of death and illness in the United States, but another behavior-related epidemic is close on its heels: obesity and excessive body weight. Today, almost 2/3 of Americans are obese or overweight, and the health risks of these conditions are staggering. Some

experts argue that we live in a "toxic food environment" (Bray & Champagne, 2005; Lustig, 2006) of high-caloric fast foods that encourage our excessive eating. Other experts argue that we use our cars too much, sit at computers and watch television too much, and do not exercise enough or engage in enough physical activity of other sorts. It is clear that we must control eating and increase activity if we are to tackle the growing problem of obesity. Although U.S. citizens today enjoy a better life expectancy than prior generations, they rank much lower than citizens of many other countries in life expectancy, despite a government that spends more money per person on health care than any other country in the world.

In the context of common biopsychological obstacles to healthy lifestyle, consideration of tobacco and eating should be broadened. Specifically, the study, prevention, and treatment of tobacco use also are relevant to the study, prevention, and treatment of other substance abuse (including alcohol, opiates, amphetamines, and so on). The study, prevention, and treatment of eating must include conditions of eating disorders (including anorexia nervosa, bulimia nervosa, and eating disorders not otherwise specified).

There is one other important topic that we categorize as a common biopsychological obstacle to healthy lifestyle: sleep hygiene and sleep disruption. We spend roughly 1/3 of our lives sleeping, yet this behavior has received too little research attention with regard to its impact on health. There has been a marked increase in the study of sleep and health recently, including dramatic data regarding the inverse relationship between hours of sleep on one hand and obesity, type II diabetes and a wide range of physical and mental health conditions on the other (Jennings, Muldoon, Hall, Buysse, & Manuck, 2007; Knutson, Ryden, Mander, & Van Cauter, 2006; Knutson, Spiegel, Penev, & Van Cauter, 2007). Sleep is a crucial topic of study in the context of biopsychological variables that affect healthy behavior.

Individual Differences

Genetics

Since 1990, there has been an explosion in knowledge about genetics and an increased emphasis on the importance of genetic contributions to health conditions. This development is relevant to the present topic in several ways. First, there are likely to be biologically based individual differences in susceptibility to each of the effects that we delineate throughout this chapter. For example, certain individuals are more likely to experience a given side effect of particular medications or in response to a behavioral treatment. Second, there are likely to be marked biologically based differences in the likelihood of developing pathophysiologic conditions, psychopathologic conditions, and biobehavioral conditions that can become obstacles to compliance. For example, certain individuals are more likely to develop obesity, senile dementias, mood disorders, or substance abuse. These biologically based differences in the likelihood of developing a particular condition can differentially contribute to the role of the condition as a biopsychological obstacle to compliance. Third, there are likely to be genetically based differences in the moderation or mediation of a given set of

variables (e.g., a given medication, dietary regimen, or physical activity) on the development of an adverse side effect, not simply because of individual differences in effect but because of individual differences in interaction. Fourth, there are ethical dilemmas that emerge as genetic mapping may allow prediction of probabilistic development of particular pathophysiologic conditions (e.g., cardiovascular disease, stroke, lung cancer, breast cancer, chronic obstructive lung disease, diabetes); biobehavioral conditions (e.g., obesity, anorexia nervosa, substance abuse, sleep disorders, AIDS); and psychopathologic conditions (e.g., depression, anxiety, obsessive-compulsive disorder, schizophrenia). For example, should we know what we are at risk of getting as a way to help us prevent the unwanted condition and to enhance our compliance with preventive measures and treatments? Or, does such knowledge give us excuses for developing these conditions and, thereby, act to deter compliance? At this point, this information may sound like science fiction, but the rate of information acquisition makes it all worthy of serious consideration.

We suspect that, within our lifetimes, we each will use our own genomic information to help determine the optimal pharmaceuticals that we each should take. We wonder if, within our lifetimes, we each will use our own genomic information to help determine the best strategies (i.e., behaviors, cognitions, and motivations) to optimize our healthy lifestyles.

Age and Gender

Most of the information relevant to this chapter is based on research, epidemiological data, and clinical reports focused on adults, both men and women. Age, of course, is relevant to biology, motivations, behaviors, cognitions, social interactions, and so on. In addition, women live longer than men. Therefore, it is reasonable to speculate that age and gender are relevant to the biopsychological obstacles to adoptions and maintenance of a healthy lifestyle. We know that appetites and taste preferences differ in children, middle-aged adults, and elderly adults and between men and women. We also know that physical ailments, recovery from injury, experiences of pain, and sleep patterns differ according to age and gender. We know that most if not all of the topics discussed in this chapter are affected by age and gender. We do not, however, have a clear and complete understanding of this information or how to use what knowledge we have to tailor enhancement of a healthy lifestyle to each age and gender group.

Ethnic, Cultural, and Socioeconomic Variables

Perhaps the most important topics that need increased attention are ethnic and cultural variables that affect healthy lifestyles. The health disparities that currently exist based on ethnic, cultural, and socioeconomic variables are truly disturbing (Seeman & Crimmins, 2001). Some of these disparities are understandable, such as lack of money to pay for health care and lack of transportation to travel to health care professionals. However, these logistical issues do not account for the extreme disparities that exist (Crimmins, Kim, Alley, Karlamangla, & Seeman, 2007).

Conclusions

Biopsychological obstacles are important and must be considered if we are to make headway in increasing the adoption and maintenance of behaviors that can lead to a healthy lifestyle and an improved quality of life. Over the past 20 years, there has been an impressive increase in knowledge about biopsychological obstacles that affect health. In this chapter, we categorize these obstacles in ways to help focus understanding, research, and therapeutic intervention. In light of the increased attention to these topics in the research, clinical, and public health literatures, we are optimistic that biopsychological obstacles can be surmounted. We hope to encourage increased research, clinical, and public health attention to these topics.

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Adolescent Tobacco Use and the Social Context

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The slowing decline of adolescent smoking rates continues to prompt the need for the development of even more robust prevention programs (Eaton et al., 2006). In the United States, a primary public health response to adolescent to-bacco use has been school-based prevention programs. Data from evaluations of these programs suggest that their effects have been generally modest in the short term and uncertain in the long term (Glynn, 1989; Rooney & Murray, 1996; Thomas & Perera, 2006; U.S. Department of Health and Human Services, 1994). A notable exception is a 6-year longitudinal evaluation of a school-based program in 56 schools that presented the first encouraging news about the long-term efficacy of a model school-based intervention. In this study, the investigators found that smoking rates were 15%–25% lower in the interven-tion group (Botvin, Baker, Dusenbury, Botvin, & Diaz, 1995). Unfortunately, such

high-quality programs have limited national dissemination. More commonly, schools around the country routinely implement untested or ineffective programs.

In a review of school-based programs, only modest evidence for a positive long-term impact was found (Thomas & Perera, 2006). In this review, among all interventions marked as high quality, only one scored high on both intervention quality and methodological rigor of the evaluation (the Hutchinson Smoking Prevention Project, or HSPP) (Peterson, Kealey, Mann, Marek, & Sarason, 2000). This large trial was well implemented and sufficiently powered and followed participants for 2 years after they left school. The study did not find evidence that the intervention influenced smoking prevalence, either immediately after leaving school or at the follow-up. Thomas and Perera (2006) examined the results of successful interventions pooled with interventions that were not successful (e.g., HSPP), and the end result was a beneficial, but not significant, effect on smoking behavior in the short and long terms.

The discrepancies between pro-health concepts taught in school-based prevention programs and the pro-smoking messages that youth observe and experience firsthand in their communities contribute to adolescent tobacco use. Preventing adolescent tobacco use is not simply a matter of equipping individuals with peer-pressure resistance skills. Teaching resistance skills is an important component of a comprehensive intervention, but neglecting factors that engender peer norms is a strategic error and is an example of focusing on a mediating rather than an antecedent cause of the problem. The Master Settlement Agreement of 1998 provided an opportunity to target many of these factors by funding the development of comprehensive tobacco control programs. However, allocation of funds used for adolescent prevention programs has been modest at best (Jones, Austin, Beach, & Altman, 2007). Given the predominant focus of interventions currently employed, it is not surprising that adolescent tobacco use continues to be a problem.

An Ecological Approach to Tobacco Control

Adolescent tobacco use is a complex behavior, rooted in biological, social, environmental, historical, and cultural contexts. In this chapter, we focus on how environmental, policy, and interpersonal factors influence tobacco use and offer suggestions for preventing adolescent tobacco use. Our approach is influenced by ecological and systems theories. These theories view behavior as a function of the surrounding context. Articulation of an ecological approach has been provided by others writing in diverse disciplines (Binder, Stokols, & Catalano, 1975; Bronfenbrenner, 1977; Ennett et al., 2006; Kelly, 1966, 1971; McLeroy, Bibeau, Steckler, & Glanz, 1988; Rappaport, 1977; Stokols, 1992). At its most basic level, ecological theory posits that individuals and settings are mutually influential, that this influence occurs in subsystems at multiple levels of analysis, and that influence changes over time and settings. Ecological theory is thus guided by the principle that the whole is more than the sum of its parts and that behavior and environment are viewed as interdependent rather than independent (Wicker, 1979). Furthermore, an ecological perspective considers different levels of analysis like the layers of an onion, each system nested within another, with each system constrained both by the system it surrounds

and the system that surrounds it (Wicker, 1979). Central to this chapter are the implications for applying a social ecological perspective to design and implement tobacco control interventions. An interventionist committed to the ecological model would search for points of leverage at multiple levels of analysis in the sociocultural context and would use multiple approaches to change the behaviors.

Few studies of health behavior specify the sequence or causal linkages by which individuals influence, and are influenced by, the larger social context (Chuang, Ennett, Bauman, & Foshee, 2005; Ennett et al., 2006; Winett, King, & Altman, 1989). The ultimate goal of all interventions directed at tobacco-related behavior, regardless of the level of analysis, is to improve the health status of individuals, since individuals, not systems or environments, experience illness and health. The focus of macro-level interventions (e.g., increasing the tax on cigarettes) can also influence the actions that individuals take (e.g., not purchasing cigarettes). Similarly, a goal of many micro-level interventions (e.g., teaching worksite employees how to quit smoking) can influence actions taken at higher levels of analysis (e.g., implementation of a worksite smoking policy). There are interactional and synergistic connections among levels of analysis. The means by which individuals are reached and influenced, however, can vary as a function of the level at which one intervenes. In more cases than not, there is a reciprocity of influence between levels of analysis (Winett et al., 1989).

Cross-Disciplinary Research

In an effort to understand and intervene in adolescent tobacco use in multiple contexts, collecting and analyzing data at different levels of analysis are often required. This can be achieved through working with other fields or disciplines collaboratively (Maton, Perkins, & Saergert, 2006). Indeed, for future progress to be made on adolescent tobacco use, cross-disciplinary approaches will be needed. Within cross-disciplinary research, integrative research that spans across multiple disciplines can be viewed in three distinct forms: multidisciplinary research, interdisciplinary research, and transdisciplinary research (Stokols, 2006).

Multidisciplinary research occurs when researchers work independently from each other, concentrating on their field, to address a particular topic. Interdisciplinary research entails more communication and coordination among researchers, though the researchers remain committed to their discipline's perspectives and methods. On the other hand, transdisciplinary research is a process by which researchers work collaboratively to develop an integrative conceptual framework that incorporates, from the different disciplines, concepts, theories, and methods to address a shared research topic (Stokols, 2006). Recent developments in cross-disciplinary research have largely focused on the latter two forms.

Interdisciplinary research can present several challenges, including the fact that researchers often have different perspectives on design, measures, and the best analytic framework for addressing multiple levels of analysis; simply bringing together collaborators from multiple disciplines and community partners itself offers a challenge. Maton, Perkins, and Saegert (2006) identify

several factors that contribute to successful interdisciplinary research. Successful interdisciplinary research teams have good leadership (shared mission and vision), good relationships among researchers (respect, commitment, and openness), and research questions that either are high-profile public issues or are problem focused, rather than theory focused. Individuals within successful teams are usually passionate, committed, willing to invest time for collaboration, and able to constructively negotiate conflicts or disagreements. External factors that facilitate successful interdisciplinary research include supportive organizational contexts, consistent external funding, and physical proximity of the team (Maton et al., 2006).

Transdisciplinary research has been offered as a solution to some of the challenges that interdisciplinary research has faced (Smith, 2006). Transdisciplinary research collaborations aim to produce shared and integrated conceptual formations (Stokols, 2006). In fact, several federal agencies and private organizations, including the National Institutes of Health and the Robert Wood Johnson Foundation, have invested in establishing transdisciplinary research that focuses on different societal problems, such as substance use, obesity, and smoking. The success of these collaborations will depend on the extent to which they promote the development of common, shared conceptual frameworks that integrate and extend concepts, theories, and methods from different fields (Stokols, 2006).

The Environmental Context of Tobacco Use Policy

Tobacco control policies not only work independently to reduce smoking by youth but can also interact with other social resources, including community, peer, and family influences. Policy can act to remove individual choice in smoking behavior, such as by prohibiting smoking in certain areas. In addition, the awareness of such policies can serve as a source of education on the harmful effects of tobacco use and can even influence the stigmatization of smoking in general. In particular, cigarette prices, youth access laws, clean air laws, and the Master Settlement are factors that have reduced the rates of smoking among the young.

Prices

Much of the research on tobacco control policies has centered on increasing cigarette prices through excise taxes. Over 40 years, a tax increase of $1.00 has the potential to reduce the smoking rate by 30% and the number of premature deaths by 17% (Levy, Cummings, & Hyland, 2000). Higher cigarette prices can have indirect and direct effects on cigarette availability and on the decision to smoke (Liang, Chaloupka, Nichter, & Clayton, 2003). Price increases can affect smoking initiation and experimentation, as well as cessation (Tauras, 2004). Although increases in cigarette prices affect all smokers, adolescents are more sensitive to price, especially established adolescent smokers (Chaloupka, 1999; Liang & Chaloupka, 2002; Warner, 1986). Young men are more sensitive to price changes than are young women, regardless of race. However, young Black men are more price sensitive than young White men;

a 10% increase in price results in a 16.5% decrease in smoking prevalence among young Black men but only an 8.6% decrease among young White men (Chaloupka & Pacula, 1999).

Higher cigarette prices can affect other contextual factors, in particular, the availability of tobacco from social sources (Jones, Sharp, Husten, & Crossett, 2002). When the cost is high and obtaining cigarettes is more difficult, peers are less willing to share them (Chaloupka, 2003). Also, when prices are high, families may make it more difficult for adolescents to take cigarettes, and they experience a reduction in general smoking, as well (Chaloupka, 2003). Thus, increasing the price of cigarettes on tobacco is an effective tobacco control intervention.

Youth Access Laws

Youth access laws are newer than other tobacco control policies and include minimum-age laws, bans on self-service displays, and license revocation for vendors who continue to violate these laws (Liang et al., 2003; Woollery, Asma, & Sharp, 2000). In 1992, Congress mandated that every state and territory must legally prohibit the sale of tobacco to minors by 1994 (U.S. Department of Health and Human Services, 1995). This federal law also mandates random, unannounced checks every year. Unfortunately, many states are not in full compliance with these laws (DiFranza, 2005; DiFranza & Rigotti, 1999).

If enforcement of tobacco sales laws is done right, it can have a major impact on adolescent tobacco use (DiFranza, 2000, 2005). If the enforcement is effective, access and availability are curtailed, leading to a reduction in smoking. There have also been discussions and recommendations to increase the legal minimum age for smoking to 21 (Ahmad, 2005). As with higher cigarette prices, there are direct (e.g., limited access) and indirect (e.g., reduction in smoking by peers) influences on adolescents' likelihood of smoking. As is the case for intervening across several contexts, combining youth access laws with increased taxation and other policies aimed at reducing adolescent smoking is likely to be most effective.

Clean Air Laws

There are health risks associated with exposure to secondhand smoke or environmental smoke, especially for nonsmokers and children. The vast majority of the states (49 plus the District of Columbia) has consequently adopted clean indoor air policies. These laws typically prohibit smoking in schools, public transportation, shopping malls, retail stores, workplaces, restaurants, and bars (Liang, Chaloupka, Nichter, & Clayton, 2003). Clean air laws have not been in place long enough to yield conclusive results, though there is some early evidence of their effectiveness (Abrams et al., 2006). In addition, some data have shown that clean air laws account for a small percentage of the success of tobacco control policies (Levy, Hyland, Hibgee, Remer, & Compton, 2007; Levy, Ross, Powell, Bauer, & Lee, 2007). Clean air laws likely operate through more indirect influences, such as by stigmatizing and changing social norms of smoking. Thus, changes due to clean air laws may occur at a slower pace, and, therefore, the effects of clean air laws will take longer to observe.

Master Settlement Agreement

In November 1998, attorneys general for 46 states, the District of Columbia, and five U.S. territories signed the Master Settlement Agreement (MSA) with the major tobacco companies (National Association of Attorneys General, 1998). The MSA required tobacco companies to pay more than $200 billion over the next 25 years in response to pending lawsuits by states for health care costs from tobacco-related illnesses. In addition, the settlement included restrictions on marketing and advertising tobacco to youth. Funds were also made available to support a national antismoking campaign targeted at youth.

While the MSA was intended to incentivize states to use funds for preventing and reducing tobacco use, especially among youth, allocation of funds for this purpose has been limited. In 2000 and 2001, 43% of the funding was allocated to general health care and only 9% to actual tobacco-related measures (Pollack & Jacobson, 2003). In North Carolina, in the period 2000–2004 the percentage of funds that went to youth tobacco use prevention and cessation programs was only 9.6%. When diverted funds and payments to tobacco quota owners and growers are included, this drops down to 2.3% (Jones, Austin, Beach, & Altman, 2007). The Centers for Disease Control and Prevention (CDC) developed tobacco control program guidelines, which require about 20%–25% of the state's settlement funds. Unfortunately, only four states (Arkansas, Delaware, Maine, and Mississippi) are at the minimum levels set forth in the guidelines. The sale of cigarettes decreased in states that spent more money on comprehensive tobacco control programs (Farrelly, Pechacek, & Chaloupka, 2003). If states had spent the CDC's minimum recommended funding between 1999 and 2000, it is estimated that the prevalence of smoking among the young would have been between 3.3% and 13.5% lower than what was observed (Taurus et al., 2004).

Despite these obstacles, the MSA has led to several public health achievements. First, there have been major changes in social norms by youth. The "Truth Campaign," a product of the American Legacy Foundation funded by the MSA, changed adolescents' beliefs and attitudes towards the tobacco industry (Hersey et al., 2005a). There are also fewer environmental visual cues such as billboards and sporting event sponsorships. Paraphernalia designed to attract youths' attention to smoking and cartoon figures, such as Joe Camel, are practically nonexistent. The removal of such cues to smoking and the encouragement of antismoking attitudes are large steps in the right direction. Nationally, tobacco control efforts have succeeded in changing public policy, influencing public attitudes and social norms, and encouraging discourse on tobacco use (Pollack & Jacobson, 2003). Policies can increase public awareness of the effects of secondhand smoke and thereby motivate families and parents to be more involved in antismoking socialization (Chaloupka, 2003).

Marketing

Expenditures

Tobacco company marketing expenditures increased rapidly in the past few decades, climbing from about $261 million in 1964, to $491 million in 1975, to more than $9 billion by the year 2000. During the mid-1990s, expenditures

increased by almost $1 billion each year. In 2003, the amount spent on cigarette advertising and promotion exceeded $15 billion dollars. This represents a 35.0% increase from 2001 ($11.2 billion) and a 21.5% increase from 2002 ($12.5 billion) (Federal Trade Commission, 2005).

Effects on Adolescents

There is some evidence of an association between attention and participation in promotional campaigns and susceptibility to tobacco use (Altman, Levine, Coeytaux, Slade, & Jaffe, 1996). Altman and colleagues found that when an adolescent was aware of tobacco promotions, the predicted odds that that adolescent was a tobacco user or was susceptible to tobacco use were two times greater than those for an adolescent who was unaware of promotions. When an adolescent was aware of promotions, had an adolescent friend who owned a promotional item, had received tobacco, and had participated directly in a tobacco promotional campaign, the odds of becoming a smoker increased to about 22 (Altman et al., 1996). Pierce and colleagues (2005) found that curiosity and susceptibility to smoking were independently associated with smoking initiation; adolescents reporting curiosity about smoking were more likely to become susceptible to tobacco use, a factor that has often been viewed by advertising theorists as an intermediate goal to encouragement. Similarly, candy cigarette use in youth has been found to be associated with increased risk of smoking as adults (Klein, Thomas, & Sutter, 2007).

After a thorough review of the evidence, the FDA concluded that there was substantial quantitative and qualitative evidence supporting a causal relationship between tobacco product marketing and adolescent tobacco use. Likewise, the FDA suggested that there was strong evidence supporting the efficacy of antismoking media campaigns (Food and Drug Administration, 1995). While, in 2000, the U.S. Supreme Court ruled that the FDA does not have the legal authority to regulate tobacco, other studies have continued to demonstrate the link between marketing and adolescent smoking (cf. Wakefield, Flay, Nichter, & Giovino, 2003).

Evaluations of established antismoking media campaigns in California, Massachusetts, and Florida have shown that the campaigns do reduce smoking in adults and adolescents (Hersey et al., 2005b; Institute of Medicine and National Research Council, 2000; Sly, Heald, & Ray, 2001). California was the first U.S. state to have an ongoing comprehensive tobacco control program. Evaluations of the campaign demonstrated that children in grades 4–12 who participated had an increase in recall of the media campaign, more unfavorable attitudes toward smoking, a decrease in intention to smoke, and a decline in 30-day smoking prevalence (Popham, Potter, & Hedrick, 1994). Similarly, evaluations of antismoking campaigns in Massachusetts, which had the highest level of per capita funding in 1993, and of the "Truth" Campaign, launched in Florida in 1998, showed that both led to high recall of antismoking advertising and subsequent reduction in adolescent smoking (Harris, Connolly, Brooks, & Davis, 1996; Sly et al., 2001). Other evidence has shown that the impact of antismoking campaigns on adolescent smoking can be seen when funding for such efforts is cut. In 2003, when Minnesota's successful campaign was defunded, trends in measures of susceptibility to smoking, attitudes toward smoking, and intentions

to smoke changed in the same direction that would increase risk for smoking, showing that discontinuing successful campaigns can have a negative impact (Sly et al., 2001). Overall, as a result of the MSA, significant tobacco product marketing aimed at youth has been curtailed.

Media Practices Affecting Modeling of Smoking

The portrayal of tobacco use in the mass media may play a role in the way that adolescents perceive social norms about use. In a sample of the top 20 highest-grossing films from 1990–1996, an average of 5 minutes per film involved a tobacco-related incident, of which only 43 seconds involved an antismoking message (Stockwell & Glantz, 1997). Movie stars may have the potential to be seen as role models because their behavior on screen and in real life is highly visible; it has been shown that having a favorite movie star who smokes increases teens' susceptibility to becoming smokers themselves (Distefan, Gilpin, & Sargent, 1999). In an experimental study assessing how on-screen smoking might influence young viewers (Pechmann & Shih, 1999), researchers compared the responses of 9th-graders to movies with and without smoking scenes. Movies with smoking scenes positively aroused the young viewers, enhanced the perception of a smoker's social stature, and increased their intent to smoke. Interestingly, if the young viewers were shown an antismoking advertisement before seeing the movie, these effects were nullified (Pechmann & Shih, 1999). While tobacco use is less frequent on television than in movies, there is evidence that depictions of smoking increased during the 1990s (Hazan & Glantz, 1995). Tobacco use also is recounted in music videos and lyrics. One study found tobacco use mentioned in 12% of country music videos and in 26% of videos on MTV (Durant, Romes, Rich, & Allred, 1997). The promotion of cigarettes in movies, on television, and in videos is planned and strategic, rather than coincidental. While the effects of these exposures on actual tobacco use behavior are difficult to assess, they contribute, in conjunction with other advertising and promotional strategies, to the idea that tobacco use is desirable.

Access to Cigarettes by Minors

Although most states have laws regulating tobacco sales to minors, these laws are rarely enforced (Food and Drug Administration, 1995; Inspector General, 1995; USDHHS, 1990, 1994, 1995), and minors have little trouble obtaining tobacco. A national survey representative of students attending school found that more than 76% of 8th-graders and 90% of 10th-graders believed that it would be "fairly easy" or "very easy" for them to obtain tobacco (Johnston, 1995). While over-the-counter access to cigarettes has been increasingly difficult for adolescents in recent years, there is some evidence that shoplifting and "bumming" cigarettes can be other sources for minors, especially among early adolescents (Cismoski & Sheridan, 1994; DiFranza, Eddy, Brown, & Ryan, 1995). Local laws restricting youth access to tobacco, including minimum-age laws and verification requirements, have been successful in the short term; long-term effects are still inconclusive (Chen & Forster, 2006). However, some researchers would argue that youth access interventions are simply not working (Craig & Boris, 2007; Fitchenburg & Glanz, 2002).

Access to cigarettes is a critical determinant of whether people (particularly children and adolescents) experiment with or maintain tobacco use. Since few smokers begin smoking after high school (Johnston, O'Malley, & Bachman, 1994), some begin even before high school (Johnston, O'Malley, Bachman, & Schulenberg, 2006), and the majority of adult smokers began to smoke at an early age, efforts to prevent the adoption of smoking must focus on preventing children and adolescents from becoming addicted. Limiting access to tobacco can contribute to prevention, but poor enforcement and advances in technology may be undermining recent achievements in tobacco control policies, including youth access laws.

Tobacco and the Internet

Stronger regulation and enforcement directed at those who sell cigarettes to minors and the imposition of consequences for such activities have made youth access to over-the-counter sources more difficult. One unintended consequence of this achievement is that youth may be more likely to use the Internet to obtain tobacco. When data on internet use in U.S. households were first collected in 1997, 18% of households reported having access (U.S. Census Bureau, 2004). Access more than doubled, to 41.5%, in 2000 and increased again to more than 50% in 2001. In 2001, approximately 65% of youth ages 10–14 and 68% of those ages 15–17 reported having access in the home.

The number of domestic Internet cigarette vendors has increased rapidly, from 88 in 2000 to more than 300 in 2005 (Ribisl, Kim, & Williams, 2001, 2007). In 2005, a total of 664 sites were identified, including those with domestic, international, and unknown vendor locations. The nature of the Internet makes it difficult to regulate and enforce youth access to tobacco. This is even more complex for vendors located in tribal lands and countries outside the United States (Ribisl et al., 2007). More than 75% of Internet cigarette vendors are estimated to advertise tax-free cigarettes (U.S. General Accounting Office, 2002). The sale of cheaper cigarettes is attractive to price-sensitive smokers, which includes adolescents and those who reside in high-excise-tax states (Ribisl et al., 2007; Turner, Mermelstein, & Flay, 2004). The availability of cheaper cigarettes may curtail the normal progression of price-sensitive smokers toward quitting or reducing tobacco use.

Adolescents are more responsive to price than are adults (Turner et al., 2004), which further reinforces the concern about youth access to cigarettes online. Several studies found that adolescents are capable of searching for and placing orders with tobacco vendors (often in under 20 minutes) and that more than 90% of them purchase products (Jensen, Hickman, Landrine, & Klonoff, 2004; Ribisl, 2003). Ribisl (2003) found that only 11% of the vendors asked for a copy of the buyer's photo ID for age verification. Even when ID was not provided, half of vendors still fulfilled the order. In 2005, 6.5% of 9th-grade smokers reported having bought cigarettes online, with 5.2% having bought cigarettes online in the past 30 days. The number of cigarettes bought by youth online in the past 30 days more than doubled between 2001 and 2005 (Fix et al., 2006). While a small proportion of youth smokers are currently buying cigarettes online, those who do are more likely to report difficulty in obtaining cigarettes from commercial and social sources (Ribisl et al., 2007). This suggests that, as

completing over-the-counter purchases becomes more difficult for minors, they will turn to online sources.

As part of an Institute of Medicine report, Ribisl and colleagues (2007) proposed a framework of multiple policy strategies and recommendations aimed at effectively regulating Internet cigarette sales to youth. The framework, Q.U.I.T. (Quarantine of Unhealthy Internet Trade), recommended regulating the supply of cigarettes to Internet vendors, blocking or seizing Web site domains of vendors that are noncompliant with tax laws and age verification, preventing the major payment-processing companies (e.g., VISA, MasterCard) from approving transactions, regulating delivery services, and educating consumers about tax requirements. Several of these strategies have begun to be implemented, with some positive effect. For example, several major credit cards have stopped approving Internet cigarette sales, and shipping companies such as UPS and DHL have ceased shipping cigarettes to consumers. These actions have started to reduce Internet cigarette sales, but more collaborative work is needed. While the number of youth smokers who buy cigarettes online is still relatively low, as for other consumer products, the Internet has become a major method for gaining access to products.

Family Socialization Processes

Tobacco use by children and adolescents may be influenced by socialization processes within the family. Parents can have both direct and indirect influences on tobacco use, for example by influencing adolescents' affiliation with peers who smoke (Simons-Morton, Chen, Abroms, & Haynie, 2004). Siblings can also have considerable influence on tobacco use, since those with siblings who smoke are more likely to smoke themselves. High levels of social connectedness between siblings further enhances the effect of a shared environment (Slomkowski, Rende, Novak, Lloyd-Richardson, & Niaura, 2005). Particularly important to consider are general parenting style and tobacco-specific parenting practices, both of which can predispose some children to engage in risk-taking behaviors.

Parenting style refers to the general child-rearing practices of parents. Developmental theorists have identified parental demandingness, responsiveness, and degree of warmth and acceptance as the key dimensions of parenting style (Baumrind, 1978; Roberts, 1986; Steinberg, Elmen, & Mounts, 1989). Each dimension is a composite of parenting behaviors; for example, demandingness refers to setting and enforcing clear standards of behavior; active monitoring and supervision of a child's activities; maintenance of structure and regimen in a child's life; and making demands for maturity consistent with the child's developmental phase. Parental responsiveness includes supporting a child's independence and individuality; relating to the actual child rather than to an idealized child; respecting a child's rights; and expecting the child to respect a parent's rights.

The authoritative parenting style, defined by both high levels of demands and high levels of responsiveness and warmth, has been associated with reduced tobacco use among children and adolescents. Adolescents whose parents are more authoritative are less likely to smoke than are adolescents whose parents are less authoritative (Chassin et al., 2005; Pierce, Distefan, Jackson,

White, & Gilpin, 2002). In addition, parents with authoritative parenting styles are more likely to have children who see them as influential authority figures regarding substance use (Jackson, 2002). Chassin and colleagues (2005) found that adolescents in homes with authoritative parents reported having significantly more tobacco-specific discussions than did those in homes with authoritarian parents (high on demandingness, low on acceptance).

A parent's role in socialization related to tobacco can take several forms. Parents' own tobacco use is an important predictor of their children's use (Foster et al., 2007; Murray, Kiryluk, & Swan, 1985; Nolte, Smith, & O'Rourke, 1983; Peterson et al., 2006). Children of parents who smoke may be receiving cues that unintentionally encourage them to smoke. Parents are encouraged to quit smoking while their children are young. However, research has shown that children of parents who practice antismoking socialization (e.g., by communicating strong antismoking messages, establishing household smoking bans, perceiving that they can influence their child not to smoke) can impact children's smoking behavior, despite the parent's own smoking (Conley, 2005; Harakeh, Scholte, de Vries, & Engel, 2005; Jackson & Dickinson, 2006; Turner et al., 2004). Through these and other socializing mechanisms, parents influence their children's perceptions of the prevalence, social acceptability, and personal and social consequences of tobacco use.

Parenting style and tobacco-specific parenting practices not only are associated with smoking initiation but also have implications for regular smoking among adolescents and for the persistence of smoking into adulthood (Turner et al., 2004). As such, it is important to intervene in tobacco use when children are young. Jackson and Dickinson (2004) found that small increases in the number of cigarettes consumed when children were young translated to a significantly higher likelihood of current, established, and daily smoking in adolescence. While some parents may be proactive in socializing their children against tobacco use, it is likely that the majority of parents view tobacco use as a problem of adolescence and thus remain passive during the children's early years. Importantly, a passive orientation is not devoid of a socializing effect. Baumrind, for example, posits that children often interpret parent passivity as tacit approval or lack of disapproval (Baumrind & Moselle, 1985). Thus, parents who do not actively challenge the many prosmoking influences to which their children are exposed may effectively allow these other social influences to take effect.

Summary

A theme of this chapter is that tobacco-related behavior and the settings in which such behavior occurs are interdependent. Recognizing this point will help tobacco control researchers and advocates focus both on the settings in which tobacco use is most encouraged and salient and on the individual tobacco-related behaviors that occur in these settings. The physical and policy environments are central influences on the beliefs and behaviors of individuals. It can be difficult, however, to develop interventions that effectively target the multiple levels of influence on specific tobacco-related knowledge, attitudes, and behaviors. Similarly, assessing the interrelationships and potential synergistic effects among these levels of influence is difficult. The critical issue is how behavior is

influenced by, and influences, multiple levels of analysis in a complex web of place and time. To address the need for multilevel analysis will require methodological advances. While the tools for measuring the social context of health phenomena are perhaps less developed than the tools for measuring psychosocial constructs, their development is essential if we are to develop an adequate understanding of contextual effects on health-related behaviors. Collaboration among social and health scientists in a search for complementary theories, concepts, and methodologies can assist in this endeavor.

Overall, few studies with a focus on the policy context of adolescent smoking incorporate micro-level factors such as community, family, and peer influences. Research that aims to examine multiple contexts, as well as their interaction, from a transdisciplinary perspective is needed. This would help to improve our understanding of the complex interaction of various influences on adolescent smoking, which would in turn help to inform the formulation of more effective policies and new prevention methods to reduce smoking among youth.

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Psychosocial Barriers to Adherence and Lifestyle Change

23

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Despite the implications for patients' well-being and the danger of poor health outcomes, nonadherence to treatment and lifestyle recommendations continues to persist. Why do many patients ignore health advice in the face of disease progression, worsening symptoms, and the waste of precious health care dollars? How can the seemingly irrational act of patient nonadherence persist?

Despite decades of research on patient adherence, there remain many unanswered questions about its causes and treatment. Adhering to even a relatively

simple medication regimen can be intimidating, and major lifestyle changes can be daunting as patients face challenges to the management of their daily lives and routines. While some barriers to adhering are practical and relatively straightforward, such as having limited funds to purchase expensive medication, other barriers are more nuanced and complex, involving psychological and social impediments to action.

Patient adherence generally refers to the degree of success a patient has in carrying out prevention or treatment recommendations offered by a health professional (e.g., a nurse or physician) (DiMatteo & DiNicola, 1982). Research suggests that failure to adhere is a widespread problem; between 25% and 40% of patients are nonadherent, depending upon the length and complexity of medical recommendations (DiMatteo, 2004a; DiMatteo, 1994a; Dishman & Buckworth, 1997).

Psychosocial Factors Affecting Patient Adherence

Decades of research on patient adherence have identified myriad correlates. Nearly every psychological, social, interpersonal, and contextual element of patients' lives has been found to bear some relationship to their ability to follow health lifestyle and/or medical treatment recommendations. These correlates tend to fall into three general categories that provide a simple template for organizing and analyzing research findings, and for guiding clinical care. Simply put, in order to adhere, patients need to *know* what they must do to care for themselves, *want* to take those actions, and be *able* to take the necessary steps toward adherence. Thus, cognitive, motivational, and resource-based factors influence adherence. Improving adherence requires the patient's knowledge and understanding of the medical recommendations, the desire and motivation to adhere, and the ability and resources to carry out the required behaviors (DiMatteo & DiNicola, 1982).

Instrumental Communication in Adherence

Knowledge and understanding of the health care regimen requires effective cognitive functioning and planning. Patients forget much of what is told to them in their medical visits; the anxiety and novelty of the medical situation can interfere with their retention of information. Often, patients do not initially understand their medical directives, and as they attempt to adhere their confusion may increase (Kravitz et al., 1993; Ley & Spelman, 1965). Patients' health literacy may initially determine their comprehension of what they are told, and the quality of communication in the physician-patient interaction can serve as a prominent and essential element in determining whether or not the patient can adhere to the medical recommendations offered. Good rapport and a trusting physician-patient relationship can determine whether patients ask essential questions and voice preferences that are likely to guide their health behaviors.

Knowledge and Understanding

The medical visit exchange requires knowledge and understanding of the process of medical care, including the initiation and management of recommended

treatments. It is vital, for example, that patients understand various aspects of the medical regimen, including dosage instructions, timing, and other treatment characteristics. When medical regimens and dosing schedules are complex and require habit and lifestyle changes, nonadherence can be as high as 70% (Chesney, 2000; Li, Brown, Ampil, Burton, Yu, & McDonald, 2000). Adherence to exercise, for example, can be as low as 19% (Kravitz et al., 1993).

Language barriers are associated with decreased patient adherence. Further, even when patients understand the *language* of their medical instructions, it can be difficult for them to comprehend the complexity of that information and precisely what is necessary for proper adherence (Williams et al., 1995). Likewise, a patient's beliefs about health and about treatment can influence how they adhere. Research has shown that patients on lifetime daily doses of medication such as antihypertensive treatments often believe that their medication need be taken only when they are symptomatic (Anarella, Roohan, Balistreri, & Gesten, 2004).

Studies indicate that patient satisfaction and adherence to regimen plans are related to the quality of information given and the patient's ability to comprehend it (Falvo & Tippy, 1988; Jolly, Scott, Feied, & Sanford, 1993; Krishal & Baraff, 1993). When patients are of low income, with little education, and have limited access to follow-up care, adherence may be in serious jeopardy. In the emergency department of an urban hospital, where patients were at risk for low adherence because of their limited understanding of treatment, one study found that cartoon illustrations effectively taught patients to properly care for themselves after release from the emergency department (Delp & Jones, 1996). Engaging and easily understood health information may be essential in the provision of information to patients toward the goal of adherence.

Cognitive Functioning, Planning, and Remembering

Planning and implementing the medical regimen can be a complex process requiring careful explanation, as well as scheduling, and tailoring the regimen to the patient's individual needs and circumstances. In a study of adherence to inhaled steroid use among asthmatic patients, direct clinician-to-patient feedback (i.e., constructive, positive discussion about the patient's adherence and problems adhering and information on techniques and strategies to improve adherence), significantly improved patients' adherence to their treatment (Onyirimba et al., 2003).

Recalling crucial information from a medical visit can be challenging, but it is essential that patients return home with a regimen plan they fully understand and have the ability to follow. Confusion about medication often leads to nonadherence, and patient distraction is a common cognitive factor that jeopardizes adherence. After leaving their provider's offices, patients may be able to recall only about 50% of the information given to them about their regimen (Ong, de Haes, Hoos, & Lammes, 1995). One reason may be that providers often speak in medical jargon and use technical medical language with which patients are unfamiliar, threatening patients' ability to understand and retain critical information (Jackson, 1992). Particularly when physicians operate under time limitations, they may fail to fully explain regimen details to their patients. Failure to ask patients to plan and rehearse the regimen in the presence of the physician can reduce the chances of patient adherence

(Stanton, 1987). Research has suggested the value of adherence-enhancing strategies such as additional treatment education and the use of adherence aids (e.g., medication lists, dosette boxes) (George, Kong, Thoman, & Stewart, 2005).

Patient Involvement

During the medical interaction, physicians may fail to take into account the patient's perspective on illness and thus fail to incorporate patients' explanations and concerns when reviewing presenting symptoms. Research has found that patients specifically mention their main concerns to their physicians in only 24% of all encounters (Korsch & Negrete, 1972). When patients are encouraged by their physicians to share their concerns and when physicians engage in active listening, use focused questions, follow up on patient cues, and engage patients in their interpretations of their conditions, patients tend to be more satisfied and reveal more adherence-relevant information to their providers (Lang, Floyd, Beine, & Buck, 2002).

Health Literacy

Limited literacy skills and poor understanding of spoken and written health information may be the larger and more problematic context in which nonadherence occurs, however (Davis et al., 1996, 1998; Williams et al., 1995). The concept of health literacy has gained considerable research attention in recent years and has broad effects on patients' adherence to treatment, as well as on healthy lifestyle practices. Health literacy can involve health knowledge and information about the body, disease, health risks, and the organization and functioning of the health care system, medical vocabulary, basic health concepts, and many other medically related issues; it is strongly related to overall literacy and can influence what happens with patients before they arrive at the medical visit. Health literacy affects the use of preventive measures such as screening and immunizations (Holloway et al., 2003; Lerman et al., 1992) and offers a context in which patients can interpret their symptoms and identify their need for medical treatment.

Health literacy can affect patient adherence at several points in the process of care, including visit preparation. It also touches on patient's skills and efficacy in identifying the details of precipitating events and symptoms and their reporting of actions they have taken to manage the condition. Health literacy affects patients' awareness of strategies available for risk avoidance and reduction, medical decision making, and participation in care, and it is essential for patient communication with the physician. Health literacy also influences how patients access health care information (e.g., through printed materials, Internet resources, or information and communication-technology resources) and media health issues to which patients attend (Eysenbach & Kohler, 2002; Query & Wright, 2003; Walters, Wright, & Shegog, 2006). Culturally competent health care contexts are also centrally important to adherence. Race, ethnicity, and language can affect the physician-patient relationship; minority patients who are not proficient in English are less likely to engender empathic communication from their physicians, are less likely to have good rapport with their physicians,

and are less likely to receive adequate health information and to be encouraged to ask questions and be more active in their care (Ferguson & Candib, 2002).

Low health literacy is likely to affect adherence in multiple ways before, during, and after the medical visit (Kalichman, Ramachandran, & Catz, 1999) and has been linked to poor physician-patient communication, depression, and the quality of patients' conversations with their physicians (Schillinger et al., 2003; Kalichman et al., 1999). Low levels of health literacy can exacerbate chronic disease by leading to poor management or failure to use preventive health measures (DiMatteo, 1994a; DiMatteo & DiNicola, 1982; Dunbar-Jacob & Sereika, 2001; Health Literacy, 2004; Shumaker, Schron, & Ockene, 1998). Patients who are low in health literacy may be less likely to understand the risks and benefits of their treatments, putting them at greater risk for nonadherence (Paasche-Orlow et al., 2005). Among asthma patients, inadequate health literacy and limited knowledge of self-management skills has been associated with having less knowledge of asthma and medications, as well as with less appropriate use of metered-dosed inhalers (MDI) by patients (Paasche-Orlow et al., 2005). With complex regimens, such as those required for HIV patients, those with low health literacy were at greater risk for nonadherence to combination antiretroviral (ARV) therapies (Kalichman et al., 1999). Such patients also tend to have greater difficulty in the management of their illness and in implementing physician directives about care. Adherence to preoperative surgery recommendations, while generally poor in the elderly population, is an even greater problem for patients with low levels of health literacy, who have greater difficulty deciphering instructions from their physicians and understanding information given to them in printed pamphlets (Chew, Bradley, Flum, Cornia, & Koepsell, 2004). The potential difficulties presented by nonadherence to preoperative instructions can include increased morbidity, delays in surgery, surgery cancellations, and even increased risk or operative mortality (Chew et al., 2004).

Research suggests that adherence to disease management strategies partially depends on patients' confidence in their ability to exercise management options. Low health literacy threatens essential aspects of patients' relationship to their illness, and, without the skills and efficacy to gather essential management information (e.g., by asking questions and communicating clearly with health care providers), patients may remain unaware of the strategies available to them for improved adherence. Inadequate access to medical information or to the health care system may lead patients to have difficulty following recommended instructions (e.g., follow-up appointments, visits to specialists) and to feelings of discouragement.

Physician Communication and Empathy

Effective communication in provider-patient interaction requires that a physician demonstrate empathy, understanding of patients' feelings, trust, and rapport with patients. If a provider attends to biomedical issues alone, neglecting patients' emotional needs, the therapeutic relationship may fail, threatening the interpersonal elements necessary for healing and positive outcomes. Trust, open communication between provider and patient, and interpersonal rapport have been associated with patients' greater willingness to seek care

and better adherence to treatment recommendations (Trachtenberg, Dugan, & Hall, 2005). Early research on adherence identified the physician-patient interaction as an essential element in care and found that adherence was enhanced both when patients were able to release tension in their interaction and when their questions received a response from the physician (Davis, 1968). Physician-patient rapport is essential to motivating patients to adhere (Jahng, Martin, Golin, & DiMatteo, 2005). Research findings demonstrate that patient satisfaction with physicians' *affective concern* is more important than patient satisfaction with physicians' technical competence in determining patients' commitment to treatment plans (Segall & Burnett, 1980). A provider's collaborative communication style influences treatment outcomes, including patient adherence, by enhancing the patient's knowledge of the medical regimen and by encouraging patients' commitment to and confidence in the regimen and their ability to follow it (Bultman & Svarstad, 2000).

Several interpersonal behaviors, both verbal and nonverbal, on the part of the physician have been found to foster patient outcomes such as recall of medical information and adherence to prescribed treatment (DiMatteo, 1994a). Verbal behaviors such as direct expressions of empathy, reassurance, support, patient-centered questioning, humor, psychosocial talk, health education and information-sharing, friendliness, and summarizing and clarifying the interaction have been associated with both patient satisfaction and adherence (Beck, Daughtridge, & Sloane, 2002). Likewise, nonverbal behaviors such as nodding the head, leaning forward, using a direct body orientation, uncrossing the arms and legs, placing the arms in a symmetrical position, and engaging in a limited amount of mutual gaze have been associated with patient satisfaction and adherence (Beck et al, 2002).

Adherence is greatest when patients feel that their expectations for the visit are being met and when providers elicit and respect patients' concerns and provide responsive information and feedback concerning the condition, diagnosis, method for treatment, and plan for adherence. Strategies for improved provider-patient communication may include ensuring that patients' health concerns are being addressed, taking patients' concerns seriously, asking questions of the patient and engaging in active listening, and determining the potential barriers that might impede the patient's knowledge and acceptance of the importance of the regimen. By taking steps toward improved patient health literacy and better provider-patient communication built on trust, respect, honesty, and integrity, health care providers can contribute directly to patients' adherence to their recommendations.

Motivational Elements in Adherence

Patients' motivations to adhere to lifestyle change and therapeutic regimens depend upon their health beliefs, perceptions, motivations, expectations about medical care and the health care system, and cultural values. Is the patient positive and optimistic or negative about treatment or recommended health behaviors? Does the patient believe that he can follow recommendations and fit those recommendations in with his lifestyle? And, is the patient willing to commit to behavioral changes and adopt new health behaviors and practices? Addressing these issues with patients and exploring their thoughts and beliefs about care may be essential to promoting patient adherence.

Patients' Perceptions: Health Beliefs, Attitudes, and Expectations

Patients' subjective health perceptions reflect their feelings, attitudes, and be-liefs about their health status and about health care; such factors can influence patients' health decisions and participation in health behavior change (Olfson, Gilbert, Weissman, Blacklow, & Broadhead, 1995; Sewitch, Leffondre, & Dobkin, 2004; Sherbourne, Hays, Ordway, DiMatteo, & Kravitz, 1992). Patients' beliefs about their condition can strongly influence their behavior, and providers must thoughtfully and thoroughly listen to patients' concerns if they are to have an influence on their beliefs (Becker & Maiman, 1980). In posttransplant care, for example, patients may develop a false sense of security due to improved immu-nosuppressive drugs. Unrealistic beliefs in the power of a medication to cure, rather than simply manage, a condition such as renal transplant may interfere with patients' rigorous adherence to their posttransplant regimen (Rodriguez, Diaz, Colon, & Santiago-Delpin, 1991).

Beliefs about medication, particularly about side effects, can also be robust predictors of patient adherence; lower adherence is reported among patients who believe that their medication causes problematic side effects (Horne & Weinman, 1999). Between 30% and 83% of patients who begin antidepressant medication discontinue treatment prematurely, often because of incorrect be-liefs about the value and the dangers of antidepressant medication (Aikens, Nease, Nau, Klinkman, & Schwenk, 2005). Patients' beliefs in treatment efficacy can also influence adherence. In a sample of Mexican-American women receiv-ing dialysis treatment, adherence was related to the perceived efficacy of the regimen required of them. Those who believed, because they experienced no ill effects, that their nutritional and fluid restrictions made no difference in their outcome were much less likely to adhere than were those who believed in the regimen's efficacy (Tijerina, 2006).

Patients' perceptions of and experiences with the health system can also influence their adherence to treatment and medical recommendations. In one study of ethnically diverse, economically disadvantaged patients with rheuma-toid arthritis and systemic lupus, nonadherence to treatment was correlated with patients' difficulties navigating the health care system and obtaining pub-lic funding (Garcia Popa-Lisseanu et al., 2005).

Physicians' understanding of their patients' health perceptions can have a positive impact on many health outcomes, particularly adherence (Chesney, Brown, Poe, & Gary, 1983; Starfield, Wray, Hess, Gross, Birk, & D'Lugoff, 1981; Stewart, McWhinney, & Buck, 1979). Physicians who seek to understand the health beliefs of their patients (such as those with HIV, who face the challenges of taking antiretroviral medications) and who educate their patients on the benefits of antiretroviral therapy can help improve their adherence (Schneider, Kaplan, Greenfield, Li, & Wilson, 2004). Strategies to improve adherence are most likely to be successful if they include attempts to modify patients' beliefs and percep-tions regarding medication effectiveness and to address patients' concerns and fears about the risk of side effects (Garcia Popa-Lisseanu et al., 2005).

Patients' Cultural Background

Patients' unique social contexts, ethnicity, and cultural backgrounds are cen-tral factors that affect their adherence (Freimuth & Quinn, 2004). In a study

of colorectal cancer screening, for example, researchers found that subjective norms, emotional support from family and friends, perceived behavioral control (over colorectal cancer screening), and perceived benefit of screening for colorectal cancer served to mediate the pathway from patients' contextual environment to adherence (Freimuth & Quinn, 2004).

Patients' cultural beliefs are often intricately tied to their health beliefs and illness perceptions; both personal and cultural beliefs influence medication taking and lifestyle changes (Gould, 1999; Rudd, 1993). Among elderly patients (over the age of 65 years), adherence can be less than optimal, often because of personal and cultural beliefs (Chia, Schlenk, & Dunbar-Jacob, 2006). African American older adults have been found to express more negative opinions or suspicions about their physician's recommendations than nonminority patients, and their distrust was found to relate to ethnic disparities in quality of care (Siegel, Karus, & Schrimshaw, 2000).

The Illness Behavior Model attempts to better understand the connections among patients' culture, health behaviors, and adherence (McHugh & Vallis, 1985). This model views an individual's response to illness as resulting from the dynamic interaction of factors clustering around four major dimensions: physiological, affective, cognitive, and phenomenological. These dimensions are shaped by the individual's ethnocultural context, within which day-to-day circumstances influence the individual's beliefs, norms, and experience of illness.

Central to adherence and health behavior change are the patient's motivation to follow medical recommendations, the belief that they are worth adhering to, and confidence in the ability to follow them. Overall, patients' health beliefs, attitudes, cognitions, health perceptions, expectations, and motivations can determine their success or failure with the regimen. Management of these elements of the patient's response to health care recommendations is a central task of the physician-patient relationship; thus, it is critical that health professionals listen to what their patients reveal about their motivations and establish treatment goals together with and individualized to their patient's needs and circumstances.

The Necessity of Resources

Resources, both practical and emotional, can strongly influence patient adherence to treatment; patients' socioeconomic status, education, and income can strongly influence their ability to follow through with health recommendations. Economically vulnerable patients, such as those at the poverty level, tend to be considerably less adherent than are patients with financial resources (Tijerina, 2006), and individuals in socially vulnerable subpopulations, such as the elderly, tend to be at increased risk of nonadherence (Balkrishnan, 1998). Limitations in emotional resources and the experience of stress, anxiety, depression, anger, guilt, and withdrawal can also impair a patient's ability to follow through with health behavior changes or to maintain necessary health behaviors (DiMatteo, Lepper, & Croghan, 2000). Social resources can also affect adherence. The degree and type of social support available to a patient is largely associated with the patient's ability to adhere. Without both practical and emotional support for following recommended guidelines for treatment, patients often have difficulty managing their illnesses (DiMatteo, 2004b).

Distressed Psychological States

Depression

Depression can thwart adequate adherence and improvements in health behavior for a number of reasons. Depression involves hopelessness and pessimism, making any positive action seem futile and undermining positive expectations about treatment efficacy (DiMatteo et al., 1993). Depression is also associated with social isolation and withdrawal from friends and family, limiting access to the social support that is essential to patient adherence (DiMatteo, 1994b; DiMatteo & DiNicola, 1982). Depression may also be associated with decreased cognitive functioning and diminished ability to concentrate, plan, and remember to follow through with recommendations and new health behaviors (Carson, Butcher, & Mineka, 2002). Mental health problems, particularly depression, are common among patients with serious diseases such as HIV and cancer and painful conditions such as arthritis, and can contribute to poor adherence (Morrison et al., 2002; Taal, Rasker, Seydel, & Wiegman, 1993; Tucker et al., 2004; Turner et al., 2001).

Despite the important role played by psychological problems in threatening patient adherence, physicians often fail to recognize or refer patients for psychological services or treatment (Badger et al., 1994; Higgins, 1994; Mechanic, 1992). Many physicians view psychological problems as common and as normal concomitants of illness (Peyrot et al., 2005; Thompson et al., 2000). Patients' mental health needs to be considered, however, and interventions are essential to address this important barrier to adherence.

Anxiety and Stress

The relationship of anxiety and stress to adherence is variable across a number of studies, and the exact relationship is not yet fully understood (DiMatteo et al., 2000). Anxiety can range from panic to obsessive-compulsive behaviors and generalized anxiety about health; anxiety is often comorbid with depression, and its unique effects are difficult to determine (Mineka, Watson, & Clark, 1998). Nonetheless, both disorders tap into negative affect such as distress, anger, fear, worry, and guilt (Watson et al., 1995), which can negatively affect the practice of health behaviors and adherence to medical recommendations (Ng & Jeffery, 2003). Worry often characterizes the experience of many ill patients, who fear that their illness will progress and prevent them from living their lives as they wish. Many also worry about their inability to work and to carry out family responsibilities while ill, about their financial futures, and about the effect of illness on their appearance (Peyrot et al., 2005). Psychological distress can influence patients' perceptions of support and contribute to negative social interactions, further reducing the practical and emotional social support available to them (Alferi, Carver, Antoni, Weiss, & Duran, 2001; Coyne, 1976).

Social Support

Social support benefits health by acting as a buffer against stress, influencing health behaviors and affective states (Cohen, 1988), and allowing individuals to take more positive action toward adherence (Wallston, Alagna, & DeVellis,

1983). Support from friends and family can encourage an individual to be optimistic, have increased self-esteem, less depression and pessimism, better sick-role behavior, and increased functional and emotional support during difficult times (Shumaker & Hill, 1991). Social support can also influence an individual's ability to adjust to and live with illness (Hegelson & Cohen, 1996), including adhering to treatment (DiMatteo, 2004b).

Social support comes in many forms, such as functional and tangible support, emotional support, and informational support. Functional social support (e.g., physical resources, information) has been shown to have stronger effects on adherence than structural social support (e.g., number of family members), suggesting that it is the *quality* of the relationships that the individual has with others rather than the number of friends and family (DiMatteo, 2004b). The value of social support for adherence may partially depend upon the type and severity of the individual's illness and the complexity of the treatment regimen (Martin, Davis, Baron, Suls, & Blanchard, 1994; Penninx et al., 1998). Patients who underwent coronary artery bypass surgery and who had significant emotional support demonstrated better emotional status (evidenced less anxiety and depression) and adhered better to recommended lifestyle changes and medication regimens than similar patients without such support (Kulik & Mahler, 1993).

The social control hypothesis theorizes that the presence of close others may facilitate adherence through the internalization of norms conducive to good health and the experience of sanctions for deviating from those norms (Lewis & Rook, 1999). Nonsupportive social networks, on the other hand, can actually work against patient adherence and positive health behavior change by robbing the patient of the time and energy to effectively manage an illness or engage in a healthier lifestyle (Kaplan & Hartwell, 1987; Revicki & May, 1985). Meta-analysis shows that, overall, the following social support variables are positively associated with higher levels of patient adherence: practical support, emotional support, unidimensional social support, family cohesiveness, being married, and living with someone (DiMatteo, 2004b). Low social support has been found to be related to biological and physiological variables such as increased prostate-specific antigen levels (Stone, Mezzacappa, Donatone, & Gonder, 1999), and patients with poor social support are less likely to adhere to their ARV medication regimens (HIV), although many do not recognize that their social support can play a role in their adherence (Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000; Gifford et al., 2000; Gordillo, del Amo, Soriano, & Gonzalez-Lahoz, 1999).

Social support can improve patient adherence by enhancing cognitive functioning, self-efficacy, intrinsic motivation, sense of personal control, confidence, self-esteem, mood, and by reducing emotional conflict, interpersonal strain, distress, and depression (DiMatteo, 2004b). Strong social ties can help a great deal in combating the psychosocial difficulties that threaten adherence to treatment.

Patient Adjustment to Illness

Psychosocial adjustment to illness can strongly influence the adherence process. Research shows that up to 30% of women with breast cancer fail to complete necessary chemotherapy following mastectomy, often as a result of

psychological distress (Gilbar & De-Nour, 1989). Those who drop out or fail to follow through with treatment tend to have greater difficulty adjusting psychologically to their illnesses and adapting to the changes in functioning brought about by the illness in various areas of their lives. Cancer patients undergoing chemotherapy often must deal with many sources of stress arising from threats to bodily comfort, changes in self-perception, emotional variability, changes in social roles, threats to future plans, and day-to-day life hassles (Gilbar & De-Nour, 1989). Patients with cancer often deal with identity losses resulting from changed body image, heightened awareness of death, and family stressors such as family conflict; those with more stressors are more likely to be nonadherent (Tijerina, 2006).

Socioeconomic Status, Education, and Income

A patient's socioeconomic status (SES), education level, and income can strongly influence adherence. Lifestyle change may be difficult, or impossible, in the context of significant social and economic vulnerability. Factors such as lack of transportation and child care, unfamiliarity with the medical care system, and lack of or inadequate medical insurance coverage can threaten adherence, adding to the growing concern that economic disparities exist in the U.S. health care system. Patients with lower incomes, less education, and lower socioeconomic status are likely to face greater challenges to the achievement of good health behavior than those with higher incomes and socioeconomic status.

Lack of resources can constitute a significant impediment to behavior change despite the best of intentions from patients (DiMatteo & Martin, 2002). Economic vulnerability can lead to discontent, and even depression, and can contribute to limitations in adherence (Brand, Smith, & Brand, 1977). Low levels of education are often associated with poor adherence, and research on diabetics has found that low levels of education are associated with poor glycemic control (Lloyd, Wing, Orchard, & Becker, 1993). Cancer patients of lower socioeconomic status have lower rates of adherence to their chemotherapy medical regimens than those of higher socioeconomic status, likely because they possess fewer coping resources and are more vulnerable to the effects of illness on their lives (Lebovits et al., 1990). Research has shown that low socioeconomic status (SES) and low income strongly influence disease screening activities, as well as interactions with health care providers, especially among women patients. Women of lower SES continue to be less likely to receive adequate screening for breast cancer than those of high SES (O'Malley, Forrest, & Mandelblatt, 2002). Screening rates tend to rise, however, when physicians discuss mammography screening in a primary-care setting with low SES women and are enthusiastic about the screening (Friedman, Puryear, Moore, & Green, 2005).

Subpopulations

Patients who face limited resources in their later years often have difficulty adhering to medical regimens and lifestyle changes. Many older adults experience reductions in their income and health care insurance as they enter retirement, introducing significant challenges and limitations in the quality of health care

coverage they receive (Chen & Landefeld, 2007). Despite government health care programs for older adults (Medicare), elderly adults often must pay for many of their medical expenses out-of-pocket, jeopardizing the use of preventive services and putting them at risk for poor management and control of disease (Sudano & Baker, 2006). Older patients often have more chronic conditions than others and as a result may receive prescriptions for a greater number of medications. Other changes that accompany aging also may negatively affect patient adherence (Balkrishnan, 1998). Elderly patients tend to be less likely to ask questions and be actively involved in their care, often leave the medical visit with questions unanswered, and are unclear about what they are supposed to do to care for themselves (Breemhaar, Visser, & Kleijnen, 1990; DiMatteo, Hays, & Sherbourne, 1992). To be effective in communicating and treating elderly patients, physicians must take factors that affect their elderly patient's adherence into account.

A patient's race, ethnicity, language, and income status all pose challenges to proper adherence. Many studies have documented these disparities in health care and their effects on patient adherence. Effective physician-patient communication is essential to adherence success, yet studies have shown that minority patients rate their medical visits as less participatory than do White patients (Cooper-Patrick et al., 1999). Minority patients also report less positive perceptions of their physicians and have less trust in their physicians than do White patients (Doescher, Saver, Franks, & Fiscella, 2000). Many poor and underserved women experience a lack of continuity and quality in their care and thus can develop distrust of the medical interaction and in their physicians (LaVeist, Keith, & Gutierrez, 1995). Trust is essential, however, and is significantly related to treatment continuity and to adherence (Safran et al., 1998; Thom, Ribisl, Stewart, & Luke, 1999).

A variety of patient psychosocial variables can interfere with the ability to adhere to a medical regimen, even if the patient understands what to do and is motivated. Helping patients overcome barriers has the potential to greatly increase the likelihood that they will follow through with medical recommendations and lifestyle changes.

Summary and Conclusion

Each of the psychosocial variables discussed in this chapter plays an important role in shaping patients' knowledge and understanding of their illness and medical treatment, in shaping their beliefs in the efficacy of the prescribed regimen, in motivating them to follow through with recommended health behaviors, and in shaping their ability to carry out the behaviors required to adhere effectively to treatment. Health care professionals and providers have at their disposal a variety of means to enhance patients' knowledge and understanding of, and beliefs in, treatment, as well as to improve the provider-patient relationship and to deal effectively with the barriers faced by a diverse population of patients. By examining and carefully attending to the steps involved in adherence to medical recommendations, providers can begin to untangle the web of psychosocial factors that may impede a patient's adherence to medical recommendations and health behavior change and thereby ultimately help to improve patients' health care outcomes.

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Changing Clinical Behavior: Implementing Guidelines to Improve Primary Care Practice

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Modifying any human behavior is not easy, and changing the behavior of health care providers presents an even greater challenge because of the many factors that influence clinical practice. Theories of behavior change, a number of them elegantly explained elsewhere in this book, tend to note the importance of two concepts: self-efficacy and the readiness for change. However, interventions to improve clinical behavior require more than targeting a provider's readiness to change or fostering a strong belief that the desired change is possible. Clinical behavior occurs within a complex, and sometimes remarkably dysfunctional, health care system—and each component of the system (e.g., a provider, a practice setting, a state or region, a health maintenance organization, insurance providers, the medical profession, the federal government) exerts forces that may impede or facilitate desired behavior change.

Yet, clinical practice guidelines—the blueprint for desired improvements in clinical behavior—continue to be developed at an impressive rate. There are more than 2,000 guidelines available at the National Guideline Clearinghouse (www.guideline.gov), which is maintained by the Agency for Healthcare Research and Quality (AHRQ) and is, by far, the best-regulated repository of guidelines. AHRQ defines clinical guidelines as systematically developed statements to help patients and providers make decisions about appropriate health care. Guidelines usually contain recommendations about prevention, screening, diagnosing, treating, and living with diseases and conditions. Clinical practice guidelines are valuable because they summarize the vast scientific evidence surrounding a clinical issue and provide guidance as to the best practices for that specific issue. Thus, they are a great help to practitioners who do not have the time, expertise, or interest to carefully evaluate all of the latest research findings about a disease.

It is encouraging to note that the field has grown substantially since the previous edition of this volume. Recognition of the long trajectory of translating research findings into clinical practice—estimated at 17 years (Antman, Lau, Kupelnick, Mosteller, & Chalmers, 1992; Kumar, 1992)—has spurred efforts to address this unacceptable lag. For example, there is now a journal *(Implementation Science)* that focuses on the "scientific study of methods to promote the uptake of research findings into routine healthcare in both clinical and policy contexts" (Eccles & Mittman, 2006). Canada has formed the Improved Clinical Effectiveness Through Behavioral Research Group, which is supported by the Canadian Institutes of Health Research and the Ontario Ministry of Health (ICEBeRG, 2006). In the United States guideline research funding opportunities, such as those funded by the National Institutes of Health, have increased. Finally, theoretical constructs on which to base this research are steadily emerging (Newton et al., 2007; Sladek, Phillips, & Bond, 2006), as is the development of more accurate measures (Hakkennes & Green, 2006). Yet, even with the promising growth in the field, many researchers and clinicians still struggle when trying to improve primary care practices. Despite the development of theory and methods to smooth implementation of effective interventions, there is still often a large gap between the desired and the delivered quality of care.

A systematic review of 235 studies designed to improve practices illustrates the problem. Overall, the interventions showed a very modest impact—in fact, the absolute improvements in care ranged from only 6% to 14.1% (Grimshaw et al., 2006a). Moreover, there are even fewer studies that look beyond the documentation of changes in the processes of care to improvement in patient outcomes, and these demonstrate only modest impact.

Why Is It Hard to Change Clinical Behavior?

Unfortunately, there is often a gap between the best practice as outlined in a clinical practice guideline and what actually happens in everyday clinical practice (McGlynn et al., 2003). Those of us involved in medical education recognize that much of what we teach to medical students and residents is out of date in just a few years because of the rapid development of new medications, medical

devices, and procedures. We stress the importance of lifelong learning to our students because they will need to be proactive in order to maintain excellent clinical skills. Guidelines are important learning tools. Yet, there are barriers to their use. The sheer number of guidelines available to study is one barrier. For example, there are guidelines focused on a range of important issues, such as hypertension, diabetes, incontinence, smoking cessation, or depression. Primary-care practice is demanding, and the time pressures are significant. There isn't time to read all the guidelines, and they are not all of the same quality, so the process of how to select the best guideline is unclear.

Another barrier to guideline implementation is the difficulty of objectively assessing one's own clinical performance. Remember that clinical behavior change requires effort. If there is no perceived problem, why would anyone invest the effort to change? Providers may believe they are delivering outstanding care (when they are not), and thus may not be motivated to make any sort of change. Quality reporting (e.g., monitoring of administrative data by health plans to determine if a quality-of-care indicator—like cancer screening mammography—is performed) provides some objective, but limited, information about provider performance.

Individual provider-level factors play a role in clinical behavior change. Cabana et al. (1999) noted six barriers to clinical behavior change: lack of awareness; lack of familiarity; disagreement with the guideline; disbelief that the guideline will result in the intended outcome; lack of self-efficacy to perform the behavior; and practice inertia. Some providers are not ready or prepared to make a change in their clinical behavior.

Similarly, there are patient factors that can impede guideline implementation. For example, patients may be resistant to a change. To illustrate, consider the case of Dr. Kidd, who decided, after attending a seminar, to improve screening for domestic violence in her general internal medicine primary-care practice. To prepare for the change she read up on the topic, became familiar with local resources, and had one of her staff add programmed alerts to her computerized medical record system to remind her to routinely integrate screening questions into the history section of every patient interview. Yet, by the end of the quarter, she noted that a surprisingly large number of patients in her rural Colorado practice were upset about being asked about a stigmatized condition. The patients resisted her *new and improved* clinical behavior. As a result of the patients' reactions, Dr. Kidd reevaluated the situation and decided to drop the domestic-violence screening questions and abandoned her efforts to implement the clinical practice guideline.

Not only do patient and provider factors conspire to impede clinical behavior change, but aspects of the practice setting, such as resources (materials, staff, hours of operation) may also interfere (Gravel, Legare, & Graham, 2006). At the system level, the reimbursement policies of health insurers are potential barriers to clinical improvement. To illustrate, let's consider Dr. Kidd again. She read an alarming article in the *Journal of the American Medical Association* about very high rates of medication errors and serious adverse drug events in older adults. Dr. Kidd wants to talk with all her older patients at every visit about *all* the medications (e.g., prescription, over-the-counter, herbs) they are taking. But she also wants her practice to remain financially solvent and has found that primary-care visits for her older patients tend to take longer than those for her younger patients, because of differences in the average number

of chronic conditions that have to be addressed and the numbers of medications prescribed. Yet, insurance reimbursement rates generally do not reflect this reality and pose a barrier to her achieving a potentially life-saving clinical improvement goal. Thus, making this change in clinical behavior will cost her both time and money.

What Interventions Facilitate Clinical Behavior Change?

The best interventions usually focus on more than one component in the system and are described later in this chapter. But multilevel and multimethod interventions are expensive, resource intensive, and difficult to implement. As a result, most clinical behavior change strategies have focused on the individual provider. Typical interventions targeting providers aim to increase knowledge and motivation for change. Printed materials or the recommendation of a respected local opinion leader may be disseminated to providers to facilitate clinical behavior change. Interventions aimed at the systems level include administrative policies, care plans, treatment protocols, provision of free samples, and audit and feedback.

Education Materials and Continuing Medical Education

Continuing medical education (CME) and the distribution of educational materials are the most widely used interventions, despite evidence suggesting only modest effects on clinical behavior (Sohn, Ismail, & Tellez, 2004). They are widely used because of familiarity and ease of implementation. While passive educational strategies hold little promise, active educational interventions do show moderate benefit (O'Brien, 2007). The most effective educational strategies use multiple interventions, two-way communications, printed and graphic materials delivered in person, and locally respected health personnel as educators (Cauffman et al., 2002; Griffin et al., 2004).

Soumerai reviewed a number of educational interventions and identified the characteristics of those activities most likely to influence behavior. Ignoring design limitations of the studies reviewed, the researchers found that educational materials alone showed no significant effect, while participatory guideline development did lead to significant changes. Three other strategies—educational materials along with drug sample distribution; one-on-one education; and group education—all showed mixed results (Soumerai & Avorn, 1987; Soumerai, McLaughlin, & Avorn, 1989; Soumerai et al., 1993a, 1993b).

Time constraints may pose a barrier to physicians' participation in educational activities. However, one method to overcome this barrier is to present educational materials within the context of already scheduled events. For example, successful dissemination of new knowledge may occur with the integration of educational seminars within the context of grand rounds or monthly departmental meetings.

Conferences and Seminars

Continuing medical education may be provided via conferences and seminars; however, it can be difficult to recruit physicians to attend because of scheduling

conflicts (Cabana et al., 2004). Physician recruitment necessitates personal and multiple contacts and careful planning of seminar location, time, and content.

Industry-sponsored luxury conferences can be powerful agents of change (Orlowski & Wateska, 1992). In a natural experiment, two new drugs were introduced via all-expenses paid symposia for MDs at the Cleveland Clinic. Drug A, an intravenous antibiotic, was launched at a California luxury beach resort over 4 days. Drug B, an intravenous cardiovascular agent, was introduced during a 5-day Caribbean island resort conference. Although 85% of physicians asked before the symposia predicted that the trips would have absolutely no impact on their prescribing patterns (only 5% thought that they might), time trend data show that prescribing of Drug A *doubled* and prescribing of Drug B more than *tripled* after the trips (Orlowski & Wateska, 1992). Even though conferences are a passive strategy of information transmission, if conducted in a luxury setting they seem to be extraordinarily effective in changing behavior.

Advertising

Studies of intensive marketing campaigns conducted by pharmaceutical companies show they can be effective in changing practice, even when the care provided may be contrary to evidence (Avorn, Chen, & Hartley, 1982). Following heavy advertising of the analgesic propoxyphene, Avorn et al. surveyed physicians' opinions on whether it was better than aspirin. Eighty percent of doctors said that the drug was better or the same as aspirin, when in fact the drug was no better, possibly worse, and more expensive than aspirin.

Opinion Leaders

Opinion leaders and local consensus exert influence on clinical behavior. Promotion of a particular intervention, method, or process by opinion leaders often leads to adoption by medical associations, hospitals, and providers. Opinion leaders are a major source of information diffusion. In fact, medical innovations introduced by opinion leaders are quickly adopted by physicians as the diffusion process is expedited. Clinicians often rely on local sources of information to seek knowledge about an issue they are uncertain about (Buller, Young, Fisher, & Maloy, 2007). Specific opinion leaders are more appropriate for a particular issue than are others (Grimshaw et al., 2006b).

Medical professional societies serve as natural opinion leaders and have become involved in promoting behavior change, both in developing guidelines and in encouraging their adoption. Genuine interest in improving health outcomes and eagerness to maintain autonomy in monitoring and directing practice pattern changes have prompted professional societies to embark on quasi-experimental research to impact practice. Examples include the American College of Cardiology's Guidelines Applied in Practice and the American Heart Association's "Get With the Guidelines" modules for stroke, coronary artery disease, and heart failure.

Academic Detailing

The pharmaceutical industry invests billions of dollars per year on "detailing," an estimated $8,000 to $13,000 per year for each physician (Wazana, 2000).

Given the for-profit nature of the industry, this approach must be effective to justify the investment. "Academic detailing" was developed in response to the "detailing" of health care providers that pharmaceutical sales representatives perform. Harvard's Jerry Avorn and colleagues (1982) recognized that successful pharmaceutical salespersons were usually attractive, articulate, and engaging professionals who provide user-friendly information and, often, lunch, all the while seeking to promote the sales of their company's drugs. Avorn believed and has proven that a noncommercial approach can change clinical behavior, too. Academic detailing is an "unsales" approach—where unbiased, commercial-free information about optimal care is provided to a clinician to improve care. Educational interventions are delivered by clinician-educators (generally physicians or pharmacists) who are experts in the field and specially trained in communication strategies. These experts visit the practice site and provide tailored information and encouragement to targeted clinicians. Academic detailers explore the provider's current knowledge and motivation, define clear educational and behavioral objects, and support the provider in making the desired change. For example, in a randomized controlled trial of 435 physicians with patterns of overprescribing three ineffective, harmful, and expensive drugs—propoxyphene, cerebral vasodilators, and cephalexin—academic detailing caused a 25% decrease in the troublesome prescribing (Avorn et al., 1982).

Detailing interventions seem most effective if physicians are targeted for intervention on the basis of need (e.g., prescribing data, opinion leaders); credible messengers and data sources are used; person-to-person interactions occur; key messages are repeated and reinforced over time; behavioral alternatives are discouraged; and brief, graphic educational materials are used (Soumerai & Avorn, 1990).

Audit and Feedback (Practice Reports)

The National Institute for Clinical Excellence (NICE) defines audit and feedback as a quality improvement practice aimed at improving patient care and outcomes through systematic review of care against specific criteria and the implementation of change. A five-step process is used to initiate and sustain the audit process. These steps include (1) preparing for the audit, (2) selecting criteria, (3) measuring the level of performance, (4) making improvements, and (5) sustaining improvement. In preparing for an audit, an organization should secure stakeholders' involvement, determine the purpose and goal of the audit, and identify what resources will be necessary to carry out the audit process. Selection, process, and outcome criteria must be chosen on the basis of their measurability, their relations to important aspects of care, and whether they are evidence based. Clear and concise definitions should be developed to adequately measure performance levels. For example, key elements that need defining are the user group, the professionals involved, and the time period over which criteria will be applied. External relationships and utilization of other supporting interventions should be considered when making improvements. Identifying potential barriers and implementing change will also help to make successful improvements. Once improvements have been made, they must be sustained by continuous monitoring and evaluation, development of an organizational framework, and leadership.

Audit and feedback as a method to improve clinical behavior have had mixed results. Feedback of aggregate data alone has not produced consistent results, but feedback strategies that target specific patients or provide work-sheets, additional clinical services, or other tools have produced mixed results. In a systematic review of 118 studies, adjusted change among audit and feed-back strategies ranged from a 10% drop in performance as measured against a control to a 70% improvement (Jamtvedt, Young, Kristoffersen, O'Brien, & Oxman, 2006).

The variation in effectiveness may be a result of the specific behaviors tar-geted or the person conducting the feedback. Further research is necessary to determine how and in what environments audit and feedback works best. The strategies shown most effective in the Jamfvedt and colleagues review (2006) were those where baseline compliance to guidelines was low and the intensity of the interventions was high. Several qualitative studies have explored char-acteristics of effective feedback strategies. Radford and colleagues noted that the *perceived accuracy* of the feedback and the source of data (internal vs. ex-ternal) conferred validity on the data. Further, timeliness of effective reports was based on the *frequency of reporting* performance feedback. The impact of the feedback was heightened if the physician was compared to like providers (e.g., same specialty and same type of practice setting). Finally, the useful-ness varied by who received the data and in what forum, who provided the data, and how the data were formatted (Bradley et al., 2001). Another study of high- and low-performing facilities' use of clinical audit data for feedback purposes suggested that high-performing sites provided timely, individual-ized, nonpunitive feedback to providers, while low-performing sites showed more variability in timeliness and punitive action and relied more heavily on standardized, facility level reports (Hysong, Best, & Pugh, 2006).

Incentives and Financial Rewards (Pay for Performance)

Pay for performance embraces the idea that providers should be rewarded for outstanding quality-of-care performance. It is reasonable to believe that finan-cial incentives will have a positive impact on clinicians' behavior. A common type of financial reward is value-based purchasing. Value-based purchasing is a system in which employers and other purchasers collect and analyze data re-lated to the costs and quality of various competing providers and health plans (Rowe, 2006). In this system, the best-performing plans and health care pro-viders are rewarded with greater volume of enrollees or patients. The degree to which health care providers respond to value-based purchasing initiatives is greatly influenced by the extent to which a clinical practice is dependent upon the purchasing entity making the payments. Approximately 40% of man-aged care organizations offer financial incentives to affect practice patterns, a much lower rate of utilization than that for other behavior change strate-gies (Soumerai et al., 1989). Currently, most incentives are less than 10% of a provider's salary.

More recent policy initiatives have layered financial incentives with account-ability for good patient outcomes at a systems level. Medicare's Pay for Perfor-mance initiative is one example. Under pay-for-performance pilot programs, hospitals scoring in the top 10% received a 2% bonus payment in addition to their

standard Diagnosis-Related Group payment. The next highest-scoring 10% received a 1% bonus, and hospitals that did not meet threshold score were subject to *reductions* in payment. Evaluation of the pilot program indicated that the pay-for-performance demonstration initiative had a significant impact on the rate and magnitude of performance improvement at one hospital (Grossbart, 2006), and early indicators suggest the 10 large, multispecialty group practices participating in the 3-year trial are making strides in identifying Medicare patients with chronic, high-cost conditions and closing the gaps in their care (Klein, 2006).

Public Reporting of Quality-of-Care Indicators

Report cards have been developed to measure and compare health plans (e.g., Healthcare Effectiveness Data and Information Set, Consumer Assessment of Healthcare Providers and Systems) and the Leapfrog Group, a consortium of employer payers, has designated minimum criteria for health care quality and requires public reporting of these indices. In some instances the risk adjustment methodologies are inadequate and sometimes not even reported. However, to date, the release of information to the public does not appear to have had an effect on patients' decisions to select particular physicians as their provider (Rosenthal, Fernandopulle, Song, & Landon, 2004).

Organizational Interventions

A review of organizational interventions showed inconsistent effects. But, on the basis of the weak designs of the studies, Wensing, Wollersheim, and Grol (2006) suggest that revision of professional roles and computer systems changed provider behavior and that implementation of multidisciplinary teams, integrated care services, and computer systems impacted patient outcomes. However, they concluded that the benefits of quality management strategies remained uncertain.

Administrative Policies

At the systems level, incentives and disincentives have been used to influence provider behavior. Almost all managed care organizations report using formularies, and approximately 90% use drug utilization review, to direct specific prescribing practices (Soumerai et al., 1989). Formulary approaches can reduce medication use and costs. However, the impact on total health care costs and health outcomes has received little attention. Other administrative policies such as mandatory switching, coverage limits, and use of prior authorization can increase prescribing of preferred drugs, although a small percentage of patients do switch back to the original therapy, and forced switching may result in a temporary increase in office visits (Soumerai et al., 1989).

One tenet of system strategies is to make it easy to do the right thing and difficult to do the wrong thing. Prior authorization, in which the practice is not reimbursed for care that has not been authorized by the payer in advance, is one such barrier and has been implemented in 80% of managed care organizations (Soumerai et al., 1989).

Care Plans, Protocols, Pathways

Other organizational plans and policies may reduce variation by standardization. Care pathways may help clinicians select and make adjustments to appropriate medications quickly, reduce risk of errors, and have a positive impact on outcomes.

Care protocols document required actions that should be taken in a specific circumstance. Clinical pathways are patient-focused tools that describe the time frame and sequencing of routine, predictable, multidisciplinary care patterns and the patient outcomes expected from them. They are most successful in situations in which care is provided for a high volume of patients with similar needs (e.g., hip fracture patients have similar hospital courses following surgery, so rehabilitation services can be standardized by day postsurgery).

One successful approach is the Guidelines Applied in Practice (GAP) program (Mehta et al., 2002). GAP used standard orders, pocket guidelines cards, clinical pathways, patient information forms, and patient discharge forms to improve care of acute myocardial infarction patients and showed small, but significantly increased trends in health care providers' adherence to prescribing beta blockers, aspirin, and cholesterol lowering medications, and reductions in time to acute care therapies (Mehta et al., 2002).

Drug Samples

Distributing drug samples is one approach to encourage specific prescribing patterns. The pharmaceutical industry spends an estimated $8 billion per year in the United States on drug samples. Not surprisingly, the use of generic drugs has been shown to be negatively influenced by the presence of brand samples in a primary care clinic (Miller, 2005). In a survey of physicians who used drug samples, 91% stated the sample given was not their preferred drug, but 69% of them would not switch the patient to their preferred drug once the patient's hypertension was controlled (Chew et al., 2000).

Reminders

Many interventions are built upon the simple concept of reminding physicians of guidelines, preventative tests due, and other processes of care to be followed. Several systems have been utilized, including chart-attached reminders, nurse-prepared checklists, and computer prompts. A review of reminder interventions looked at nine comparisons between physicians who received reminders and those with no intervention and showed absolute increases in preventive services varying from 5% to 24% (Hulscher, Wensing, van Der, & Grol, 2001). In a review of cluster randomized trials of various reminder strategies, Grimshaw et al. (2006b) found a median absolute improvement of 14.1% among physicians who received reminders, but the researchers doubt that these effects can be replicated outside a rigorous trial setting. Computerized reminder systems are becoming more common. However, it seems that paper-based reminders are a more effective reminder strategy (Dexheimer, Sanders, Rosenbloom, & Aronsky, 2005).

Decision Support Tools (Point-of-Care Calculators, Care Protocols)

In a landmark article, McDonald (1976) suggested that humans were limited in data-processing capacity and that computers held the promise of helping clinicians to reduce errors and improve patient care. More than two decades later, in *To Err Is Human* (2000) and *Crossing the Quality Chasm* (2001), the Institute of Medicine declared that information technology is a cornerstone of efforts to improve patient safety. Two health information technologies are essential to improving patient safety: electronic medical records (EMR) and computerized physician order entry (CPOE). These technologies narrow variation from evidence-based practice and prevent medical errors (Berwick, 2003). A cadre of national organizations, including the Institute of Medicine, the Leapfrog Group, and the Agency for Healthcare Research and Quality (AHRQ), have endorsed CPOE as an intervention that may dramatically improve patient safety (Institute of Medicine, 2000, 2001). There have also been legislative initiatives at both the state and the federal levels to promote implementation of information technology in hospitals (Institute of Medicine, 2000).

Use of computer-based clinical decision support systems (CDSSs) are thought to improve adherence to guideline recommendations; improve patient outcomes; reduce inappropriate variation in clinical practice; reduce errors and oversights; and decrease costs of care. CPOE may significantly improve patient care and safety by eliminating illegible orders and reducing transcription errors (Mekhjian et al., 2002). CPOE provides a platform for diagnosis-specific order sets and corollary orders, which enhance compliance with evidence-based guidelines and improve medication monitoring (Overhage, Tierney, Zhou, & McDonald, 1997). CPOE facilitates the use of reminders to enhance adherence to preventive-care routines or protocols (Dexter et al., 2001). The approach constrains choices such as selection of medications, both improving medication selection and dosage and reducing time to therapeutic level (Teich et al., 2000). It reduces medication errors and facilitates allergy identification, leading to substantial reductions in potential adverse drug events (Bates et al., 1998; Teich et al., 1999).

A key to the effectiveness of CPOE is the linkage to computerized clinical decision support systems (CDSS). In medication management, for example, CDSS can provide computerized rules and algorithms to "alert" physicians to the presence of potentially unsafe drug-drug interactions, the need to adjust drug dosage, and contraindications to specific drugs based on the presence of a medication allergy or comorbidity (Wang, Shabot, Duncan, Polaschek, & Jones, 2002). As with other implementation strategies, the evidence base has not caught up with the enthusiasm.

Although clinical decision support (CDS) tools may positively affect the cost, quality, and safety of health care delivery, studies find a rather low acceptance rate among clinicians. It takes an investment of time to use CDS effectively, and time constraints are a reason why more physicians do not use them. Even if a physician is inclined to use CDS, the effects of the system's support may not be optimal, as many physicians can override or ignore the messages the system provides. Physicians who do effectively use CDS, however, claim that it helps them take better care of their patients and reminds them of important activities or appointments. Physicians using handheld decision support

tools in a critical care setting have decreased their patient's length of stay and their prescribing of antibiotics (Sintchenko, Iredell, Gilbert, & Coiera, 2005).

Patient Activation Tools

The pharmaceutical industry has capitalized on direct-to-consumer advertising to promote the sale of target drugs. Several academic interventions have also capitalized on the physician-patient interaction to promote guideline adherence. These patient activation approaches engage the patient as a catalyst to remind the care provider of guideline protocols. Other strategies have employed posters in the exam room describing appropriate care and engage patients in their own care by providing care records or test results such as written blood pressure results with notes regarding threshold values and encouragement to discuss abnormal results with the physician (Ellis et al., 2007). Evidence suggests that such interventions can alter the interaction between patients and practitioners (Griffin et al., 2004).

Multifaceted Interventions

A review of the impact of multifaceted interventions found 14 comparisons between groups that received multifaceted interventions and controls that received no intervention that showed an absolute change in the performance of preventive services of between negative 3% and positive 64% in the group that received multifaceted interventions; 6 comparisons between groups that received multifaceted interventions and groups that received group education produced absolute changes ranging from negative 31% to 28% in the first group (Hulscher et al., 2001). Grimshaw, Eccles, & Tetroe (2004a) found that multifaceted interventions were no more effective than single interventions and also found no relationship between the number of components and the effects of multifaceted interventions (Grimshaw et al., 2006a). In response, more rigorous studies have been designed to test the incremental effects of patient-specific reminders delivered at the point of care with brief treatment guidelines endorsed by local opinion leaders (McAlister et al., 2006) and other mixed-methods approaches (Johnson et al., 2006).

Tailored Interventions

Tailored interventions are designed to be flexible enough to allow providers to select aspects of the intervention that will "fit" in their setting. This flexibility recognizes that no one size fits all and that if providers are able to choose aspects of the intervention, they are more likely to be influenced by it. Tailored interventions have been effective in research studies using nonexperimental designs (Bonds, Ellis, Weeks, Palla, & Lichstein, 2006) and experimental designs (Eccles et al., 2006).

Why Does It Matter?

Unfortunately, there is often a chasm between the gold standard of care as outlined in clinical practice guidelines and the care that is actually delivered on

a day-to-day basis. The practice of medicine usually involves a dynamic relationship between a health care provider and a patient. Thus, a patient who is cared for by a physician using best practices is going to have every advantage in achieving adherence over a patient who is not seen by a high-performing clinician. The physician's behavior has clear implications for the patient's health behavior and outcomes. If that weren't reason enough to learn about the challenges of guideline implementation, the fact that the health care landscape is constantly changing provides another compelling reason. As advances in techniques, diagnostic equipment, and medications emerge at rapid rates, clinical behavior will have to change in response if clinical excellence is to be realized. In this chapter, we highlighted the challenges in changing clinical behavior in primary care practice. We emphasized the importance of thinking about clinical behavior change as occurring in a context and of developing systems to support the desired behavior change. The approaches and models that seem to work best have been noted, as have notable failures. Future research in this area should consider whether it is important to disentangle the effects of multilevel and multimethod interventions and how such effects could be isolated and measured.

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Lifestyle Change and Adherence Issues Within Specific Populations

Section

5

Sally A. Shumaker
Editor

There are many factors discussed throughout the current volume that influence lifestyle changes and adherence that are common across groups. However, there are also factors that are specific within groups. Such population strata variables include economic status, education, gender, ethnicity and race, rural versus urban, access to care, and age. Each of these strata contain characteristics that differentially explain a group's receptiveness and ability to initiate healthy lifestyle changes as well as the group's ability to maintain new behaviors over time. To maximize the effectiveness of strategies designed to initiate and maintain healthy behaviors it is important for behavioral scientists and health care providers to be sensitive to both within- and between-group differences. And,

as noted throughout this volume, it is critical to go beyond these two levels of analysis and consider health behaviors within the broader and complex social system. In the previous edition, we explored the role of adherence and health behavior among three specific population groups: the young, adolescents with chronic diseases, and the elderly. In this edition, in addition to significantly updating each of the previous chapters, we added chapters on older adults with cognitive impairments and health disparities and minority health.

In "Lifestyle Interventions for the Young," Ievers-Landis and Witherspoon present a compelling argument for developing healthy behaviors as early as possible in a person's development, as such behaviors influence both current and future health. Further, the behaviors instilled in childhood (whether healthy or unhealthy) are most likely to be sustained throughout the lifetime. This latter point is underscored by the difficulty with which health behavior changes (e.g., increased physical activity, smoking cessation, and a healthy diet) are initiated and sustained in adulthood. In considering healthy lifestyles in the young, Ievers-Landis and Witherspoon address two age groups: preschool and middle childhood (i.e., ages 3–12). Noting that the success of healthy lifestyle interventions is dependent on the developmental stage of the child, the authors discuss where such interventions are likely to be most successful at different age groups and present different approaches by age and situation—considering the family and home environment, the classroom, the built environment, and the primary care physician's clinic. The authors conclude with a critical review of interventions that have been developed to enhance healthy behaviors in children and discuss the relative merit of each program.

Murdaugh and Insel provide an update on the chapter in the previous volume (Murdaugh, 1998) in "Problems With Adherence in the Elderly." The elderly represent the fastest growing portion of the population in the United States, and an increasing number of aging adults are living into their 80s and further. And, for many older adults, the behaviors required to improve their health run counter to lifelong habits that are well-established and resistant to change. Further exacerbating this situation is the fact that chronic illnesses increase with age, and often older adults are faced with multiple comorbidities that require complex behavioral and pharmacological interventions. In this chapter, Murdaugh and Insel begin with a description of the types of nonadherence that occur in the aging population. They provide an in-depth review of the complex nature of nonadherence and the multiple factors that influence it among older adults (e.g., ability, desire, physical and emotional health, the social environment, and pharmacokinetics). Although they focus primarily on adherence to prescribed medication regimens for chronic conditions, these authors note that many of the factors that promote nonadherence and adherence are applicable to other types of regimens or lifestyle changes in which adherence is an issue. Recognizing the heterogeneity of the elderly population, these authors go on to consider methods to assess an elder's capacity to adhere. They conclude the chapter with a critical analysis of potential strategies for enhancing optimal adherence among the elderly.

Resnick, Galik, Nahm, Shaughnessy, and Michael discuss the complex challenges involved in "Optimizing Adherence in Older Adults With Cognitive Impairment." The prevalence of dementia and mild cognitive impairment increases dramatically over age 65. About 5%–8% of people over age 65 suffer

from dementia. Currently, it is estimated that 4.5 million Americans suffer from Alzheimer's disease, and because of increases in life expectancy it is projected that by 2050 approximately 13.2 million Americans will be affected by the disease. When less dramatic declines in cognitive functioning are considered, the rates of elderly with some cognitive impairment are significantly higher. Health-promoting behaviors are the same for adults with cognitive impairment (CI) as the general population. Further, adults with CI benefit from successfully achieving health behavior changes (e.g., increased physical activity). However, cognitive impairment presents a unique set of challenges within the context of adherence and sustained health-behavior changes. In this chapter, Resnick and colleagues provide a detailed review of the evidence supporting the value of health-behavior change interventions among older adults with cognitive impairment. In addition, they discuss the factors that predict poor or good adherence in this cohort. In the final section of the chapter, the authors discuss the value of applying a social-ecological model to interventions designed to enhance health behaviors among cognitively impaired adults. They provide several excellent examples of specific intervention programs and critically assess the relative value of each. This chapter represents a unique and valuable resource to the health professional working with the cognitively impaired—whether within an institutionalized population or living at home. The authors provide a sense of efficacy and hope for improving the outcomes for this growing population.

In "Adherence Issues Among Adolescents With Chronic Diseases" Rapoff and Smith provide an excellent update on the chapter from the previous volume (Rapoff, 1998) in which this critical issue was addressed. The authors begin by defining adherence versus compliance—a critical distinction for any population and particularly sensitive during adolescence when individuals are testing their independent status. Rapoff and Smith also distinguish between volitional and nonvolitional nonadherence—further clarifying the importance of choice, knowledge, and independence among adolescents. They note that although chronic diseases are present in a relatively small percentage of the adolescent population in the United States, the consequences of such conditions are major with respect to the quality of life of the teen and the significant medical and psychosocial implications. In addition, chronic diseases among adolescents carry a disproportionate economic burden. Further, although rates are relatively low, with increased obesity, sedentary lifestyles, and diabetes among young adults, the rate of chronic disease in adolescents is increasing. Also, adolescents are at particularly high risk for nonadherence to medical and healthy lifestyle interventions. In this chapter the authors review the degree to which nonadherence is a problem among teens, and its consequences. In addition, they critically review potential strategies for improving adherence.

A major issue in today's health arena revolves around ethnic and racial diversity and its relationship to health disparities. In their chapter, "Health Disparities and Minority Health," Whitt-Glover, Beech, Bell, Jackson, Loftin-Bell, and Mount tackle this important and complex issue—and relate it to healthy lifestyle behaviors and adherence. The authors set the stage for their analysis by providing two critical historical pieces that lay the groundwork for the remainder of the chapter and underscore the importance of context in understanding how minority status influences health behaviors and change. They first

provide a history of the concept of *minority,* and its changing use, meaning, and application over time in the United States. In addition, they consider the implications of these changes for how minorities are viewed historically and how this influences data collection and ultimately our understanding of the health status of various groups. The next section is an analysis of the term *health disparities*—again noting the variability with which the term has been used over time and how it is currently applied to a range of health behaviors and conditions. With this grounding established along with the implied caveats in place, the authors then move on to a review of the literature on the prevalence of a selected group of lifestyle and clinical behaviors, and adherence rates and their predictors, among minorities. The chapter concludes with suggested strategies for enhancing adherence among minority groups—within a social-ecological model. The authors consider strategies at the individual and community levels of analysis and discuss the degree to which various interventions have been successfully adapted to the intended culture.

Lifestyle Interventions for the Young

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In this chapter we provide an overview of the rationale for lifestyle interventions in the young (early and middle childhood) and brief descriptions of recent examples of the wide range of such interventions. Lifestyle interventions influence both the current and future health status of children, even into their older years (e.g., the prevention of osteoporosis) (Ievers-Landis et al., 2003, 2005). Health behavior change interventions may be most cost-efficient and effective when delivered early in an individual's life. We begin this chapter by providing an overview of the need for delivering lifestyle interventions to the young. The variety of these interventions and the choices researchers make during the design and implementation phases of research

are highlighted throughout the remainder of the chapter. Lifestyle interventions can be designed for a number of health-related targets and goals, and some of the most common and novel ones are described. In addition, the relationship of the design and implementation of lifestyle interventions to age and developmental stage is considered. Finally, the range of approaches selected to implement interventions are presented, as well as the types of intervention strategies used.

Research shows that intervening with children to promote healthy lifestyles is vitally important. When children are taught appropriate health behaviors early, these behaviors are more likely to become habitual and continue into adulthood (O'Brien & Bush, 1997; Taylor, 1999). Intervening with a population before it has developed habitually unhealthy behaviors is an added benefit of the timing of such interventions. The health behaviors of children are strongly influenced by early experiences and socialization, especially from parents as both positive and negative role models. Parents' eating behaviors, for example, may play a role in the development and maintenance of childhood obesity. In one study researchers found that children ages 3–6 years had more difficulty adjusting their eating in response to increases in the caloric density of the diet if their parents reported higher dietary disinhibition (e.g., eating large amounts of food without regard for hunger or fullness cues) (Johnson & Birch, 1994). In contrast, parents may model healthy behaviors for their children that become automatic, like wearing seatbelts (Damashek & Peterson, 2002).

Efforts to promote health in children often focus on educational opportunities to prevent poor health behaviors from developing (Turrisi et al., 2004). Early interactions align with "teachable moments," that is, moments when a child is cognitively ready to learn about a health behavior and has not yet developed a poor health habit in that area. Children benefit from intervention programs designed specifically for their level of cognitive development. As early as preschool, children can develop responsibility for some of their own health behaviors, such as crossing the street safely and wearing seat belts (O'Brien & Bush, 1997; Taylor, 1999).

Another reason to promote appropriate health behaviors in the young is that precautions taken either before or during adolescence may be more likely to prevent some diseases in later adulthood rather than waiting to improve health behaviors until initial symptoms arise (Chavarro, Peterson, Sobol, Wiecha, & Gortmaker, 2005; Cummings, Kelsey, Nevitt, & O'Dowd, 1985). Chronic conditions that arise in adulthood may be directly linked to childhood health habits. Examples include osteoporosis and skin cancer (Davis, Cokkinides, Weinstock, Connell, & Wingo, 2002; Ievers-Landis et al., 2005).

A number of lifestyle behaviors are identified as the leading causes of morbidity and mortality in the United States (Mokdad, Marks, Stroup, & Gerberding, 2000). The most prevalent among these are physical inactivity, unhealthy dietary patterns and behaviors that contribute to unintentional injury, and all of these are linked to behaviors that can be established in childhood and adolescence. (Other important behaviors linked to morbidity and mortality are substance abuse and unsafe sexual behaviors—both of which are covered in other chapters in this book.)

Child Age Range

Early Childhood

Some interventions are best suited for children in the "preschool" age range (3–6). These interventions usually include parental involvement (e.g., Fitzgibbon et al., 2004) and may be wholly directed to changing the parents' beliefs, attitudes and behaviors in order to benefit the children's health (e.g., Sääkslahti et al., 2004). Beginning interventions at this time is important as food preferences and physical activity habits are set relatively early in life (Sullivan & Birch, 1990; Trost, Sirard, Dowda, Pfeiffer, & Pate, 2003), and both are important for future health behaviors (Sherry, 2005). Also, early intervention can affect the timing of adiposity rebound, which is the second rise in body mass index (BMI) that occurs between 3 and 7 years of age. Early age at adiposity rebound is known to be a risk factor for later obesity (Cole, 2004; Trost et al., 2003). Additionally, children who are overweight between the ages of 3 and 5 are 7.9 times more likely to be obese as adults than their normal-weight peers (Whitaker, Wright, Pepe, Seidel, & Dietz, 1997). As children become older and remain overweight, their risk of remaining obese into adulthood dramatically increases.

Middle Childhood

Interventions aimed at middle childhood (6–12 years of age) usually involve a much larger component directed to the child than do interventions for younger children. These interventions often use creative strategies, such as multimedia games (Cullen, Watson, Baranowski, Baranowski, & Zakeri, 2005) or creative physical activities such as jump roping (Ievers-Landis et al., 2005), which are inappropriate for younger children and less appealing to the majority of older adolescents. Children in this middle age group are at the concrete-thinking stage of cognitive development and benefit from direct information and practice in performing healthy behaviors (O'Brien & Bush, 1997). In many cases, adding the participation of parents to the intervention leads to greater long-term success in changing the child's health behaviors because parents and caregivers are still primarily responsible for most of the child's choices and actions, and the parents continue to function as important role models.

   Reasons to intervene to promote healthy lifestyles during middle childhood are quite similar to those for preschool-age children. However, many more lifestyle interventions are aimed at children in this age group than at preschool-age children. The reason is that some of the physical factors that lead to chronic diseases in adulthood begin during middle childhood. For instance, peak bone mass, which is a predictor of later osteoporosis, is built and enlarged during middle childhood and early adolescence (Cummings et al., 1985). Another reason is that it is easier to work with older children as they are able to complete self-report questionnaires and provide fairly reliable responses regarding their own perceptions and feelings (e.g., self-efficacy, social support). To date, researchers have been unable to develop valid methods to reliably assess young

children's internal thought processes. Older children are also more accessible, as the majority of them attend schools in which intervention programs can be implemented, whereas a smaller proportion of younger children regularly attend preschool.

Intervention Approaches

Classroom

The school environment is used increasingly to implement interventions for improving the health of children. One advantage of designing interventions for children in the school setting is that most of the targeted population can be reached (Taylor, 1999). This is especially true for younger children and pre-adolescents, who have lower rates of skipping school than older adolescents. Schools also have a natural intervention setting—the classroom. Classes provide structured settings of approximately 1-hour duration, and this characteristic is adaptable to interventions (Taylor, 1999). Additionally, schools are already involved in promoting the health of students. Local and state laws typically require public schools to obtain records of required immunizations and physicals before children begin classes, and school nurses provide information to students and parents regarding recommendations for preventing the spread of acute illnesses. Also, Head Start programs usually have a health component that promotes preventive healthy behaviors in a preschool setting.

Parents/Family

As the primary caregivers of children, parents play a significant role in the development of a child's health behaviors, beliefs and practices. Parents' lifestyle behaviors such as dietary intake and physical activity levels correspond to their children's behaviors (Cullen et al., 2001). For example, the amount of time parents allow their children to spend outdoors is positively related to children's physical activity behavior (Ferreira et al., 2006). Conversely, children can develop unhealthy behaviors that are similar to their parents' and other family members' (Cullen et al., 2001). Parental obesity has been found to be one of the strongest factors in predicting whether children will be overweight from birth to 9.5 years (Agras, Hammer, McNicholas, & Kraemer, 2004). In addition to a genetic influence, parents influence their children's weight by their practices during mealtimes, which may play a role in the development of childhood overweight. The less parents monitor children's food selections, the greater the children's consumption of nonnutritious foods and the higher the caloric content of their meals (Klesges, Eck, Hanson, Haddock, & Klesges, 1990). If children grow up in homes in which healthy behaviors are infrequently practiced, then other interventions (i.e., through school or clinic) may be less effective (Winett et al., 1992). Family-based behavioral interventions or the inclusion of a parent component in another type of intervention (e.g., school-based) may exert influence both directly on the child and through the family by educating parents regarding the health recommendations for their children.

Environment

The built environment can be important in efforts to improve the lifestyle be-
haviors of children. The built environment is defined as consisting of neighbor-
hoods, roads, buildings, food sources, and recreational facilities in which people
live, work, are educated, eat, and play (Sallis & Glanz, 2006). Environmental
influences on food choices and physical activities such as aspects of the home
and school are associated with children's lifestyle behaviors. For example, the
physical activity–related policies in schools significantly influence children's
engagement in physical activity (Ferreira et al., 2006). Environmental aspects of
the local neighborhood, such as parents' perceptions that the neighborhood has
heavy traffic and no lights or safe crossings or that children need to cross sev-
eral roads to reach play areas, are related to a decreased likelihood of children
walking or cycling at least three times per week, depending on the child's age
and gender (Timperio, Crawford, Telford, & Salmon, 2004). Social ecological
models support the hypothesis that behaviors are influenced by both the social
and physical environments, as well as by intrapersonal factors (Sallis & Owen,
1999). The focus of interventions drawn from a social ecological model is on
the implementation of structural changes in the environment rather than on
individual-level approaches (Matson-Koffman, Brownstein, Neiner, & Greaney,
2005). Examples include increasing the availability of low-fat foods (e.g., through
school policies aimed at reducing fat in school lunches) and implementing reg-
ulations requiring sidewalks within a community.

Clinic/Primary Care

Health behavior change interventions that are delivered by physicians or other
medical staff in the clinic are usually perceived as credible by the targeted per-
son. Physicians also are able to monitor children's health and to check their
health status against national norms (e.g., BMI) over time (Wald et al., 2005).
The one-on-one setting promotes discussion about the individual child's health
needs (Taylor, 1999), and parents may be more willing to voice their concerns
about their child's health to a trusted family pediatrician than to an unfamil-
iar behavioral interventionist. In many cases, the family doctor will also have
knowledge about the child's family's medical history and health behavior (e.g.,
history of cancer, diabetes, obesity, or smoking). Another advantage is that par-
ents may be more likely to follow a pediatrician's recommendations for health
change. Some innovative physician practices are attempting to integrate "health
coaches" to better motivate patients to make health behavior changes (Adelman
& Graybill, 2005). One drawback to implementing health behavior change inter-
ventions through a physician's office is that only one child is helped at a time.
Also, depending on the age of the child and the frequency of medical visits, the
follow-ups may be too few and far between.

Intervention Strategies

The types of interventions used with children vary and may include a combi-
nation of behavioral, educational, and environmental components. Behavioral

interventions may include such strategies as self-monitoring via charting, goal setting, and the earning of rewards for appropriate gains. Educational interventions are based on the belief that children and parents will change their health behaviors if they are given adequate information about desirable health behaviors. Environmental interventions use strategies that involve changing the physical surroundings and social, economic or organizational systems to promote individual behavior change.

Interventions to Improve Lifestyle Behaviors in the General Population

Two of the most common causes of disease, disability, and premature death in the United States are the health risk behaviors of consumption of an unhealthy diet and physical inactivity (Mokdad et al., 2000). Therefore, a general purpose of lifestyle interventions for the young, regardless of risk status, is to promote the adoption of healthy lifestyle behaviors for reducing the risk of diseases such as type 2 diabetes mellitus, cardiovascular disease, hyperlipidemia, and certain types of cancer that may occur in childhood or later in adulthood. These interventions target dietary intake, physical activity, sedentary behavior, or a combination of these.

As an example of a dietary change intervention, a school-based program targeted fruit, 100% juice, and vegetable (FJV) consumption changes by meal among fourth graders participating in "Squire's Quest!," a 10-session individualized multimedia game (Cullen et al., 2005). The game involves many meal- and environment-specific behavioral change techniques and is based on social cognitive theory (Bandura, 1986). At each session, students set goals to make at home the recipe prepared in the virtual kitchen and to eat an FJV serving at a specified meal and snack at home and at school. A total of 26 elementary schools were randomly assigned to treatment or control groups. Results were that students in the intervention group consumed one more serving FJV per day, with significantly more servings of fruits and 100% fruit juice at snacks and more vegetables at lunch than did children in the control condition schools. Conclusions were that while multimedia games with meal- and environment-targeted goal setting may improve dietary habits within the school setting, additional research is needed to generalize these improvements to meals eaten outside school.

As an example of a lifestyle-intervention targeting physical activity, 30 pre-adolescent girls from two after school programs were randomized to a Pilates intervention or control group (Jago, Jonker, Missaghian, & Baranowski, 2006). The Pilates classes were provided free for an hour per day, 5 days a week, for 1 month. Mean attendance was 75%. Findings were significant time by group interactions for BMI percentile, with small changes in BMI percentiles for the intervention group. Another intervention targeted the physical activities of 228 children over a 3-year period, from ages 3 to 7 years (Sääkslahti et al., 2004). Parents in the intervention group attended annual hour-long meetings to discuss the importance of physical activity for children. Twice yearly they were provided with printed education materials and activity posters. In addition, they were given a board game that involved practicing many different fundamental motor skills. Children in the intervention group spent significantly more time

playing outside, and engagement in high-activity play increased with age in the intervention group but not for the controls.

Interventions for the Prevention or Treatment of Childhood Obesity

Other lifestyle interventions for the young are specifically designed for the prevention and treatment of childhood overweight. The prevalence of childhood overweight is growing at an alarming rate and is linked to serious short- and long-term morbidity (Freedman, Dietz, Srinivasan, & Berenson, 1999; Strauss, 1999; Williams et al., 2002). Unfortunately, young children are not immune from the growing trend, and even preschool-age children are evidencing increasing rates of becoming overweight (Mei, Scanlon, Grummer-Strawn, Freedman, Yip, & Trowbridge, 1998; Ogden et al., 1997). In an overview of obesity prevention, Baranowski and colleagues (2000) noted that increased activity and improved diet are beneficial for everyone regardless of their risk for obesity. Testing broad, population-based prevention programs may be reasonable to reduce adiposity for the overweight, to potentially lower the overall incidence of obesity, and to improve protective behaviors against chronic disease among all children who are targets of the programs. Targeting interventions to children who are already overweight or obese is valuable because it directs a program at those most likely to benefit. Much progress has been made in the treatment of childhood obesity (Epstein, Myers, Raynor, & Saelens, 1998), and reviews suggest that behavioral treatments of childhood obesity targeting lifestyle behaviors are considered to be empirically validated treatments (Jelalian & Saelens, 1999).

Prevention of Childhood Obesity

An obesity prevention program specifically targeting preschoolers is "Hip-Hop to Health, Jr." (Fitzgibbon et al., 2004; Stolley et al., 2003). This is a well-designed 5-year randomized clinical trial of a dietary and physical activity intervention targeting 3- to 5-year-old minority children enrolled in Head Start. Children in the intervention arm participated in a 14-week healthy eating and physical activity program (40 minutes at three times per week) that involved a 20-minute lesson with colorful handheld puppets and 20 minutes of physical activity. Parents of children in the intervention arm received weekly newsletters with information on healthy eating and physical activity that included a homework assignment, and they received a $5 coupon for each assignment they turned in. The controls received a 14-week program on general health with a similar parent newsletter. Results for 197 intervention and 212 control children were that the intervention group had significantly smaller increases in BMI than did controls at 1- and 2-year follow-ups (approximately .54 kg/m^2). No significant differences were found for parent-reported food intake/physical activity except that the percentage of calories from saturated fat was higher in controls at 1-year follow-up. The sample included primarily African American children, and approximately 1/3 of the children were overweight or obese. Relative effects of the intervention were similar for children who were of normal

weight and those who were either overweight or obese (i.e., at or above the 85th percentile of BMI) at baseline.

Treatment of Childhood Obesity

Interventions targeted at high-risk groups, such as children who are obese or who have one or more obese parents, are an alternative approach to prevention (Baranowski et al., 2000). In one study of 63 8–12-year-old obese children, various methods for reducing sedentary behavior were compared. Epstein and colleagues (Epstein, Paluch, Kilanowski, & Raynor, 2004) evaluated family-based behavioral treatment that included either reinforcement or stimulus control of sedentary behavior. In the reinforced group, positive reinforcement was contingent on reducing targeted sedentary behaviors; in the stimulus control group, positive reinforcement was contingent on recording targeted sedentary behaviors. The treatment program for both groups included 16 weekly meetings, followed by four follow-up meetings during a 6-month period. Families received workbooks for weight self-monitoring, information on the *Traffic Light Diet* and behavior change techniques, and suggestions for maintenance of behavior change. Findings were significant, with equivalent improvements in lifestyle behaviors noted for both groups. Children who substituted physical activity for sedentary behaviors had significantly greater BMI z-score changes at 6- and 12-month follow-ups.

The primary care setting has been a recently expanding area for intervening to prevent or treat childhood obesity. In a pilot study by Wald et al. (2005), an intervention was tested in two diverse primary care settings where physicians were trained in using brief motivational strategies to help parents make health behavior changes related to nutrition and physical activity for their overweight or obese children. The intervention was successful at increasing physicians' willingness to engage in discussions about nutrition and weight status with parents of their high-risk child patients. The practice of measuring and charting the children's BMI-for-age percentiles was easily integrated into current practice.

Interventions for Risk Reduction for Specific Future Health Conditions

Osteoporosis

Prevention of osteoporosis provides an opportunity to test behavioral interventions for improving healthy lifestyle behaviors among children (Ievers-Landis et al., 2003). Although commonly associated with postmenopausal women and the elderly, osteoporosis has been linked to bone development during childhood and adolescence (Cummings et al., 1985). Peak bone mass is one of the major predictors of the risk of fracture in osteoporosis, and approximately 40% of the skeletal structure is built and enlarged during late childhood and early adolescence (Cummings et al., 1985). Females are particularly at risk for development of osteoporosis. The risk of developing osteoporosis can be reduced by the adoption of healthy lifestyle behaviors (e.g., increasing dietary calcium [Ca]

intake and weight-bearing physical activity [WBPA]) (Teegarden, Lyle, Prouiz, Johnston, & Weaver, 1999).

A randomized controlled trial of a behavioral-educational intervention for the primary prevention of osteoporosis was conducted for 247 preadolescent girls via their Girl Scout troops (Ievers-Landis et al., 2005). Troops were randomly assigned to two intervention groups, girls only or girls with their mothers, or to a healthy lifestyles control group. The program, *Know Bones About It,* involved skills training in enhancement of dietary Ca intake and WBPA using self-monitoring, feedback on goal attainment, social persuasion, problem-solving training, role modeling, and practice of the desired behaviors (e.g., jumping rope and eating Ca-rich snacks). Sessions for the group that included mothers were the same as those for the girls-only group but included two interactive sessions led by a psychologist who focused on maternal role modeling, creating a healthy environment, and positive reinforcement. Among girls who met the recommended levels of Ca at baseline, those in the intervention groups were significantly more likely to maintain or improve their intake at follow-up visits than were girls in the control group. No significant group differences were found for changes in WBPA.

Risk Reduction for Skin Cancer

The American Academy of Dermatology reports that almost one in six people will develop some type of skin cancer in his or her lifetime, and other reports show 25% of people under the age of 40 will develop melanoma (Ahmedin, Thomas, Murray, & Thun, 2002; Turrisi et al., 2004). The majority of the reported cases of skin cancer are now believed to be the result of the use of tanning equipment and salons, inadequate sun protection (misuse or lack of sun block) and excessive intentional sun bathing (Hall, May, Lew, Koh, & Nadel, 1997; Thompson, Jolley, & Marks, 1993; Turrisi et al., 2004). Interventions aimed at reducing unsafe sun behaviors have addressed individuals' beliefs about sun safe behaviors and sun risk through educational programs (Turrisi et al., 2004). Hypotheses are that beliefs about risks posed by exposure to the sun will influence intentional sun-related behaviors (tanning and sunbathing) and consequences (Clarke, Williams, & Arthey, 1997; Turrisi et al., 2004).

An intervention study by Turrisi et al. (2004) was designed to prevent skin cancer in children and young adolescents by using parents as the primary change agents. Four hundred and sixty nine children were divided into intervention and control groups. Parents in the intervention group were given a handbook that provided background information on the incidence of skin cancer and consequences of UV exposure. The handbook included intervention materials that instructed parents on how to initiate conversations about skin cancer, including discussions of high-risk and positive "sun-safe" behaviors. Other materials included teaching children assertiveness skills and techniques for dealing with peer pressure. Evaluation of the intervention outcomes found significant differences between treatment and control groups; participants in the treatment group became sunburned less often and had less severe burns than did those in the control group. The groups also differed significantly in terms of sunbathing tendencies and attitudes and beliefs about sunbathing, tanning, appearance, and skin cancer risk.

Risk Reduction for Other Types of Cancer

Risk reduction efforts for other types of cancers related to lifestyle behaviors should begin in childhood and continue throughout all stages of life (Uauy & Solomons, 2005). Even among young children, being overweight is linked to potentially increased cancer risk (Berkey, Gardner, Frazier, & Colditz, 2000; Freedson, Melanson, & Sirard, 1998; Strauss, 1999). By age 6, children who are overweight show hormonal changes that are risk factors for cancer in adults who are obese (Gascon et al., 2004). Girls who are overweight and inactive in preadolescence may experience early menarche, a risk factor for breast cancer (Chavarro et al., 2005). Physical activity and body size and composition are well-recognized strong predictors of the initiation of menses (Berkey et al., 2000). If the trend toward a greater incidence of childhood overweight continues, we can expect an increase in the incidence of certain types of cancer as these children become adults. Obesity in adulthood is a proven risk factor for cancers of the colon, female breast, endometrium, kidney, esophagus, and liver (Bugianesi, 2005; Key, Allen, Spencer, & Travis, 2002; Key et al., 2004). Cancer risk reduction beginning with young children is also vital because food preferences and physical activity habits are set relatively early in life (Birch et al, 2001), and both may be important for prevention of cancer (Key et al., 2002, 2004). Fruit and vegetables may reduce the adult risk for cancers of the oral cavity, esophagus, stomach, and colon, and physical activity reduces risk for colorectal and possibly breast cancer (Key et al., 2004).

Although not yet a common focus, interventions are being designed to address the link between lifestyle behaviors in childhood and future cancer risk. For example, recently published results from a school-based obesity prevention program demonstrated that a one-unit increase in baseline BMI was associated with a 7% increased risk of early menarche. Attending a school assigned to intervention status was associated with a decreased risk of experiencing early menarche during the 19-month study period (Chavarro et al., 2005). Other interventions with children that focus on healthy lifestyles or prevention and treatment of obesity may have an impact on later cancer incidence. Specific mediators in addition to weight status, hormonal changes and time of menarche related to health behaviors may predict future cancer risk for children and should be explored. Examining animal models may lead to the identification of other mediators to be examined, though the time factor in determining whether risk reduction interventions will be effective in reducing cancer incidence makes this area quite challenging.

Interventions to Reduce Accidents or Unintentional Injury

A majority of children and adolescents are at risk for death due to preventable accidents or unintentional injuries. According to the Centers for Disease Control statistics (Centers for Disease Control, 2004), accidents or unintentional injuries were the leading cause of death for this population. Children are at a greater risk for morbidity and mortality due to unintentional injuries than are adults. In Westernized countries, unintentional injuries have replaced infectious disease as the major cause of death in childhood (Bockholdt & Schneider, 2003). The strongest predictors of injury are male gender, inadequate supervision, and an impulsive temperament (Brehaut, Miller, Raina, & McGrail, 2003).

Every year about 1 million people die and about 10 million are seriously injured on the roads across the globe (Murray & Lopez, 1996). The World Health Organization (WHO) has reported that for children, adolescence and young adults ages 3–35 years, road traffic crashes are now the leading cause of disablement and death. Children are particularly vulnerable, and pedestrian injuries account for most of the childhood road deaths each year (Duperrex, Bunn, & Roberts, 2002; Murray & Lopez, 1996; Rivara, 1990). To reduce and possibly prevent pedestrian injuries, educational measures to teach children how to cope with traffic are considered to be an important part of any intervention (Duperrex et al., 2002). Duperrex et al. (2002) reviewed current randomized controlled trials on pedestrian road-crossing behavior. Their aim was to identify the effectiveness of safety education interventions for pedestrians in improving knowledge and behavior as a means for preventing pedestrian-related motor vehicle accidents. Their findings were mixed, partly because of the multiple risk factors for child pedestrian injuries. They found that behaviorally oriented interventions might be best able to address these issues.

One such intervention designed by Barton, Schwebel, and Morrongiello (2006) tested a skill-based training intervention for increasing safe road-crossing behaviors in children. The intervention targeted multiple basic pedestrian skills, such as waiting for safe traffic gaps and looking right and left before crossing. The intervention components were designed to be delivered in a single brief session (less than 15 minutes) and could be taught by parents. The intervention was delivered to 85 children ages 5–8 and utilized a pre-post design. Results of the study indicate that children behaved more safely following training. Specifically, children attended more to traffic patterns, waited longer before crossing the street and waited for larger gaps between vehicles prior to crossing. The study also found that girls and older children engaged in safer pedestrian behaviors than did boys and younger children.

Future Directions

Sleep Enhancement Interventions

Sleep is often overlooked in discussions of lifestyle behaviors, but children's sleep habits are as important as diet and activity levels for their present and future health (Ievers-Landis & Redline, 2007). As a prime example, insufficient sleep is one potentially vital factor that has been neglected in interventions to prevent or reduce childhood overweight; lack of sleep is emerging as a novel risk factor for overweight in both children and adults. A review by D. B. Allison and colleagues (Keith et al., 2006) of novel risk factors for the obesity epidemic recently identified a number of environmental and sociocultural factors that have changed since 1970 with the substantial increase of obesity. In addition to environmental changes that focus on food marketing practices and institution-driven reductions in physical activity, this group identified at least 10 additional explanations, including sleep debt. Longitudinal data suggest a causative role for short sleep in the preschool period for the later development of childhood overweight (Agras et al., 2004). In a prospective study of 150 children, hours of sleep reported annually for children ages 3 to 5 were negatively related with overweight status at 9.5 years of age (Agras et al., 2004). Children who were to become overweight were reported to sleep 30 minutes less on average in a

24-hour period than those who remained normal weight. Several large cross-sectional studies of childhood obesity have reported strong associations between obesity and short sleep duration, including among children as young as 5 (Locard et al., 1992; Sekine et al., 2002; Von Kries, Toschke, Wurmser, Sauerwald, & Koletzko, 2002). Short sleep duration has emerged as a stronger predictor of childhood overweight than parent education, parent BMI, children's birth weight, snacking habits, and sedentary behavior. An urgent need exists for the development, validation, and dissemination of sleep enhancement interventions for children of all ages.

Primary Care Practice for Supporting Healthy Behaviors

Many of the issues in this chapter may be addressed by prevention counseling practices of primary care pediatricians. Further efforts are needed to improve the ability of pediatricians to effectively deliver educational materials, individualized advice and recommendations of resources for further reading (e.g., specially created Internet portals) or for local classes and memberships (e.g., referral to a dietitian, recommendation to join a gym) to parents. As examples, currently primary care pediatricians may not be adequately addressing osteoporosis and obesity prevention. According to a survey of 187 primary care pediatricians, knowledge of the U.S. recommended daily allowance for Ca in children and adolescents was limited, with only 23.7% and 32.3% correctly identifying the recommended values for children and adolescents, respectively (Fleming & Patrick, 2002). Additionally, fewer than half reported that they counseled patients to reduce osteoporosis risk because other issues took priority or they lacked the sufficient time to bring up such issues. A survey of 1,066 physicians regarding their attitudes and practices related to treatment of childhood overweight in primary care settings found that only 26.6% of physicians discussed weight with children age 12 and younger who were mildly overweight, while 95.5% discussed weight with children who were morbidly overweight (Jelalian, Boergers, Alday, & Frank, 2003). Physicians may benefit by obtaining ongoing education about lifestyle behavior (e.g., obtaining specialized training by attending workshops) and by reading brief information sheets about the prevention of future health conditions such as osteoporosis and skin cancer (Fleming & Patrick, 2002).

Another area of growth could be via the inclusion of motivational interviewing (MI) techniques into the primary care setting. MI is designed to increase intrinsic motivation in patients by exploring and resolving areas of ambivalence (Miller & Rollnick, 2002). MI is a patient-centered directive therapy that is based on the five guiding principles of showing empathy, being aware of ambivalence, understanding resistance to change, avoiding arguments, and supporting self-efficacy (Miller & Rollnick, 2002). In a study by Adelman and Graybill (2005), the use of MI-consistent strategies by a "health coach" in primary care settings led 48% of the adult patients studied to initiate health behavior change in their physical activity or eating habits. Exploring the use of MI-consistent strategies delivered by a health coach in pediatric offices to work with both parents and with older children regarding their ambivalence about behavior change is an area for further exploration.

Summary

Lifestyle interventions for the young include a wide range of approaches and settings, including the classroom, with parents and family in the home, and environmental, clinic-based, and primary care settings. Strategies to change behaviors often take into account a combination of behavioral, educational, and environmental factors. Although many of these interventions focus on improving children's dietary intake and activity levels, the stated purposes of the interventions vary from general prevention of later health conditions regardless of risk status to specific goals for treatment of childhood obesity or prevention of osteoporosis, various cancers and accidents or unintentional injuries. In the future, researchers are encouraged to consider the addition of sleep as a vital lifestyle behavior because of the consistent finding of a strong relationship between insufficient sleep and childhood obesity. Also, efforts for greater involvement of pediatricians are strongly encouraged to strengthen existing pilot work and to build on successful programs with adult patients, such as the use of MI-consistent strategies using a "health coach."

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Problems With Adherence in the Elderly

26

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The aging population in the United States is one of the major public health challenges in the 21st century. Two factors, longevity and aging baby boomers, will influence the growth of Americans 65 years or older during the next 25 years (Centers for Disease Control and Prevention [CDC] and Merck Company Foundation [MCF], 2007). Baby boomers, those born between 1946 and 1964, represent nearly one-third of the population and will begin turning age 65 in 2011; by 2020, all of the baby boomers will be age 65 or older. As a result, older Americans are expected to make up 20% of the total population (U.S. Bureau of the Census, 2000).

Improved medical care and prevention efforts have contributed to dramatic increases in life expectancy. Persons born in 1900 could expect a life expectancy of 47 years, whereas those born in 2001 can expect to live 77 years (CDC & MCF,

2007). As a result of longer life spans, major shifts have occurred in the leading causes of death. Infectious and acute diseases have been replaced by chronic and degenerative diseases. The three leading causes of death in persons 65 years and older are heart disease, cancer, and stroke. It is estimated that 80% of older Americans have a minimum of one chronic disease, and 50% have at least two (National Center for Health Statistics [NCHS], 2006). More than two-thirds of health care costs are currently spent treating chronic illness conditions in older adults, with 95% of the health care expenditures for the three major chronic diseases. By 2030, it is expected that health care expenditures will increase by 25%, without taking inflation into account, because of the demographic shift to an elderly population.

The expanding aging population and its accompanying increased burden of chronic diseases have created new challenges to ensure that the added years are quality ones. A major challenge is management of medical regimens (CDC & MCF, 2007). Almost half of all older Americans are treated for hypertension or arthritis. Other chronic conditions requiring treatment include heart disease, cancer, stroke, and diabetes. At some point, all chronic conditions require adherence to complex medication regimens or other types of treatments to effectively manage the disease and postpone disability and death. However, adherence rates to long-term regimens average 50%, regardless of the illness, regimen, or adherence criteria (World Health Organization [WHO], 2003). Nonadherence is most common with chronic conditions, in long-term therapy, and in preventive efforts (WHO, 2003). Thus, adherence is and will persist as a major health care issue in the elderly.

This chapter discusses the multiple factors that contribute to nonadherence to medical regimens in the elderly. First, types of nonadherence are described. Factors that influence one's ability or desire to adhere, such as quality of patient-provider relationships, regimen complexity, presence of adverse side effects, personal and cultural beliefs, health literacy, physical changes, cognitive alterations, depression, and adequacy of social and financial resources, are then summarized. Methods to assess an older person's capacity to adhere are described, and the chapter concludes with a review of strategies to increase adherence in the elderly. Adherence to prescribed medication regimens for chronic conditions is the focus of the chapter. However, many of the factors that promote nonadherence, as well as the strategies to promote adherence, are applicable to other types of regimens or lifestyle changes in which adherence is an issue.

Types of Nonadherence

Persons 65 and older are the largest consumers of pharmaceutical agents. Although the elderly comprise only 13% of the population, they use more than 34% of all prescription medications and approximately 30% of nonprescription drugs (Haynes et al., 2005). An average of 11 prescriptions is filled each year by elderly persons living in the community. The elderly also purchase and consume seven times the number of over-the-counter medications purchased by younger persons (Anderson, Ory, Cohen, & McBride, 2000). The commonly used over-the-counter drugs are analgesics, laxatives, antihistamines, and sympathomimetics.

Medication costs are second only to nursing home costs in out-of-pocket expenses in this age group. Health care costs are also incurred because of the large number of hospitalizations for drug-related illnesses. More than 200,000 elderly are admitted to hospitals annually because of adverse drug reactions, or they may have prolonged hospital stays because of an adverse drug reaction during hospitalization (Esposito, 1995).

Medication adherence in the elderly has been estimated to be as low as 40% and as high as 75% (Haynes et al., 2005). Medication nonadherence places an elderly person at risk for debilitating health problems, increased hospitalization, and death. Approximately 11% of hospitalizations in persons over the age of 65 have been attributed to medication nonadherence (Vik, Maxwell, & Hogan, 2004). Increased physician outpatient and emergency room visits, hospitalizations, and nursing home admissions place the cost of nonadherence at $13 to $22 billion per year. Nonadherence is not a dichotomized behavior, as medication use is complex. Persons may not adhere intentionally or unintentionally. Or nonadherence may result from taking an incorrect dosage of medication or taking medications at an incorrect time or sequence.

Intentional and Nonintentional Nonadherence

Intentional and nonintentional medication overuse and underuse are two types of nonadherence to medication regimens in the elderly (Atkins & Fallowfield, 2006; Brookhart et al., 2007). Intentional nonadherence occurs when a patient makes a specific decision not to take the medication as prescribed. Intentional nonadherence may be due to (1) lack of information about the pros and cons of treatment, (2) lack of immediate benefit from the medication, and/or (3) negative beliefs about the value of the medication (Atkins & Fallowfield, 2006). Intentional underuse may occur when elders deny the diagnosis of an illness. Intentional underuse also occurs when the patient does not believe the medication is needed or does not want to be overmedicated. Medication "hoarding," or saving medication for a future problem, is another example of intentional underuse and is often related to the high costs of drugs. Intentional underuse may result from a lack of financial resources to pay for prescriptions, as some prescriptions are never filled. Uncomfortable side effects of medications may also result in intentional underuse or even termination of the medication. For example, diuretics are often considered a hindrance to activities and may be taken only in response to symptoms, instead of as prescribed. Medication regimens that are disruptive to the person's daily activities or routines result in intentional underuse. For example, doses may be skipped or eliminated if they interfere with social or lifestyle activities. Intentional overuse is often attributed to the belief that the prescribed dose is ineffective or that "more is better" to relieve symptoms or promote recovery.

Drug holidays, another form of intentional nonadherence, refer to interruptions in medication use lasting more than 3 days (Brookhart et al., 2007). Drug holidays have been observed when medications have been electronically monitored in controlled settings. Long, unexplained drug holidays have been commonly reported among users of osteoporosis medications, as women stop and restart medications (Brookhart et al., 2007). Women are more likely to restart if the drug holiday is less than 120 days. Cyclic nonadherence points to the

complexity and need to evaluate both intentional and nonintentional nonadherence simultaneously to better understand medication taking.

Unintentional nonadherence may be due to forgetting or misunderstanding instructions. Forgetfulness may result in unintentional overuse if the patient does not remember taking a medication and takes a second dose. Forgetfulness is the most common reason for unintentional underuse of medications. The inability to perform simple tasks that depend on adequate functional performance, such as the ability to open a medication bottle or cut pills, may also result in unintentional underuse.

Nonadherence may also occur when medications are not taken at the correct time or in the correct sequence. Patients have reported modifying doses and dosing regimens to accommodate their daily activities and commitments. For example, a medication prescribed twice a day may be taken only once daily, or a medication prescribed every 6 hours may be taken every 4 hours. Timing errors may result in what the health care provider perceives as treatment failure or precipitate unnecessary or inappropriate treatment changes.

Factors That Promote Nonadherence in the Elderly

Multiple factors contribute to the problem of nonadherence in elderly persons. First, patient-provider relationships are a key factor. Second, the complexity of the medical regimen may promote nonadherence, as may adverse side effects of the medications. Physical changes that occur with aging, such as declining functional performance and visual and hearing alterations, as well as cognitive changes, may have an effect on adherence (Lehane & McCarthy, 2007).

Emotional health, specifically depression, is also considered a factor in nonadherence in older persons. The lack of resources, including social networks and social support (presence of companions or friends, living arrangements) and financial resources, also promotes nonadherence. Personal and cultural beliefs and health literacy have also been documented to contribute to nonadherence. Each of these factors is described in detail to provide an understanding of their potential role in the problem of nonadherence in the elderly.

Patient–Provider Relationships

The relationship between patients and health care providers has long been associated with adherence, presumably because good relationships are associated with improved communication (Honda & Kagawa-Singer, 2006; Madigan, Majumdar, & Johnson, 2005). The behavior and attitudes of health care professionals, as well as the amount of time spent with patients in a supportive environment, can have either positive or negative effects on adherence (Tarn et al., 2006). Providers may lack the expertise to assess adherence appropriately, or they may not have the time to discuss adherence. Closed-ended questions, requiring just a yes or no response from the patient, do not provide opportunities for discussion (Bokhour, Berlowitz, Long, & Kressin, 2006). If patients are not satisfied that their questions are being answered or if their expectations for the encounter have not been met, they are more likely to be nonadherent (Burge

et al., 2005). Although patients expect their health care providers to be their primary information resource, they report that they often feel inferior or do not understand the provider's medical jargon or think they are given too little information for it to be helpful (Gordon, Smith, & Dhillion, 2007).

Complexity of Drug Regimen

Regimen complexity is routinely cited as a reason for nonadherence (Dunbar-Jacobs, Erlen, Schlenk, et al., 2000; McNabb, Nicolau, Stoner, & Ross, 2003), although some reports also indicate that complexity may not influence medication adherence (Shalansky, 2002, Burge et al., 2005). Polypharmacy regimens report adherence rates 10% to 20% lower than monotherapy regimens (Larson, Vaccherei, Anderson, Montanaro, & Berbman, 2000; Melekian, White, Vanderplas, Dezeii, & Change, 2002). Patients with type two diabetes have been shown to have adherence rates of 79% with once daily dosing compared to 38% for three times daily. In addition, medications were taken at the correct prescribed time in 77% of cases for once daily dosing compared to 5% for three times a day dosing (Rubin, 2005).

The presence of more than one chronic illness in many elderly patients results in the administration of a large number of medications. More than one specialist may be consulted, resulting in multiple prescribers and prescriptions. Thus, polypharmacy is commonplace. Excessive and often inappropriate prescribing is not uncommon. Reasons for this have been documented and include the failure to make an accurate diagnosis due to inadequate clinical assessment before issuing the initial prescription; the influence of the pharmaceutical industry, which promotes prescribing; overenergetic treatment, which leads to incremental prescribing; patient or family demands; failure to conduct careful medication histories; inadequate review of patient records, resulting in a failure to discontinue drugs; and lack of continuity of care between acute and outpatient facilities (Walley & Scott, 1995). Having a larger number of drugs associated with a more complex administration schedule is also a deterrent to adherence. Multiple dosing schedules, rather than a single dose or twice-daily doses, may interfere with leisure activities or sleep and are more likely to be forgotten by the elderly. In addition, the consumption of multiple drugs may result in unpleasant drug-drug interactions in which one drug may either interfere with or enhance the action of another, or one drug may change the manner in which the body handles a second drug (Yee & Williams, 2002). Changes in drug regimens or switches from brand names to generic drugs are also confusing to the elderly and may result in nonadherence (Sorenson, Stokes, Purdue, Woodward, & Roberts, 2005).

Adverse Side Effects

Drug–Age Pharmokinetics

Because of age-related changes that occur in the body, older persons respond differently from younger people to medication. Pharmokinetic alterations include changes in absorption, distribution, metabolism, and elimination. Absorption of drugs by passive diffusion is not affected by aging. However, alterations in gastric motility and blood flow can influence drug absorption. Distribution or transportation of drugs throughout the body may be altered by age-related

changes, including decreased lean body mass, increased body fat, and decreased total body water. Thus, dosages of water-soluble drugs, including digoxin, propranolol, and cimetidine, need to be altered, as well as those for drugs that are distributed into adipose tissue. In addition, fat-soluble drugs such as barbiturates and phenothiazines produce prolonged actions or adverse effects due to the large amounts that may be stored in fat.

The major site for drug metabolism is in the liver. Hepatic mass and hepatic blood flow decrease with age. The decreased blood flow means a decreased extraction (first pass) of the drug by the liver, which produces an increase in serum drug levels and strengthens the clinical effects of certain drugs, such as propanalol, verapamil, and some opiates.

The kidney is the major organ of drug excretion. Renal blood flow and perfusion decrease with age. Therefore, dosages must be reduced for drugs that are dependent on renal blood for excretion, such as digoxin, lithium, and antibiotics. In addition to the effects of aging, common chronic illnesses, such as congestive heart failure, cirrhosis, nutritional deficiencies, hypertension, and kidney diseases, may impair absorption, metabolism, and excretion.

Adverse Effects

Significant adverse side effects and toxicity may occur if the physician does not understand age-related changes in pharmokinetics when prescribing pharmacologic therapies and prescribes incorrect doses. Deleterious effects or perceived lack of benefits result in nonadherence, as well as increased health care costs due to hospitalizations.

Adverse side effects are thought to be the most common reason for nonadherence. Adverse side effects increase the risk of nonadherence, as they are often more troublesome than the disease itself, as in the case of hypertension, which is usually asymptomatic. In addition, many side effects make it difficult for an elderly person to continue the treatment regimen because of the annoying nature of the symptoms, such as confusion, sedation, dizziness, diuresis, appetite and mood changes, constipation, sleep disturbances, and problems with gait instability and physical performance. Antihypertensive agents, the most commonly prescribed medication in the elderly, may cause psychiatric symptoms (Siegel, Lopez, & Meier, 2007). Any of these side effects may cause deterioration in both physical health and quality of life. Although adverse side effects may be serious and long lasting, they are rarely addressed in office visits, as it has been documented that fewer than 25% of patients mention side effects to their health care providers (Rubin, 2005). Many elderly do not report side effects because they do not consider the side effects to be abnormal, or they may not know what to do if side effects occur. In addition, they may be embarrassed to report symptoms, such as forgetfulness or confusion, because they believe they will be labeled demented.

Lack of Information and Inadequate Instructions

Lack of knowledge of medications and their side effects is a major factor in nonadherence; the problem is twofold. Physicians and other health care professionals often do not provide adequate information, and many elderly are

hesitant to ask for information. Many older persons believe they do not receive adequate information about their prescriptions from their health care providers (Gordon et al, 2007). It is estimated that as many as 50% of patients leave physicians' offices without understanding their medical regimens. When explanations are provided, they are couched in medical terminology that is foreign to most people, including elderly patients. Persons are less likely to follow a prescribed regimen when the instructions are not clear and understandable. Elderly patients do not want to be viewed as what they perceive to be a "problem patient," so they do not acknowledge their lack of understanding. Hearing and visual difficulties, as well as increased forgetfulness and decreased attention span, also interfere with an elderly person's ability to understand and remember instructions. Persons adhere to regimens they understand and believe in and have the ability to follow. Patients vary in the type and level of information needed, so tailoring information and instructions is key to promoting medication adherence.

Personal and Cultural Beliefs

The personal and cultural health beliefs of older adults may influence adherence both positively and negatively. Older adults have higher reported adherence when they believe that the prescribed medication is essential for their health and that they will derive benefits from taking it and when they have few concerns about side effects (Chia, Schlenk, & Dunbar-Jacobs, 2006). Patients must believe in the value of the regimen and also believe that they have the ability to overcome barriers to adherence.

The health care environment in which older persons receive treatment must not be in conflict with their cultural beliefs if they are to adhere to treatment for chronic diseases (Hughes, 2004). If patients' views of illness and treatment are not consistent with the views of the health care provider, they are less likely to accept the prescribed therapy. All cultures have explanatory models of health, and many are not congruent with the traditional biomedical model (Schraufnagal, Wagner, Miranda, & Roy-Bryne, 2006). Strong ties with family and friends reinforce patients' cultural beliefs, often resulting in a reluctance to seek treatment and a tendency not to adhere to treatment regiments. For example, older persons who believe that natural products and home remedies will be more effective than conventional therapies are more likely to take home remedies than their prescribed medications.

Persons who hold fatalistic beliefs or accept an external locus of control are also more likely to exhibit poor adherence. Both types of beliefs have been associated with decreased access to care and low adherence, as these persons believe they have little control over their own health and are often more passive in health care encounters (Schraufnagal et al., 2006).

Health Literacy

It is estimated that 48% of the adult population in the United States lack the literacy proficiency needed to understand and act on health information (Institute of Medicine [IOM], 2004). Health literacy, defined as the degree to which the patient has the capacity to obtain, process, and understand health information

and services needed to make appropriate health decisions, goes unrecognized by health care providers, who rarely verify patients' recall and comprehension of their treatment regimens (Schillinger, Grumbach, & Piette, 2002; Selden, Zorn, Ratzan, & Parker, 2000). Limited health literacy predicts less successful self-care and worse health outcomes, as studies show that patients with lower health literacy are less likely to understand verbal or written instructions for self-care, including medication regimens (Kripalani et al., 2007). Patients with low health literacy may not be able to read or understand medication labels, leading to nonintentional nonadherence. There are economic consequences to limited health literacy; these individuals are more inefficient in their use of health care services and incur greater health care costs than people with greater health literacy (Howard, Gazmararian, & Parker, 2005). In persons with limited health literacy skills, nonadherence and other adverse health outcomes are associated with limited chronic disease knowledge, poor self-management skills, and failure to use appropriate preventive services (Wolf, Gazmararian, & Baker, 2007).

Functional Performance Changes

Functional performance declines in the elderly. More than poor posture results from decreases in strength and flexibility. Loss of strength and flexibility compounds problems in walking or performing activities of daily living (Lewis, 2002). However, decreases in strength may go unnoticed for long periods because normal daily activities do not require great strength. Strength, flexibility, and balance ensure adequate gait or mobility. Bilateral standing balance is necessary to free the upper extremities for activities, while unilateral balance is essential for stepping over obstacles and climbing stairs. Changes in gait that occur in aging include slowed walking speed, flexion in the thoracic spinal area, a loss of the lordic curve in the lumbar spine, a forward head position, short shuffling steps, and a loss of normal arm movement. Functional performance is essential to accomplish everyday activities such as bathing, dressing, toileting, shopping, preparing meals, using transportation, and performing simple psychomotor skills. Functional performance is important in taking medications, as older persons may experience problems in manipulating packaging, especially child-resistant containers and blister packs. Any changes that result in a deterioration in functional performance and the capacity to maintain independence affect one's ability to perform activities necessary to adhere to certain treatments regimens.

Visual Changes

Visual changes occur with aging; reduced vision is the most common sensory problem in the aged, and at least 90% of persons over age 60 need vision correction (Heath, 1992a). The major visual impairment in the elderly, presbyopia, is caused by a loss of elasticity and increased density of the lens. The ciliary muscles that hold the lens also lose their ability to accommodate rapidly, resulting in the need for bifocal lenses. Age-related ocular changes include altered depth perception, increased light threshold, arcus senility, increased eyelid laxity, and decreased tear production. Cataracts are the most common ocular disease in the elderly. Two

other major ocular diseases affecting the elderly are glaucoma and macular degeneration. All three of these diseases result in visual impairments, and glaucoma and macular degeneration can result in blindness. In addition, chronic diseases, such as diabetes mellitus, cause eye changes that may result in blindness. Visual problems often go undetected until late in the disease process, because these changes may be associated with aging and overlooked. Visual deficits create nonadherence due to patients' difficulties in reading and following written instructions, as patients cannot adhere if they are unable to read the instructions.

Hearing Changes

Hearing loss, or presbycusis, is the most underreported and unrecognized sensory impairment in geriatric medicine (Heath, 1992b). Elderly persons with hearing problems may wait 5 years or more before seeking medical assistance. Hearing loss results in a decreased perception of higher frequency tones, as well as auditory signal distortion, which may result in inappropriate responses. Such responses are often misinterpreted, and elderly people who experience this problem may withdraw in frustration. Withdrawal from conversations, inappropriate responses, inattentiveness, and difficulty following directions are often interpreted as confusion or cognitive decline in the elderly instead of being seen as a potentially correctable hearing problem. Because hearing loss is usually not diagnosed and managed appropriately, elderly people who do not hear or who misinterpret medical information or who are reluctant to ask questions because they are concerned they will not hear the response may be more likely to be nonadherent to medical regimens.

Cognitive Alterations

Age effects on adherence are thought to be mediated through cognitive function (Hutchinson, Jones, West, & Wei, 2006). Older age is associated with changes in cognitive abilities, including declines in memory, judgment, perception, attention and concentration, perceptual speed, spatial manipulation, and reasoning (Anstey & Low, 2004; Schonknecht, Pantel, Kruse, & Schroder, 2005). The ability to recall and plan medication regimens may be sufficiently reduced in patients with mild cognitive impairments to result in medication errors. Age-associated cognitive decline has been shown to have a prevalence rate of 20% to 27% in elderly populations and 13% in the 60–64-year-old population (Schonknecht et al., 2005). Most cognitive deficits remain subtle over a long period, and silent or unrecognized dementia has been reported to be as high as 52% among persons with early cognitive deterioration (Ross et al., 1997). Early signs of cognitive impairment are often ignored or diagnosed as "normal" aging, hearing loss, or depression, and the impairment may remain undetected until the advanced stages.

Age differences have been noted in the comprehension of medical information. Understanding medical information requires several cognitive and noncognitive processes. Information must be presented, learned, and remembered at the appropriate time. Older adults have more difficulty attending to information and inhibiting irrelevant information or stimuli (Salthouse, 2003). Many older adults experience changes in memory at a stage in life when there is an increasing need to follow complex medication regimens (Craik, 1999; Craik & Salthouse, 2007).

Executive function and working memory are cognitive processes that are particularly susceptible to the effects of aging. These two cognitive processes are not automatic. Executive function is involved in maintaining attention to a task, switching tasks, planning, organizing, making decisions, and sequencing goal-directed behavior (Fuster, 1997). Each of these executive-function tasks is involved in behaviors associated with medication taking. Working memory has also been shown to decline among older adults. Working memory is described as the capacity for online processing, which is the holding of information while manipulating it. Holding information about the medication while listening to further instructions may be more difficult for older adults. Changes in executive function and working memory in one's later years have been shown to be associated with adherence among older adults living in the community and taking at least one prescribed medication (Insel, Morrow, Brewer, & Figueredo, 2006).

Cognitive abilities are considered to be the most important resource for maintaining everyday functioning. Thus, cognitive changes, namely memory loss, become issues when an elderly person is unable to recall and use the information necessary to perform everyday activities, including the ability to remember information needed to plan and follow treatment regimens.

Emotional Health: Depression

Depression is one of the major predictors of nonadherence (DiMatteo, Lepper, & Croghan, 2000). The incidence of depression among individuals with chronic disease is significant. Losses associated with aging, such as death of a spouse or friends, moving from one's home, and termination of a career, are also thought to contribute to depression. Older adults as a group are more active and healthier in retirement than in prior years; however, role transitions contain both opportunities and challenges. Signs of depression should be noted, as they can influence motivation to adhere to treatment regimens.

Depression may produce physical, psychological, and cognitive symptoms (Teri & Wagner, 1992). Physical symptoms include sleep disturbances, appetite or weight changes, fatigue, and loss of libido. Emotional aspects include a pervasive dysphoric mood, feelings of worthlessness, suicidal thoughts, and loss of self-esteem. Cognitive symptoms may include difficulty with memory and concentration and confusion. As with other changes in the elderly, depressive symptoms are often considered predictable complaints of chronic illnesses and ignored.

Several aspects of depression are thought to have negative effects on adherence. These include a pessimistic attitude about the effectiveness of the treatment; changes in memory, attention, and cognition; decreased desire for self-care; lack of motivation, isolation, and even possible intentional self-harm (Wang et al., 2002). Depression has been reported to have a negative effect on adherence to medications in multiple chronic diseases, including coronary artery disease, HIV disease, asthma, renal transplantation, and hypertension (Wang et al, 2002). These findings point to a need to screen for depressive symptoms and to monitor adherence, as elderly depressed patients are particularly vulnerable to nonadherence because of multiple chronic illnesses and, consequently, multiple medications regimens (Schraufnagel et al., 2006).

Resources: Social Network and Social Support

Social networks and supports are well-documented links to the health and well-being of older persons (Antonucci, 1990). Social networks provide access to support and other needed resources. The major types of social support are emotional, informational, and instrumental or tangible support. Supportive contacts and relationships may positively affect health by allowing for earlier recognition of the adverse effects of medications, increasing the likelihood that the person will seek medical care, and providing assistance needed to sustain treatment regimens. The lack of social and community relationships has been associated with poor adherence (Tucker et al., 2004). Estimates indicate that between 25% and 35% of persons over age 65 live alone. Elderly persons who live alone, especially elderly women, are also more likely to have lower incomes than those who live with other people. Both of these factors contribute to the difficulties encountered by elderly persons in adhering to a treatment regimen.

Resources: Financial

One of the major challenges created by an increased life span and the growing burden of chronic illnesses is health care costs (CDC & MCF, 2007). The cost of providing health care for a person over age 65 is three to five times higher than the cost of caring for a person younger than age 65. Between 1980 and 2002, Medicare spending grew from $33.9 billion to $252 billion. This increase is a result, in part, of the increased numbers of persons over age 65.

The high costs of prescriptions and medical supplies are barriers to adherence for persons with low or fixed incomes. Many elderly cannot afford to pay for all of the medications prescribed and make their own decisions about which ones to omit. Persons on fixed incomes usually have limited funds available after paying for food, housing, and other medical care, resulting in unfilled drug prescriptions or intentional dose skipping, dosage reductions, such as cutting pills in half, or drug hoarding.

Assessment of the Capacity to Adhere

The first step in facilitating adherence in the elderly is to assess the person's capacity to follow a regimen, as physical, cognitive, and social environmental barriers place older persons at risk for nonadherence. Such an approach needs to occur before a medication or treatment regimen begins, not after a program has been implemented. Assessment enables the health care provider to evaluate the elderly person's understanding, as well as capacity to follow a treatment program. Comprehension is a key component in decision making, as elderly persons must understand information in order to make appropriate decisions. Adherence is not likely if they do not comprehend the instructions. Since impaired mental status is a major risk factor for nonadherence, assessment of cognitive status is essential. Tests, such as the Mini-Mental Status Examination, are simple to administer and will alert the health care professional to potential problems. In addition, a cognitive assessment will assist in planning strategies to promote adherence in these patients.

Physical functioning also needs to be observed when assessing the capacity of elders to adhere. For example, the ability to perform self-care and the instrumental activities of daily living provides information on elderly persons' ability to care for themselves. Hearing and visual difficulties also need to be assessed, as they may interfere with comprehension and implementation of the treatment regimen.

Assessment of cognitive functioning, as well as physical functioning, prior to initiating a regimen is achieved through open communication with a health care professional. The time allotted to an initial detailed assessment will pay off over time. Short, reliable, and valid questionnaires that are easy to administer are available to assess cognitive functioning, self-care, and the ability to perform the instrumental activities of daily living. It must be kept in mind that many factors influence compliance other than the ability to initiate and follow a regimen. However, an initial thorough assessment provides a major step in reducing potential barriers to adherence.

Strategies to Increase Adherence in the Elderly

In spite of many studies of adherence and the identification of factors that predict variability in adherence, there is still not enough evidence to support any one type of strategy or intervention (Higgins & Regan, 2004; Patel & David, 2004). The many factors that predict nonadherence point to the need for tailored interventions that incorporate multiple strategies. Successful interventions are complex and need to include tailored educational strategies appropriate for the person, as well as behavior strategies with external cognitive supports. Patients must be active participants in their care, and health care providers must acknowledge the complexity of the problem and be supported by multidisciplinary teams.

Adherence to the current medication regimen should be evaluated following assessment of the elderly person's capacity to follow the prescribed therapy. A detailed medication history is necessary prior to implementing an educational program so that strategies to increase adherence can be tailored to the person's individual needs. As stated earlier, communication between the elderly person and the health care professional, using the appropriate language, is a major factor in improving adherence. Therefore, the health care provider must understand the elements of effective communication that promote adherence, as well as the principles of health literacy. Since forgetting is a major problem in adherence in the elderly, educational and behavioral strategies that promote remembering to take medications should be initiated. Last, a multidisciplinary approach is central to promoting adherence in the elderly.

Medication History Assessment

Initially, a detailed medication history should be taken to obtain information about the use of current prescription and over-the-counter medications, prior prescription and over-the-counter medications, and home remedies. Social drug use, including alcohol, tobacco, and caffeine intake, should also be ascertained, as these may interfere with or alter the absorption of prescribed drugs.

A successful strategy is to request that the person bring in all prescription, over-the-counter, borrowed, and outdated medications in the home to the initial visit. This "brown bag assessment" will provide a picture of the person's medication habits (Bergman-Evans, 2006). Next, the elderly person should be queried about the medications. Questions need to be asked to obtain information about dosages and schedules, side effects and other problems when taking the medications, and knowledge about the drugs and disease being treated. Questions should be open ended and asked in a supportive, nonpunitive manner in language understandable to the patient. A supportive atmosphere will facilitate honest answers about adherence issues without fear of reprisal.

Medication Regimen Analysis

Potential adherence issues may be addressed through an ongoing review of the medication regimen, while focusing on the patient, as well as the disease. First, prescription instructions should be given in detail, avoiding directions such as "take as directed" or "take as needed," as these may not be understood. Easily administered dosage forms that consider such problems as difficulty in swallowing pills are preferable. The physician should undertake a careful review to simplify the regimen as much as possible, as the elderly should take as few drugs as necessary. Drugs that can be administered in a single or twice-daily dose should be prescribed whenever possible. The idea of a "polypill," in which one combination pill contains multiple medications, has generated interest in the literature as a way to increase adherence, as only one pill daily would be required (Wald & Law, 2003). The prescriber should time the dosage so that the schedule does not conflict with the person's daily activities. Therapeutic endpoints for prescribed drugs should be established, and medications that are no longer needed should be discontinued as soon as possible. In general, dispensing pharmacies should avoid safety caps, as many elderly are unable to open medications with these caps. Ongoing attention through regular visits and consistent assessment of all aspects of the medication regimen decreases the potential for adverse side effects and increases the likelihood of adherence. Physicians and other health care providers who prescribe need to be educated, in addition to educating the elderly.

Effective Communication

Timing of communication episodes, quality of the encounter, and involvement of a supportive other have been shown to promote constructive communication between health care professionals and elderly persons. Effective communication enables health care providers to furnish essential information in a meaningful manner, as well as to elicit the elderly person's concerns and questions about the medication regimen. Effective communication also enables the health care provider to learn about any personal and cultural beliefs that may interfere with the person's adherence to the prescribed regimen.

Timing

Scheduled ongoing contacts with a consistent health care provider, rather than "as needed" visits, are necessary to prevent or reduce side effects and polypharmacy and to monitor cognitive and physical changes which may interfere with

adherence (Patel & David, 2004). Follow-up visits are critical after a hospital or other health care facility discharge, the death of a spouse, a change in living arrangements, or a decline in cognitive or physical functioning, as any transition increases the elder's risk for nonadherence, as well as other potentially debilitating consequences.

Quality of Encounter

The quality of the patient-health care provider relationship has a significant bearing on satisfaction with care, which in turn influences an elderly person's motivation to adhere to a prescribed regimen. The health care provider-patient interaction may be the most important ingredient in whether behavior change occurs, as research has shown that it influences the patient's care seeking and active participation in the treatment regimen (Schilder et al., 2001). Empathic listening and genuine interest in the person convey respect, instill trust, and decrease communication barriers. Sensitivity to cognitive, physical, and social environmental barriers enables health care providers to plan and implement realistic regimens with supports essential for success. The quality of the encounter is enriched when sufficient time is spent with the person to allow the health care provider to offer individualized information, assess the patient's response to current medications, answer questions, address concerns, and provide encouragement and support. A quality encounter occurs when health literacy barriers of the patient are assessed and addressed. Patients with limited literacy have less general knowledge of their disease and its treatment. The provider may need to administer scales that measure literacy in health care settings early in the encounter to know the knowledge and language level to use with the particular person. For example, the Rapid Estimate of Adult Literacy in Medicine (REALM) is a health word recognition test in which patients are asked to read aloud medical terms (Davis, Kennen, Gazararian, & Williams, 2004). Education, at a level and in a language that are understood, is critical to promote comprehension of the disease and prescribed treatments.

Involvement of a Supportive Other

Inclusion of the spouse or another family member or friend is a major factor in facilitating management of the elderly person's chronic-illness treatment regimen, especially in the presence of declining cognitive or physical functioning. Household members can contribute information about the person and his living environments that is crucial to understanding potential adherence issues. A supportive other may also administer the medications or ensure that the person is taking the medication. Illness is a family affair, as everyone in the household is affected. Therefore, active participation by another person facilitates adherence to medication and other treatments that may be prescribed. In addition, side effects or other problems are likely to be observed and reported earlier when there is a supportive other monitoring the functioning of the patient, decreasing the need for hospitalization. Supportive others need to be present during provider-patient communications about the medication regimens and during all educational activities.

Educational Strategies

Educational strategies have traditionally been the mainstay of efforts to improve adherence to medication and other treatment regimens and have achieved varying levels of success for persons of all ages (Haynes et al, 2005). Educational strategies are based on the premise that providing patients with information about their disease and its treatment is a necessary first step. In other words, elderly persons must first understand their illness and its consequences and comprehend the benefits of the prescribed regimen before they are able to make the lifestyle adjustments needed to implement a regimen. Multiple educational strategies are more effective than a single strategy. For example, a combination of verbal and written information is more beneficial than written information alone. Multiple strategies that take into account verbal, visual, and auditory channels are particularly effective to reinforce information in the elderly. Strategies to facilitate comprehension include simplifying language, organizing information to match patients' expectations, and including pictorials that reinforce verbal and written instructions. Medical and technical terminology should be avoided when possible, and the provider must be careful not to present too much information in one session, as a reduced attention span may result in the elderly person's remembering only some or none of the information. A stepwise approach, in which information is presented in small increments, enables the elderly person to believe that adherence is both beneficial and possible. Individualized educational sessions that are flexible are more effective than structured group approaches. Tailoring the educational process is critical to adjust for varying levels of involvement, difficulties with comprehension, and changes in beliefs and attitudes. Other educational strategies include active involvement of the elderly as much as possible in the teaching-learning process. Active involvement enables the health care provider to evaluate how much the person understands of the information being provided and gives the elderly person opportunities to ask questions and practice new skills, such as insulin injections or urine checks. The "show and tell" technique is an effective teaching strategy. First, the medication is shown to the patient. The patient is then told what the medication is for, how is it to be taken and what types of problems, if any, might be experienced. Attention to design and packaging information, which takes into account visual and physical functional problems and health literacy levels, is also critical to promote adherence.

Behavioral Strategies

Behavioral strategies are based on the premise that behavior is learned and can be modified. Behavioral strategies include such things as reminders and the use of self-monitoring tools or other aids to increase adherence. Behavioral strategies are effective, as they address the problem of declining cognitive and physical functioning in the elderly. Research indicates that instructions aimed at the process (medication taking) are more effective than instructions aimed at the health behavior goal (Theunissen, de Ridder, Bensing, & Rutten, 2003). Reminders may be as simple as a chart, special medication containers such as a daily dispenser or weekly medication tray, or a special calendar or mealtime dispensing pack. These organizers help the patient identify whether the medication has

been taken, eliminating confusion at a later time. Color-coded bottles have also been used. Special packaging simplifies the medication regimen by organizing the medications. The packaging can also serve as a mechanism to monitor adherence. Telephone or mail prompts to refill prescriptions are also helpful in promoting adherence.

Additional strategies to address declining memory have been implemented with varying levels of success. Interventions that support remembering to take medications and monitor completion of medication taking are important (Insel & Coe, 2005). Cues within the environment that are specific to the patient's home and routines are frequently used as reminders. Elderly persons can be taught to establish a routine for taking the medication. For example, taking medications everyday can be associated with drinking morning coffee or juice, meal times, or certain television programs. Or patients may devise their own cues. Research indicates that linking an intended action (medication taking) with an event improves adherence (Einstein, McDaniel, Manzi, Cochran, & Baker, 2000). Reminders from a significant other are valuable complements to environmental cues.

The formation of implementation intentions has also been found to be effective in promoting adherence (Liu & Park, 2004; Milne, Orbell, & Sheeran, 2002). Implementation intentions refer to planning when and where medication taking will occur, rather than just planning to take the medicine. For example, adherence is more likely to occur if patients plan the time and location for taking the medication and associate the taking of the medication with certain activities, rather than having a general plan for taking the medications. Forming implementation intentions is also associated with success in beginning and adhering to other types of treatment regimens, such as physical activity.

Multidisciplinary Approach

A team approach, in which the expertise of physicians, pharmacists, and registered nurses is incorporated, is essential for comprehensive care and successful adherence (Yam et al., 2006). Each provider contributes special expertise that is complementary, rather than competitive. For example, physicians are responsible for diagnosing and prescribing medications. Physicians also monitor patients for adverse side effects and provide education. Pharmacists fill prescriptions and review drugs for potential drug-drug interactions. They conduct drug reviews to reduce the cost of medications, as well as reduce the number of medicines prescribed. Pharmacists dispense information and may provide education as well. The responsibilities of registered nurses vary with their role. Nurse practitioners may prescribe medications, educate, and monitor for adverse side effects. Nurses in institutional-care settings administer medications and monitor patients for effectiveness and adverse side effects. In addition, nurses provide information about the medication regimen and teach skills that may be needed to administer medications, such as insulin injections. In the community setting, nurses make home visits to monitor the elderly for side effects and other issues that may influence adherence to the medication regimen. Ongoing communication among all health care providers is essential to optimize care and promote adherence.

Summary

The number of persons over the age of 65 is increasing faster than that for any other segment of the population and has become the largest consumer of health care services. The increase in life span and the increased burden of chronic illnesses in the elderly necessitate lifelong, complex medication and treatment programs that may produce unpleasant and uncomfortable side effects. Problems with adherence result from multiple issues, including health care provider factors, patient factors, and regimen factors. Thus, improving adherence in the elderly is complex. Health care providers need to begin with an assessment of factors that influence an elderly person's capacity to adhere. Potential causes of nonadherence, including the complexity of the regimen, the presence of adverse side effects, a lack of understanding, lack of health literacy, and personal and cultural beliefs should be explored by the prescriber in order to facilitate the choice of strategies to increase adherence. Consistent, effective communication between the elderly person and the health care provider is paramount. While educational and behavioral strategies may promote adherence, no one strategy is completely effective. Ongoing research is critical, as the problem of nonadherence in the elderly is considered a silent epidemic that is expected to increase as the elderly population continues to grow.

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Optimizing Adherence in Older Adults With Cognitive Impairment

27

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Dementia has been defined as a global decline in cognitive functioning that occurs in the absence of delirium and is severe enough that it affects social and occupational functioning. The prevalence of dementia increases dramatically in people over the age of 65. Among people 65 years old and older, 50–80 per 1,000 (5% to 8%) have dementia (Rabins, Lyketsos, & Steele, 2006). The prevalence of dementia is highest at 350–400 per 1,000 (35%–40%) among individuals who are 85 years old or older (Rabins et al., 2006). Currently, it is estimated that 4.5 million Americans have Alzheimer's disease, and, because of increases in life expectancy, it is projected that approximately 13.2 million Americans will be affected by Alzheimer's disease in the year 2050.

Optimizing Health Through Adherence to Healthy Behaviors

Health promotion is the science and art of helping people change their lifestyles to move toward a state of optimal health, defined as a balance of physical, emotional, social, spiritual, and intellectual health (Green & Kreuter, 2001). The purpose of health promotion and disease prevention is to reduce the potential years of life lost to premature mortality and to ensure better quality of remaining life among those with cognitive impairment (CI). Adherence to specific health promotion activities among these individuals is therefore critical and has been noted to improve clinical outcomes particularly with regard to mental health and quality of life (Markle-Reid et al., 2006).

Health promotion activities include the use of immunizations to prevent the occurrence of acute problems such as influenza and pneumonia, risk factor reduction through lifestyle modifications such as smoking cessation or regular physical activity, and the prophylactic use of medication to prevent cardiovascular disease or musculoskeletal disorders. In addition, health promotion includes screening to facilitate the early identification of disease so that treatment can be initiated and unnecessary pain and discomfort avoided.

There are multiple guidelines for health promotion activities available for health care providers, as well as patient-specific information to help older individuals decide what type of health promotion activities they want to engage in. These guidelines are no different for those who have CI. The decisions about whether to adhere to these guidelines are, however, complicated by the cognitive status of these individuals and about decisions related to their length and quality of life. Decisions about health promotion activities for individuals with CI are generally made by the power of attorney (POA) for health care once it has been deemed that the individual is incompetent (Raik, Miller, & Fins, 2004).

Prevalence of Nonadherence

Compliance with recommended immunization guidelines for older adults has improved (Daniels, Nguyen, Gildengorin, & Pérez-Stable, 2004), although the goal set in *Healthy People 2010* of 95% adherence to immunization has not been met. To facilitate compliance, the federal government in 2002 approved standing orders for annual influenza vaccinations and pneumococcal pneumonia vaccination for older adults in institutional settings and home health agencies for all Medicare and Medicaid beneficiaries. With regard to smoking cessation, despite the fact that older adults are less likely to get counseled for smoking cessation, they have the same quit rates as younger individuals. Annually, it is reported that 70% of older smokers want to quit, and 46% make some attempt each year at quitting (Hyland, Rezaishiraz, Bauer, Giovino, & Cummings, 2005). While there is some support to indicate that quitting smoking even after age 65 can increase years of life (Houston et al., 2005), it may be more important to focus on the potential improvement in quality of life with smoking cessation such as safety issues related to fires and improvement in cardiovascular function and memory (Reitz, Luchsinger, Tang, & Mayeux, 2005).

Moderate alcohol intake is believed to be health promoting (Byles, Young, Furuya, & Parkinson, 2006). Unfortunately, however, 5.6% of people 65 years of age or older engage in binge drinking, 1.6% engage in heavy alcohol use, and .5% are known to be alcohol dependent (Office of Applied Studies, 2000). Although older adults with CI do not drink more than other older individuals (Reid, Boutros, O'Connor, Cadariu, & Concato, 2002), alcohol has the potential to be beneficial or harmful to health and quality of life.

Physical activity is an important aspect of health promotion among CI older adults as physical activity may help them maintain function and optimize quality of life, even at relatively low levels of physical activity or exercise intensity (defined as activities that use a metabolic energy equivalent of <4.0) (Roddy et al., 2005). For older adults living in nursing homes, at least half of whom are likely to have moderate to severe CI (Magaziner, Zimmerman, Fox, & Burns, 1998; Rosenblatt et al., 2004), lack of physical activity exacerbates functional impairment (Luukinen et al., 2006). A recent study of 21,670 nursing home residents examined the change in physical function in adults with moderate and severe CI with no comorbid illness over a 6-month time period (Carpenter, Hastie, Morris, Fries, & Ankri, 2006). Overall physical function of residents with moderate CI worsened significantly by 1.78 points (95% CI; 1.67 to 1.91) on the Minimum Data Set Activities of Daily Living (MDS-ADL) with dependence on staff being highest for functions related to personal hygiene, dressing, and toileting (Carpenter et al., 2006). Overall physical function of residents with severe CI also worsened significantly by 1.70 points on the MDS-ADL (95% CI; 1.59 to 1.83) over the 6-month time period, with dependence on staff being highest in activities related to eating (Carpenter et al., 2006). Each ADL item, such as bed mobility, transfer, locomotion, dressing, eating, toileting, and personal hygiene, showed a significant worsening at both 3 and 6 months for both groups of cognitively impaired residents (Carpenter et al., 2006).

Evaluating food intake in older adults is particularly important as inadequate intake can result in weight loss and loss of muscle mass, which may result in decreased strength and power, decreased walking speed and impaired balance, and a decline in activity (Bourre, 2006). Most micronutrients (vitamins and trace elements) have been directly evaluated in the setting of cerebral functioning. For instance, to produce energy, the use of glucose by nervous tissue implies the presence of vitamin B1, and this vitamin modulates cognitive performance, especially in the elderly. Vitamin B9 preserves brain during its development and memory during aging. Vitamins B6 and B12, among others, are directly involved in the synthesis of some neurotransmitters. Vitamin B12 delays the onset of signs of dementia (and blood abnormalities), provided it is administered in a precise clinical timing window, before the onset of the first symptoms. The Modified Food Pyramid can be used to guide individuals toward adequate nutritional intake.

There is no evidence to support differences in micronutrient status among those with or without dementia. Although the association is not always strong, there is evidence to suggest a relationship between body weight and CI such that those with CI are more likely to have body mass indexes (BMI) higher or lower than normal. CI was also more frequently detected in subjects with metabolic syndrome (MetS) than in subjects without MetS (7.2 vs. 2.8%; $p < 0.001$) (Vanhanen et al., 2006). Specifically, it was noted that Alzheimer's disease was

associated with obesity (odds ratio [OR] 9.5, 95% confidence interval [CI] 2.4–37.3, p = 0.001), being underweight (OR 5.4, CI 0.9–33.7, p = 0.07) and abdominal obesity (OR 2.5, CI 1.1–5.7, p = 0.027), after adjusting for age, sex, and living location (e.g., institution versus community) (Razay, Vreugdenhil, & Wilcock, 2006). Women who developed dementia between ages 79 and 88 years were overweight, with a higher average BMI at age 70 years (27.7 vs. 25.7; P = .007), 75 years (27.9 vs. 25.0; P < .001), and 79 years (26.9 vs. 25.1; P = .02) than was found among non-demented women. A higher degree of overweight was observed in women who developed AD at 70 years (29.3; P = .009), 75 years (29.6; P < .001), and 79 years (28.2; P = .003) than in nondemented women. For every 1.0 increase in BMI at age 70 years, AD risk increased by 36%.

The impact of screening or not screening for cancer among older adults has not been well studied among older adults with cognitive impairment. There is some evidence, however, that these individuals are less likely to adhere to screening; researchers found that individuals with CI tend to be diagnosed with breast cancer at later stages than individuals without evidence of CI. Patients with CI were not diagnosed until tumors were larger and the likelihood of lymph node involvement had increased. Likewise, with colon cancer, patients with CI were twice as likely to have colon cancer reported after death (i.e., autopsy or death certificate) (adjusted odds ratio [AOR] = 2.31, 95% confidence interval [CI] = 1.79–3.00) (Gorin, Heck, Albert, & Hershman, 2005).

Impact of Nonadherence

Lack of adherence to health-promoting activities such as maintenance of optimal weight and dietary intake, particularly of micronutrients; adherence to physical activity recommendations; cancer screening; smoking cessation; and moderate use of alcohol may have a significant impact on the quality of life of older adults with CI and their ability to function at their highest cognitive and physical level. Optimal dietary intake and maintaining an ideal body weight may help to ensure the highest level of cognitive ability and physical activity in individuals with CI and thereby improve health (Zizzi et al., 2006). With regard to alcohol intake, CI is noted to be higher for those who exceed one wine-equivalent liter among men and 0.5 liter among women, daily. Nonadherence to moderate alcohol intake may exacerbate cognitive function and cardiovascular disease and increase the risk of accidents (Hollingworth et al., 2006; Li et al., 2006; Wendel-Vos et al., 2004).

Analytic reviews provide strong evidence that participation in either nonspecific physical activity or specific aerobic or resistive exercise is associated with a variety of health improvements, such as decreased risk of coronary heart disease and stroke (Cornelissen & Fagard, 2005; Lee, Folsom, & Blair, 2003; Wendel-Vos et al., 2004); decreased progression of degenerative joint disease (Roddy, Zhang, & Doherty, 2005; Roddy et al., 2005); prevention of osteoporosis of the lumbar spine (Palombaro, 2005); decreased incidences of falls (Chang et al., 2004; Weatherall, 1994); increased gait speed if the activity is of sufficient intensity and dosage (Lopopolo, Greco, Sullivan, Craik, & Mangione, 2006); improved cognitive function in sedentary older adults (Colcombe et al., 2006) and in those with dementia (Heyn, Abreu, & Ottenbacher, 2004); a modest benefit

in quality of life for frail older adults (Schechtman & Ory, 2001); and successful aging (Depp & Jeste, 2006). Given the strong support for adherence to physical activity guidelines for older adults, lack of adherence among older adults with CI can have multiple consequences, all of which are critical to quality of life rather than longevity. Moreover, the well-known association between CI and functional decline is exacerbated by inadequate amounts of time spent in physical activity.

In addition to clinical benefits associated with physical activity, the impact that lack of activity has on functional decline can have serious implications for the amount of care needed, increasing health risks associated with decreased mobility, the cost of providing care, and the quality of life for individuals with CI (Hill, Fillit, Thomas, & Chang, 2006; Vestergaard, Kronborg-Andersen, Korsholm, & Puggaard, 2006). Researchers conclude that in older adults with dementia, functional disability increases the cost of Medicare services by more than $399 per additional ADL disability per year. Functional decline is costly, and individuals with disabilities caused by disorders of the central nervous system, such as dementia, represent a group of ever increasing size (Thomas et al., 2002). Until CI can be prevented or cured, promoting the maintenance of functional abilities through physical activity in this population remains a priority in clinical practice and research (Rolland et al., 2007). Volicer and colleagues (2006), for example, were able to demonstrate that a continuous-activity program for nursing home residents with severe CI resulted in a significant decrease in behavioral symptoms and a decline in the use of psychotropic medications among the study participants. It appears that providing opportunities and motivating nursing home residents with CI to engage in meaningful activities is an important strategy for preventing agitated behaviors and ultimately improving residents' quality of life.

There continues to be a clinical and ethical debate about screening for cancer among older adults in general, and specifically for those with CI. This debate generally is based on the cost/benefit associated with screening to the individual and the health care system. The impact of nonadherence to screening has not been well studied.

Factors That Influence Adherence Among Older Adults With Cognitive Impairment

Memory

Given that older adults with moderate to severe CI may not be able to elucidate their wishes with regard to health-promoting behaviors or explain their rationale for nonadherence, it is possible to address only relationships between factors that are known to influence adherence by non-CI patients and these behaviors among those with CI. Underlying physical status, and the impact of this on function, can have a major influence on participation and adherence to health-promoting behaviors. In some cases, health care providers may assume that, in light of physical and functional decline, there is no benefit to health-promoting activities; they may believe that they won't make a difference in clinical outcomes or quality of life of the individual. Underlying physical status

can also influence individuals' beliefs in their abilities to engage in healthy behaviors such as exercise or to be able to tolerate health promotion screenings such as mammography or bone densitometry.

Psychosocial Factors: Mood and Fear

The most commonly noted psychosocial factors influencing adherence to healthy behaviors, particularly physical activity guidelines, are fear of falling or exacerbating underlying problems (e.g., causing a decline in memory or increasing musculoskeletal pain) (Bruce, Devine, & Prince, 2002; Fletcher & Hirdes, 2004; Martin, Hart, Spector, Doyle, & Harari, 2005) and depressive symptoms (Tinetti, 2003; van Wijk et al., 2006). Fear of falling, for example, is commonly associated with a decline in physical activity (Bruce et al., 2002; Fletcher & Hirdes, 2004; Martin et al., 2005) and influences exercise behavior. Fear of the impact of screening in terms of diagnosis and/or treatment-related issues may inhibit older adults with CI and/or their decision makers from having the older individual with CI undergo screenings (Fowler, 2006; Tessaro, Mangone, Parkar, & Pawar, 2006).

Depression, which is prevalent among older adults with CI, can also impact individuals' willingness to engage in any type of health-promoting behaviors, such as exercise, eating, or even getting immunizations (Jensen, Decker, & Andersen, 2006).

Behavioral Symptoms

The motivational challenges that face those who attempt to engage older adults with CI is exacerbated for those elderly persons who exhibit complicating behavioral and psychiatric symptoms in the context of their dementia. The prevalence of agitated and/or aggressive behaviors among nursing home residents with dementia is often greater than 80% (Aalten et al., 2006). Functional dependence and impaired mobility have also been associated with problematic behavioral symptoms and depression among long-term-care residents with CI (Boustani et al., 2005; Gruber-Baldini, 2004). The presence of behavioral disturbance may also adversely affect the adherence of older adults with CI to interventions designed to maintain or improve functional abilities or overall health. For example, Rolland et al. (2007) found that the adherence of cognitively impaired nursing home residents to an exercise intervention that occurred two times a week for 1 year was low, with only 47.8% of the subjects participating in more than one-third of the exercise sessions. Verbal disagreement and behavioral disorders among the cognitively impaired participants accounted for 75% of the nonadherence to the exercise intervention.

Apathy

In addition to the frequency of problematic behavioral symptoms among cognitively impaired nursing home residents, this population is faced with the additional motivational challenge of apathy. Apathy is a neuropsychiatric symptom

that results in a loss of motivation due to disturbance of intellect, emotion, or level of consciousness (Marin, 1991). It has been repeatedly demonstrated that cognitively impaired older adults are more likely than their cognitively intact counterparts to suffer from severe apathy (Buettner & Fitzsimmons, 2006), which is believed to affect 61%–88% of individuals with CI (Galynker, Roane, Miner, Feinberg, & Watts, 1995). While apathy does not seem to respond to medical interventions (Rabins, Lyketsos, & Steele, 2006), it has been demonstrated that caregiver behavioral approaches that assist with the motivation and initial cuing to engage in specific activities such as those related to physical activity are effective (Beck et al., 1997; Chang & Lin, 2005; Engelman, Altus, & Hosier, 2003; Teri et al., 2003; Volicer, Simard, Heartquist-Pupa, Medrek, & Riordan, 2006; Yu, Evans, & Sullivan-Marx, 2005). In addition, apathy can be decreased through the use of music (Holmes et al., 2006).

Social Support

Social support networks, including family, friends, peers, medical professionals, and nursing home staff, are important determinants of health-promoting behaviors (Resnick, Orwig, Magaziner, & Wynne, 2002). Repeatedly, motivation to perform functional activities and exercise has been found to be influenced by the social milieu of the care setting (Rose & Pruchno, 1999; Waters, 1994). The influence of any member of the social network of the older adult with CI can be positive or negative, depending on the person's philosophy and beliefs related to restorative care. There is a need to establish a system within the social network and a culture of care in which there are interactions that will motivate individuals with CI to engage in health-promoting activities and achieve realistic goals given their underlying disease.

Self-Efficacy and Outcome Expectations

Bandura (1977, 1997) described self-efficacy and outcome expectations as two of the central concepts within Social Cognitive Theory. Specifically, self-efficacy expectations are individuals' beliefs in their capabilities to perform a course of action to attain a desired outcome, and outcome expectations are the beliefs that a certain consequence will be produced by personal action. Efficacy expectations are dynamic and are both appraised and enhanced by four mechanisms (Bandura, 1997): (1) enactive mastery experience, or successful performance of the activity of interest; (2) verbal persuasion, or verbal encouragement given by a credible source that the individual is capable of performing the activity of interest; (3) vicarious experience, or seeing similar individuals perform a specific activity; and (4) physiological and affective states such as pain, fatigue, or anxiety associated with a given activity. Both self-efficacy and outcome expectations play an influential role in the performance of healthy activities (Collins, Lee, Albright, & King, 2004; Cress et al., 2005; King et al., 2000; Taylor-Piliae & Froelicher, 2005) and in the adoption and maintenance of exercise behavior (Conn, Burks, Pomeroy, Ulbrich, & Cochran, 2003; Dunstan et al., 2002; Litt, Kleppinger, & Judge, 2002; McAuley, Marquez, Jerome, Blissmer, & Katula, 2002; O'Connor, Rousseau, & Maki, 2004).

Outcome expectations are particularly relevant to older adults. These individuals may have high self-efficacy expectations for exercise, but if they do not believe in the outcomes associated with the behavior, for example, that screening for bowel cancer may identify early disease that is easily treated, then it is unlikely that they will be willing to undergo screening. Older adults with mild CI can evaluate their current self-efficacy and outcome expectations with regard to specific health behaviors, but those with moderate to severe cognitive changes may not be able to adequately articulate these beliefs. That is not to say, however, that self-efficacy-based interventions do not work with these individuals. Rather, we have multiple examples in which self-efficacy-based interventions have changed behavior among older individuals with CI (Resnick, 2004; Resnick, Allen, & Ruane, 2002; Resnick, Simpson, Galik, et al., 2006).

Innovative behavioral-care approaches with older adults with CI have utilized techniques based on components of self-efficacy theory, such as verbal encouragement, cueing, role modeling, positive reinforcement, and development of a routine to successfully motivate these individuals to perform health-promoting activities (Engelman et al., 2003; Lim, 2003; Teri et al., 2003). The theory of self-efficacy has also been applied to improving behavioral interactions between family caregivers and individuals with CI (DiBartolo, 2002; Gottlieb & Rooney, 2004).

Self-efficacy-based staff motivational systems such as behavioral supervision, observing and providing nursing assistants (NAs) with verbal feedback related to care activities (Chang & Lin, 2005; Field, 2004; Sacre, 2004; Teri et al., 2003), have been used successfully to implement interventions to improve adherence to healthy behaviors.

Resilience

In contrast to apathy, resilience is an individual's capacity to make a "psycho-social comeback in adversity" (Kadner, 1989) and is defined as the ability to achieve, retain, or regain a level of physical or emotional health after illness or loss (Felten & Hall, 2001). Resilient individuals tend to manifest adaptive behavior, especially with regard to social functioning, morale, and somatic health and are less likely to succumb to illness (Wagnild, 2003). Resilience, as a component of the individual's personality, develops and changes over time through ongoing experiences with the physical and social environment (Glantz & Johnson, 1999). Older women who have successfully recovered from orthopedic or other stressful events describe themselves as resilient and determined (Felten & Hall, 2001). Community-dwelling older adults who are resilient were noted to have better function, mood, and quality of life than those who were less resilient (Hardy, Concato, & Gill, 2004; Wagnild, 2003). Resilience is also noted to be related to self-efficacy and outcome expectations and a predictor of adherence to exercise in older women after hip fracture (Inguito & Resnick, 2007). Older adults with CI who are resilient may therefore be more likely to continue to engage in healthy behaviors.

Culture, the Environment, and Institutional Procedures

Environments that facilitate healthy behaviors such as physical activity can influence participation in these activities (Iwarsson & Isacsson, 1996; Iwarsson

& Slaug, 2001) and enable people to achieve their highest level of function and well-being (Humpel, Owen, & Leslie, 2002; Takano, Nakamura, & Watanabe, 2002). Unfortunately, many environments in which older adults with CI live are limited with regard to space for exercise. Accessible and safe walking paths are often not present, nor are heart-healthy food choices (i.e., low-cholesterol and low-fat meals) or finger foods for easy snacking available for those who need to increase their caloric content (Humpel et al., 2002; Takano et al., 2002). Altering the environment has been noted to impact behavior (Takano et al., 2002).

Policy

New practice guidelines associated with "Welcome to Medicare" (Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System) and Health Plan Employer Data and Information Set (HEDIS®) programs provide reimbursement and regulatory incentives for providers to take the time to discuss and encourage health-promotion activities such as physical activity. The availability of this opportunity should encourage providers and patients to partake of these services. It is not known, however, how extensively these guidelines are being utilized in practice or whether older adults with CI are excluded from these welcome visits because the health care provider assumes that health-promoting activities will not improve the CI patient's quality of life.

National policies have not been established related to physical activity. With regard to function, the Omnibus Budget Reconciliation Act (OBRA) of 1987 mandated that residents in nursing homes attain and maintain their highest level of function. Consequently, caregivers in nursing homes have attempted to develop and implement restorative-care programs to increase physical activity among older adults with CI. The impact and success of this policy has not been evaluated. Policy has been successful, however, in changing health behaviors in areas such as the use of seat belts, suggesting that policy can have an important impact on behavior (Salzberg & Moffat, 2004).

Use of a Social Ecological Model to Optimize Adherence

As described earlier, the reasons for poor adherence to health-promoting behaviors among older adults with CI are multifactorial and therefore best explained using a social ecological model (Sallis & Glanz, 2006; Sallis et al., 2006). Specifically, a social ecological model suggests that an individual's behavior is affected by a wide sphere of influences: intrapersonal, interpersonal, institutional/organizational/environment, and public policy. In addition to the intrapersonal factors previously addressed, such as psychological factors (e.g., mood and motivation), there are also nonmodifiable factors, including demographic variables such as age, gender, and race. While it is useful to acknowledge the presence of these factors, it is challenging to relate them directly to function, as there is a good deal of interindividual variability. Moreover, it is impossible to separate out the multiple comorbidities common in older individuals with CI. Appreciating the potential impact of these variables, however, can help guide interventions.

Interpersonal factors that influence participation in health-promotion activities are particularly important among older adults with CI whose engagement in these activities may be driven by the influence of a caregiver or by a power of attorney for health care. For example, social interactions can alter the underlying physical status of the individual with CI. Degenerative joint disease, for example, that imposes limitations in range of motion may have a smaller impact on functional limitation in dressing in individuals who are encouraged by a family member to dress themselves than in individuals who are dressed by a family member or whose family member insists that the NA dress the individual, not allowing the older individual optimal range and function.

Environment and organizational factors that optimize adherence to health-promoting behaviors can influence outcomes with regard to adherence to those behaviors (Crews, 2005; Iwarsson, 2005; Takano et al., 2002). Having visible exercise-related areas, walkable spaces, safe areas for exercise, and interesting walking destinations have been shown to improve physical activity among residents (Joseph, Szimring, Harris-Kojetin, & Kiefer, 2005). Simple and cost-efficient modifications can be made, such as improving lighting, displaying signs that specifically promote active living, and providing physical activity stations throughout the facility and outdoors. Policies and procedures within the organizational environment are also critical. For example, facility-based policies related to use of shared space areas, provision of care, and availability of services can influence participation in physical activities and function among residents. If outdoor space for walking is locked and made inaccessible, or if the underlying philosophy or culture within the facility is to provide care rather than to optimize function, perceptions and expectations among residents, staff, and families or their proxies can be affected, leading to decreased promotion of healthy activities such as exercise.

Public health policies can influence adherence to health-promoting activities for older adults with CI. Nursing homes serving Medicare and Medicaid patients have to provide immunizations against influenza and pneumococcal disease to all residents if they want to continue in the programs (Hinman, Urquhart, Strikas, & National Vaccine Advisory Committee, 2007). In some states, implementation of this policy has resulted in an increase in adherence to immunizations (Dunn, Misra, Habermann, & Griffin, 2003). Public policy related to physical activity has not been as well enforced, although increased recognition among caregivers and proxies for individuals with CI of the benefits of physical activity has led them to provide verbal encouragement to individuals with CI to engage in physical activity. The implications for reimbursement associated with screening as noted by Medicare have a significant impact on participation in screening activities. Reimbursement may be unavailable for some preventive interventions (e.g., hearing tests, over-the-counter medications, smoking-cessation products) and may be available within narrowly defined time frames for screenings such as colonoscopy (Dunn et al., 2003).

Although the components of the social ecological model were described separately, it is critical to recognize that these factors are interrelated in real-world settings. The intra-individual level of the model, for example, explains the functional changes that can occur within the individual. The interpersonal level influences the intra-individual level of the model through the theory of self-efficacy such that interactions with caregivers can help to engage older

adults with CI in health-promoting behaviors. At the institutional or organizational and environmental level, interventions can be implemented to influence the impact of the environment on the individual and the interpersonal interactions that are ongoing. Last, enforcement of policy guidelines can significantly influence all other aspects of the model. Guidelines requiring walking paths in nursing homes, for example, could influence the environment, affect interpersonal activities that occur in those settings with family, and improve intrapersonal factors related to health status by increasing physical activity of persons with CI.

Special Challenges: Adherence in Select Populations

Older Adults Poststroke

Many older adult stroke survivors struggle with the sudden onset of neurological deficits that cause profound changes in their daily lives. Many continue to have persistent risk factors that put them at significant risk for a future stroke event. In a recent study of 364 community-dwelling stroke survivors, 99% of volunteers for an exercise study had at least one suboptimally controlled cardiovascular risk factor, and 91% had two or more concurrent risk factors that were being inadequately treated (Kopunek et al., 2007). Eighty percent of the participants had prehypertension or hypertension, 67% were overweight or obese, 60% had suboptimal LDL, 45% had impaired fasting glucose, 34% had low HDL, and 14% were current smokers, all the while reportedly receiving routine medical care (Kopunek et al., 2007). Every stroke survivor should be evaluated for risk of stroke at least annually and more often if multiple risk factors are present. Patients must be queried at every visit (in the home, at the practitioner's office, or at the hospital) regarding risk factors and educated regarding the importance of aggressive management and control.

Adherence to medication, diet, or exercise regimens designed to modify risk-factor profiles may seem an overwhelming task for many older stroke survivors. Rehabilitation may focus on the development of new adaptive and compensatory strategies to facilitate independence and function, imposing a steep learning curve to acquire and restore needed skills. The combination of sudden neurological and functional changes, along with age-related declines, can present significant challenges. Alterations in perception and motivation that result from damage to specific areas of the brain further confront the ability of individuals with stroke to perform health-promoting behaviors. Add to this clinical picture the possibility of stroke-related CI, and the challenges are compounded.

Assessment of older adults' understanding of their health status is a critical starting point for any intervention. The health care provider should ask stroke survivors to explain what they have been told about each medical problem. Using this information, an educational plan can be designed to improve understanding, provide feedback, and reinforce adherence to recommended regimens. Reliable sites on the Web, such as those supported by the National Institutes of Health or disease-specific foundations, are useful sources to download and print information for patients to take home to reinforce in-person

teaching efforts. These educational tools have been adapted for stroke patients, who frequently have associated visual or hearing deficits. Font size and visual contrast must be adequate, and the language must be appropriate for the person's educational level.

With regard to medication management and adherence, the use of pillboxes may be valuable. Part of the assessment of health management should be an inquiry into whether finances influence the person's medication-taking practices. Medicare Part D has impacted most older adults and confused many recipients regarding the available benefits.

Patient education among those who have had a stroke is not sufficient to change behavior poststroke. Rather, adherence to medication, exercise, or treatment regimens is closely associated with changing their beliefs. As previously described, social cognitive theory indicates that specific efficacy expectations affect behavior, motivational level, thought patterns, and emotional reactions to any situation (Bandura, 1977). These beliefs are essential to the adoption and maintenance of self-care activities, such as engaging in physical activity after stroke (Robinson-Smith, Johnston, & Allen, 2000; Shaughnessy et al., 2005). Bolstering self-efficacy to make significant lifestyle modifications can be accomplished through (1) offering education and encouragement; (2) providing specific tasks to accomplish and directions on how to complete the task; (3) identifying and addressing barriers to compliance; and (4) cuing behaviors through role-modeling or self-modeling. Finally, education regarding expected benefits may provide further incentives and motivation to change behaviors. Helping an older adult stroke survivor to choose a healthier diet, lose weight, begin an exercise program, or adhere to a medication regimen requires time, care, and lots of encouragement in selecting goals and interventions for behavior modification and should be a routine part of medical and nursing assessment and surveillance.

In the course of a stroke, survivors have sustained some type of brain injury that may or may not affect their cognitive function. Depending on the location and extent of the stroke, patients may be independent in all matters regarding their own health care or dependent on others for many aspects of day-to-day living. As cognitive screening is part of a standardized neurological assessment for all stroke survivors, accommodations for cognitive deficits must be made accordingly, particularly for those with attention or memory dysfunction. Further, improvements in cognition may occur during the recovery process and require ongoing evaluation and adjustment of treatment plans. Alterations in cognition may signify other medical conditions that commonly occur with stroke, so astute recognition of change is important.

Older Adults With Moderate to Severe Cognitive Impairment

Older adults with moderate to severe CI do not have the underlying cognitive ability to consciously decide to adhere or not to adhere to health-promoting behaviors. Therefore, ethical decisions and decisions about the futility of interventions need to be considered by their caregivers (Resnick et al., 2005). Medical futility is described as evidence from the available data that a proposed therapy should not be performed because it will not improve the patient's medical condition (Bernat,

2005). The health-promotion plan of care for the older individual with moderate to severe CI must be established with the proxy. Once the goals are determined, then interventions can be implemented to optimize the individual's participation in the health-promotion goals. There is evidence that physical activity can be increased among individuals with CI, as well as increased participation in functional activities (Kuiack, Campbell, & Evans, 2003; Tappen, Roach, Applegate, & Stowell, 2000; Tsai, 2003). Consistently across all these studies, encouraging adherence to physical activity among older adults with moderate to severe CI optimized their participation in functional activities and walking programs.

To increase participation in eating, particularly eating independently, for older adults with moderate to severe CI, teaching interventions for caregivers have been implemented with some success (Chang & Lin, 2005). When caregivers allowed the study participants to control more of their own eating process, and when they provided verbal prompts and positive reinforcement for eating, there was improvement in independent eating. Other techniques that have been successfully utilized to engage older adults with moderate to severe CI in healthy behaviors include prompting the individual with simple one-step commands (Beck et al., 2003; Lim & Taylor, 2005).

In a recent study, Galik and Resnick (2007) specifically explored strategies that would successfully motivate nursing home residents with moderate to severe CI to engage in functional activities and exercise. This study used a qualitative design with a focus-group methodology. A total of 26 different codes were identified, which were reduced to the following four themes describing effective techniques for promoting participation in healthy behaviors: (1) communication techniques (13% of total codes); (2) caring (34% of total codes); (3) magnified sensory stimulation (19% of total codes); and (4) general innovative techniques (34% of total codes). Table 27.1 incorporates the findings from prior quantitative studies and this recent qualitative work and outlines the interventions that effectively improve adherence to healthy behaviors among older adults with moderate to severe CI.

Use of Technology to Optimize Adherence in Older Adults With Cognitive Impairment

As prevalence of dementia has become a significant public health problem among older adults (Rabins et al., 2006), researchers and professionals in various fields have been making efforts to develop innovative technologies to assist these individuals to maintain activities of daily living and overall well-being. A burgeoning scientific effort is to develop "cognitive prosthetics" or "cognitive orthoses" for cognitively impaired individuals (Center for Aging Services Technologies, 2004; Kuwahara, 2006; Wherton & Monk, 2006). The term "cognitive prosthetics" or "cognitive orthoses" is rooted in the terms for physical prostheses that augment various physical disabilities. Among different definitions (LoPresti & Kirsch, 2004; Lynch & George, 2002), Lynch (Lynch & George, 2002) defines a "cognitive prosthetic" as "any computer-based system that has been designed for a specific individual to accomplish one or more designated tasks related to activities of daily living, including work." Development of a cognitive prosthetic requires multidisciplinary collaboration in the areas of cognitive

27.1 Description of the Interventions to Facilitate Adherence in CI Older Adults

Mastery experiences

An effective way of creating a strong sense of efficacy is through mastery of experiences. Mastery involves the actual performance and successful completion of an activity.

- NAs will be encouraged to provide opportunities for cognitively impaired residents to do a functional task for themselves rather than simply doing it for residents (i.e., comb hair, wash face, put arm in shirt sleeve, drink with a no-spill cup, feed self with an adaptive utensil).
- NAs will be taught techniques to actively engage residents with moderate to severe cognitive impairment in restorative care activities by positively acknowledging any and all attempts of successful completion of goal activities.
- NAs will be encouraged to strive for a restorative care approach with every resident encounter.

Vicarious experience

Role modeling by Restorative Care Nurse to NAs.

- Demonstration of techniques to optimize functional performance of residents with moderate to severe cognitive impairment (i.e., simplify presentation of food so as not to overwhelm resident, physically model/demonstrate the functional behavior rather than using lengthy verbal directions).
- Demonstration of techniques to encourage participation (i.e., using music as a motivator, encouraging resident activities that are consistent with past life experience, such as folding clothes, packing a briefcase).
- Demonstration of exercise routine (i.e., range of motion, small-group activities with functional/physical activity focus).
- Teaching NAs how to pair cognitively impaired residents to motivate each other (i.e., pair a resident who can self-propel in her wheelchair with a resident who is more sedentary, pair a resident who is slightly more independent at mealtime with a resident who might benefit from the visual cues).
- Verbal encouragement, praise, and recognition of NAs for efforts to engage residents in restorative-care activities.

Self-modeling:

- Offer NAs an opportunity to return demonstrate or verbalize creative techniques learned to optimize physical function in residents with moderate to severe cognitive impairment.
- Encourage NAs to share resident's progress in restorative-care goals with family and significant others.

Verbal encouragement

Education regarding the philosophy of restorative care with the moderate to severely cognitively impaired during the Res-Care-CI in-service classes and during coaching/mentoring on the units.

- Review the benefits of restorative care for residents and NAs.
- Review Restorative Care Interventions with NAs in terms of ADLs (i.e., bathing [washing mitt, liquid soap, modeling action]; dressing [laying clothes out in order that they are to be put on]; feeding [adaptive utensils, no-spill cups, simplify food presentation]; continence [toileting schedule, running water as auditory cue]; communication [use of old photographs to start conversation; organization of activities around more energetic times of the day]).

27.1 Description of the Interventions to Facilittate Adherence in CI Older Adults (*Continued*)

- Offer caregiver tips on how to motivate cognitively impaired residents to participate in functional activities (i.e., use of humor, activities consistent with past life experiences).
- Discuss how to incorporate restorative care into daily routine.
- Discuss potential effects of cognitive impairment on mood, affect, and behavior of patient.
- Discuss the similarities and differences between restorative care and behavior management.

Encouragement, including initial goal identification with NA, resident, and family. During coaching and mentoring, the restorative care nurse will work with the NA, resident, and family to identify daily short-term goals for the resident. These goals will focus on performing a specific functional activity or exercise activity. A long-term goal will also be identified and will vary on the basis of what is relevant to the individual (i.e., being able to go on a trip or to a family outing).

- Goals are written on a special Goal Identification Form (Appendix).
- Completion of restorative-care activities and time spent in individual activities is documented by the NA on Documentation of Restorative Care Flow Sheet. Instruction on the use of the flow sheet is provided during the Res-Care-CI classes.
- Goals are graduated, from easy to more difficult.
- Goals are reviewed weekly with NA, resident, and/or family and revised as appropriate.

Physiological feedback	Teaching NAs to assess for and manage physiological feedback that may affect the participation of residents with moderate to severe cognitive impairment in restorative-care activities.

- Caregivers are taught to recognize symptoms such as aphasia, motor apraxia, agnosia, tremor, and increased tone/cogwheeling that may affect the individual's ability to participate in goal activities.
- Caregivers are instructed to assess residents on a daily basis to ascertain if they experience pain, anxiety, behavioral disturbance, fatigue, shortness of breath, or chest pain associated with functional activities or exercise that may make the individual not want to perform functional activities or exercise.

Interventions to decrease these unpleasant sensations will be initiated by NAs and include:

- *Management of Aphasia:*
    - Use simple words and phrases.
    - Anticipate a resident's verbal response delay. Teach NAs to wait for the resident to answer questions or respond.
    - Use physical gesturing and modeling with residents who have a difficult time understanding spoken language.
- *Management of Motor Apraxia:*
    - Teach NAs how to recognize symptoms of motor apraxia.
    - Reinforce and engage residents in physical activities and functional activities that reinforce repetitive and simple movements.

(Continued)

27.1 Description of the Interventions to Facilitate Adherence in CI Older Adults (*Continued*)

- ■ Engage residents in functional activities that they performed every day.
- ■ Simplify functional tasks (break down into steps) that are too difficult for residents to perform.
- ■ Demonstrate or model the activity for the resident.
- ■ Use adaptive clothing (Velcro, elastic-waist pants).
- ■ Teach NAs the benefit of hand-over-hand activity for residents with severe motor apraxia.
- ■ *Management of Agnosia:*
  - ■ Encourage family members to bring in familiar objects for the resident's room.
  - ■ Explain tasks/activities, provide verbal cues to prevent the resident from misinterpreting situations.
  - ■ Attempt to provide activities that are consistent with the resident's previous personal routine.
- ■ *Management of Tremor:* Discuss use of alternate clothing choices (i.e., pullovers rather than button-down shirts, loafers, elastic shoelaces). Weighted cups with lids, weighted utensils, or use of wrist weights. Use of electric razor instead of straight razor.
- ■ *Management of Increased Tone/Cogwheeling:* Review with NA how to identify cogwheeling and reinforce that this is a neurological symptom and not the resident being resistive. Provide the resident with opportunities for range of motion (creative ways to engage cognitively impaired residents in ROM include reaching for item in closet or cupboard, sweeping, kicking a ball, folding and flying a paper airplane, folding clothes, tapping a balloon, pressing down on a "gas pedal").
- ■ *Management of Pain:* Advocate for adequate pain relief (i.e., pain medications can be scheduled to be given prior to more physically active times; using complementary techniques to decrease pain as appropriate such as heat and ice; using relaxation techniques such as deep breathing and distraction to decrease pain. Also, will discuss role of range-of-motion exercises in muscle soreness and rigidity. Teach techniques for proper body alignment and positioning of residents (rolled towels, splints, specific positioning devices for bed and/or chair).
- ■ *Management of Anxiety/Behavioral Disturbance:*
  - ■ Teach NAs to approach resident with calm, unhurried, and pleasant attitude.
  - ■ Use humor and smile as cognitively impaired residents are highly influenced by the emotional state of their caregivers.
  - ■ Teach NAs to be alert to excessive levels of noise, temperature, and visual stimulation in the environment. A quieter, less stimulating environment may work better for residents who are easily overwhelmed.
  - ■ Use more cueing and modeling and less direct hands-on care (as individuals with cognitive impairment may misinterpret a caregiver's touch).
  - ■ Be patient and reapproach the resident at another time if he is anxious or uncooperative.
- ■ *Management of Fatigue:* Educate nursing assistant to (1) schedule rest periods to augment restorative-care time; (2) be flexible with restorative-care activities so that the resident can rest first and then perform the activity.

| **27.1** | **Description of the Interventions to Facilitate Adherence in CI Older Adults (*Continued*)** |

■ *Management of Shortness of Breath (SOB):* If shortness of breath is a new symptom, increases suddenly, or increases significantly with activity or at rest, the NA is to halt the activity and to call and discuss situation with health care provider. Remind NA to provide rest time between steps in completion of any activity.

■ *Management of Chest Pain:* If chest pain is a new symptom or increases significantly with activity, then the activity is to be halted and the caregiver will be taught to notify the charge nurse, who can discuss with health care provider or access emergency services.

NAs are instructed to discuss the occurrence of any unpleasant sensations with the charge nurse and the investigator so that a plan of care can be developed to specifically focus on decreasing those sensations.

science, technology, human computer interaction design, and health care (Alm et al., 2004; LoPresti & Kirsch, 2004).

Cognitive impairment can be caused by various conditions and illnesses, such as motor vehicle accidents, stroke, or dementia. Although the fundamental principles of cognitive prosthesis can be applied to most conditions or illnesses, each condition may require assistance in different areas, such as long-term memory loss or short-term memory loss (LoPresti & Kirsch, 2004). In this chapter, we focus on supportive technologies for older adults suffering from dementia or Alzheimer's disease (AD).

For individuals with dementia and AD, cognitive decline mainly affects episodic memory (memories of personally experienced events) and executive functions (planning, sequencing, and control) (Graham, Emery, & Hodges, 2004; Wherton & Monk, 2006). Executive functions are necessary to carry out individuals' activities of daily living, and many cognitive assistive devices have been and continue to be developed to compensate for losses in these functions (Adlam & Orpwood, 2004; Center for Aging Services Technologies, 2004; Chen, Kam, Zhang, Liu, & Shue, 2005; LoPresti & Kirsch, 2004; Rowe, Lane, & Phipps, 2007). The Center for Aging Services Technologies (CAST), a program of the American Association of Homes and Services, has been a leading national force in developing such technologies. Developed in collaboration with government, academia, and industry, the CAST Web site includes a comprehensive list of evolving technologies and research efforts in the field (Center for Aging Services Technologies, 2004). Selected examples include monitoring technologies, smart homes, medicine management systems, and wander management systems.

Assistive technologies can help cognitively impaired individuals maintain activities of daily living by using several approaches, such as providing cues and instructions for specific functions, alarming individuals for imminent hazardous behaviors (e.g., imminent flooding from the sink, smoking detector) (Adlam & Orpwood, 2004; Chen et al., 2005), helping frail older adults manage medications (Quirk, 2006; AgeLab, 2006), and providing information about their whereabouts or directions (Associated Press, 2007; Global Action on Aging, 2005).

A prototype computerized device, the COACH, was developed to help individuals with dementia perform activities of daily living with less dependence on a caregiver. The COACH was developed using a personal computer and a single video camera to unobtrusively track a user during an activity (e.g., hand washing). When the program detects an error by the user, it provides prerecorded verbal prompts (cues), and if the user does not correct or stop the behavior, the computer calls for a caregiver (LoPresti & Kirsch, 2004). Another example is SmartHome (Adlam & Orpwood, 2004). The Bath Institute of Medical Engineering (BIME), in the United Kingdom, partnered with commercial and nonprofit organizations and developed smart-house systems for people with dementia. This home combines several unique existing technologies. The Bath and Basin Monitor is a system that prevents flooding from the bath or basin; the Night Light provides gentle lighting to residents at night using motion-detector technologies; the Time of Day voice reminder provides messaging through voice units distributed around the house; and the Cooker Monitor and Cooker Minder monitor the stove and turns it off if smoke or gas is detected.

A great deal of effort has been put into the area of medication management. An example of an innovative device includes a "smart" pillbox (the MD.2) from Interactive Medical Developments, L.C. (2007). Currently, the researcher Karen Marek is conducting a study to examine the effects of the MD.2 on frail older adults' health outcomes. This medication box, which is connected to the service center by phone, dispenses medications and reminds patients when it's time to take their medication. If older adults do not retrieve the medicine as scheduled, the machine beeps for 45 minutes, then calls the service center (Quirk, 2006).

In the AgeLab at the Massachusetts Institute of Technology (MIT) School of Engineering's Engineering Systems Division, a multidisciplinary team of researchers, business partners, and advocates for the aging are working on innovative technologies to improve older adults' well-being. One such technology is an "Electronic Pill Pet," which uses play and emotion to remind older adults to take their medications (AgeLab, 2006).

Often, Global Positioning System (GPS) systems are being used by caregivers to locate wondering Alzheimer patients (Associated Press, 2007). However, some other services use GPS technology to provide forgetful older adults with a sense of their whereabouts or to give them directions, as well as to help caregivers rescue these frail older adults in emergencies (Global Action on Aging, 2005). For instance, Secom Company in Japan runs a service that provides positional information on these individuals through GPS satellites and mobile phones (Global Action on Aging, 2005).

Considering the rapidly changing modern technologies and the growing number of older adults, research and business in the area of cognitive assistive technology will expand exponentially. In particular, in collaboration with academia and organizations for the aging, large industry corporation labs such as those at Intel (Intel Corporation, 2007) and IBM (SeniorNet, 2006), are making great efforts toward creating new technologies for older adults. There are, however, many other issues surrounding this area, such as ethical issues, safety, and cost-effectiveness. More research efforts must be undertaken to address these issues.

Examples of Innovative Behavior Change Programs for Older Adults With CI

The Res-Care Intervention: Optimizing Function and Physical Activity Restorative nursing care program focuses on the restoration and/or maintenance of physical function and helps older adults with CI to compensate for functional impairments so that they achieve and maintain the highest possible level of function (Resnick, 2004). This type of care attempts to maximize the ability of the resident, focuses on what the individual can do instead of what they can't do, optimizes independence, reduces the level of care required, and ultimately improves quality of life, self-image, and self-esteem. Health care providers working with older adults may be familiar with restorative care, have the skills to engage in this type of caregiving, and believe in the many benefits of engaging in restorative-care activities, but the resident may resist these activities. Unfortunately, older individuals with CI may not believe that they are capable of performing physical activities, may not see the benefit to participating in restorative-care activities, or may feel that caregivers should perform their personal care activities. Consequently, a major aspect of implementing a restorative-care program is to motivate older adults to engage in these activities.

The Res-Care Intervention is a two-tiered motivational intervention that involves teaching and motivating caregivers to engage in restorative-care activities with residents. Specifically, the caregivers are taught techniques, using a self-efficacy approach, to motivate residents to engage in appropriate functional activities and exercise. The first aspect of the Res-Care Intervention involves exposure to a 6-week educational series provided by two advanced-practice nurses. The educational series includes six different 30-minute sessions covering the philosophy of restorative care, a review of specific restorative-care skills, techniques to motivate residents to perform restorative-care activities, and practical ways to integrate restorative-care activities into daily care. In addition, the Res-Care Intervention includes the direction and oversight of a restorative-care nurse coordinator (RCC).

The RCC is ideally a registered nurse with experience in restorative care and rehabilitation nursing. The RCC does an initial evaluation of the resident and, on the basis of this evaluation, the resident, the RCC, and a nursing assistant (and/or family caregiver) who know the resident establish restorative-care goals. The goals are written on a goal form to communicate to all nursing assistants, nurses, and family or friends working with the resident what activities the resident should engage in. The goal form, for example, indicates if the resident should walk to the dining room or self-propel the wheelchair, eat independently after set-up, or participate in daily range-of-motion exercises.

In addition to the goal form, all participating residents have a poster that highlights the benefits of engaging in physical activity placed in their room. The RCC checks with the nursing assistants on a weekly basis to establish whether restorative-care activities are being completed, whether goals are achieved, and/or whether new goals are needed and informally provides verbal encouragement to residents to engage in restorative-care activities. Nursing assistants are encouraged to inform the RCC of challenges related to the implementation of restorative care, and, as appropriate, the RCC attempts to remove any barriers. Exercise activities are encouraged for all residents and built into their daily activities. Such things as walk-to-dine programs, daily exercise sessions that

involve stretching and strengthening activities, and dance classes are encouraged. This type of program has been shown to be helpful in changing the philosophy of care in long-term care settings so that the focus is on the function of the resident and not on the completion of the task (Resnick, Allen, et al., 2002; Resnick & Simpson, 2003; Resnick, Simpson, Bercovitz, et al., 2006; Resnick, Simpson, Galik, et al., 2006).

The WALC Intervention

The WALC intervention (Resnick, 2002) is a self-efficacy-based intervention that incorporates all of the known sources of efficacy-enhancing information (Bandura, 1977, 1997) in an attempt to increase physical activity among older adults with mild CI. The intervention was developed for older adults with mild CI who live in the community or in a continuing-care retirement community setting. The "W" refers to participating in a walking program, and all study participants randomized to treatment were invited to join the Walking Group or to walk on their own for 30 minutes daily. The "A" within the WALC intervention refers to addressing potential pain, fear, and fatigue associated with exercise. The primary care health provider (PCP) asked the participant, initially weekly and monthly, about any unpleasant sensations they were experiencing in association with walking. Individualized interventions were implemented to decrease these unpleasant sensations. The "L" within the WALC intervention, also completed with the PCP, reviewed exercise benefits and established specific goals for each participant. Last, the "C" within the WALC intervention involved providing cues (visual cues such as a monthly calendar and the goal forms) for the participant to exercise. The WALC intervention can also be implemented in a group setting by providing education to the group and using group support and encouragement to help establish and achieve goals, and to provide ongoing verbal encouragement (Resnick, Vogel, & Luisi, 2006).

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Adherence Issues Among Adolescents With Chronic Diseases

28

Michael A. Rapoff

The term "adherence" (rather than "compliance") reflects a more active role for patients in consenting to and following prescribed treatments (Lutfey & Wishner, 1999; Rapoff, 1999). The World Health Organization defines adherence as "the extent to which a person's behavior—taking medication, following a diet, or executing lifestyle changes—corresponds with agreed recommendations from a health care provider" (World Health Organization, 2003, pp. 3–4). This definition acknowledges that regimens for chronic conditions involve multiple behavioral components with varying levels of adherence to each component and that agreement to follow regimens has been secured from the patient. In pediatrics, agreement to follow prescribed regimens may need to be obtained from caretakers, as well as patients.

Another potentially useful distinction in the adherence literature is between inadvertent (nonvolitional) and volitional (or intentional) nonadherence (Adams, Dreyer, Dinakar, & Portnoy, 2004). Inadvertent nonadherence may involve patients forgetting to take a medication dose or being away from home without access to medications. Volitional nonadherence may involve a reasoned and purposeful decision by patients to omit a medication dose because they are asymptomatic or because taking medications interferes with their lifestyle. In the case of inadvertent nonadherence, one can help patients problem-solve about how to keep track of medication doses (such as using a pill-reminder case) and to have medications with them when away from home. In the case of volitional nonadherence, one needs to negotiate with adolescents and their families to obtain agreement on what they are willing to do to treat their disease without compromising their quality of life.

Although chronic physical illnesses affect a relatively small proportion of adolescents (Newacheck, 1989; Newacheck & Taylor, 1992), they carry the potential for causing significant medical and psychosocial morbidity and even increased mortality, while consuming a disproportionate amount of health care resources (Holden & Nitz, 1995). Nonadherence to medical treatment is considered a major contributor to increased morbidity, mortality, and health care utilization and costs (Jay, Litt, & DuRant, 1984; Rapoff, 1999). Adolescents are at risk for nonadherence to regimens for *asthma* (Jónasson, Carlsen, & Mowinckel, 2000; Kelloway, Wyatt, & Adlis, 1994; McQuaid, Kopel, Klein, & Fritz, 2003; Walders, Kopel, Koins-Mitchell, & McQuaid, 2005), *cancer* (Smith, Rosen, Trueworthy, & Lowman, 1979; Tebbi, Cummings, Zevon, Smith, Richards, & Mallon, 1986), *cystic fibrosis* (Gudas, Koocher, & Wypij, 1991; Patterson, 1985), *diabetes* (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Bond, Aiken, & Somerville, 1992; Holmes et al., 2006; Jacobson et al., 1987, 1990; Johnson et al., 1992; Kovacs, Goldston, Obrosky, & Iyengar, 1992; La Greca et al., 1990; Stewart et al., 2003), *heart* or *heart/lung disease posttransplantation* (Serrano-Ikkos, Lask, Whitehead, & Eisler, 1998), *HIV* (Williams et al., 2006), *juvenile rheumatoid arthritis* (Feldman et al., 2007), *renal disease* (Beck et al., 1980; Brownbridge & Fielding, 1994), and *renal disease posttransplantation* (Feinstein et al., 2005).

In addition to negotiating the normal developmental challenges, adolescents with chronic diseases have to cope with pain, fatigue, limitations in their daily activities, and demanding medical regimens. These regimens can be time consuming, intrusive, and of little immediate benefit (Rapoff, 1999). In this chapter, I review the prevalence, consequences, and predictors of adherence problems for adolescents with chronic diseases and strategies for improving adherence. Clinical and research implications are offered from a normative developmental framework to increase sensitivity to the reality that adolescents with chronic diseases, like other people their age, are best understood within this context.

Prevalence of Adherence Problems

The average nonadherence rate to medical regimens for chronic pediatric diseases is often cited to be about 50% (Rapoff, 1999). However, nonadherence

rates vary across different diseases, types of regimens, and methods of defining and measuring adherence. There is also variability in adherence across persons and age groupings and within the same persons over time.

Table 28.1 summarizes nonadherence rates to various chronic disease regimens from 54 studies that included or reported exclusively on adolescents with chronic diseases. Several conclusions can be drawn from reviewing these studies: (1) there is wide variability in nonadherence rates across different diseases and types of regimens, with a tendency toward lower adherence to more complex and intrusive regimen components, such as dietary modifications in the treatment of cystic fibrosis (Passero, Remor, & Salomon, 1981) and dietary and blood glucose monitoring in the treatment of diabetes (Jacobson et al., 1987); (2) adherence to regimens for diabetes has been studied most frequently (26% of studies), followed by medications for asthma (20% of studies), medications posttransplantation (17%), medications for cancer (15%), and relatively few (<10%) for the remaining chronic diseases; (3) the majority of these studies (67%) assessed adherence to medications only; (4) many of these studies (41%) relied on less objective methods of assessing adherence, such as patient, parent, or health care provider ratings, but, encouragingly, 39% of studies used more objective methods, such as assays or electronic monitors; (5) varied and relatively arbitrary criteria have been used to classify patients in a dichotomous fashion (adherent or nonadherent) on the basis of cross-sectional and single assessments of adherence; and (6) adherence was higher to regimens for more imminently life-threatening conditions, such as insulin for diabetes and immunosuppressive medications for HIV.

Nonadherence Consequences

Potentially serious health consequences can result from adherence failures (Rapoff, 1999). Bauman et al. (2002) reported that those who were nonadherent to asthma regimens had increased morbidity, including higher hospitalizations, missed more school, had poorer overall functioning, and had more days with wheezing and restricted activities. The Diabetes Control and Complications Trial (DCCT) showed that maintaining excellent glycemic control through intensive therapy delays the onset and slows the progression of long-term complications of diabetes (such as blindness) and that this requires a high level of adherence to regimens for diabetes (DCCT Research Group, 1994). Nonadherence has been consistently linked to a lack of viral suppression in the treatment of HIV, which in turn results in compromised health status and disease progression (Steele & Grauer, 2003). Incomplete adherence to immunosuppressive drugs has been linked to heart, kidney, and liver transplant failures (Magee et al., 2004; Stuber, 1993). Ettenger et al. (1991) found that 64% (30/47) of adolescents were found to be nonadherent, with 15% rejecting their allograft and 26% experiencing graft dysfunction attributed to nonadherence. Jarzembowski et al. (2004) found that 5 years after renal transplantation, African Americans had a lower rate of graft survival (42%) than Whites (71%) and Hispanics (95%) and that nonadherence accounted for 71% of cases of graft loss among African Americans. These adherence-related transplant failures are particularly tragic given

28.1   Nonadherence Rates for Selected Chronic Disease Regimens (Studies That Include or Exclusively Report on Adolescents)

Reference	Sample	Regimen	Adherence measure	Results
			Asthma	
Bender et al., 2006	N = 5,504 5–96 years (N = 423, 13–20 years)	Inhaled steroid/ beta-agonist combination	Pharmacy refill data	Overall adherence = 22% of days covered by refills (16% for 13–10 year olds)
Celano et al., 1998	N = 55 6–17 years	Inhaled steroid	Canister weight	Mean adherence = 44%
Coutts et al., 1992	N = 14 9–16 years	Inhaled steroid	Nebulizer Chronolog	Underuse recorded on 55% of days and overuse on 2%
Eney & Gold- stein, 1976	N = 43 3–16 years	Theophylline	Serum assay (therapeutic range = 10–20ug/ ml or higher)	88% of sample had subtherapeutic levels; me- dian level = 2.65ug/ml; range = 0–15.4
Jónasson et al., 2000	N = 122 7–16 years	Inhaled steroid placebo (clinical trial)	Count of remaining doses in inhaler	Adherence lower for adolescents through- out the 27 months of the trial. Adherence to inhaled steroid dropped from 77% at 3 months to 49% at 27 months
Kelloway et al., 1994	N = 14 12–17 years (remainder of sample was 105 patients 18–65 years)	Theophylline inhaled steroid	Comparison of pharmacy claims to pre- scribed orders in medical charts	Theophylline adherence = 73% Inhaled steroid adherence = 30% (both figures lower for adolescents than for adults)
McQuaid et al., 2003	N = 106 8–16 years	Inhaled steroid	MDILog (electronic monitor)	Mean adherence = 48%

McQuaid et al., 2005	N = 53 (subsample of N = 115) 7–16 years	Inhaled steroid	MDILog	Mean adherence = 51%
Radius et al., 1978	N = 80 9 mos.–17 years (M = 7.7 yrs)	Theophylline	Serum Assay	34% had negative values
Simmons et al., 1997	N = 14 12–16 years	Inhaled beta-agonist (salmeterol) vs. placebo (clinical trial)	Nebulizer Chronolog	11 of 13 patients (85%) were >85% adherent to salmeterol; 7 of 13 (54%) were adherent to placebo
Walders et al., 2005	N = 75 8–16 years	Inhaled quick-relief (as needed) and longer-term controller (daily) medications	MDILog	Mean daily controller medications taken 46% of time; quick-relief medication use varied between 0 and 251 doses taken over 1 month
Cancer				
Festa et al., 1992	N = 50 (2 samples with M = 15.6 yrs and M = 19.1 yrs)	Prednisone (N = 21) for ALL. Penicillin (N = 29) for postsplenectomy prophylaxis.	Serum assay for prednisone; urine assay for penicillin	52% nonadherent to prednisone; 48% nonadherent to penicillin

Reference	Sample	Regimen	Adherence measure	Results
			Cancer	
Kennard et al., 2004	N = 44 M = 15.3 years	Trimethoprim/ sulfamethoxa- zole	Serum assay	27% nonadherent
Lancaster et al., 1997	N = 496 5–18 years	6-Mercaptopu- rine	Blood assay	42% had subtherapeutic levels 2% had completely undetectable metabolites on one or more occasions
Lansky et al., 1983	N = 31 2.1–14.3 years (M = 7.2 yrs)	Prednisone	Urine assay (<18.7 kgs/cr defined as sub-therapeutic)	42% had subtherapeutic levels (M = 19.88; range = 4.95–40.05)
Lau et al., 1998	N = 24 2.6–17 years	6-Mercaptopu- rine	MEMS (electronic monitor)	17% nonadherent (<80% of doses taken)
Phipps & De-Cuir-Whalley, 1990	N = 54 1mos.–20 years (M = 9 yrs)	Antibiotics as part of bone marrow trans- plant	Review of patient chart and notes from psy-chosocial team meetings	"Significant" adherence difficulties identified in 52% of sample
Smith et al., 1979	N = 52 8mos–17 years	Prednisone	Urine assay (<18.7kgs/cr defined as sub-therapeutic)	33% had subtherapeutic levels
Tebbi et al., 1986	N = 46 2.5–23 years (M = 6.85 yrs)	Prednisone	Patient and parent report (corroborated by serum assay). Nonadherence defined as any missed dose during preceding month.	Nonadherence rates, postdiagnoses, at 2 wks = 18.8%; at 20wks = 39.5%; at 50wks = 35%

Cystic fibrosis				
Czajkowski & Koucher, 1986	N = 40 13–23 years	Chest physiotherapy, diet, medications, Recording daily input and output, and co-operating with medical tests (on inpatient unit).	Medical and nursing notes used to rate degree of adherence (rater not specified)	35% of sample identified as being nonadherent
Passero et al., 1981	N = 58 (no specific ages given)	Antibiotics, vitamins, chest physiotherapy, and diet	Patient report	Incomplete adherence for: antibiotics = 7%; vitamins = 10%; chest physiotherapy = 60%; diet = 80%
Diabetes				
Anderson et al., 1997	N = 89 10–15 years	Blood glucose monitoring	Provider rating 3 to 4 months prior to clinic visit	39% of younger patients (10–12 years) monitored blood glucose four or more times daily; 10% of older patients ($p < 0.007$) did so
Hentinen & Kyngas, 1992	N = 47 15–17 years	Insulin; diet; glucose monitoring	Patient report (questionnaire) with patient responses used to categorize adherence as high, average, or low	Percent of patients categorized as having low adherence by regimen component: insulin = 3%; diet = 34%; glucose monitoring = 38%

(*continued*)

Reference	Sample	Regimen	Adherence measure	Results
			Diabetes	
Jacobson et al., 1987	N = 57 9–15 years (M = 12.8 yrs)	Diet; insulin usage; blood glucose monitoring	Health care provider ratings on a 4-point scale (4 = excellent, 3 = good, 2 = fair, 1 = poor) for each regimen component and a composite index	First 9-mos interval mean adherence ratings by regimen: diet = 3.2; insulin usage = 3.3 blood glucose monitoring = 2.8 composite index = 3 Second 9-mos interval mean adherence ratings by regimen: diet = 2.9; insulin usage = 3; blood glucose monitoring = 2.5 and composite index = 2.7 (second 9-mos interval significantly lower than first) Adolescents had significantly lower adherence on diet, blood glucose monitoring, and the composite index than preadolescents
Jacobson et al., 1990	N = 61 9–16 years	Diet; insulin usage; blood glucose monitoring	Health care provider ratings on a 4-point scale (4 = excellent, 3 = good, 2 = fair, 1 = poor). Composite index derived from regimen components	Mean adherence ratings by year: Yr. 1 = 3.07; Yr. 2 = 2.83; Yr. 3 = 2.63; and Yr. 4 = 2.43
Kovacs et al., 1992	N = 95 8–13 years (M = 11.1 yrs)	Insulin use; glucose monitoring; diet	Diagnosis of medical nonadherence by clinicians based on structured interviews with patients and parents	29.5% of sample were nonadherent Nonadherence emerged an average of 3.5 yrs after disease onset

Lorenz et al., 1985	N = 90 9–15 years (M = 12.8 yrs)	Diet	Observations (unobtrusively done in camp setting) Error rate calculated by summing additions and deletions to meal plan divided by the total number of exchanges	Mean error rate = .35 (standard deviation = .19)
Miller & Drotar, 2003	N = 82 11–17 years	Diabetes tasks (e.g., monitoring blood glucose)	Self-Care Inventory ratings of 14 tasks by parents (5-point scale, "never do it" to "always do as recommended without fail") and average number of blood glucose tests over the previous 2 weeks as recorded on glucose meter obtained from medical chart	Mean parent rating = 3.92 and patient rating = 3.93; mean number of glucose tests/day = 2.66
Miller & Drotar, 2007	N = 63 11–17 years	Diabetes tasks (e.g., monitoring blood glucose)	Self-Care Inventory ratings of 14 tasks by parents (5-point scale, "never do it" to "always do as recommended without fail") and provider rating of 9 aspects of care; average number of blood glucose tests over the previous 2 weeks as recorded on glucose meter obtained from medical chart	Mean rating by parent = 3.72 and by provider = 3.25; mean number of glucose tests/day = 2.77
Naar-King et al., 2006	N = 119 10–17 years	Diet, insulin injections, blood glucose monitoring, and exercise	Ratings by parents and patients (0–100%, assessing "what percent of time do you/your teen" complete each regimen component in past month)	Mean parent rating = 68.04; mean patient rating = 65.49

Reference	Sample	Regimen	Adherence measure	Results
			Diabetes	
Schmidt et al., 1992	N = 69 4–18 years (M = 14.2 yrs)	Diet	Patient dietary records over a 3 day period Registered dietitian tallied the number of food exchanges that deviated from prescribed meal plans	Mean daily deviation from prescribed food exchanges = 23.8% (patients added or deleted, on average, about one of four exchanges)
Stewart et al., 2003	N = 56 10–23 years	Insulin injection, diet, blood glucose testing, exercise, treating reactions, maintaining blood glucose levels, and remembering to do everything every day.	Patient rated each care behavior from 20 ("failure") to 100 ("an A+"); average computed across the 7 behaviors to create an adherence composite	Time 1 adherence composite mean = 65.64 vs. Time 2 (12–24 months after Time 1) mean = 67.94
Wiebe et al., 2005	N = 127 10–15 years	14 diabetes managements tasks	Self-Care Inventory patient-rated adherence to 14 tasks ("1 = never did it to 5 = always did as recommended without fail"); average ratings computed across tasks	Mean composite rating = 3.62
Wilson & Endres, 1986	N = 18 12–18 years	Blood glucose monitoring	Meters with memory (patients and parents unaware of memory capabilities)	30% of blood tests not performed over 6 wks. Mean = 40% of blood tests recorded by patient but not registered by meter. Mean = 18% of blood tests not recorded by patients were registered by meter

Wing et al., 1986	N = 62 (M = 13.5 yrs)	Blood glucose monitoring	Observation of blood glucose monitoring technique by trained observers in clinic	48% estimated blood glucose within 20% of actual value; sterile technique poor; only 10% worked on a tissue or paper towel and none washed hands; 40% incorrectly timed test; 21% did not adequately wipe blood from testing strip
HIV/AIDS				
Dolezal et al., 2003	N = 48 Parent-youth dyads 7–14 years	Antiretroviral medications	Caregiver and youths ratings of adherence over past 2 days and previous week	In 46% of caregiver-youth dyads, at least one of the pair reported adherence problems in last 2 days and 44% reported missing doses in past week; level of agreement among dyads was low (e.g., 38% in disagreement about missed, partial, or off-schedule medications)
Van Dyke et al., 2002	N = 125 4 mos–17 years	Antiretroviral medications	Caregiver or youth ratings in past 3 days	70% reported full adherence; 25% reported missing some doses; 5% missed all doses
Williams et al., 2006	N = 2,088 8–14 years	Antiretroviral medications	Caregiver or youth ratings in past 3 days	84% reported full adherence; lower for 15–18-year-olds (76%) than for younger children (83%–89%)
Juvenile rheumatoid arthritis (JRA)				
Feldman et al., 2007	N = 175 2–18 years	Medications and exercise	Caregiver rated over past 3 months	Adherence at baseline, 3, 6, 9, and 12 months for medications was 86%, 92%, 90%, 92%, and 89%; for exercises 55%, 64%, 61%, 63%, and 54%

Reference	Sample	Regimen	Adherence measure	Results
Juvenile rheumatoid arthritis (JRA)				
Kvien & Reimers, 1983	N = 25 4–15 years	Salicylates or Naproxen	Pill count	95% adherent overall
Litt & Cuskey, 1981	N = 82 (M = 12 yrs)	Salicylates	Serum assay (<20mg/dl defined nonadherence)	45% of patients nonadherent; mean serum level = 21.3mg/dl
Litt et al., 1982	N = 38 (M = 14 yrs)	Salicylates	Serum assay (<20mg/dl defined nonadherence)	45% of patients nonadherent; mean serum level = 20.79mg/dl
Rapoff et al., 2005	N = 48 2.3–16.7 years	Nonsteroidal antiinflammatory drugs	MEMS (electronic monitor)	Monitored over 28 consecutive days; 48% nonadherent (<80% of doses taken); median levels showed full adherence on 70% of days, partial on 14%, and no adherence on 7%
Seizures				
Friedman et al., 1986	N = 25 9–17 years	Phenobarbital	Saliva assay (<3.0 ug/ml defined nonadherence)	21% of patients nonadherent Mean saliva level = 5.11 ug/ml
Hazzard et al., 1990	N = 35 9–16 years	Anticonvulsant medications	Serum assay (nonadherence defined as subtherapeutic levels for 3 separate assays obtained an average of 2.52 months apart)	56% of patients nonadherent

Transplantation				
Beck et al., 1980	N = 21 3–20 years	Immunosup- pressive drug, postrenal transplant	Pill counts	43% of patients were nonadherent (all were adolescents)
Blowey et al., 1997	N = 19 13–18 years	Immunosup- pressive drug, postrenal transplant	MEMS (electronic monitor)	21% nonadherent (<80% of doses taken)
Feinstein et al., 2005	N = 79 1.7–23 years	Immunosup- pressive drug, postrenal transplant	Patient report and plasma assay	16% were nonadherent (all but one of 13 were adolescents)
Gerson et al., 2004	N = 13 2–21 years	Immunosuppres- sive drug, post renal trans- plant	MEMS (electronic monitor) and assay	Mean adherence by MEMS = 80% (mean adherence by MEMS for patients classified by assay as probably nonadherent = 69% and 95% for those classified as probably adherent)
Kurtin et al., 1994	N = 23 10–19 years (M = 16 yrs)	Medications and diet	Nurse rated adherence on a 5-point scale ("very often" to "never"); nonadherence defined as those patients rated as "sometimes," "almost never," or "never" adherent	59% of patients rated as nonadherent
Penkower et al., 2003	N = 22 13–18 years	Immunosup- pressive drug, postrenal transplant	Patient report (deemed nonadherent for failing to take medication = 3 times a month)	13.6% nonadherent at baseline and 12 months later

Reference	Sample	Regimen	Adherence measure	Results
			Transplantation	
Serrano-Ikkos et al., 1998	N = 53 Mean age = 10.2 years	Immunosuppressive drug, postheart or heart-lung transplant	Patient medication diaries and blood assays	70% had good adherence (completed 80% of diaries and blood levels in acceptable range), 21% had moderate adherence (unsatisfactory diary completion), and 9% had poor adherence (unsatisfactory drug levels)
Shemesh et al., 2004	N = 81 2–22 years	Immunosuppressive drug, postliver transplant	Physicians, nurses, caregivers, and patients ratings (1 = "I always take my medications" to 4 = "I rarely take my medications as prescribed"); blood assay	Ratings of 1 ("ideally adherent") were given to 61% of patients by physicians, to 52% by nurses, to 70% by caregivers, and to 70% by patients themselves; only assay levels were significantly correlated with rejection episodes
Tucker et al., 2002	N = 68 (26 African American and 42 European American) 6–21 years	Immunosuppressive drug, postrenal transplant	Patient and physician rating, pill counts, and blood assay (all scored on 5-point scale, with 1 = "very nonadherent" and 5 = "very adherent")	Among African American patients, mean rating by patient = 3.89, by physician = 4.06, by pill count = 3.91, and assay = 4.13; among European American patients, mean rating by patient = 4.37, by physician = 4.02, by pill count = 3.58, and assay = 4.44

that approximately 19% of adolescent heart transplant recipients die while on organ transplant lists, as do 12% of adolescent potential liver and 1% of adolescent potential kidney recipients (Stuber, 1993). Adherence failures have also been implicated in the reemergence of drug-resistant infectious diseases such as tuberculosis (Bloom & Murray, 1992; Gibbons, 1992). Drug-resistant microbes evolve when bacteria exposed to different and incomplete doses of antimicrobials develop defenses against these drugs. This is particularly critical because drug companies are not developing new types of antimicrobials (Gibbons, 1992). The potential development of drug-resistant microbes could be especially threatening to young people with compromised immunity, such as those with cancer and cystic fibrosis, who are vulnerable to opportunistic infections.

Variations in adherence can also negatively impact medical decisions and outcomes of clinical drug trials. Physicians, unaware of adherence problems, may incorrectly assume that poor therapeutic outcomes are due to inadequacies in the regimen and prescribe more potent medicines with more serious side effects (Rapoff, 1999). Nonadherence can also interfere with effectiveness trials of medications (Fletcher, Fletcher, & Wagner, 1988) or clinical trials that try to determine the effectiveness of drugs given under ordinary circumstances. The variability in drug absorption (within and across persons) commonly found in clinical trials may be partially due to variability in adherence (Haynes & Dantes, 1987).

The cost-effectiveness of medical care can also be adversely affected by nonadherence (Rapoff, 1999; Smith, 1985). Overall, noncompliance with medical regimens accounts for up to $100 billion in health care and productivity costs in the United States (National Pharmaceutical Council, 1994). The annual cost of hospitalizations due to medication nonadherence in the United States is about $13.35 billion, which represents 1.7% of all health care expenditures. Costs associated with loss of productivity and premature death due to medication nonadherence have been estimated at $4.21 billion to $26.71 billion per year (Cleemput, Kesteloot, & DeGeest, 2002). The costs associated with treating drug-resistant infections have been estimated to be between $100 million and $200 million a year in the United States (Gibbons, 1992). These potentially unnecessary expenses may add to the existing economic burden on families of chronically ill adolescents and society in general, in the form of increased insurance costs and taxes. Conversely, interventions that improve adherence may also reduce unnecessary health care costs (Cleemput et al., 2002; National Pharmaceutical Council, 1994). In a large retrospective cohort study of 137,277 patients under the age of 65 years with congestive heart failure, diabetes, hypercholesterolemia, or hypertension, disease-related and all-cause medical costs and hospitalization rates were significantly lower for patients with higher medication adherence (Sokol, McGuigan, Verbrugge, & Epstein, 2005).

These serious health and economic consequences of nonadherence illustrate the importance of identifying predictors of adherence, particularly those that can be modified to improve adherence to therapeutic regimens. These efforts have the potential of increasing treatment efficacy, reducing disease-related morbidity and mortality, reducing unnecessary health care costs, and improving the yield from clinical drug trials.

Predictors of Nonadherence

There are few extant theoretical models that have been proposed and tested that are relevant to the pediatric medical adherence literature, with the exception of variations on the Health Belief Model (HBM) (Rapoff, 1996). Most studies examine predictors of adherence through correlational or regression analyses or classify patients as adherent or nonadherent and test for significant between-group differences along factorial dimensions. Patient, family, disease, and regimen factors have been commonly studied as predictors of adherence. These types of studies can be helpful in identifying risk factors for adherence problems, even if a particular variable (e.g., age) cannot be altered to improve adherence. These empirically-derived factors can also assist researchers in formulating adherence theories that can then be tested and refined through experimentation (Rapoff, 1999). Studies relevant to each factor are reviewed followed by a discussion of the implications of these findings for improving adherence.

Patient/Family Factors

Demographics

A number of patient- and family-related demographic variables have been associated with adherence. As mentioned in the introduction, adolescents are at higher risk for nonadherence to regimens for asthma, cancer, cystic fibrosis, diabetes, heart or heart/lung disease posttransplantation, HIV, juvenile rheumatoid arthritis (JRA), renal disease, and renal disease posttransplantation. However, one study found that adolescents with asthma were more adherent than older patients (Bender, Pedan, & Varasteh, 2006), and another study found no significant differences in adherence to medications between preadolescents and adolescents with JRA (Litt & Cuskey, 1981).

The few studies that have examined patient gender effects have been less clear than those that have examined patient age. Males have been found to be less adherent to regimens for cystic fibrosis (Patterson, 1985), diabetes (Lorenz, Christensen, & Pichert, 1985; Naar-King et al., 2006), and after renal transplantation (Fennell, Tucker, & Pedersen, 2001). However, other studies found that males were more adherent to regimens for asthma (Bender et al., 2006) and diabetes (Johnson, Freund, Silverstein, Hansen, & Malone, 1990; Patino, Sanchez, Eidson, & Delamater, 2005; Stewart et al., 2003). Patients identifying as Hispanic or African American have been found to be less adherent than Caucasians to regimens for asthma (McQuaid, Kopel, Klein, & Fritz, 2003) and seizures (Snodgrass, Vedanarayanan, Parker, & Parks, 2001).

Parental and family demographics have also been studied as predictors of adherence. Lower socioeconomic status (SES), in general, and lower educational levels in parents, specifically, have been associated with nonadherence to regimens for asthma (Radius et al., 1978), cystic fibrosis (Patterson, 1985), diabetes (Bobrow, AvRuskin, & Siller, 1985), JRA (Rapoff et al., 2005), and renal disease (Brownbridge & Fielding, 1994). Adolescents whose parents are separated or divorced are less likely to be adherent to regimens for asthma (Radius et al.,

1978), heart or heart/lung disease requiring transplantation (Serrano-Ikkos et al., 1998), liver disease requiring transplantation (Lurie et al., 2000), and renal disease (Brownbridge & Fielding, 1994). In addition, patients in larger families and in families where the mother works outside the home are less likely to be adherent to regimens for cystic fibrosis (Patterson, 1985).

Knowledge/Health Beliefs

Patients who are less knowledgeable about their disease and treatment tend to be less adherent to regimens for cancer than those who are better informed (Tebbi et al., 1986), cystic fibrosis (Gudas et al., 1991), diabetes (La Greca et al., 1990), and renal disease after transplantation (Tucker et al., 2001). However, patient knowledge in one study was not associated with adherence to medications for renal disease (Beck et al., 1980). A different picture emerges when parents are knowledgeable about their child's disease and treatment. Parental knowledge of diabetes (La Greca et al., 1990) and sickle cell disease (Jensen et al., 2005) was significantly correlated with adherence for preadolescents but not adolescents.

Factors related to the HBM have been examined in several studies from parents' and patients' perspectives. The HBM posits four sets of variables that predict or explain adherence: (1) perceived susceptibility, (2) perceived severity, (3) perceived benefits, and (4) perceived barriers (Janz & Becker, 1984). In addition, the HBM emphasizes the importance of internal or external cues to action to prompt adherence.

Higher susceptibility or vulnerability and severity, as rated by mothers, has been associated with better adherence to medications for asthma (Radius et al., 1978) and, as rated by patients, for cancer (Tamaroff, Festa, Adesman, & Walco, 1992). In contrast, higher perceived threat or severity by adolescents has been associated with lower adherence to regimens for diabetes (Bond et al., 1992) and to lower adherence to chest physiotherapy for cystic fibrosis (Gudas et al., 1991). Higher levels of perceived benefits, as assessed by mothers, has been associated with better adherence to asthma medications (Radius et al., 1978) and (as assessed by patients) with diabetes regimens (Bobrow et al., 1985; Bond et al., 1992; McCaul, Glasgow, & Schafer, 1987). Among African American renal transplant patients, lower certainty that medications help to keep transplanted kidneys healthy was related to lower adherence (Tucker et al., 2001). Perceptions among parents and adolescents of higher barriers to adherence have been uniformly related to poorer adherence to regimens for asthma (Radius et al., 1978) and diabetes (Glasgow, McCaul, & Schafer, 1986; McCaul et al., 1987). The presence of relevant cues to action has been associated with better adherence to regimens for asthma (Slack & Brooks, 1995; Van Es et al., 1998), diabetes (Bond et al., 1992), and HIV (Williams et al., 2006). Interestingly, a study that included a high percent of African American adolescents found no support for HBM factors in the prediction of adherence (Patino et al., 2005).

Adjustment and Coping

Adolescent adjustment and coping variables have been frequently examined as correlates of adherence, with fairly consistent results. Higher self-esteem has

been associated with better adherence to diabetes (Jacobson et al., 1987), JRA (Litt, Cuskey, & Rosenberg, 1982), and seizure (Friedman et al., 1986) regimens. Greater autonomy and personal independence have been related to higher adherence to regimens for JRA (Litt et al., 1982) and seizures (Friedman et al., 1986). Higher social functioning, better disease-specific adjustment, an internal locus of control, and higher self-efficacy have all been associated with higher adherence to diabetes regimens (Holmes et al., 2006; Jacobson et al., 1987). A sense of optimism has been associated with better adherence to regimens for cystic fibrosis (Gudas et al., 1991) and greater problem-solving skills predicted higher adherence to diabetes regimens (McCaul et al., 1987). Patient and parental satisfaction with care has been associated with better adherence to seizure medications (Hazzard, Hutchinson, & Krawiecki, 1990). Higher scores on standardized memory scales have been associated with higher adherence to regimens for diabetes (Holmes et al., 2006). Adolescents taking medication for attention deficit hyperactivity disorder or antipsychotic medications were more adherent to medications for HIV (Williams et al., 2006).

On the negative side of the ledger, behavioral problems have been related to lower adherence to regimens for asthma, cystic fibrosis, diabetes, and renal disease posttransplantation (Gerson, Furth, Neu, & Fivush, 2004; Greening, Stoppelbein, Konishi, Jordan, & Moll, 2007; Jacobson et al., 1987; Miller & Drotar, 2003; Modi & Quittner, 2006; Naar-King et al., 2006). Adolescents who have a psychiatric disorder are also less likely to be adherent to regimens for diabetes (Kovacs et al., 1992) and to medications after liver transplantation (Lurie et al., 2000). Repeating a grade in school has been associated with lower adherence to medications for HIV (Williams et al., 2006), and a history of dropping out of school has been associated with lower adherence to medications after liver transplantation (Lurie et al., 2000). Increased anxiety and depression have also been related to lower adherence to regimens for cancer (Kennard et al., 2004), diabetes (Naar-King et al., 2006), and renal disease (Brownbridge & Fielding, 1994). Denial has been associated with poor adherence to medications for asthma (Buston & Wood, 2000) and cancer (Tamaroff et al., 1992). Higher levels of anger predicted lower adherence to medications after renal transplantation (Penkower et al., 2003) Maladaptive decision making (hypervigilance) has been associated with lower adherence to regimens for diabetes (Miller & Drotar, 2007). A history of substance abuse and physical or sexual abuse has been associated with lower adherence to medications after liver transplantation (Lurie et al., 2000).

Several studies have examined family and parental adjustment and coping as correlates of adherence, with family environment variables studied most frequently. Greater family support, communication, expressiveness, harmony, integration, cohesion, organization, balance, and collaboration with health care providers have been associated with higher adherence to regimens for asthma (Gavin, Wamboldt, Sorokin, Levy, & Wamboldt, 1999; McQuaid et al., 2005), cystic fibrosis (Patterson, 1985), diabetes (Hauser et al., 1990; La Greca et al., 1995; Lewin et al., 2006; McCaul et al., 1987), JRA (Kyngäs, 2002), renal disease (Feinstein et al., 2005; Kurtin, Landgraf, & Abetz, 1994), and seizures (Friedman et al., 1986). In addition, mother-daughter interactions characterized by clear communication, empathy, and positive conflict resolution have been associated with higher adherence to diabetes regimens (Bobrow et al., 1985).

Somewhat surprisingly, paternal nagging has been associated with better adherence to diabetes regimens (Burroughs, Pontious, & Santiago, 1993). Though poorly studied, greater father involvement (both amount and helpfulness) has been related to higher adherence to regimens for asthma, cystic fibrosis, diabetes, inflammatory bowel disease, phenylketonuria, and spina bifida (Wysocki & Gavin, 2006). In contrast, reporting by mothers of lower levels of spousal support is associated with lower adherence to regimens for diabetes (Lewandowski & Drotar, 2007).

Family dysfunction (poor problem solving and communication, conflicts, and critical parenting) has been related to lower adherence to regimens for asthma (Weinstein & Faust, 1997), diabetes (Lewandowski & Drotar, 2007; Lewin et al., 2006; Miller & Drotar, 2007), HIV (Hammami et al., 2004), renal disease posttransplantation (Gerson et al., 2004), and sickle cell disease (Barakat, Smith-Whitley, & Ohene-Frempong, 2002). Somewhat surprisingly, higher marital satisfaction has been related to lower adherence to cystic fibrosis regimens (Geiss, Hobbs, Hammersley-Maercklein, Kramer, & Henley, 1992). Parental coping difficulties have been associated with poor adherence to JRA (Wynn & Eckel, 1986) and renal (Brownbridge & Fielding, 1994) regimens. Parental depression has been related to poor adherence to asthma and renal disease regimens (Brownbridge & Fielding, 1994). Parental anxiety has been related to lower adherence to seizure medications (Hazzard et al., 1990). Parental stress, passive parental coping styles, and maternal uninvolvement have been associated with lower adherence to regimens for diabetes, renal disease posttransplantation, and sickle cell disease (Barakat et al., 2002; Gerson et al., 2004; Wiebe et al., 2005). Also, those parents who placed more behavioral restrictions on their children tended to have children who were less adherent to their seizure medications (Hazzard et al., 1990).

Parental Monitoring

Lack of parental monitoring of adolescents' adherence to treatment-related activities has been implicated as a contributor to nonadherence. Family situations where there is ambiguity about who assumes primary responsibility for regimen tasks or where parental monitoring and supervision are low have been associated with lower adherence to regimens for asthma (Walders et al., 2000), cancer (Tebbi, Richards, Cummings, Zevon, & Mallon, 1988), diabetes (Anderson et al., 1990, 1997; Bobrow et al., 1985; Holmes et al., 2006; Ingersoll, Orr, Herrold, & Golden, 1986), and renal disease (Beck et al., 1980; Feinstein et al., 2005). In a sample of 12- to 21-year-olds with diabetes, parental supervision virtually ceased by the time children were 15 years of age (Ingersoll et al., 1986). Another study found that primary responsibility for taking immunosuppressive medications after liver transplantation shifted to children at about age 12 years (Shemesh et al., 2004). The lack of parental monitoring or involvement may explain why parental knowledge of diabetes is unrelated to adherence for adolescents but significantly correlated with adherence for preadolescents (La Greca et al., 1990) and why parental ratings of adherence for older adolescents are a poor predictor of metabolic control for that group but a significant predictor for younger adolescents (Burroughs et al., 1993).

Disease Factors

Duration

Longer disease duration has been associated with poorer adherence to regimens for diabetes (Bond et al., 1992; Patino et al., 2005), JRA (Litt & Cuskey, 1981), and renal disease (Brownbridge & Fielding, 1994). Also, longitudinal studies have found significant deterioration in adherence over time to diabetes regimens, with nonadherence emerging an average of 3.5 years after the onset of the disease (Jacobson et al., 1990; Kovacs et al., 1992).

Disease Course and Symptoms

Chronic diseases often fluctuate in terms of the presence and severity of symptoms. Adherence may be particularly difficult to sustain during periods when patients are relatively asymptomatic, such as with asthma (van Es et al., 1998) and JRA (Rapoff et al., 2005). However, studies involving adolescents with JRA (Feldman et al., 2007) and seizures (Hazzard et al., 1990) found that lower disease activity was associated with higher adherence.

Perceived Severity

Patients' perception of higher severity has been related to lower adherence (Gudas et al., 1991) while parents' perception of higher severity relates to higher adherence (Radius et al., 1978). However, patients' and parents' ratings of severity seem be more useful in predicting adherence than are severity ratings by health care providers (Rapoff, 1999).

Regimen Factors

Type and Complexity

Adherence tends to be lower with complex regimens such as chest physiotherapy for cystic fibrosis (Passero et al., 1981), dietary regimens for diabetes (Glasgow et al., 1986), medications for HIV (Van Dyke et al., 2002), exercise regimens for JRA (April et al., 2006; Feldman et al., 2007; Rapoff, Lindsley, & Christophersen, 1985), and medications after renal transplantation (Tucker et al., 2002). Lower rates of adherence have been reported for inhaled than for oral medications used in the treatment of asthma (Kelloway et al., 1994) and for pills than for liquid medications in the treatment of HIV (Van Dyke et al., 2002). Bad-tasting medications or the need to swallow larger pills has been cited as reasons for lower adherence to asthma medications (Celano, Geller, Phillips, & Ziman, 1998; Radius et al., 1978; Slack & Brooks, 1995; van Es et al., 1998) and medications after renal transplantation (Tucker et al., 2002). Morning doses are reported to be more difficult to remember to take than evening doses in the treatment of asthma (Jónasson et al., 2000; van Es et al., 1998). Patients who had had heart/lung transplantation were found to be less adherent to immunosuppressant medications than were those who had received heart transplantation

only (Serrano-Ikkos et al., 1998). African American adolescents were less adherent to immunosuppressant medications after renal transplantation if they had not had dialysis prior to transplantation and if they had received a living-related organ donation (Fennell et al., 2001).

Costs

Treatment costs can be prohibitive for some families and result in nonadherence (Rapoff, 1999). A telephone survey of 138 patients with rheumatic diseases revealed that of those who had a physician visit and purchase of medication in the month before the survey, 40.7% of the parents reported difficulty paying physician-related charges and 25.3% had problems paying medication-related expenses (McCormick, Stemmler, & Athreya, 1986). Higher costs of medications have been related to lower adherence to medications for asthma (Bender et al., 2006), and lack of insurance has been associated with lower adherence to medications for seizures (Snodgrass et al., 2001).

Side Effects and Inconvenience

Having or avoiding side effects of medications has been cited as a reason for not taking medications for asthma (Buston & Wood, 2000; Slack & Brooks, 1995). The inconvenience or embarrassment of taking medications outside the home have been cited as reasons for nonadherence to medications in the treatment of asthma (Buston & Wood, 2000; Celano et al., 1998; Slack & Brooks, 1995).

Efficacy

Regimens that are perceived by parents and patients as more efficacious or beneficial are better adhered to (Bobrow et al., 1985; Bond et al., 1992; Feldman et al., 2007; McCaul et al., 1987; Radius et al., 1978). However, regimen efficacy (in terms of treatment outcome) is usually assumed to be partially determined by adherence. There is support for this connection, as higher adherence has been related to better metabolic control of diabetes (Burroughs et al., 1993; Johnson et al., 1992; Kovacs et al., 1992; Kuttner, Delameter, & Santiago, 1990). The relationship between efficacy and adherence is most likely bidirectional. A related issue is the delayed benefits of treatments even when patients are highly adherent (Rapoff, 1999). For example, an adequate trial of nonsteroidal anti-inflammatory medications in the treatment of JRA is considered to be at least 8 weeks (Lovell, Giannini, & Brewer, 1984).

Summary and Implications

The following adherence "risk profile" can be developed for adolescents with chronic diseases. They tend to come from families that are preoccupied with dysfunctional interaction patterns or, by contrast, with positive social and recreational activities outside the home that consume time, energy, and resources that could be directed to supervising and managing treatment regimens. Their families are also likely to be larger, in the lower socioeconomic strata, and from minority groups, and there is likely to be only one parent living in the home.

Their parents tend to be less educated, in general, or specifically about their children's disease and treatment. Also, their parents are prone to adjustment and coping difficulties and may place undue restrictions on their children's activities. Adolescents are also likely to have adjustment and coping difficulties and be less knowledgeable about their disease and treatment than more adherent peers. They are also likely to have primary responsibility for carrying out regimen tasks, with little or no direct supervision by their parents. Both the parents and the adolescents tend to hold beliefs that undermine adherence efforts; for example, they may perceive more costs than benefits from adhering to treatment regimens. These adolescents have also had to cope with their disease and treatment over a period of years, with fluctuations in the type and severity of symptoms associated with their disease. They have also been prescribed regimens that are often complex, intrusive, and costly, that produce negative side effects, and that are not immediately efficacious.

On the positive side, there are "resource" factors that can also be gleaned from these studies that point to specific ways patients can be helped to achieve better adherence. A positive family environment is critical for supporting adolescent adherence to chronic-disease regimens. This makes perfect sense from a normative developmental context. Despite the widespread notion that adolescent-parent relations are "stormy," most adolescents report being close to their parents, respect them, and rely on them for support (Coleman & Hendry, 1990; Crockett & Petersen, 1993). Part of this support by parents involves shared responsibility for treatment regimen tasks and monitoring. Again, this makes sense from a developmental perspective. Developing autonomy from parents is an important developmental task for adolescents, and close supervision by parents is not as feasible or, in some cases, desirable (Coleman & Hendry, 1990; Crockett & Petersen, 1993). For some adolescents, this decrease in parental supervision increases the likelihood of engaging in misconduct and health-risking behaviors (Crockett & Petersen, 1993). Thus, parents have to balance their adolescent's needs for autonomy with the need for supervision.

Adherence Improvement

Adherence improvement strategies can be broadly classified as educational, organizational, or behavioral (Rapoff, 1999). Educational strategies rely primarily on verbal and written instructions designed to inform patients and their parents about the illness, regimen tasks, the importance of adherence, and strategies for improving adherence. Organizational strategies target changes in the health care delivery system, such as increasing accessibility to health care services, simplifying regimens, and providing more intense supervision of patients by health care providers. Behavioral strategies refer to behavior change procedures, such as patient or parental monitoring, contracting, and token economy programs, designed to alter specific adherence behaviors. Most studies utilize these strategies in combination.

Table 28.2 provides details on adherence improvement studies, primarily conducted with chronically ill adolescents. Overall, there are strikingly few intervention studies. Nine of the 17 studies located were concerned with improving adherence to diabetes regimens, and no studies were located that

were relevant to regimens for cancer, cystic fibrosis, renal disease, seizures, or posttransplantation. However, several conclusions can be drawn from these studies.

Educational strategies are rarely attempted in isolation but are usually combined with behavioral strategies (e.g., Pieper, Rapoff, Purviance, & Lindsley, 1989). This may occur because educational strategies have limited utility in improving adherence, in part, due to ceiling effects. That is, those patients selected for intervention studies were probably exposed to extensive educational efforts that had their impact on adherence prior to the patient's entry into the study (Rapoff & Barnard, 1991). Also, knowing about something (declarative knowledge) is quite different from knowing how to do something (procedural knowledge) or performing in accordance with expectations (Glaser & Bassok, 1989; Reese, 1989).

The primary organizational strategies used have been monitoring by a physician and simplification of regimens. Increased physician monitoring has improved adherence to asthma medications (Eney & Goldstein, 1976). Simplifying regimens, by reducing the number of medication doses, has improved adherence to medications for asthma (Tinkelman, Vanderpool, Carroll, Page, & Spangler, 1980) and JRA (Rapoff, Purviance, & Lindsley, 1988a).

By far the most frequently tested and effective strategies have been behaviorally based, including explicit training and feedback (Epstein, Figueroa, Farkas, & Beck, 1981), goal setting and contracting (Schafer, Glasgow, & McCaul, 1982), and reinforcement programs (Carney, Schechter, & Davis, 1983; Rapoff et al., 1988a, 1988b; Wysocki, Green, & Huxtable, 1989). Sometimes punishment procedures have been added when reinforcement contingencies have not been sufficient (Snyder, 1987). However, most of these studies have included small samples and have used fairly complicated interventions that are not likely to be feasible for routine use in subspecialty settings.

Several studies are noteworthy. One of the most intriguing studies reviewed in Table 28.2 is reported by Satin, La Greca, Zigo, and Skyler (1989), who employed a parent simulation component whereby parents simulated their children's diabetes regimens (gave themselves normal saline shots, followed the diet, checked blood glucose levels, and so on). This simulation, coupled with weekly support and educational sessions, resulted in improvements in metabolic control of patients' diabetes. Perhaps parents became more sensitized to adherence-related issues and were more attentive to and supportive of their children's efforts to adhere. Regimen simulation has been added as a component in behavioral family systems therapy for improving adherence to regimens for diabetes (Wysocki et al., 2006) and warrants replication with other chronic diseases. It might be interesting to extend these simulations to providers; they might enhance providers' sensitivity to adherence-related barriers and possible responses to these problems. Intensive home- and community-based family therapy ("multisystemic therapy") has been effective in increasing adherence to blood glucose testing in adolescents with diabetes (Ellis et al., 2005, 2007) and warrants further replications with other chronic conditions. Finally, the study by our group of JRA patients (Rapoff et al., 2002) was unique in that we focused on preventing the expected drop in adherence over time that has been documented for other chronic diseases by intervening with newly diagnosed patients. We were successful in that the experimental group showed maintenance

28.2 Adherence Intervention Studies Involving Adolescents With Chronic Diseases

Reference	Sample	Regimen/measure	Procedures	Outcome
			Asthma	
Chan et al., 2007	N = 120 (6–17 yrs)	Inhaled steroids; pharmacy refill; symptom diaries completed	Random assignment to office-based (traditional in-person education and case management) or virtual group (received computers, Internet connections, in-home Internet-based education and case management via study Web site) over a 12-month period	No differences between groups on adherence to inhaled steroids; significantly greater diary completion in the virtual group (35.4%) than in the office-based group (20.8%); no differences between groups in ER visits, hospitalizations, unscheduled asthma-related clinic visits, pulmonary function, asthma knowledge scores, or quality of life
Eney & Goldstein, 1976	N = 90 (3–16 yrs)	Theophylline; serum/salivary assays	Random selection but not assignment to 2 groups: Gr 1 had no specific intervention; Gr 2 patients informed that drug ingestion was being monitored and physicians were more directive in discussing adherence	11% of patients in Gr 1 and 42% in Gr 2 had therapeutic drug levels
Tinkelman et al., 1980	N = 20 (11–18 yrs)	Theophylline; serum assay and pill counts	Random assignment to short-acting (q 6 hr) or sustained-release (q 12 hrs) theophylline; dosing instructions given for both preparations	Significantly higher adherence with sustained-release than with short-acting theophylline by pill counts; no significant difference in serum levels
			Diabetes	
Carney et al., 1983	N = 3 (10–14 yrs)	Blood glucose testing; patient records and used t	Multiple baseline-across-subjects with baseline followed by point system exchanged for money and special activities	All 3 patients showed improvement in % of tests performed, with 2 patients improving from <5% in baseline to 87% and 93%

		esting strips; Ghb levels		after treatment; gains were maintained at 4-mos follow-up; Ghb levels improved from baseline (10.1%, 15.2%, & 9.1%) to follow-up (9.4%, 11.7%, & 6.0%)
Ellis et al., 2005	N = 127 (10–17 yrs)	Insulin use, diet, and blood glucose testing by 24–recall interview; blood glucose by electronic monitor (glucometer)	Random assignment to standard care or multisystemic therapy (MST). MST is an intensive home- and community-based family therapy approach that includes a variety of interventions that can be selected, including cognitive-behavioral therapy, parent training, family therapy, support from school personnel and peers, and work with health care team (mean length of MST was 5.7 months)	Significant improvement in the frequency of blood glucose testing (24-hr recall and glucometer) in the MST group over the standard-care group; no significant difference between groups on metabolic control, insulin or dietary adherence, or ER visits; youth in MST groups showed significant reductions in hospital admissions
Ellis et al., 2007	N = 127 (10–17 yrs)	Blood glucose testing; electronic monitor (glucometer)	Random assignment to standard care or multisystemic therapy (MST). MST is an intensive home- and community-based family therapy approach which includes a variety of interventions that can be selected including cognitive-behavioral therapy; parent training, family therapy, enlisting support from school personnel and peers, and working with health care team (mean length of MST was 5.7 months)	Significant improvement in the frequency of blood glucose testing in the MST group over the standard-care group. Trend for youths receiving MST to show greater improvements in metabolic control; youths in the MST group from single-parent families showed a significant improvement in metabolic control No differences in primary caregiver support for diabetes; youth in two-parent families did report significantly greater increase in secondary caregiver support than did controls in two-parent families

28.2	**Adherence Intervention Studies Involving Adolescents With Chronic Diseases (*continued*)**		

Reference	Sample	Regimen/ measure	Procedures	Outcome
			Asthma	
Epstein et al., 1981	N = 17 (6–16 yrs)	Urine glucose testing; direct observation	Random assignment to practice condition (patients tested 20 prepared samples but were not informed of results) or feedback condition (patients tested samples and given feedback about accuracy)	Mean number of correct urine glucose estimations were significantly higher for feedback (7.2) than for practice (3.8) conditions posttraining
Satin et al., 1989	N = 32 (mean age = 14.6 yrs)	Insulin use; urine glucose testing; diet; exercise Parental ratings of self-care (1 = very careful to 5 = careless) Ghb levels Attitudes toward teenager with diabetes scales Family Environment Scale.	Random assignment to one of three groups: Gr 1–patients and parents met for 6 weekly sessions to discuss diabetes and management; Gr 2–identical to Gr 1 plus included a parent simulation of diabetes regimen; or Gr 3–control group	No significant differences between groups in self-care ratings; significant decrease in Ghb levels at 6-wk postintervention for Gr 2 compared to Gr 3; significant difference in attitudes towards teenager with diabetes (more positive) for Gr's 1 & 2

Schafer et al., 1982	N = 3 (16–18 yrs)	Urine glucose testing, insulin use, exercise; wearing diabetic information bracelet; blood glucose testing; assessed by patient self-monitoring records	Multiple baseline-across-behaviors design with baseline followed by goal setting and (if needed) contingency contracting conditions	Goal setting alone effective in improving adherence to wearing info, exercise, & urine testing for subject 1 & for urine testing and exercise for subject 2; goal setting plus contracting improved adherence to insulin use for subject 2; nothing effective for subject 3, who was experiencing severe family problems
Snyder, 1987	N = 1 (14 yrs)	Insulin use; urine glucose testing; diet patient self-monitoring records with independent checks by mother and school nurse	Quasi-experimental single-subject design. Following self-monitoring baseline, patient exposed to self-monitoring plus monetary incentives and then to an additional condition involving hospitalization contingent on hypo- or hyperglycemic episodes for 36 hrs in a private room with no TV, visitors, books, and minimal staff interaction. Behavioral contacting and communication/conflict resolution training also implemented for antisocial behavior and mother–child conflict	Mean number of diabetes self-care activities performed was 5.6 during self-monitoring baseline, 6.3 during self-monitoring + reinforcement, and 8.5 during self-monitoring + reinforcement + punishment; 1-mos follow-up showed maintenance of gains. Decreases in antisocial behavior and conflicts and increases in school attendance noted; however, anecdotal reports at 6-mos posttreatment indicated deterioration of gains, with patient hospitalized for drug abuse

(*continued*)

28.2 Adherence Intervention Studies Involving Adolescents With Chronic Diseases (*continued*)

Reference	Sample	Regimen/ measure	Procedures	Outcome
			Asthma	
Wysocki et al., 1989	N = 42 (mean age = 14 yrs)	Blood glucose testing; insulin use; diet; exercise; automated recording of blood glucose (reflectance meters). 24-hr recall patient and parent interviews. Ghb levels. Attitudes toward diabetes and diabetes adjustment scales	30 patients randomly assigned to meter-alone (MA) or meter-plus-contract (MC) groups; remaining 12 patients in conventional-therapy (CT) control group. MA Gr patients earned money for bringing meters to clinic; MC Gr patients earned money contingent on glucose testing frequency	By 8th week, MC Gr had significantly higher frequency of glucose testing; no differences in overall adherence, Ghb levels, or patient/parent attitudes and adjustment to diabetes

| Wysocki et al., 2006 | N = 92 (11–16 yrs) | Insulin use, blood glucose testing, diet, exercise, and managing hypoglycemia by structured interview | Random assignment to standard care (SC), educational support (ES; 12 multifamily meetings for diabetes education and support), or behavioral family systems therapy for diabetes (BFST-D; 12 sessions focusing on problem-solving, communication, cognitive restructuring, and family therapy). The BFST-D revised for this study to also include having families target two or more diabetes-related problems, go through behavioral contracting training, use self-monitoring of blood glucose data, and have parents simulate living with diabetes for 1 week | Main effect of group and the group X time interaction showed no significant differences on adherence.
BFST-D did yield significant improvements (or fewer declines) for youth with higher baseline HbA1c levels when compared to the other groups
Main effect of group and the group X time interaction showed no significant differences on metabolic control.
Improvements in metabolic control were significantly greater for those with higher baseline HbA1c for the BFST-D and ES groups than for the SC group.
Diabetes responsibility and conflict scores significantly improved for the BFST-D but not for the other groups.
Parental–adolescent relationship scores (conflict, extreme belief, family structure) did not differ among the groups. |

Reference	Sample	Regimen/measure	Procedures	Outcome
			HIV	
Garvie et al., 2007	N = 23 (4–22 yrs)	Highly active anti-retroviral therapy (HAART) by pharmacy pill counts	Retrospective chart review of 23 patients clinically referred for pill-swallowing problems; modeling and shaping (starting with small pieces of candy and progressing to placebo pills the size of prescribed medications) used to teach pill swallowing	Adherence increased by a median of 9.8%; percentage of patients showing no evidence of immune suppression increased from 50% at baseline to 81.8% at ~6 months
			Rheumatic Diseases	
Pieper et al., 1989	N = 3 (11–18 yrs) 2 patients with Systemic Lupus Erythematosus & one with Dermatomyositis	Medications; pill counts	Multiple baseline-across-subjects; following baseline, patients and parents given instructions in clinic about medications, adherence, and monitoring/reinforcement strategies	Because over as well as underdosing occurred, patients classified as adherent if pill counts indicated 80–120% of doses were taken; mean % of pill counts in acceptable range was baseline = 38%, 7%, and 33%; intervention = 89%, 67%, & 88%; 6-mos follow-up = 100% for all patients; and 12-mos follow-up = 67% for 2 patients

| Rapoff et al., 1988a | N = 1 (14 yrs) with JRA | Medications; pill counts | Single-subject withdrawal design; following baseline, regimen simplified (q.i.d to t.i.d); token system in the home for 10 weeks, then withdrawn for 7 weeks, reinstated for 7 wks, and then maintenance phase for 8 wks (where token system reintroduced if adherence was <80% for 2 consecutive weeks); token system then completely withdrawn. | Mean adherence levels by condition were baseline = 44%; simplified regimen = 59%; token system = 100%; withdrawal of token system = 77%; token system reinstated = 99%; maintenance phase = 92%; and 9-mos follow-up = 97%; less disease activity evident during simplified regimen and token system phases |
| Rapoff et al., 1988b | N = 3 (3, 10, & 13 yrs) with JRA | Medications; pill counts | Multiple-baseline across subjects design. Following baseline, treatment introduced across participants in a time-staggered fashion and involved a single home visit where information was reviewed about type and purpose of medications prescribed, the importance of consistent adherence, how to prevent medication side effects, and monitoring of adherence and positive feedback | By visual inspection, adherence improved for the 10- and 3-yr-old participants from mean baseline levels of 38% and 54%, respectively, to 97% and 92%, respectively during intervention; at 4-mos follow-up, mean adherence levels were 56% and 89%, respectively; for these participants. Adherence increased only slightly for the 13-yr-old participant, averaging 44% at baseline and 49% during intervention; at 4-mos follow-up, adherence dropped to an average of 24% |

Reference	Sample	Regimen/ measure	Procedures	Outcome
Rapoff et al., 2002	N = 34 (2–16 yrs) newly diag- nosed patients with JRA	Medications; elec- tronic monitor (MEMS)	Random assignment to education/behav- ioral intervention or education-only con- trol group. Procedures for both groups in- troduced during 30-min clinic visit by the clinic nurse, following which the nurse phoned participants every 2 weeks for 2 month and then monthly for 10 months. Audiovisual programs and handouts used with both groups. Education group re- ceived information about types of JRA, signs and symptoms, and treatments; education/behavioral group received in- formation identical to control group plus strategies for maintaining adherence, such as cueing, monitoring, positive rein- forcement, and discipline	Over the 52-wk period of study, participants in the education/behavioral group showed significant better overall mean adher- ence than controls (77.7% vs. 56.9%); no significant differences between groups on measures of disease activity (active joint counts, morning stiffness, global disease severity, or functional limitations)

of adherence over a 52-week period (mean = 77.7% vs. 56.9% for controls), but there was no effect on disease activity, possibly due to "floor" effects (patients in both groups had low disease activity at baseline).

Clinical and Research Implications

On the basis of this and other reviews (Friedman & Litt, 1987; Jay et al., 1984; Meichenbaum & Turk, 1987; Rapoff, 1999; Rapoff & Barnard, 1991; Rapoff & Christophersen, 1982; Varni & Wallander, 1984), several clinical and research implications can be drawn.

Clinical Implications

Cooperative Alliance

Patients and their families are no longer satisfied (if they ever were) with a passive role in their health care. They want a greater role in making decisions regarding their health (Cassell, 1991). Chronic disease care needs to be a collaborative effort among adolescents, their parents, and providers. A first step in this approach is to set explicit and mutually agreed upon treatment goals. Patients and their families may be less inclined to follow treatment plans that fail to address their goals, which are usually related to functional concerns such as relating to peers, achieving academic success, and engaging in recreational and social activities. Greater involvement of adolescents in this clinical alliance also recognizes their need for autonomy and their increased cognitive sophistication (Coleman & Hendry, 1990; Crockett & Petersen, 1993).

Developmental Sensitivity

Providers who treat adolescents need to be sensitive to their developmental needs, challenges, and capacities. Among these are physical, cognitive, self-identity and esteem, and autonomy issues (see Crockett & Petersen, 1993, for an excellent review of individual and social factors that affect health promotion with adolescents). For example, we expect adolescents, in their transition to adulthood, to be more self-governed and responsible for their behavior. However, there needs to be a balance between giving adolescents opportunities to exercise their autonomy and minimizing risks to their health and well-being (Crockett & Petersen, 1993). The role of parental monitoring and support is critical in this process.

Parental Monitoring and Support

Clearly, parental involvement, in the form of appropriate monitoring, shared responsibility, and articulation and enforcement of reasonable limits, is critical to enhancing adherence to medical regimens and the competencies of adolescents, in general (Crockett & Petersen, 1993). An authoritative parenting style seems to be the most useful approach. This style has been characterized as a constellation of parent attributes that includes emotional support, high

standards, appropriate granting of autonomy, and clear, bidirectional communication (Darling & Steinberg, 1993). As shown in this review, this type of parenting approach has been associated with better adherence to medical regimens for adolescents. The message for parents and health care providers seems clear: *be careful not to abruptly or completely discontinue monitoring and support* (Ingersoll et al., 1986; La Greca et al., 1995). Part of this support by providers is educational in nature.

Education

Most likely, educational strategies are *necessary but not sufficient* to maintain adherence to regimens for chronic diseases (Rapoff & Christophersen, 1982). However, they are necessary, and the content needs to be expanded to include not only disease and treatment information but specific instructions on how to maintain adherence and why consistent adherence is important (Rapoff, 1999). Educational methods also need to be expanded beyond verbal and written information giving to include modeling, behavioral rehearsal, and contingent performance feedback (e.g., Epstein et al., 1981). Educational content and methods need to capitalize on the developing ability of adolescents to engage in abstract thinking (Crockett & Petersen, 1993). In addition, education needs to be viewed as an ongoing process for patients and families. When patients are first diagnosed, they and their parents may be too anxious to adequately attend to and retain complex information required to master multicomponent chronic-disease regimens. Also, regimens are periodically altered, which necessitates educational updates or booster sessions.

Health Care Delivery

Providers may blame patients and their families for adherence problems while ignoring how they interact with patients and families to deliver health care (Dunbar-Jacob, 1993; Rapoff, 1999). Generally, consumer-friendly clinical settings need to be developed in order to enhance satisfaction with medical care and thereby promote adherence. This includes pleasant physical surroundings, prompt and accessible care, and a consistent provider (Rapoff, 1999). Also, providers need to take care how they prescribe regimens. Patients and their families have a finite amount of time, energy, and resources to devote to medical regimens, if they are to maintain some semblance of a normal family life (Patterson, 1985). Providers need to minimize the complexity, costs, and negative side effects of regimens. It is also incumbent on providers to prescribe regimens that are efficacious. Patients and families want their provider to be sensitive and caring, but not at the expense of competency.

Adherence Incentives

Ideally, patients are prescribed treatments that rapidly and pervasively control their disease symptoms. Thus, the natural reinforcer for adherence is that patients get and feel better. However, this rarely happens in the treatment of complex chronic diseases. This situation creates the necessity of using contrived reinforcers, such as token systems, to improve and maintain adherence until

disease symptoms abate or remit. This review and others (Friedman & Litt, 1987; Jay et al., 1984; Meichenbaum & Turk, 1987; Rapoff, 1999; Rapoff & Barnard, 1991; Rapoff & Christophersen, 1982; Varni & Wallander, 1984) clearly show the effectiveness of behavioral procedures in improving adherence to chronic-disease regimens. But, positive reinforcement may not be sufficient in some cases (e.g., Snyder, 1987). Parents may need assistance in the use of appropriate discipline strategies, such as token fines (Rapoff, 1994). This may be particularly difficult for parents of chronically ill patients, as evidenced by studies that show that these parents (more than parents of healthy children) are more likely to excuse their children's misbehavior and fail to set limits (Ievers, Drotar, Dahms, Doershuk, & Stern, 1994; Walker, Garber, & Van Slyke, 1995). The importance of setting and enforcing reasonable limits can be explained to parents as vital to fostering self-discipline in their children. This is particularly important for adolescents with chronic diseases, who need a higher level of self-discipline than healthy adolescents, given the increased demands and challenges of living with a chronic illness.

At-Risk Patients and Families

In some cases, medical nonadherence can be symptomatic of, or exist concurrently with, patient or family dysfunction. For some adolescents, nonadherence may be part of a broader pattern of externalizing (e.g., oppositional and defiant disorder) or internalizing disorders (e.g., depression). There may also be parental or family problems. These types of problems may need to be addressed before or concurrent with efforts to manage medical nonadherence and are better addressed by mental health professionals who have extensive experience with adolescents in medical settings (Rapoff, 1999). Family- and community-based interventions may be needed to improve adherence among at-risk patients and their families (Ellis et al., 2005, 2007; Wysocki et al., 2006).

Research Implications

Assessment and Classification of Adherence Levels

All measures of adherence have advantages and disadvantages (Rapoff, 1999). Therefore, the use of multiple measures may yield a more complete assessment of adherence than the use of one indicator. The gold standard in adherence assessment might well be the combination of assays and electronic monitors for medications and direct observation for nonmedication regimens. Also, research is needed to establish what level of adherence is necessary for particular regimens to produce acceptable therapeutic outcomes (Rapoff & Christophersen, 1982). In general, this has not been done for pediatric chronic diseases.

Samples and Regimens

There is a need to expand adherence research to include patients with diseases other than diabetes and to nonmedication regimens. Also, adolescents from minority groups need to be included in adherence studies. As argued by Tucker and her colleagues (Tucker et al., 2002) a "difference model" research approach

is needed when studying minority groups to identify culture-specific (within-group) factors in adherence rather than a "deficit model," which interprets differences between ethnic groups by using the behavior of the dominant ethnic group (Whites) as the norm (between-groups comparison). Given some of the common regimens (e.g., medications) and predictors of adherence, a noncategorical approach may be also useful to include patients with a variety of chronic diseases (cf. Stein & Jessop, 1989). This would be helpful given the relatively small samples of homogeneous patient groups that are available in most settings.

Correlations and Causation

As noted in this review, much of the literature on adherence is concerned with identifying predictors of adherence. However, many of these variables have limited utility because they are "marker" or "higher-level" variables (Haynes, 1992). A marker variable (such as age, gender, or SES) is one that is statistically associated with a parameter but does not have causal properties; it marks other variables that function as causal agents. For example, adolescent age has been associated with poorer adherence. What does this mean? Why are adolescents more likely to be nonadherent? The answers to these questions will help elucidate the potential underlying causal mechanisms. For example, adolescents may be less adherent because they are trying to be independent of parental influence or fit in with their peers.

Some of the correlational studies have investigated higher-level variables, which are molar or more inferential variables (such as family cohesion, autonomy needs, and negative self-concept). Higher-level variables are problematic because they subsume more multiple causal pathways than lower-level variables and are subject to greater measurement problems (Haynes, 1992). Thus, higher-level variables need to be disentangled and translated into lower, more utilitarian, levels. For example, what are the elements of cohesive families? What do such families look like in terms of how they interact, solve problems, and conduct their lives? The answers to these questions are likely to lead to specific and testable hypotheses regarding causal mechanisms (see Snyder, 1987, for an example of this approach utilizing Patterson's coercion theory).

Adherence Theories

With the exception of variants of the HBM, there are no explicit and comprehensive theories related to pediatric medical adherence. Theories are important because they influence methodological considerations, the data collected, and how researchers react to their data (Rapoff, 1996). Data on predictors of adherence can be combined to refute or support existing theories or to help formulate new theories, which can then be further refined through continued experimentation. For example, correlates of adherence reviewed in this chapter are supportive of the HBM and family systems models.

Controlled Studies

There is a clear need for prospective studies involving experimental manipulation of variables to improve adherence (Rapoff, 1999). This is the most stringent

test of causal models. Single-subject designs may be particularly well suited for this endeavor because they accommodate small sample sizes and allow for repeated assessments of adherence over time (Barlow & Hersen, 1984; Powers, Piazza-Waggoner, Jones, Ferguson, Daines, & Acton, 2006; Rapoff, 1999). These designs are also flexible, allowing for changes in the treatment protocol depending on the patients' responses. Once effective strategies are isolated using single-subject designs, they can be tested in comparisons with each other or control conditions in conventional, between-group designs. This phase requires larger samples and argues for multicenter collaborative trials.

Cost-Effective Computer-Based Interventions

Adolescents have grown up with computers and are sophisticated users of CD-ROM games and the Internet. Interactive CD-ROM and Internet-based programs have been developed for children with asthma and cystic fibrosis (Chan et al., 2007; Davis, Quittner, Stack, & Yang, 2004; McPherson, Glazebrook, Forster, James, & Smyth, 2006), but they have not directly assessed or targeted adherence. These types of programs can be cost-effective, standardized, and tailored or flexible when needed, and are more accessible than direct contact interventions.

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Health Disparities and Minority Health

29

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In 2005, the total U.S. population was 288,378,137 and was composed of a large proportion of racial and ethnic minorities (~26%), including ~35 million Blacks/ African Americans (12.1%), ~12.5 million Asians (4.3%), ~2.4 million American Indian and Alaska Natives (0.8%), nearly 400,000 Native Hawaiians and other Pacific Islanders (0.1%), and ~42 million Hispanics/Latinos (14.5%) (U.S. Census Bureau, 2005). Although racial and ethnic minorities make up only 26% of the U.S. population, they share a disproportionate burden of chronic disease. In 2004, 4 of the 10 leading causes of death among racial and ethnic minorities, as well as among the general population, were chronic diseases directly related to modifiable risk factors associated with lifestyle and clinical behaviors (National Center for Health Statistics, 2006). These chronic diseases were heart disease, cancer (specifically colon and breast cancer), diabetes, and stroke. For each of

these health outcomes and their related risk factors, morbidity and mortality rates are also higher among racial and ethnic minorities than for non-Hispanic Whites.

The increased morbidity and mortality rates for chronic diseases among racial and ethnic minorities is associated with lower adherence to recommendations for healthy lifestyle and clinical behaviors. This may be related to reduced access to adequate health care (Hargraves, Cunningham, & Hughes, 2001; Hargraves & Hadley, 2003); lower participation in early and regular screening for disease (Bazargan, Bazargan, Farooq, & Baker, 2004; Wells & Roetzheim, 2007); and reduced access to resources associated with healthier lifestyles (e.g., parks, sources for healthy foods) (Gordon-Larsen, Nelson, Page, & Popkin, 2006; Taylor, Floyd, Whitt-Glover, & Brooks, 2007) among racial and ethnic minority groups, which leads to an increased burden on the health care system. Despite major advances in public health, medicine, economic prosperity, and wealth, disparities in morbidity and mortality rates for certain chronic diseases persisted into the current century and increased for some health outcomes (e.g., diabetes). Thus, addressing and reducing morbidity and mortality rates among minorities, particularly those health outcomes with modifiable risk factors, is a major public health priority. Such efforts will be integral to achieving the two overarching goals set forth in *Healthy People 2010*—increase the years of healthy life, and eliminate health disparities among different groups within the overall population (U.S. Department of Health and Human Services, 2000).

No consensus definition exists for the term "health disparity" or for the related terms "health inequality" and "health inequity." Generally, each of these terms refers to health-associated differences among groups. However, the terms "health inequity" and "health disparity" carry the additional connotation of health-associated differences that are judged to be ethically unfair and unjust. Definitions for the term "health disparity" have been proposed by various organizations and agencies. The National Institutes of Health (NIH) defines health disparities as "differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States" (U.S. Department of Health and Human Services, 2002). Health disparities are measured by comparing the health of one group (usually defined as the reference group) to that of different groups. Health disparities reveal important information about the health of a population that is not as evident using population-wide health measures. Disparities indicate that certain groups of individuals are experiencing worse health or are at greater risk of poor health than are other groups in a population. Assessing the underlying causes of disparities can help provide policymakers, health care providers and educators, public health officials, and the lay public with important information related to how the distribution of efforts and resources is used to reduce or eliminate disparities.

In this chapter, we discuss adherence issues related to lifestyle and clinical behaviors among racial and ethnic minority groups. We highlight the prevalence of selected recommended lifestyle and clinical behaviors among racial and ethnic minorities, discuss factors associated with adherence and nonadherence to these recommended behaviors, and review several strategies for increasing adherence to recommended lifestyle and clinical behaviors among racial and ethnic minorities.

Prevalence of Selected Lifestyle and Clinical Behaviors Among Minority Populations

Lifestyle Behaviors

While some variation exists across studies and population subgroups, racial and ethnic minorities generally fare worse than non-Hispanic Whites in their rates of healthy lifestyle behaviors for primary and secondary disease prevention. Factors that may affect variations across these groups include age, gender, geographic region, socioeconomic status, and country of origin (for Hispanics and Asian Americans) or tribal affiliation (for American Indians).

Data from the National Health Interview Survey (Adams & Schoenborn, 2006) indicate that rates of physical inactivity and obesity are highest for African Americans and American Indians, with notably high rates for African American women. Rates of physical inactivity among African American women have declined significantly in recent years; the rate of physical inactivity among African American women was 45.7% in 1994 and 33.9% in 2004, but these rates remain higher than those of other racial and ethnic groups of women (Centers for Disease Control and Prevention, 2005). Rates of cigarette smoking are highest among American Indians, with nearly one-third of adults classified as current smokers. However, data from other sources indicate significant variation across tribes and regions in smoking rates and in the number of cigarettes consumed among current smokers (Denny, Holtzman, & Cobb, 2003; Levin, Welch, Bell, & Casper, 2002; Welty et al., 1995). Consumption of at least five alcoholic drinks in 1 day in the preceding year is highest for Native Hawaiians and other Pacific Islanders, non-Hispanic Whites, and American Indians and lowest for Asian Americans and African Americans (Adams & Schoenborn, 2006).

Racial and ethnic variations exist with regard to many of the nutritional factors associated with chronic diseases. Data from the Multi-Ethnic Cohort study showed that, among five ethnic groups, African Americans had the highest energy density from their diet and Japanese Americans had the lowest, which may partially explain the wide variations in body mass index in these populations (Howarth, Murphy, Wilkens, Hankin, & Kolonel, 2006). The 2000 National Health Interview Survey showed that intake of calories from fat was higher among both African American men and women than among Hispanic, non-Hispanic White, and other non-Hispanic men and women (Thompson et al., 2005). However, Hispanic men and women had higher levels of intake of fruits and vegetables and dietary fiber than did members of other racial and ethnic groups.

High rates of sexually transmitted diseases among many ethnic minority groups, particularly African Americans, largely reflect these groups' unsafe sexual practices. Data from the 2002 National Survey of Family Growth showed that African American young adults had higher rates of increased risk for HIV transmission than Hispanic and non-Hispanic White young adults (Anderson, Mosher, & Chandra, 2006). The differences were most pronounced among those who had lower levels of formal education. Nearly one-third of African American young adults with less than a high school education were at increased risk of HIV transmission, whereas approximately 15% of Hispanics and Whites had high risks of transmission. These rates dramatically decline to approximately 14% for African American college graduates, but there is no appreciable change

with differences in education level for Hispanics and Whites (Anderson et al., 2006).

Clinical Behaviors

A number of clinical practices are recommended for prevention or management of acute and chronic illnesses and for general well-being (U.S. Preventive Services Task Force, 1989). Despite our wealth of knowledge about the importance of these practices in maintaining overall health and well-being, disparities continue to exist among racial and ethnic groups in the receipt of many of these services. Many of these disparities exist even after researchers control for socioeconomic status and access to health care providers.

Regular screening for some of the major forms of cancer, including breast and colon cancer, is important for early detection and effective treatment of these conditions (Maciosek, Solberg, Coffield, Edwards, & Goodman, 2006). Unfortunately, racial and ethnic minority women are less likely than White women to receive adequate mammography screening, and African American women in particular are more likely to have advanced tumors on diagnosis than are women from all other racial and ethnic minority groups (Smith-Bindman et al., 2006). Similarly, racial and ethnic minorities are less likely to receive colorectal cancer screening than are non-Hispanic Whites. Data from the 2000 National Health Interview Survey showed that Hispanics were 29% less likely and African Americans were 18% less likely to be adherent to colorectal cancer screening guidelines, defined as a sigmoidoscopy or proctoscopy test within the past 5 years, colonoscopy test within the past 10 years, or home fetal occult blood test within the last year (James, Greiner, Ellerbeck, Feng, & Ahluwalia, 2006).

One of the more sizable racial and ethnic disparities exists in the receipt of influenza and pneumococcal vaccinations, which African Americans are significantly less likely to obtain than members of other groups in the population (Egede & Zheng, 2003; Winston, Wortley, & Lees, 2006). Data from the 2000–2001 National Health Interview Survey showed that rates of pneumococcal vaccination among African American and Hispanic adults >65 years of age were nearly 50% lower than those for non-Hispanic Whites and nearly 25% lower for influenza vaccinations. This disparity exists even in uniformed health care settings such as the Veterans Administration health care system (Straits-Troster et al., 2006), and in high-risk populations such as those with diabetes (Brown et al., 2005).

Adherence and Nonadherence to Selected Lifestyle and Clinical Behaviors Among Minorities

Despite clinical recommendations for lifestyle and clinical behaviors related to improved health, the data presented in the previous section suggest that adherence to these recommendations is lower among racial and ethnic minorities than among non-Hispanic whites. Demographic characteristics such as age, education, income, and acculturation have a major impact on adherence to lifestyle behavior and clinical recommendations. Increasing age, education, and income are associated with increased adherence to recommendations for

breast and cervical cancer screening and knowledge about cancer screening (Bazargan et al., 2004; Breitkopf, Pearson, & Breitkopf, 2005; Halbert et al., 2006; Jennings-Dozier & Lawrence, 2000; Juon, Kim, Shankar, & Han, 2004; Leong-Wu & Fernandez, 2006; Rosenberg, Wise, Palmer, Horton, & Adams-Campbell, 2005; Russell, Champion, & Skinner, 2006). Increasing age has also been associated with lower levels of participation in healthy lifestyle behaviors such as participating in physical activity and following dietary recommendations (Berrigan, Troiano, McNeel, DiSogra, & Ballard-Barbash, 2006; Weir et al., 2000). Data suggest that those more likely to adhere to dietary recommendations include those with higher levels of education, Hispanics older than 31 years, Hispanic women, and unacculturated Hispanics (Hulme et al., 2003). Those least likely to adhere to dietary recommendations include Korean Americans (Kim, Ahn, Chon, Bowen, & Khan, 2005). Being single or not living with a partner has been associated with adherence to safe sexual practices, including using a female condom and being tested for HIV (Sly et al., 1997) and engaging in increased levels of physical activity (Weir et al., 2000).

Acculturation impacts adherence to certain lifestyle health behaviors. Among Asian Americans, speaking fluent English and the number of years in the United States is associated with adherence to recommendations for mammography screening (Juon et al., 2004; Leong-Wu & Fernandez, 2006). The evidence for Hispanic women is less clear. A study of cervical cancer screening showed that better ability to speak English was associated with lower likelihood of screening among underserved Hispanic women (Bazargan et al., 2004). A separate study found that Hispanic women who reported adherence to Pap smear screening recommendations were more likely to have been born in the mainland United States and to speak English at home than were those who were nonadherent (Jennings-Dozier & Lawrence, 2000). Lower adherence to recommendations for self-monitoring of blood glucose levels among Hispanics and Asian and Pacific Islanders was associated with difficulties communicating in English or preferring a language other than English (Karter, Ferrara, Darbinian, Ackerson, & Selby, 2000). Adherence to general healthy behaviors among Hispanics has been associated with acculturation (increased acculturation is related to increased adherence) (Hulme et al., 2003).

Many factors that are specific to the patient can impact adherence to recommendations for clinical and lifestyle behaviors. Among the most important factors is the perception of barriers. Data suggest that individuals, regardless of racial and ethnic minority status, who perceive fewer barriers and have greater self-efficacy are more likely to adhere to recommendations for clinical behaviors. For example, Black women who had had five mammograms in the past 5 years perceived a lower mean number of barriers (e.g., inconvenience, time involved, forgetfulness, worry about finding cancer, embarrassment, pain, costs, and worry about radiation) than did the rest of the study group (Russell et al., 2006). In addition, this subgroup had the highest self-efficacy (confidence in ability to get a mammogram, including knowing the process, having the needed resources, talking with staff about concerns, and getting a mammogram even if worried or did not know what to expect) (Russell et al., 2006). Black women who had no child care responsibilities were more likely to undergo mammography on a regular basis (Rosenberg et al., 2005). Perceiving fewer barriers was also associated with adherence to flexible sigmoidoscopy for colorectal cancer

screening (Brenes & Paskett, 2000). Research has shown that knowledge about the purpose of screening tests, screening guidelines, and protocols for what to do about abnormal findings is associated with increased cancer screening rates (Breitkopf et al., 2005; Juon et al., 2004; Russell et al., 2006).

Adherence to recommendations for lifestyle behaviors may be hampered by patient perceptions such as feeling that recommendations are unrealistic, the goals are unattainable, recommendations do not fit their lifestyles, or recommendations are unclear or not specific enough (e.g., a recommendation to "get more exercise" is not as clear as a recommendation to walk five or more days per week for at least 30 minutes at a time at an intensity level that increases your heart rate and breathing) (Dailey, Schwartz, Binienda, Moorman, & Neale, 2006). Patients may also feel that they do not have the tools necessary to implement the recommended lifestyle changes (e.g., patients may feel the need for special kitchen equipment for healthy cooking). Potential barriers that apply to all groups but may be more prevalent among racial and ethnic minority communities include a lack of social support or positive community norms and role models; lack of access (e.g., to safe and affordable means to be physically active or to healthy food options); multiple role obligations, including caregiving responsibilities; a higher priority on caregiving than on self-care; busy schedules and limited time for discretionary physical activity; perceived lack of energy; attitudes that predispose to resting rather than being physically active as a way of restoring health balance; a significant number of problematic life events and other sources of stress; health problems such as knee pain, foot problems, or extreme obesity that directly increase the difficulty of and lower self-efficacy for exercise; role expectations or identities (e.g., being a grandmother) that may be perceived as making certain types of activities socially inappropriate; limited understanding of or belief in the positive benefits (short term or long term) of changing lifestyle behaviors; some negative perceptions of the effects of changing lifestyle behaviors (e.g., exercising raises blood pressure, makes one sweaty, may require the use of public showers, ruins hair, boredom); and general attitudes of distrust with respect to messages perceived as coming from outside of the Black community (Airhihenbuwa, Kumanyika, Agurs, & Lowe, 1995; Baranowski et al., 1990; Broman, 1995; Dattilo, Dattilo, Samdahl, & Kleiber, 1994; Eyler et al., 2002; Fisher, Auslander, Sussman, Owens, & Jackson-Thompson, 1992; King et al., 2000; Lewis et al., 1993; Mayo, 1992; Yancey, 1999). Additional research points to factors associated with increased levels of physical activity, including family centeredness (e.g., among African Americans); a preference for exercising with friends and family members and for certain types of active recreation (e.g., participation in sports, exercising and dancing in general and particularly when music can be selected that is culturally relevant and appropriate); having a relatively positive body image even if obese (e.g., potentially less self-consciousness about exercising); and positive expectations about the effects of increased participation in physical activity (feeling better, sleeping better, increased sense of well-being, decreased anxiety and ability to manage stress, better cognitive ability, alleviation of some health problems such as lower extremity edema, facilitating weight loss, and improving appearance [e.g., "toning"]) (Airhihenbuwa et al., 1995; Eyler et al., 2002; Klesges, Klesges, Swenson, & Pheley, 1985; Kumanyika & Charleston, 1992; Lasco et al., 1989; Mayo, 1992; Sullivan & Carter, 1985).

Even if individuals have knowledge related to clinical behaviors, lack of access to health care may pose a problem for screening adherence. Data suggest that health insurance coverage is strongly associated with adherence to recommendations for cancer-screening mammography among Black and Asian American women (Jennings-Dozier & Lawrence, 2000; Leong-Wu & Fernandez, 2006; Rosenberg et al., 2005). Underserved Hispanic and Black women who reported having no medical coverage, those who reported lack of continuity of care, and those who reported a lower level of use of public services and benefits were less likely to report having a Pap smear within a 12-month period (Bazargan et al., 2004). Although not specific to racial and ethnic minority groups, out-of-pocket costs (e.g., for testing supplies, medical appointments) have been shown to be associated with lower adherence to recommendations for care seeking and disease self-management and treatment (Karter et al., 2000). Even those who are employed but who do not have health insurance report lower adherence to recommendations for cancer screening than those who have health insurance (Juon et al., 2004).

Engaging in health-related behaviors other than the one targeted has been associated with improved adherence to cancer screening. Among Black women, having a Pap smear within the 2 years before baseline and practicing breast self-exam was significantly associated with regular mammography use (Rosenberg et al., 2005). Black women who reported taking a multivitamin or female hormone supplements and those who did not smoke were more likely to be regular mammography users (Rosenberg et al., 2005). Abstinence from cigarettes and alcohol was associated with shorter time to cessation of use of drugs among injection drug users (Shah, Galai, Celentano, Vlahov, & Strathdee, 2006).

Engaging in risky health behaviors may also impact adherence to recommendations for lifestyle or clinical behaviors. A study among inner-city minority patients with type 2 diabetes mellitus showed that drinking alcohol was associated with poorer adherence to prescribed dietary recommendations and attendance at outpatient follow-up visits (Johnson, Bazargan, & Bing, 2000). Use of illicit drugs or abuse of other substances (e.g., cigarette smoking) has been shown to be associated with nonadherence to disease treatment protocols (e.g., hemodialysis treatments among hemodialysis patients) (Unruh, Evans, Fink, Powe, & Meyer, 2005). Those least likely to adhere to dietary recommendations include individuals who consume moderate to high amounts of alcohol (Johnson, Bazargan, & Bing, 2000).

Presence of a health outcome or known family history of disease is associated with increased screening for disease. Among Black women, those with fibrocystic breast disease or a family history of breast cancer are more likely to be regular mammography users (Rosenberg et al., 2005). Asian American women with a family history of breast cancer were twice as likely to have ever obtained a mammogram (Leong-Wu & Fernandez, 2006). Underserved Black and Hispanic women who reported a better level of perceived health status were less likely to receive a Pap smear in the 12 months prior to interview (Bazargan et al., 2004).

Providers' advice regarding clinical behaviors can also play an important role in individuals' adherence to recommendations. Research suggests that provider recommendation is associated with increased odds of cancer screening among minority groups members (Brenes & Paskett, 2000; Juon et al., 2004;

Russell et al., 2006). Among underserved Hispanic and Black women, those who reported that no health practitioners had ever recommended a Pap smear were less likely to have received a Pap smear in the 12 months before interviews (Bazargan et al., 2004). Despite the knowledge of their importance for patient health, physicians do not always offer advice or recommendations related to patients' health behaviors. According to Dailey et al. (2006), physicians reported barriers to their offering recommendations that included lack of patient education; lack of time; perceived unrealistic guideline goals (Dailey et al., 2006); inadequate knowledge about the factors on which to counsel (e.g., inadequate knowledge of diet and physical activity recommendations); personal attitudes; and lack of confidence about their lifestyle counseling skills. Physicians are also influenced by their perceptions of patient barriers, patients' willingness and ability to change lifestyle behaviors or to adhere to clinical recommendations, and a belief that patients will be noncompliant ("Barriers to guideline adherence. Based on a presentation by Michael Cabana, MD," 1998). Reported physician barriers to counseling on the JNC-VI guidelines for high blood pressure included lack of awareness, lack of agreement with the guidelines, lack of self-efficacy that they can effectively counsel on the guidelines, lack of outcome expectancy, and lack of a cuing mechanism or reminders to initiate counseling ("Barriers to guideline adherence. Based on a presentation by Michael Cabana, MD," 1998).

Many patients present to physicians with multiple comorbidities or health issues, and another barrier to provider counseling is having too many problems on which to focus (Dailey et al., 2006). This can sometimes result in a provider electing to treat one condition at a time, rather than treating all conditions together. Providers' perceptions of the patient's knowledge of the condition also influences counseling behavior (i.e., physicians who perceive more patient knowledge of a condition may be more likely to provide counseling as they feel more confident with patients who are educated because they feel their job is easier) (Dailey et al., 2006).

Nested within issues related to adherence to lifestyle behavior recommendations is the limited minority health care workforce in place to address the dynamic needs of the U.S. minority population (Sullivan Commission, 2003). The percentage of African Americans (11.5% to 20.5%) and Latinos and Hispanics (10.5% to 15.4%) who earn college degrees has increased. However, access to graduate-level education in the health professions for these groups has not increased accordingly (Reede, 2003). Following the civil rights movement in the late 1960s, a slight increase in minority medical school enrollment was observed in 1974; however, this was slowed by the decision by the U.S. Supreme Court in the 1978 case of *Regents of the University of California v. Bakke*, which deemed unlawful special admission programs (e.g., active recruitment of specified percentages of students from certain minority groups) implemented by the medical school at the University of California at Davis. Secondary to federal mandates, affirmative-action initiatives, and other programs to offset the adverse impact of discrimination, another wave of increased minority enrollment in medical schools occurred between 1982 and 1995, with enrollment spiking anywhere from 8.4% to 12.4% (Reede, 2003; Saha, Taggart, Komaromy, & Bindman, 2000). Since 1995, several states with relatively large minority constituencies have eliminated race, ethnicity, and gender as factors in the medical school

admission process. American Indian, Hispanic and Latino, and African American doctorate-level health care providers are underrepresented relative to their proportion of the general population. In 2000, 1.6% of medical students and 5.5% of medical school faculty were from these groups, although these traditionally underserved groups collectively represent greater than 25% of the population in the United States (Reede, 2003; Saha et al., 2000). This trend is potentially problematic given the research suggesting that minorities prefer receiving care from race-concordant providers (Cooper et al., 2003; LaVeist & Carroll, 2002; LaVeist & Nuru-Jeter, 2002). The Sullivan Commission on Diversity report provides 37 recommendations to address the lack of diversity in the health professions, a challenge that represents one historical phase of the differential legacy of health and health care in North America (Sullivan Commission, 2003). It is plausible to conclude that the growing interest in cultural competency is an acknowledgment of the low availability of minority doctoral-level providers, although no such suggestion has been made in the literature.

Strategies for Improving Adherence to Lifestyle and Clinical Behaviors Among Minority Populations

Improving adherence to lifestyle interventions among racial and ethnic minority populations is particularly critical given the disproportionate burden of chronic disease experienced by populations of color in the United States. Illness and health behavior occur within a cultural context. Many racial and ethnic minority populations are characterized by having a collectivist culture, that is, one in which individuals characterize themselves in relation to others and identify as part of a network of interconnected people. In contrast, in an individualist culture, people distinguish themselves from others and identify as autonomous (Lewis et al., 2002). Although the material presented in this section is organizationally divided into individual and community-level strategies to improve lifestyle adherence among minority populations, this material should be considered within a collectivist context.

Individual-Level Strategies

The need to tailor behavioral intervention strategies to subgroups defined by demographic, health, and psychosocial characteristics and particularly to align such strategies with the cultural and ethnic milieu of the target population has been recognized in recent years (Harris-Davis & Haughton, 2000; Resnicow, Baranowski, Ahluwalia, & Braithwaite, 1999; Taylor, Baranowski, & Young, 1998). The challenges are to identify the relevant tailoring variables and then to operationalize these in the design of intervention strategies. Many variables relevant to the design of obesity-related interventions in African Americans have been deemed effective (Airhihenbuwa et al., 1995; Flynn & Fitzgibbon, 1998). For example, Airhihenbuwa et al. (1995) reported that among African Americans, rest was considered more important to one's health than exercise; in addition, their work activities were considered an important form of exercise.

Motivational interviewing (MI) is a second individual-level strategy that has shown preliminary efficacy in improving adherence to lifestyle interventions.

Originally used in alcohol treatment, MI is a client-centered counseling style for eliciting behavior change by helping clients resolve ambivalence (Rollnick & Miller, 1995). MI differs in several ways from traditional health education and social marketing. Rather than attempt to persuade clients, in MI, the counselor enables clients to write their own "advertisement for change." Rather than "pushing" information or persuasive messages to the client, in MI the counselor elicits the client's subjective pros and cons for change and helps create discrepancies between the person's current health behavior and his core values and life goals. The goal is to elicit change generated by the client. The use of MI has evolved from its initial use in the addiction field (Rollnick, Heather, Gold, & Hall, 1992) to a broader use in health promotion and disease prevention, including diet and weight control (Berg-Smith et al., 1999; Mhurchu, Margetts, & Speller, 1998; Resnicow et al., 2000; Smith, Heckemeyer, Kratt, & Mason, 1997), smoking (Colby et al., 1998; Lawendowski, 1998; Velasquez et al., 2000), physical activity (Harland et al., 1999), preventive screening (Rakowski et al., 1992; Taplin et al., 2000), HIV prevention (Carey et al., 1997) and diabetes management (Stott, Rollnick, Rees, & Pill, 1995). MI has been shown to be effective in addressing multiple risk behaviors, supporting smoking cessation, weight loss, dietary change, and elimination of substance abuse among various minority population groups. For example, coupled with behavioral counseling and case management, motivational interviewing has been shown to be effective in helping Hispanic intravenous drug users to reduce drug use and HIV-risk (Robles et al., 2004).

Community-Level Strategies

Culturally relevant conceptual models and frameworks are needed for the development and implementation of effective behavioral strategies to enhance adherence to lifestyle interventions. The PEN-3 conceptual framework is such a framework. Originally developed for use in African countries and since adapted for use with African Americans in the United States (Airhihenbuwa, 1995; Airhihenbuwa & Webster, 2004), the PEN-3 model was designed as a culturally relevant framework for the development of health education strategies and programs. It consists of three interrelated and interdependent dimensions of health (cultural identity, relationships and expectations, and cultural empowerment). As shown in Figure 29.1, each dimension has three components, which form the PEN acronym.

The first dimension of the framework, cultural identity, assists in defining the target audience (person, extended family, and neighborhood). The second dimension of the PEN-3 framework is relationships and expectations. This dimension focuses on determining, through interviews, focus groups, or surveys, the factors that influence the person, family, and/or community actions (perceptions, enablers, and nurturers). Perceptions include the knowledge, attitudes, and beliefs that may contribute to or hinder engagement in a particular health behavior. Enablers are community or structural factors such as availability of resources, accessibility, referrals, skills, and types of services. Nurturers are the reinforcing factors that the target audience receives from their social networks. A third and unique component of the model is cultural empowerment. This component is crucial in the development of culturally relevant interventions and instruments to assess the target health behavior of ethnic minority cultures. Its components are positive, existential, and negative. The "positive"

29.1

PEN-3 conceptual framework.

<p style="text-align:center">
Educational Diagnosis
of Health Behavior

Cultural Appropriateness
of Health Behavior
</p>

Perceptions
Enablers
Nurturers

Positive
Existential
Negative

Person
Extended Family
Neighborhood
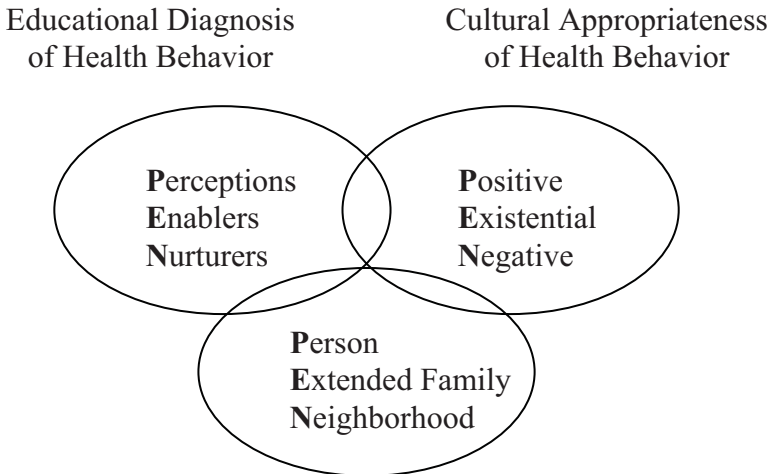
component refers to perceptions, enablers, and nurturers that lead the target audience to engage in the health behavior. The "existential" component refers to practices that have no harmful health consequences and should not be changed but incorporated in the intervention or instrument. The "negative" component refers to perceptions, enablers, and nurturers that prevent the target audience from engaging in the health behavior or that lead them to engage in a harmful behavior (e.g., smoking). This framework has been effective in the development of effective strategies for smoking cessation (Beech & Scarinci, 2003); obesity prevention (Airhihenbuwa, Kumanyika, TenHave, & Morssink, 2000), and physical activity (Airhihenbuwa et al., 1995) interventions for African Americans.

Culturally Adapted vs. Nonadapted Strategies

In the previous sections, we mentioned that adherence to healthy lifestyle behaviors has been and continues to be an issue, particularly for those who are low income, of racial and ethnic minorities, older, less educated, un- or underinsured, and living in rural areas (Beswick et al., 2005; Vellozzi, Romans, & Rothenberg, 1996). However, by acknowledging the issue of adherence among racial and ethnic minority populations, many researchers have sought to develop alternative strategies, including more culturally appropriate or culturally sensitive strategies. For the purposes of this discussion, culturally adapted strategies are defined as interventions that are specific to a particular culture—activities, language, and cultural norms that are aptly identified by a particular racial or ethnic group (e.g., gospel aerobics). Nonadapted strategies include interventions that do not relate to a specific culture, that is, interventions that can be implemented across the board with limited modifications for particular populations.

While many interventions have been developed to increase health among minority populations, there is limited research available that specifically relates

to interventions to increase adherence to healthy behaviors and medication uptake in these groups. To make the distinction, many interventions have been developed to address the concern of health disparities among minority populations; however, even after the primary causes of the disparity, such as access, have been addressed, issues of compliance remain. Furthermore, most of the available research focuses on identifying the barriers to adherence to medically recommended health behaviors and broadly focuses on the general population. However, the current research does overlap in basic concepts, while providing insight and overarching themes of culturally adapted and nonadapted strategies for improving adherence.

Interventions for addressing disparities in health often have been designed around specific cultures (i.e., African American, Latino/Hispanic). These interventions incorporate strategies that include developing healthy recipes of traditional foods or using culturally related music (e.g., gospel or hip hop) in aerobics classes or utilizing locations of trust within specific communities (e.g., churches or other places of worship), which, it has been suggested, increase adherence. For instance, a program in Arkansas titled "Witnessing in the Delta" put into practice the act of "witnessing," which is often part of African American church experience, by utilizing role models to discuss their personal experience with breast cancer with a small group of women in a church setting (Vellozzi et al., 1996). This intervention was successful not only in reaching low-income African American women who believed that they were not at risk for breast cancer but also in increasing the frequency with which the women performed breast self-examinations and obtained mammograms (Erwin, Spatz, & Turturro, 1992). A study aimed at improving metabolic control among Puerto Ricans with type 2 diabetes incorporated a *telenovela*, a popular Spanish-styled soap opera often watched by both genders, that included health messages related to the maintenance of diabetes (Rosal et al., 2005). Throughout the reading of the *telenovela*, discussions focused on key health issues. The final assessments showed statistically significant differences in glycated hemoglobin levels between the intervention and control groups, in addition to a trend toward increased physical activity in the intervention group. Other types of culturally adapted strategies include faith-based efforts (Vellozzi et al., 1996), use of lay health advisers (Vellozzi et al., 1996), and development of race-concordant services (Paschal, Lewis, Martin, Shipp, & Simpson, 2006). There are some strategies that are both culturally adapted and traditional. These strategies include television and radio campaigns and use of other forms of media (Vellozzi et al., 1996). These strategies contain elements that are both culturally adapted, such as language or style, and nonadapted, but the basic idea can be used across cultures.

Nonadapted strategies include making modifications to the management systems, such as sending patient tracking or reminder letters or postcards to providers and consumers, and the use of community-based outreach. An intervention aimed at increasing breast cancer screening among Hispanic American women used both patient and physician reminders about the need for screening and led to a 13% increase in the number of women being screened (Zapka et al., 1993). A study aimed at low-income African American women used a variety of unadapted strategies, including a "Women's Fest," educational brochures, mass media, monthly classes, birthday cards with the study logo, targeted mailings, and one-on-one sessions in women's homes (Paskett et al.,

1999) and increased the percentage of women reported having a mammogram in the intervention city from 31% at baseline to 56%. Interestingly, a review of research on adherence to HIV and general medication regimens indicated that persons who had more complex medication regimens were more likely to adhere to the medical instruction (Burge et al., 2005; Fogarty et al., 2002). Other nonadapted strategies include integration of preventive services at primary health care sites (e.g., provider reminder systems [Vellozzi et al., 1996]), provider and consumer education [Beswick et al., 2005; Vellozzi et al., 1996], use of nurses and nurse practitioners), mobile mammography units and mobile clinics, community-based outreach (e.g., education delivered at community sites, consumer incentives, door-to-door recruitment), personalized communications (e.g., direct mailings, telephone reminders) (Vellozzi et al., 1996) and behavioral tools (e.g., providing pill boxes, role-playing medication schedule adjustments, teaching self-monitoring skills) (Fogarty et al., 2002).

In conclusion, a variety of interventions are available to increase adherence among racial and ethnic minority populations. While much of the research has not specifically focused on adherence or uptake of interventions, it does provide insight into additional methods for improving adherence. One review of the literature indicated that a combination of strategies should be used because not all strategies work for all target populations (Vellozzi et al., 1996). Determining the most effective will depend upon the types of strategies, the number of strategies, and the target population. Continued work is needed to determine the most effective strategies to increase adherence of health behaviors among minority populations.

Summary

Lifestyle and clinical behaviors that can lead to poor health are more prevalent among racial and ethnic minority communities, and many of these behaviors result in increased morbidity and mortality rates in these communities. Factors related to adherence and nonadherence grow out of both lifestyle and clinical behaviors. While many of these factors are not unique to racial and ethnic minority communities, these factors are often more common among racial and ethnic minorities (e.g., perceived barriers to behavior change, poor access to health care, difficulty communicating in English), which can lead to poor health-related behaviors and poor health. Several strategies to improve adherence to recommendations for healthy lifestyle behaviors have been identified. Some of these strategies take culture into account; however, many successful strategies do not necessarily rely on culture. Rather, they require targeted strategies for increasing awareness of recommendations for health-related behaviors, increasing access to resources necessary to engage in healthy behaviors, and potential changes in management systems that encourage participation in healthy behaviors. Strategies grounded in conceptual models and frameworks with appropriate cultural adaptations may have more promise for success; however, additional work is needed to identify the most successful strategies for increasing adherence to healthy lifestyle behaviors among racial and ethnic minority groups, which should lead to the elimination of health disparities.

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Section

6

Lifestyle Change and Adherence Issues Among Patients With Chronic Diseases

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Editor

As the population ages and medical care innovations advance, more and more people will be living with a chronic illness that requires daily adherence to an often complicated regimen. Section VI highlights the difficulties of maintaining positive health behavior and adherence when one is living with a chronic health condition.

Chronic Obstructive Pulmonary Disease (chapter 30) and Heart Disease (chapter 34) are consistently among the top causes of mortality worldwide. As described in these chapters, rehabilitation services and multidisciplinary care, which include intensive medical management as well as diet, exercise, or other risk-reduction counseling, are the standard of care for patients with

these conditions in the United States. While randomized trials of multidisciplinary care have shown that such care has the potential to improve health outcomes, there has been remarkably little attention to either the influence of adherence to medication or lifestyle recommendations on health outcomes or whether the inclusion of counseling on these topics improves adherence.

Two chapter focus on the effect of cognitive decline on adherence to a diabetes regimen. Mount (chapter 35) describes the association between diabetes and dementia, the effect of cognitive deficits on adherence, and how specific cognitive deficits can affect patient care and self-management of type 2 diabetes. In contrast, Coker (chapter 31) focuses on cognitive and functional declines commonly seen among older adults with diabetes and how these may affect adherence, when and how to involve a caregiver in diabetes management and, importantly, the educational and support needs of the new caregiver, as well as the person with diabetes.

Cancer and HIV are diseases whose diagnosis was once viewed as an inevitable death sentence, but, with medical advances, they have now evolved into chronic long-term illnesses that require long-term regimen adherence and lifestyle changes to maintain quality of life. As Peterman, Victorson, and Cella (chapter 32) highlight, however, there has been remarkable little research on rates of nonadherence to treatment, and even less is known about interventions to support adherence to cancer regimens. Similarly, as Rhodes and colleagues (chapter 33) discuss, HIV affects many people already marginalized by society, and regimen adherence has implications not only for the patient's well-being but also for public health. For these reasons, it is all the more important to understand the factors that affect lifelong HIV regimen adherence and design interventions not only to improve adherence in the short-term but to sustain it for the long term.

Common to all chapters in this section is the call to move beyond merely assessing the prevalence of nonadherence toward studies that advance our knowledge of which intervention strategies are efficacious in improving adherence.

Adherence for Patients With Chronic Obstructive Pulmonary Disease

30

Robert M. Kaplan

Chronic Obstructive Pulmonary Disease (COPD) is a chronic medical condition associated with airflow obstruction due to chronic bronchitis or emphysema or a combination of the two. Emphysema is characterized by abnormal permanent enlargement of the air spaces resulting from destruction of the walls of the alveoli. Alveoli are clusters of air spaces at the ends of the airways in the lung. As the alveolar walls break down, individual alveoli collapse, and the

lung gradually loses its elasticity. This loss of lung elasticity means that the air-ways are not held open during expiration and tend to collapse. Air gets trapped in these damaged areas, and the lungs become inflated and enlarged ("Patient information series. Chronic obstructive pulmonary disease (COPD)," 2005). Chronic bronchitis is defined as the presence of chronic productive cough for 3 months in each of 2 successive years in a patient in whom other causes of chronic cough have been excluded. It is the result of chronic inflammation of the cells lining the breathing passages (bronchi). The inflammation causes the cells to swell and to produce excess quantities of mucus. The swelling and ex-cess mucus result in a narrowing of the bronchi, which, in turn, obstructs the airflow and produces chronic cough ("Patient information series. Chronic ob-structive pulmonary disease (COPD)," 2005).

Symptoms of COPD result from restrictions of airflow into and out of the lungs. It has been estimated that 80% to 90% of all cases of COPD result from long-term tobacco use (Buist, 2006). COPD is the fourth leading cause of death in the United States, and is on the increase in most countries (Buist, 2006; Lopez et al., 2006). It is projected that by 2020,COPD will rank 5th in the world as a cause of disease burden (Rabe et al., 2007). In addition to its effect on life expec-tancy, COPD results in significant loss in daily function and increases in health care costs (Mannino, 2002), including high rates of hospitalization (Strassels, Smith, & Mahajan, 2001). Following hospitalization, COPD patients remain vul-nerable to rehospitalization and death. One-year post-hospitalization mortality rates range from 22% (Almagro et al., 2002) to 36% (Yohannes, Baldwin, & Con-nolly, 2005).

Patients with COPD experience significant limitations in daily activities. COPD has a profound effect upon functioning and everyday life. The increase in tobacco use among women in the later part of the 20th century (Han et al., 2007; "The rise in chronic obstructive disease mortality," 1989) resulted in in-creased rates of COPD among women. Current estimates suggest that COPD is diagnosed in approximately 11% of the adult population, and the incidence is increasing. The epidemic of COPD is expanding worldwide (Rabe et al., 2007). The human lung has a large reserve, and patients can have relatively advanced disease before they come to clinical attention. The disease can be present with-out symptoms for many years, and most patients are first diagnosed late in the course of disease.

Treatment Options

Despite major advances in diagnosis and medical therapeutics, many patients do not receive optimal benefit from standard medical care. While some aspects of COPD are treatable, the medical regimen is extremely complex. Medical manage-ment of COPD requires multiple medications. George and colleagues, using self-report measures, noted that only about 37% of patients with chronic lung diseases are fully adherent with their medical treatments (George, Kong, Thoman, & Stew-art, 2005). However, treatment may also include respiratory chest physiotherapy techniques, exercise, and advice to quit smoking. Most patients are confronted with complex combinations of antibiotics, bronchodilators, anti-inflammatory drugs, and, in some cases, supplemental oxygen. Pulmonary rehabilitation is one

of the most important interventions for COPD (Ries et al., 2007). Surgical interventions, such as lung volume reduction surgery (LVRS) or lung transplantation, may also be appropriate in selected patients (Fishman et al., 2003). However, it is widely recognized that these measures cannot cure COPD.

Some evidence suggests that nonadherence is common among patients with serious illnesses who are in poor health (DiMatteo, Haskard, & Williams, 2007). This is often the case with COPD patients. A variety of behavioral intervention programs that emphasize behavior change and adherence have been shown to improve outcomes for patients with chronic obstructive pulmonary disease (COPD), interstitial lung disease, and other lung diseases that cause activity limitations (Ries, 2007; Ries et al., 2007*).*

Adherence

Medical encounters typically end with advice and recommendations. Patients are advised to fill a prescription, take a medication, stay on a prescribed diet, or give up cigarettes (DiMatteo, 2004). Often, medical advice is given by managed care organizations or nonprofit agencies such as the American Lung Association. Chronic disease management modules provide instructions for self-care, and physician records are used as evidence that certain services have been completed by the patient (Dunbar-Jacob, 2005). Several groups offer guidelines. For example, the American Lung Association recommends that people with chronic bronchitis get vaccinated against influenza and pneumococcal pneumonia (see www.lungusa.org). Patients are asked to adhere to many different instructions. Nonadherence is defined as the failure to follow such advice.

Adherence to Pharmacological Interventions

We have reviewed published papers on adherence with the COPD regimen published after 1980. In addition, we examined literature reviews published prior to 1980. Overall, the search revealed few studies that have directly addressed adherence, especially regarding traditional medical regimens for COPD. The studies considered different treatments in diverse samples and employed various definitions of, and measurements for, adherence. Unfortunately, few conclusions, if any, can be drawn from the current literature.

Published studies have considered adherence with regard to a variety of different regimens. Adherence to oxygen therapy in Scotland was reported by Morrison, Skwarski, and MacNee (1995). Among patients with COPD prescribed 24-hour oxygen, only 14% were fully adherent. The average use was 14.9 hours per day, and 44% used their oxygen less than 15 hours per day. These patients also had poor adherence to other aspects of the regimen. Although all patients were requested to have acute arterial blood gas measurements within 12 months, only about half obtained the tests. In another study from the United Kingdom, it was shown that patients who are prescribed oxygen for less than 24 hours (in this case, 15 hours/day) obtained high levels of adherence to the prescription (Restrick et al., 1993). In Denmark, about 66% of patients appear to have appropriate medical follow-up when on oxygen therapy, but adherence with therapy was often low (Ringbaek, 2005). Neri and colleagues studied more

than 1,500 patients in Italy. They found that 84% of their sample had a mobile oxygen delivery device but that only 40% of these patients used the device daily (Neri et al., 2006). Some of the more recent studies that measure adherence by examining medication refills are difficult to interpret because they lump asthma and COPD into a single category (Krigsman, Nilsson, & Ring, 2007). Many people with asthma have reversible airways disorders.

Long-term adherence with inhaled medications was evaluated in the Lung Health Study (Rand, Nides, Cowles, Wise, & Connett, 1995). This was one of the first trials to evaluate inhaled bronchodilator medication used regularly over of time. The Lung Health Study was a large clinical trial (N = 3,923) of smoking intervention and the use of bronchodilator therapy in the early stages of COPD. Early in the trial, self-report data suggested that nearly 70% of the patients adhered to the regimen. This rate dropped off only slightly over the next 18 months. In addition to self-reports, the investigators weighed the canisters containing the medications. Self-reports confirmed by canister weights showed that 48% of the patients had good adherence at 1 year. Some nonadherence involved overuse of medication. Further analysis demonstrated that those who overused medication were also likely to incorrectly report their true smoking status.

Personality measures tend not to be good predictors of adherence. A scale designed to assess medication adherence in COPD has been developed and reported by Powell (1994), but it is not clear if it has clinical value because it does a poor job of predicting adherence. A variety of studies have investigated demographic characteristics associated with COPD self-care behaviors. For example, the Lung Health Study suggested that adherence was associated with being married, older, White, and having more severe disease. More adherent patients also had less shortness of breath and were hospitalized or confined to bed less often (Rand et al., 1995). Studies of adherence with nebulizer therapy from the intermittent positive-pressure breathing study showed that about half of the patients were adherent and half were nonadherent. Predictors of adherence included being White, being married, abstaining from alcohol and cigarette use, and having more severe shortness of breath. Further, those patients with more severe disease were also more likely to adhere to the therapy (Turner, Wright, Mendella, & Anthonisen, 1995). There have been very few trials that evaluate interventions to improve adherence. Solomon et al (1998) failed to demonstrate that having instructions given by clinical pharmacy residents significantly improved adherence over usual care.

Some variables thought to predict adherence often fail to do so. For example, it is commonly assumed that heavy drinkers will be less likely to follow the regimen than those who drink less. In the Lung Health Study, alcohol consumption was tested as a predictor of the ability to quit smoking. The results revealed that heavy alcohol use (more than 25 drinks per week) was not a significant predictor of relapse in smoking cessation. However, binge drinking defined as having eight or more drinks per occasion once a month or more was associated with greater relapse (Murray, Istvan, Voelker, Rigdon, & Wallace, 1995).

Estimated or measured adherence values do not appear to converge on a specific rate or even a specific pattern of nonadherence. James and colleagues (1985) reported that only half of their patients took their medicine regularly. Corden and colleagues also found that about half (56%) of their patients failed

to comply with home nebulized therapy (Corden & Rees, 1998). The Intermittent Positive Pressure Breathing (IPPB) clinical trial, which used objective assessments of actual time on IPPB therapy, found that only half of the patients used the nebulizer at least 25 minutes per day ("Intermittent positive pressure breathing therapy of chronic obstructive pulmonary disease. A clinical trial," 1983). Adherence does appear to be related to health quality of life. Patients with higher scores on the St. George's Respiratory Questionnaire have been shown to be more likely to comply with nebulized therapy (Corden & Rees, 1998).

Electronic medication monitors may be valuable methods for improving adherence among patients with COPD. Evidence suggests that measures of oxygen expenditure may not be the most accurate estimates of adherence. New methods that allow direct assessment of oxygen inhalation may be more reliable (Lin, Kuna, & Bogen, 2006). One study evaluated 251 COPD patients who participated in a multisite clinical trial of meter dose inhaler therapy. The patients were divided into an intervention and a control group. Using an electronic medication monitor known as the nebulizer chronolog, the intervention group was given feedback on the accuracy of their medication use. Patients who received feedback were significantly more likely to adhere to the regimen and to use medications correctly than those in the control group (Nides et al., 1993).

To date, few studies have systematically evaluated adherence with regard to the COPD regimen, and in these few cases, the focus has been on drug and oxygen therapy. Further, only a few studies evaluating interventions to improve COPD patients' ability to manage their disease have been reported. Several commentaries have offered strategies for enhancing adherence; however, none have been systematically studied. Some individuals with asthma mistakenly stop steroid inhalers but continue bronchodilator inhalers because they do not notice any acute effect from the steroid inhaler (Williams et al., 2007).

Overadherence

Most of the literature on adherence behaviors focuses on the extent to which patients underuse medications. A less common but perhaps equally important problem involves the overuse of medication. Overadherence is a more common problem when medications provide prompt symptomatic relief. Chryssidis and colleagues (1981), for example, studied the use of high doses of aerosol therapy, doses that often exceeded prescription rates. The mean percentage of prescribed dose actually used was 98.5% at 1 month follow-up and 110.8% at 2 month follow-up. Since there was variability for each of these estimates, it appears that some percentage of the patients took considerably more medication than was prescribed (Chryssidis et al., 1981). It is not surprising that patients suffering from COPD, a highly symptomatic disorder, would overuse a medication that provides rapid symptomatic relief. Since the 1980s, surprisingly little attention has been given to medication overuse.

Adherence With Exercise

An important component of most pulmonary rehabilitation programs has been the establishment of a regular exercise regimen. Specific physical conditioning

exercises, such as walking, can be undertaken by the patient to help maintain lung function and improve the remainder of the oxygen delivery system (Ries, 1994). Specifically, appropriate physical conditioning exercises can improve maximum oxygen consumption and endurance, reduce heart rate, improve ventilator efficiency, and increase tolerance for exercise. Lacasse and colleagues (2006) reviewed 23 RCTs on pulmonary rehabilitation and found significant improvements on all measured aspects of quality of life, including functional or maximal exercise capacity and dyspnea. Some evidence suggests that community-based programs can significantly improve adherence to exercise in COPD patients (Cockram, Cecins, & Jenkins, 2006). However, Beswick and colleagues (2005) considered 3,261 studies on cardiac rehabilitation and found only a dozen that considered methods for improving adherence.

Few studies have evaluated factors associated with long-term exercise maintenance among COPD patients. However, a rich literature in cardiac rehabilitation may provide useful suggestions. For example, Gupta and colleagues (2007) have shown good maintenance of cardiac rehabilitation benefits. One literature review analyzed 24 studies that had reported 12 or more months of follow-up (Simons-Morton, Calfas, Oldenburg, & Burton, 1998). Long-term maintenance of exercise was associated with supervision of the exercise, availability of equipment, frequent contact with program staff, the inclusion of a behavioral component, involvement in moderate rather than high-intensity activity, and specific interventions to maintain the behavior. Some success has been shown for difficult-to-reach patients. For example, Friedman and colleagues (1997) offered a rehabilitation program to the medically indigent. By individualizing instructions and providing guidance for specific community activities such as mall walking, stair climbing, and use of neighborhood facilities, they were able to obtain a self-reported adherence rate of 90%.

Exercise as a Component of Rehabilitation

A few controlled trials documented the benefits of exercise programs for patients with COPD (Resnikoff & Ries, 1998). Cockcroft, Saunders, and Berry (1981) randomly assigned 39 patients to a 6-week exercise program or to a no-treatment control group. Patients in the exercise group experienced more subjective benefits and a greater increase in the amount of distance they could walk in 12 minutes than did those who received no intervention. However, the length of follow-up was only 2 months. McGavin and coworkers randomly allocated 24 COPD patients to a 3-month unsupervised stair-climbing home exercise program or to a non-exercise control group. The 12 patients in the exercise group noted subjective improvements and an increased sense of well-being and decreased breathlessness. They also reported an objective increase in the 12-minute walk distance and in their maximal level of exercise on a cycle ergometer. These changes did not occur in the control group. However, the length of follow-up was limited to 3 months (McGavin, Gupta, Lloyd, & McHardy, 1977). Ambrosino and coworkers (1981) randomly assigned 23 patients to a 1-month medical and rehabilitative therapy group and 28 patients to medical therapy alone without exercise training. The experimental group improved in exercise tolerance and respiratory pattern, as evidenced by a decrease in

respiratory rate and an increase in tidal volume. Again, these changes were not present in the control group.

One argument for the importance of exercise is that programs that do not have an exercise component are less effective. Sassi-Dambron et al. (1995) conducted a randomized clinical trial to evaluate a modified pulmonary rehabilitation program focused on supporting coping strategies for shortness of breath but without exercise training. Eighty-nine patients with COPD were randomly assigned to the 6-week treatment or to a 6-week general health-education control group.

The treatment consisted of instruction and practice in techniques of progressive muscle relaxation, breathing retraining, pacing, self-talk, and panic control. Outcomes included the 6-minute walk test, quality of well-being, depression and anxiety scales, and six commonly used dyspnea shortness of breath measures. There were no significant differences between the treatment and the control groups at the end of treatment or at 6-month follow-ups. The authors conclude that, while dyspnea management strategies are an important component of COPD management, they should be taught in combination with other aspects of comprehensive pulmonary rehabilitation, namely structured exercise training.

We have conducted several studies designed to improve adherence to exercise for patients with COPD. One of these experiments randomly assigned 119 COPD patients to either comprehensive rehabilitation or to an education control group. Pulmonary rehabilitation consisted of 12 4-hour sessions distributed over an 8-week period. The sessions focused on education, physical and respiratory care, psychosocial support, and supervised exercise. The education control group attended four 2-hour sessions that were scheduled twice per month. These education sessions did not include any individual instruction or exercise training. Topics included medical aspects of COPD, pharmacy use, breathing techniques, and a variety of interviews about smoking, life events, and social support. Lectures covered pulmonary medicine, pharmacology, respiratory therapy, and nutrition. Outcome measures included lung function; maximum and endurance exercise tolerance; symptoms such as perceived breathlessness, and perceived fatigue; self-efficacy for walking; and the Centers for Epidemiologic Studies Depression (CES-D) and the Quality of Well-Being scales. The patients were evaluated at the baseline and then again after 2, 6, 12, 24, 36, 48, and 60 months.

Figure 30.1 shows the differences between those in pulmonary rehabilitation and those in the education control groups over the first year of the study. The top portion of the figure shows changes in exercise endurance. Those randomly assigned to rehabilitation had significantly higher endurance at 2, 6, and 12 months. This was complemented by differences in breathlessness; those in the rehabilitation program were less breathless at the end of the treadmill exercise after 2, 6, and 12 months than those in the control group. Similarly, patients in the rehabilitation group were significantly lower in perceived muscle fatigue at each follow-up period (lower section of Figure 30.1) (Ries, Kaplan, Limberg, & Prewitt, 1995). There were no differences between the groups on measures of lung function, depression, or general quality of life. However, both groups experienced reductions in quality of life. Among the exercise variables, benefits tended to relapse toward baseline after 18 months of follow-up.

30.1

Results of treadmill endurance exercise tests for patients in the rehabilitation (Rehab) and education groups at baseline and for 12 months of follow-up. A. Exercise endurance time. B. Perceived breathlessness rating at the end of exercise. C. Perceived muscle-fatigue rating at the end of exercise. Asterisks indicate $P <$ 0.05 for within-group change from baseline; values and error bars represent the mean ($\pm$SD).
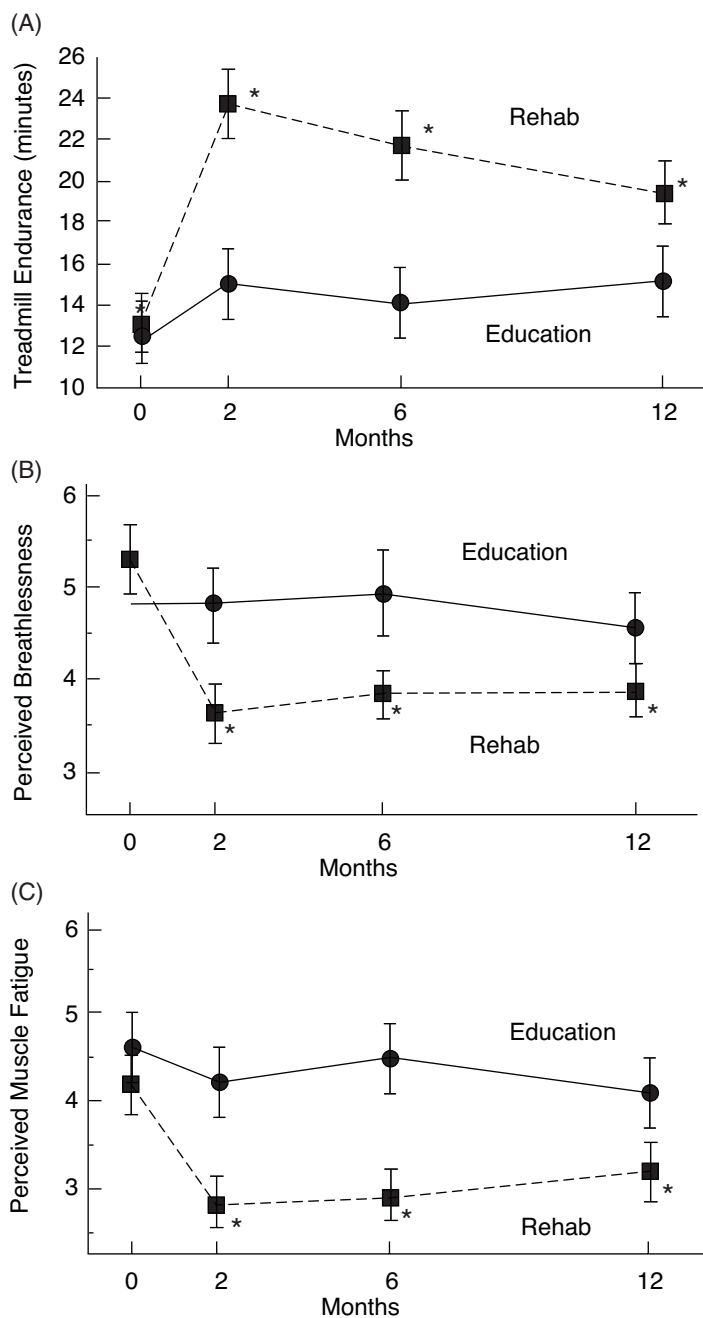
We have reason to believe that there is a systematic relationship between adherence to physical activity and a variety of outcomes. In an earlier study, we demonstrated a linear relationship between quartile of adherence with physical activity and exercise endurance measured in minutes. The study involved 57 moderate to severe COPD patients who were participating in a rehabilitation program. All participants were advised to exercise up to 60 minutes per day. Each patient kept a log of physical activity, making it possible to determine

self-reported adherence to the exercise component of the program. Each 3 minutes of physical activity per day translated into an estimated 1-minute of improvement on treadmill exercise endurance (Eakin, Kaplan, & Ries, 1993).

In a more recent study, 160 patients with chronic lung disease participated in a comprehensive rehabilitation program. At the end of the rehabilitation program, the patients were randomly assigned to a program designed to improve adherence and maintenance of the rehabilitation lessons or to routine follow-up. Outcome measures included quality of life, symptoms, health care utilization, measures of pulmonary function, measures of psychological function, and survival. All patients were evaluated prior to the pulmonary rehabilitation and then again after the 8-week program had been completed. Following the second evaluation, patients were evaluated at 6 months, 12 months, and 24 months (Ries, Kaplan, Myers, & Prewitt, 2003). The effect of the postrehabilitation intervention was not significant in relation to the control group. Across both groups, the patients were classified according to their adherence to exercise during the follow-up period. Two groups were created—those who were regular walkers and those who walked irregularly. Regular walking was defined as walking most days or every single day, whereas irregular walking was defined as walking some days, rarely, or never. The core psychosocial measures included a generic quality of life measure known as the Quality of Well-Being (QWB) scale. Other measures included the UCSD Shortness of Breath questionnaire and a measure of self-efficacy for walking. Quality-of-life results are summarized in Figure 30.2. Regular walkers maintained better quality of life scores than irregular walkers. Similarly, those who walked on an irregular basis had more shortness of breath than those who walked on a regular basis (Heppner, Morgan, Kaplan, & Ries, 2006).

Our group has produced other evidence that walking adherence is related to better health outcomes. In one of our earlier studies, COPD patients were randomly assigned to one of five groups. One group was designed to increase adherence to physical activity using cognitive-behavior modification. Cognitive-behavior modification combines traditional behavior modification with cognitive therapy and is believed to be superior to either the behavior modification alone or the cognitive component alone. The study also involved a behavioral and a cognitive group. The fourth group got attention, while the fifth group received no treatment. All patients were evaluated at baseline and followed over the course of 12 weeks. Cumulative time spent walking was measured through patient reports in a diary. Those in the cognitive-behavior modification group accumulated significantly more walking time than those in control groups (Figure 30.3). Adherence to physical activity was associated with changes in endurance as evaluated on a treadmill after 12 weeks. Further, these changes in endurance were associated with changes on the QWB scale (Figure 30.4). All three groups experiencing a cognitive or behavioral intervention showed improvements on the QWB, while those in the two control groups declined on the QWB (Atkins, Kaplan, Timms, Reinsch, & Lofback, 1984).

There are several potential explanations for the failure to demonstrate long-term benefits from comprehensive pulmonary rehabilitation. One explanation is that behavioral interventions, without long-term follow-up or maintenance sessions, such as rehabilitation, are inadequate to produce long-term change. Long-term maintenance of behavior change has also been difficult to demonstrate in research on smoking cessation (Ockene et al., 1994b), weight-loss

30.2

Changes in the Quality of Well-Being Scale (QWB)—excluding deaths for regular and irregular walkers at post rehabilitation and 6-, 12-, and 24-month follow-ups. Higher scores indicate better overall health-related quality life.
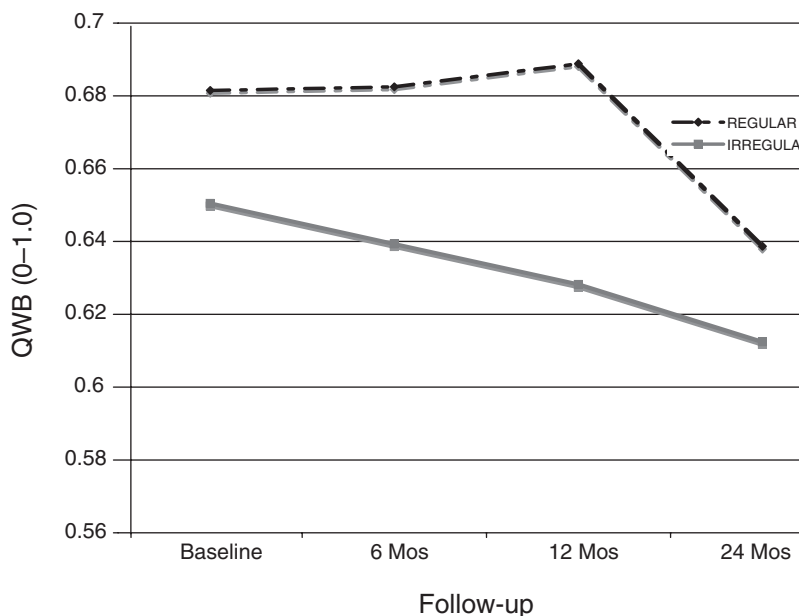
(Mann et al., 2007), and exercise adherence (Dubbert, 1992). The finding that patients experience behavior change during treatment that is not maintained after treatment is consistent across a variety of different behavioral interventions (Mann et al., 2007). Discovering ways to maintain behavior change over extended periods of time remains a high priority for research.

In summary, patient adherence to exercise is perhaps the most difficult and least studied component of pulmonary rehabilitation. Exercise requires alteration in lifestyle, coping with uncomfortable sensations, and changes in daily schedules.

Adherence in Smoking Cessation Programs

Because of the well-documented association between smoking and COPD, successful smoking prevention programs are expected to reduce the incidence of these diseases. Smoking cessation programs are also valuable. There is considerable interest in the effects of smoking cessation for smokers with mild airway obstruction who may be at risk for COPD. In addition to the role of smoking as a cause of COPD, active cigarette smoking also affects the course of the illness. For example, cigarette smoking is associated with mucous hypersecretion, acute

30.3

Walking compliance by cognitive, behavioral, or control groups.
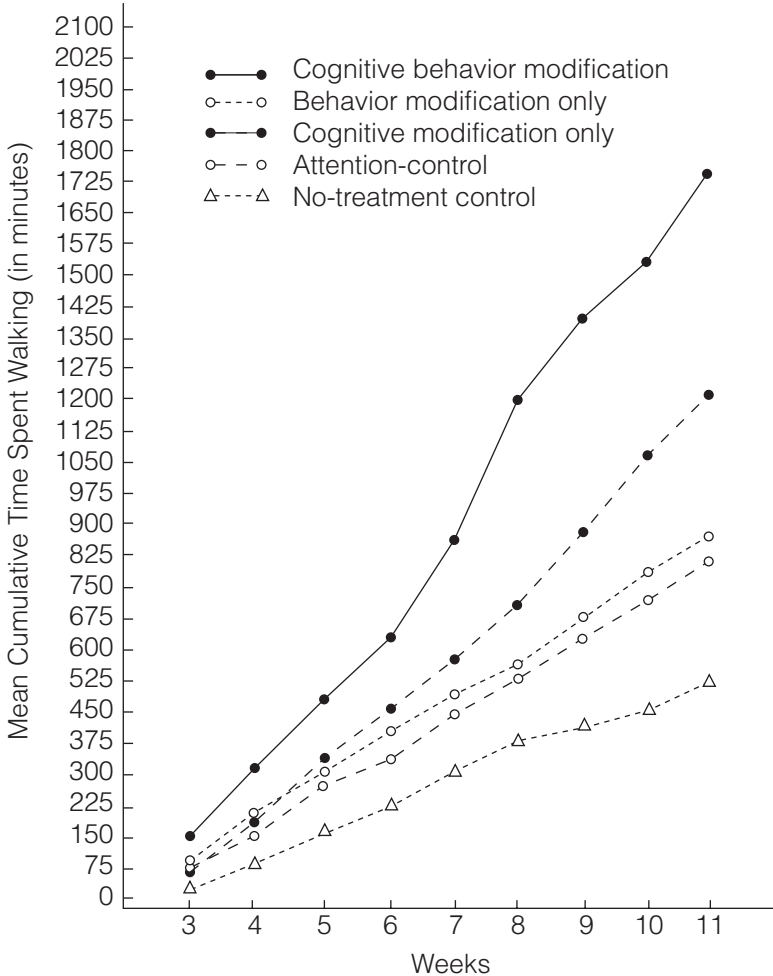
Note. From "Behavioral Exercise Programs in the Management of Chronic Obstructive Pulmonary Disease," by C. J. Atkins, R. M. Kaplan, R. M. Timms, S. Reinsch, & K. Lofback, 1984, *Journal of Consulting Clinical Psychology, 52*(4), p. 599. Copyright 1984 by the American Psychological Association. Reprinted with permission of the American Psychological Association.

respiratory illnesses, altered airway reactivity, and increased risk of mortality from other causes, including coronary heart disease. Some of the relations between smoking and problems in the airways have been reviewed elsewhere (Lopez et al., 2006). A variety of studies have suggested that loss in lung function is associated with total duration of cigarette use (Dockery et al., 1988). Longitudinal studies indicate that there is a progressive loss of pulmonary function with continued cigarette smoking. However, there is at least some evidence that there is partial recovery of lung function for those who cease cigarette smoking, particularly for those who do so early in life (Buist, 2006).

30.4

Mean change in QWB (multiplied by 100) by group.
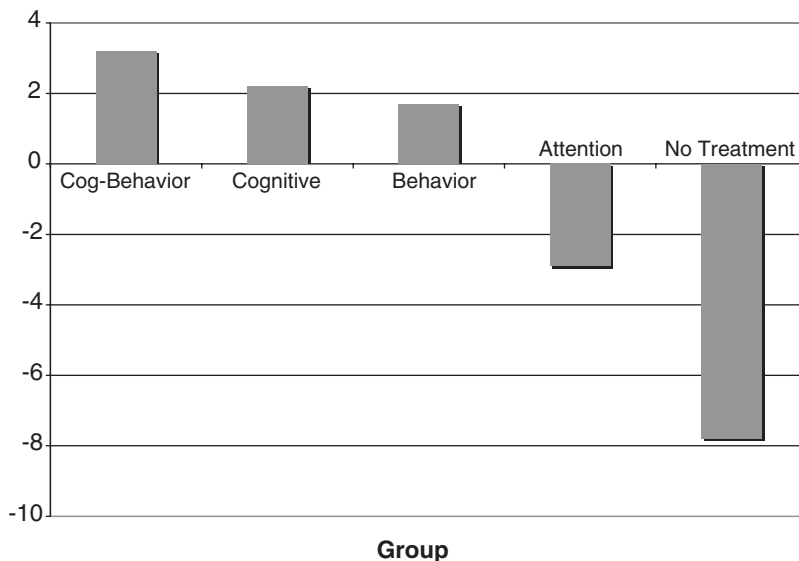
Group

Note: From "Behavioral Exercise Programs in the Management of Chronic Obstructive Pulmonary Disease," by C. J. Atkins, R. M. Kaplan, R. M. Timms, S. Reinsch, & K. Lofback, 1984, *Journal of Consulting Clinical Psychology, 52*(4), p. 599. Copyright 1984 by the American Psychological Association. Reprinted with permission of the American Psychological Association.

Because of the potential benefits of smoking cessation, efforts to improve adherence to smoking cessation programs are of great importance. Evidence has accumulated suggesting that the physician may play a critical role in helping patients to stop smoking and to maintain this behavioral change (Ockene & Zapka, 1997). Several experimental trials have trained physicians to deliver a smoking cessation intervention. The components of the intervention include approaches for taking a smoking history, personalizing the health risks, setting a quit date, prescribing nicotine chewing gum, and counseling techniques for follow-up. In one study, Ockene and associates (1994a) assigned physicians to receive training in behaviorally oriented counseling techniques or to a control group in which patients were provided with only brief advice to stop smoking. Some of the interventions involved the use of nicotine gum, whereas others did not. The results suggested that the behavioral intervention, with or without the use of nicotine gum, resulted in greater reductions in cigarette use among patients. Further, differences between these groups remained at 6-month follow-up. The Agency for Health Care Policy and Research offered guidelines for smoking cessation in primary care medicine (Fiore, 1998). Despite the well-established health consequences of tobacco use, early studies suggested that fewer than one half of physicians commonly advise their patients to give up cigarettes (Ockene, Aney, Goldberg, Klar, & Williams, 1988). By 2006, rates of referral for smoking cessation remained low, although three-quarters of primary-care physicians reported that they advised their smoking patients to

quit (Schnoll, Rukstalis, Wileyto, & Shields, 2006). Among those who discuss smoking with their patients, few go much further. For example, only about one in four physicians makes any effort beyond simply stating that the patient should quit smoking (Ockene et al., 1988). One of the biggest challenges in getting patients to quit smoking is the recognition that relapse is common. Most smokers who stop will begin using cigarettes again within 3 months. Among smokers who have abstained for 48 hours, nearly 20% relapse within the first week and an additional 13% relapse during the second week (Gulliver, Hughes, Solomon, & Dey, 1995). About 23% remain smoke free for 6 months. Relapse rates among those who participate in formal programs are somewhat better than those for self-quitters (Brandon, Tiffany, Obremski, & Baker, 1990). Recent studies suggest that those smokers who slip are most likely to relapse. For example, a smoker who takes an occasional cigarette is significantly more likely to relapse than one who does not slip (Baer, Kamarck, Lichtenstein, & Ransom, 1989; Brandon et al., 1990). Readiness to change should also be assessed. Many smokers may be in a "precomtemplation" phase in which they are nonreceptive to messages about quitting. Those who are already contemplating a quit might be better targets for a quitting message (Boudreaux, Carmack, Searinci, & Brantley, 1998; Boudreaux, Hunter, Bos, Clark, & Camargo, 2006).

Perhaps the best predictor of relapse is low personal expectations for remaining smoke free. Using electronic daily diaries, Shiffman and colleagues (Shiffman, 2006; Shiffman et al., 2006) have been able to determine what factors precipitate relapse. These studies suggest that lapses associated with self-reported stress or good mood were more likely to progress to relapses than those associated with eating or drinking.

A large literature on smoking cessation techniques has developed and is best summarized in the AHCPR Smoking Guideline (Fiore, 1998). Overall, self-help groups tend not to achieve better outcomes than control groups (Ranney, Melvin, & Rohweder, 2005). We urge the use of self-help materials in combination with some counseling intervention. Telephone counseling appears to offer significant benefits. In addition, several free 800 numbers are now available. Many of these are summarized at www.helpguide.org/mental/quit_smoking_cessation.htm. Evidence does suggest that physicians and other health care providers can offer brief smoking cessation counseling in combination with pharmacological intervention (Ranney et al., 2005) and that these simple interventions enhance abstinence rates at 6 and 12 months (Morgan et al., 1996). The addition of Nicotine Replacement Therapy has also been shown to increase long-term maintenance. Pharmacotherapy may be more effective for men than for women, particularly when it is used with combination with smoking cessation counseling (Perkins, Grobe, Caggiula, Wilson, & Stiller, 1997).

Summary

The typical regimen for patients with COPD requires many different behaviors. These may include the use of several different medications, exercise, oxygen, respiratory and physiotherapy techniques, and other aspects of self-care. Adherence to this regimen can be challenging. In contrast to nearly every other medical condition, there are relatively few published studies evaluating the

benefits of interventions to improve adherence among patients with COPD. Further, we do not know the extent to which overuse of medication is associated with poor outcomes for patients with COPD. Behavioral intervention may enhance adherence with medicine taking, smoking cessation, and exercise. However, considerably more research is necessary to evaluate the long-term benefits of these interventions.

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Aging, Cognition, and Diabetes: The Transition From Self-Care to a Caregiver for Diabetes Self-Management

31

Laura H. Coker

Cognitive declines across a broad spectrum, from "normal" age-related declines to dementia, and type 2 diabetes are common among people aged 65 years and older (see chapter 35 for the epidemiology of cognition and diabetes). Briefly, some longitudinal epidemiologic studies have established an association between diabetes mellitus and both Alzheimer's (Leibson et al., 1997; Ott et al., 1996; Yoshitake et al., 1995) and vascular dementias (Ott et al., 1996; Yoshitake et al., 1995) in older adults, while others support the link between diabetes and vascular dementia only (Curb et al., 1999). The relationship between diabetes and dementia is suggestive but does not confirm that type 2 diabetes causes cognitive dysfunction independent of dementia (Coker & Shumaker, 2003). These relationships are under study in the ongoing National Heart, Lung, and Blood Institute (NHLBI) funded Action to Control Cardiovascular Risk in Diabetes—Memory in

Diabetes (ACCORD-MIND) clinical trial, which addresses the effect of diabetes and cardiovascular risk factors on age-associated cognitive declines in men and women age 55 years and over (Williamson et al., 2007).

The gerontologic literature suggests that declining cognitive abilities are important predictors of decrements in self-care behaviors and lifestyle choices that support health maintenance in general. Cognitive declines are also associated with decreased ability to self-manage medical regimens for secondary prevention and treatment of chronic disease. Self-care regimens for diabetes are complex and difficult to manage for people with normal cognitive abilities, and they pose a real challenge to those with impaired thinking, remembering, and planning skills. The transition from self-care to care provided by an "informal" family caregiver provides a way for the cognitively impaired person to maintain diabetic self-management. Ideally, this transition takes place gradually, with both the caregiver and the care recipient negotiating their roles. Regardless, when a caregiver enters the equation, a number of variables are introduced to the ultimate goal of improving management of the care recipient's treatment regimen. These include, but are not limited to, the caregiver's knowledge of the disease process, the complexity of the care required, the physical "work" of providing care, and the caregiver's health. Important interpersonal factors involve the relationship between the care recipient and caregiver, acceptance of the care recipient and caregiver roles, and the combined resources of the care recipient and caregiver. Informal caregivers perform an enormous role in the day-to-day care of dependent elderly with chronic disease in the United States, and this trend will increase with the current demographic of an aging population.

This chapter classifies types of cognitive declines commonly seen in older adults and describes typical functional abilities associated with each type. It also explores the transition from diabetes self-care to care provided by an informal family caregiver. Description of this transition includes a discussion on recognizing the need for a caregiver, followed by a section on emergence of the caregiver. Finally, findings from the literature describe the experiences of the caregiver and the structural and policy issues that suggest that supporting the caregiver is the ultimate strategy for promoting self-management of the cognitively impaired person with diabetes. This exploration uses a biopsychosocial framework by Glasgow & Eakin (1998), which includes six levels of influence that affect diabetes self-management. Finally, we discuss factors that are supportive and those that act as barriers to the well-being of the cognitively impaired diabetes patient, the caregiver, and the dyad they compose.

Types of Cognitive Decline and Effect on Self-Care Behaviors

Cognitive declines are common as one ages, hence the terms *normal cognitive aging* and *age-associated cognitive decline,* which frequently appear in the gerontologic and neuropsychologic literature (Arenberg, 1978; Resnick, Trotman, Kawas, & Zonderman, 1995). Both terms refer to a range of mild to marked declines in cognitive abilities that occurs due to aging rather than to specific disease processes. Age-associated cognitive decline affects memory and the ability to plan, organize, and shift from one task to another while sparing other

cognitive abilities such as well-learned verbal skills and vocabulary (La Rue, 1992) (see chapter 35 for an explanation of domain-specific cognitive issues and diabetes). Although cognitive declines due to aging are a source of great concern and social anxiety among older adults (Resnick et al., 2004), the declines do not necessarily predict a downward course to dementia—and generally do not interfere with the ability to conduct daily activities and manage one's own affairs, including one's health.

Mild cognitive impairment (MCI) is a newer classification that continues to be refined and portends further declines in a small subset of people who bear this classification. For example, people with MCI generally exhibit poor cognitive performance (10th percentile or lower) in at least one area in the Modified Consortium to Establish a Registry for Alzheimer's Disease (CERAD) cognitive battery (Morris et al., 1989), a report of some functional impairment that is not severe enough to interfere with basic activities of daily living (ADLs), such as eating, bathing, dressing, and grooming, and absence of a psychiatric disorder or medical condition that could account for the decline in cognition and the absence of dementia. (Petersen et al., 2001). Sources suggest that approximately 15% of people with MCI convert to the classification of dementia every year; however, this figure may be higher in cohorts that include amnestic MCI, which is viewed by most as part of the continuum to dementia, whereas the conversion to dementia is lower in cohorts with nonamnestic MCI. Also, the number of people who convert to dementia also varies depending on whether functional impairment is required for the definition of dementia (Fisk, Merry, & Rockwood, 2003; Lopez et al., 2003). Although the majority of people with MCI are able to manage their own basic ADLs, they may have difficulty with specific instrumental activities of daily living (IADLs) such as cooking, driving, gardening, balancing a checkbook, or using public transportation. People with MCI do have a measurable decline in cognitive functioning, and progression to dementia is higher in this group than in same-age cohorts without MCI. Therefore, the classification of MCI alone suggests that close attention be paid to the patient's ability to adequately manage self-care.

The diagnosis of *all-cause dementia* is reserved for people who meet the criteria set forth in the American Psychiatric Association Diagnostic Manual of Mental Disorders (American Psychiatric Association, 1994). These criteria require that individuals who suffer from cognitive declines score poorly on two or more tests in the CERAD battery (or similar standardized neurological tests); demonstrate a degree of functional decline that makes them dependent on others; not have psychiatric or physical illness that could account for the cognitive decline; and not be abusing alcohol or drugs that could explain the cognitive symptoms.

Significant declines in cognitive functioning associated with dementia have been shown to increase the risk of difficulty performing basic ADLs and IADLs, including self-care behaviors (Kelly-Hayes, Jette, Wolf, D'Agostino, & Odell, 1992; Stuck et al., 1999). Declines in self-care behaviors affect routine health maintenance and preventive health practices, as well as specific daily care regimens that are required for diabetes self-management. The clinical diagnosis of dementia suggests a level of dependency on others that may be met by an informal family caregiver, formal paid assistance, or formal supportive living arrangements such as assisted living or nursing home care.

Aging, Cognition, and Diabetes Self-Management

When cognitive declines result in poor adherence to the medical treatment regimen, the severity of diabetes increases (Sinclair, Girling, & Bayer, 2000). Ideally, precipitous declines in health status can be prevented by early recognition of the need for a caregiver and early identification of an able and enthusiastic person to accept the role. Glasgow & Eakin's (1998) "pyramid of influences" provides a biopsychosocial framework to systematically examine supportive factors, as well as barriers to diabetes self-management. The factors include six levels, arranged from micro- to macro-levels: 1. personal, 2. family and significant other, 3. health care system, 4. worksite or organization, 5. neighborhood and community, 6. media, policy, and culture. This framework may also be useful to evaluate whether these factors differ or are magnified when the patient with diabetes has concomitant cognitive declines and has an informal family caregiver.

In *Level 1: Personal Factors* of Glasgow & Eakin's (1998) framework, the concepts of empowerment, high self-efficacy, and good problem-solving skills are identified as supportive for diabetes self-management, while lack of knowledge and low self-efficacy are named as barriers. When one adds the concept of *aging* as a personal factor, viewed from a biopsychosocial perspective, the effect on self-management can be mixed, depending on health status and developmental stage. For example, aging is often linked to negative health outcomes but holds positive connotations for life-span developmental stages. Erikson (1959) discussed the developmental milestones of old age and the stage of *personal integrity*—described as the ultimate stage of personality development. Older adults operating in this stage have a strong preference to remain independent, to reflect on the mark they are leaving on the world, to be an example to others, and to contribute to the well-being of others, especially their own families. For many older adults, becoming a burden on one's own spouse and children is to be avoided at all costs. However, when faced with significant problems (health, financial, safety), these same older adults can reach out to their spouses and other family members and take an active part in decision making about their own care. Theoretically, being able to recognize the need for and help plan for one's own care facilitates the process of adapting to the role of becoming a care recipient, but this process has not been well studied.

On the other hand, older adults with waning cognitive abilities may lack the judgment or problem-solving skills to assess their need for assistance from others. It may be that empowerment and high self-efficacy, which are supportive factors to older adults with *normal* cognitive functioning, are not as important as "insight" into their abilities in people with impaired cognitive functioning. There is evidence that some cognitively impaired older adults lack insight with respect to their limitations and overestimate their abilities. Cotrell, Wild, & Bader (2006) studied the relationship among cognitive status, deficit awareness, medication management skills, and actual adherence among individuals 65 years and older with mild AD and compared this group to age-matched cognitively normal participants. They found those with AD were seemingly unaware of their cognitive limitations and significantly overpredicted their ability to adhere to timing and dosing requirements.

Also, the literature suggests that *awarene*ss of one's own cognitive abilities may be more important than cognitive status per se in achieving good adherence. Branin (2001) reported that older adults who expressed greater concern about their memory were more likely to rely on "external props" to prompt flagging skills in memory and organization. Life-span adherence studies report that despite strong evidence for age-related cognitive decline, adults in the "young-old" category adhered adequately and had fewer errors than busy middle-aged adults, whereas the oldest-old had more difficulty adhering (Morrell, Park, Kidder, & Martin, 1997; Park, Hong, Lee, Ha, & Sung, 2004). Individuals who retain a certain level of insight with respect to their cognitive abilities may be able to effectively use scheduling and contextual cues to compensate for their waning cognitive skills. For example, individuals who experience psychomotor slowness, a common sign of age-related cognitive decline, may adjust by simplifying their schedules to provide more time to attend to medication adherence and other self-care activities. Those who are aware of memory problems may adopt any number of behaviors, such as making lists, filling pill dispensers for the week (with or without help), or using a diary to record self-care requirements such as checks on blood pressure, weight, and medication time, dosing, and side effects. Those who retain the ability to plan, coordinate, and set priorities may be able to link contextual cues such as bath time or preparation for bed with self-care activities such as checking feet and taking evening medications (Branin, 2001; Brown & Park, 2003; Gould, McDonald-Miszczak, & King, 1996).

Recognizing the Need for a Caregiver for Diabetes Self-Management

Consistent with Glasgow & Eakin's (1998) diabetes self-management framework, at *Level 2: Family and Significant Other,* family and friends among the diabetic patient's close social network are most likely to recognize when the diabetic person needs help. This is especially important when the patient is cognitively impaired or lacks the insight to ask for help. Elderly people with diabetes display excess cognitive dysfunction that is associated with decrements in self-care and increased dependency needs (Sinclair et al., 2000). The literature records a number of signs of worsening disease or events that may indicate that the patient with diabetes is having difficulty with cognition and/or self-care and needs assistance. These include poorer glycemic control as measured by Hgb A1c (Perlmuter et al., 1984); declines in cognitive screening scores (Sinclair et al., 2000); lower ADL scores or functional declines (Langa et al., 2002; Sinclair et al., 2000); development of neuropathy (Perlmuter et al., 1984); hospitalization for diabetes symptoms (Sinclair et al., 2000); diagnosis of comorbidity such as stroke or heart disease (Langa et al., 2002); complicated medication regimen, including the addition of insulin therapy (Hendra & Taylor, 2004; Silliman, Bhatti, Khan, Dukes, & Sullivan, 1996); declines in vision (Langa et al., 2002); and infection and/or delayed wound healing (Nabuurs-Franssen, Huijberts, Nieuwenhuijzen Kruseman, Willems, & Schaper, 2005). This list of events or signs and symptoms associated with diabetes is not exhaustive, but any one of them may indicate the need for some degree of assistance from someone in monitoring the day-to-day needs of the person with diabetes.

Emergence of a Caregiver for Diabetes Self-Management

Glasgow & Eakin (1998) identify the diabetes patient's family and friends as the source of social support when the patient is dealing with diabetes self-management issues. It follows, therefore, that the older, cognitively impaired patient would also look to his close social network for care. Supportive factors include an environment that is conducive to responding to the patient's specific needs (e.g., glucose monitoring, therapeutic diet, medication regimen), while also actively encouraging the patient to remain independent, active, and as productive as possible. Lack of expected support from one's close network serves as a barrier to the patient's well-being. Ideally, emergence of a capable and dedicated caregiver takes place gradually, so the caregiver has ample opportunity to acquire needed information and to understand which of the patient's needs require caregiver assistance. It is often the case that some of the care activities are maintained by the patient, while others are transferred to the caregiver. Ideally, the caregiver and the care recipient work together, each negotiating roles that are dynamic over time. But how is the caregiver chosen, and who is he or she?

Family systems theory provides a way to think about how the need for care is recognized and how the caregiver role emerges. The theory holds that behaviors within the family system are more intimate and enduring than those outside the system. Within the system, dependency needs are shared and interdependence is accepted as a norm. Therefore, when one person has increased needs for care, a member of the family is likely to recognize and meet that need. As the person in need adapts to the role of the care recipient, another person emerges as the caregiver. When the care recipient is married, the caregiver is most often the spouse (Whitchurch & Constantine, 1993). Also, when the care needs involve intimate physical care, these needs are usually managed by the spousal caregiver. Unmarried care recipients look to other family members for care, and the role is most likely assumed by a close female member—mother, sister, sister-in-law. Male caregivers tend to manage specific tasks, such as heavy physical work like lifting or transferring patients or transporting the patient to medical appointments. Men may also assist by performing typical gender role tasks, such as financial management and home, yard, and automobile maintenance for care recipients who have lost the ability to perform these instrumental activities. Numerous clinical studies have borne out these theoretical underpinnings of the care recipient and caregiver roles (Nabuurs-Franssen et al., 2005; Silliman et al., 1996; Stone, Cafferata, & Sangl, 1987).

Little is known about the process of how the patient and the caregiver negotiate which self-care tasks are to be retained by the patient and which are to be transferred to the caregiver. Ideally, the patient should remain as independent as possible, asking for assistance with only those tasks that are especially complex or physically difficult. But how do the patient and the caregiver sort this out? There is a lack of pertinent psychosocial research in the area of caregiving and role adjustment associated with diabetes self management (Anderson, 1996). The literature on cardiac disease and spousal caregiving suggests that changes in lifestyle (dietary requirements; physical activity), encounters with health professionals, and each spouse's reaction to illness are important sources of stress. Primary coping strategies include seeking "informational support" and

"protective buffering" and are used by both the caregiver and care recipient. Care recipients complain of "miscarried helping" referring to perceived loss of independence resulting from the overprotective caregiver (Coyne & Smith, 1991; Coyne, Wortman, & Lehman, 1988; Stewart, Davidson, Meade, Hirth, & Makrides, 2000).

There is some evidence that when cognition is normal or only mildly affected, patients are able to recognize subtle needs and may take the lead in asking for help. Hendra & Taylor (2004) studied adult diabetics with only mild age-associated cognitive decline (Mini Mental State Exam mean score = 26; Folstein, Folstein, & McHugh, 1975) and good functional status (Barthel Index mean score = 19; Collins, Wade, Davies, & Horne, 1988). Although the patients said they provided self-care, they also recognized the need for periodic caregiver assistance when there were changes in the diabetes medication regimen. Cognitively impaired patients often lack insight and fail to recognize when they need help from others. Therefore, they are at high risk for declines in diabetes self-management and development of complications of diabetes and comorbidities.

Caregiving to Promote Diabetes Self-Management

Soon after the caregiver emerges, she will need information about diabetes in general and about the care recipient's needs specifically. Although there is an extensive literature on caregiving to dependent elderly and cognitively impaired persons, surprisingly few studies have addressed specific caregiving tasks performed by informal caregivers to older adults with diabetes. Some of these tasks may be learned through patient education activities (e.g., instructions for checking blood glucose, correct dosage and timing of medications, diet planning) that are provided by the physician and health care team directing the patient's medical regimen. At *Level 3: The Health System* in Glasgow & Eakin's (1998) framework of diabetes self-management, states that advice from one's physician highly influences self-care behaviors. However, in busy medical practices today, time with the physician is brief and the physician's advice is often supplemented by counsel from others who provide education and support to the patient. These professionals (nurses, nutritionists, social workers, psychologists), some of whom hold the credential Certified Diabetes Educator, use innovative teaching methods and scientific and experiential evidence in their practice (Funnell et al., 2006).

The health care setting has provided the scientific expertise, facilities, and personnel for numerous studies of interventions that support self-management for diabetes. These interventions include goal setting and shared decision making between medical personnel and the patient (Heisler et al., 2003; Warsi, Wang, LaValley, Avorn, & Solomon, 2004; Williams, McGregor, Zeldman, Freedman, & Deci, 2004); small-group interventions for self-care skill development (Anderson et al., 1995; Litzelman et al., 1993; Parchman, Arambula-Soloman, Noel, Larme, & Pugh, 2003); and use of technology for patient education (Glasgow, Toobert, & Hamson, 1996). There is also good evidence that the health care system recognizes the value of an ecological approach to self-care, with the patient integrating self-management skills with support from the environment, including family and friends (Fisher, Brownson, O'Toole, Anwuri, & Shetty, 2007; Fisher et al., 2005). The literature is not clear, however, on how the health care system

recognizes the need for a family caregiver to assist the patient or how the health care system assists the caregiver in coping with the burden of providing patient care. A medical system that is supportive to diabetes self-management provides a patient-family education component that the caregiver and the care recipient can attend singly or as a dyad, both interacting with the health care team for collaborative goal setting and planned follow-up. Opportunities for the caregiver to schedule sessions alone are ideal, because the caregiver may need to ask questions or express feelings in private. A health care system that does not actively involve the diabetic patient's caregiver creates barriers to diabetes self-management.

Recognizing and Understanding Caregiver Burden

Caregiver burden, the most commonly measured outcome of informal (usually family) caregiving, is thought to emerge from a subjective belief that current and future resources are insufficient to meet the demands imposed by the role (Zarit, Reever, & Bach-Peterson, 1980; Zarit, Todd, & Zarit, 1986). As a result, burden is believed to be a predictor of negative physical and psychological outcomes, such as depression. Caregivers for patients with diabetes are at risk for mild to severe burden because of the chronicity of the disease, the range and complexity of diabetes self-management activities, and comorbidities such as heart disease, visual problems, renal insufficiency, microvascular disease associated with wound healing and amputations, and cognitive decline. Although the range of expected outcomes among those who care for persons with diabetes is broad, surprisingly few studies have addressed these diverse outcomes. If the decline in cognition is mild and occurs in the absence of physical complications of diabetes, the caregiving needs may be limited to monitoring and/or assisting the patient in checking blood sugar, taking medications, maintaining a therapeutic diet, and continuing regular health maintenance and preventive care. Hendra & Taylor (2004) reported that caregivers of diabetic patients randomized to one of three medication regimens—two of which included insulin therapy—reported low stress as measured by the General Health Questionnaire (Goldberg, 1986), a widely used instrument for screening psychological distress. In this case, the diabetes patients were only mildly impaired and could ask for help with new insulin dosages during the course of this short-term study. Another study looked at the effect of a foot ulcer on health-related quality of life (HRQL) for patients with diabetes and their caregivers. Patients' mean age was 60 years, 72% were male, and the duration of diabetes averaged 17 years. At intake, the ulcer was examined and HRQL was measured independently in the patient and the caregiver; these tests were repeated at 20 months. Caregivers and patients whose ulcers healed during the 20 months had a significantly higher HRQL than caregivers and patients whose ulcers had not healed. This study is interesting in that patients and caregivers who had dealt with diabetes for a number of years showed significant declines in HRQL in less than 1 year because of the additional burden posed by a commonly occurring complication of diabetes—a nonhealing foot ulcer (Nabuurs-Franssen et al., 2005).

Many factors related to the caregiver and the care recipient merge or overlap to compound the caregiver's sense of burden, but the chronic nature of diabetes and the likelihood that the physical work of caregiving will increase over

time suggest that diabetes caregivers are at high risk. For example, informal care has been shown to increase from 10.1 hours per day when oral medication alone is sufficient to 14.4 hours per day (p < 0.01) when insulin therapy is required (Langa et al., 2002). Similarly diabetic care recipients with macrovascular (heart disease and stroke) and microvascular (visual) complications have significantly higher need for informal care (Langa et al., 2002). Silliman et al. (1996) examined family caregiving among a community-based sample of 357 caregivers of patients with type 2 diabetes. Family caregivers, who had a mean age of 65 years, were primarily female (76%) and spouses (71%). Up to 50% of caregivers provided assistance in some type of diabetes-specific care, and more than one-third were present and played a role in the patient's medical appointments. Caregiver involvement increased in association with the patient's functional disability. Caregivers' perceived unmet needs included education about diabetes and diabetes-related care to support them in their diabetes management roles.

While caregivers provide a major contribution to the day-to-day support of patients with diabetes and other chronic illnesses, the burden takes its toll and frequently leads to negative outcomes such as isolation and financial constraint (Gahagan, Loppie, Rehman, Maclellan, & Side, 2007) and declines in emotional and physical health (Schulz et al., 1997). Vulnerable caregivers are at particular risk for undergoing significant health declines and giving up the caregiver role. A recent nationally representative study of 1002 informal caregivers found that 36% were vulnerable and suffering from fair to poor health or experiencing serious health conditions. This group was older (≥65 years), married and had fewer than 12 years of education (Navaie-Waliser et al., 2002). Models of caregiver stress suggest that coping skills and social support may ameliorate stressful outcomes for the caregiver. However, it is also the case that chronic illness may drain supportive resources and lead caregivers to become isolated, overwhelmed, and ill (Stewart et al., 2000). Vulnerable caregivers are an understudied group and are particularly important because they represent the last opportunity for at-home informal care for a large number of care recipients who, without such care, will enter the formal institutional care system, at great cost to both private and public funding sources.

The caregiving literature has focused much attention on the negative or stressful outcomes of caregiving, with the construct of "burden" being the most often studied. However, Pearlin, Mullen, Semple, & Skaff's (1990) model of caregiver stress demonstrates that caregivers bring personal attributes to the caring process, including intrapersonal coping mechanisms and social and/or material resources, that lead them to find personal meaning and a sense of accomplishment or well-being in caregiving, rather than consistently negative outcomes. Gaugler, Kane, & Newcomer (2007) studied caregiver resilience—"the ability of certain caregivers to persevere in at-home caregiving roles while remaining stable or reporting decreasing levels of burden or depressive symptoms." Over a period of 3 years, high caregiver resilience (low perceived burden in the face of frequent care demands) was associated with less frequent institutionalization of the care recipient and loss to follow-up, as well as more frequent care recipient mortality. The interpretation was that the resilient caregiver was able to remain in a caring role throughout the life of the dependent care recipient. More research is needed on the ways in which caregiver resiliency can be supported.

Level 4: Worksite and Organization of Glasgow & Eakin's (1998) diabetes self-management framework is important to the extent that macro-level organizations, such as the workplace and its policies, may ameliorate caregiver burden by supporting the needs of both the caregiver and the care recipient. Many caregivers continue to work outside the home while coping with the additional responsibilities of providing care for another. Working outside the home provides regular social contacts and prevents caregiver isolation, which is an important source of caregiver burden (Rochette, Desrosiers, Bravo, St-Cyr Tribble, & Bourget, 2007). In addition, some workplaces offer flexible schedules and telecommuting, which increases the caregiver's options for work schedules. Other workplaces provide on-site exercise programs, food service with a range of healthy choices, health clinics for minor illnesses and preventive health maintenance, and referral for psychological services. The array of work-related benefits also includes health, dental, and disability insurance, health- and dependent-care spending accounts, and financial counseling services that directly benefit the caregiver. Some larger employers provide support groups for caregivers and elder care programs at or near the workplace, but these are the least frequently offered among the work-related benefits (Walston, 1995). When the care recipient is cognitively impaired or dependent on the caregiver, workplace policies and services that benefit the caregiver also benefit the care recipient. The care recipient who is no longer employed may continue to benefit from group health insurance obtained earlier through the workplace. In this sense, the workplace is very important to the caregiver and to the care recipient with diabetes, and absence of workplace benefits present barriers to diabetes self-management.

Similar to the macro-level benefits from the workplace, according to Glasgow & Eakin's (1998) framework, *Level 5: Neighborhood and Community,* are the supports for and the barriers to diabetes self-management provided by community-based organizations and services. The cognitively impaired patient with diabetes may benefit directly from community-based (senior services, social service, church-sponsored) adult day care programs, which provide a safe and caring environment that also promotes social interaction. Some adult day care programs go beyond these basic offerings and provide rehabilitative and educational activities, entertainment, and outings (Baumgarten, Lebel, Laprise, Leclerc, & Quinn, 2002; Zarit et al., 1998). The patient's caregiver may benefit from the support groups and respite services associated with adult day care services (Baumgarten et al., 2002; Hedrick et al., 1993). A quasi-experimental U.S. study reported that caregivers who used adult day care services for at least 2 days a week for 3 months were less depressed and had less burden than did caregivers who did not use day care services (Zarit et al., 1998). Other innovative models for community-based respite services and their cost-effectiveness are under study (Mason et al., 2007). Safe neighborhoods with shopping, libraries, meeting places, and easy access to parks or "green areas" encourage social and physical activity. There is evidence that adverse neighborhood environment interacts with caregiver status to modify (increase) health-related outcomes (Brummet et al., 2005). Environments that provide little or no sense of community or support for the patient or caregiver place excess burdens on both and serve as barriers to diabetes self-management.

Supporting Caregivers: The Ultimate Diabetes Self-Management Strategy

Level 6: Media, Policy, and Culture of Glasgow & Eakin's (1998) diabetes self-care framework suggests that societal-level influences have not been consistently supportive of diabetes self-management, due in part to the lack of a health policy that promotes healthy living and in part to advertisements and media endorsements that are aimed more at a youth culture than at the maintenance of good health. Patients with diabetes and their caregivers have much to gain from a societal interest in healthy living. There is some evidence that the sheer economics of care provided at home may boost a national discourse on reasons to support caregivers of people with chronic illness. The American Association of Retried Persons (AARP) Public Policy Institute has prepared an issue brief that directly addresses the economic value of unpaid informal care provided at home (Gibson & Houser, 2007). Moreover, the report was made available to the public at large. A conservative estimate of the annual economic value of unpaid informal caregiving activities in 2006 was reported at $354 billion, which is more than the total spending for Medicaid, including both federal and state contributions and both medical and long-term care (Burwell, Sredl, & Eiken, 2006). The brief discusses out-of-pocket cost to caregivers, lost wages and retirement income, and the effects of the long-term-care and health care systems.

Another current work with policy implications comes from social scientists who have spent long careers studying the structure, function, and effects of one person providing informal care for another. New constructs of "patient suffering" and "caregiver compassion" are discussed from a theoretical, hypothesis-generating perspective. The history, definitions, and cultural meanings of suffering and compassion are discussed and a conceptual model of perceived suffering and caregiver compassion and their relation to caregiving and health are provided. This thoughtful work places the discussion of suffering and compassion in the context of family caregiving and aims to promote an empirical approach that will enrich researchers' understanding and lead to strategies that will improve the human condition (Schulz et al., 2007).

Summary

Declining cognitive abilities associated with aging and chronic disease, including diabetes, are important predictors of decrements in self-care behaviors. Self-care regimens for diabetes are complex and difficult to manage in people who have normal cognitive abilities, and they pose a real challenge to those with impaired thinking, remembering, and planning skills. The transition from self-care to care provided by an "informal" family caregiver provides a way for the cognitively impaired older adult to maintain diabetes self-management.

Diabetes self-management skills and behaviors and the resources to encourage or barriers that impede these are described from biopsychosocial (Glasgow & Eakin, 1998) and social ecological (Stokols, 1996) frameworks. The diabetes patient's behaviors are influenced by an environment stratified by a close personal social group composed of family and friends, a larger system-level environment,

which includes worksites and the health care system, and the macro-level influences of the community and policy. The patient whose environment holds key resources from which to choose (e.g., social support, accessible health care, healthy diet) is likely to fare better than one who lacks a supportive social group and has limited access to care. This line of thinking suggests that older diabetes patients with cognitive decline are not only more likely to have difficulty with self-management regimens but also are more likely to have difficulty choosing valuable resources from their environment. The informal family caregiver provides a means by which the cognitively impaired patient can receive the type and amount of assistance required through a process of transitioning from total self-care to care provided by a caregiver. Ideally, this transition takes place gradually, with both the caregiver and the care recipient negotiating their roles. Despite a large literature on caregiver burden, few studies report how the caregiver assumes the role and how the patient and the caregiver negotiate how they will work together. Studies are also needed on how the health care system recognizes the need for a caregiver and interacts with the caregiver to maximize patient care and/or to deal with caregiver burden. Although there are some complex studies (Langa et al., 2002; Silliman, 1996), research on diabetes and caregiving is largely at the exploratory and descriptive stages and does not yet address interventions to improve caregiver stress or caregiver outcomes. For example, there is a study of the perceptions and experiences of family members of diabetes patients (Rosa, Sunvisson, & Ahlstrom, 2007); focus groups that address the needs of family caregivers who provide complex care at home (wound care, dialysis) (Hennessy, John, & Anderson, 1999) and culturally competent self-management for Latinos (Vincent, Clark, Zimmer, & Sanchez, 2006); small, subjective quality-of-life studies of caregivers and patients (Awadalla, Ohaeri, Al-Awad, & Tawfig, 2006; Brod, 1998; Li, Lee, Lin, & Amidon, 2004); a small study of children as caregivers to adult patients with diabetes (Jacobson & Wood, 2003); and small clinical treatment trials that incorporate the impact on the caregiver as an outcome (Hendra & Talyor, 2004; Shelmet et al., 2004).

Supporting the family caregiver may be the ultimate diabetes self-management strategy for older, cognitively impaired and/or dependent adults. Research on the economic value of unpaid informal care provided at home has laid some ground to understanding the contribution of family caregivers (Gibson & Houser, 2007; Langa et al., 2002). Research of this kind and research on how to support family caregivers could provide critical information to inform policy that would provide assistance for care in the home, a preference of many and an alternative to costly institutional care.

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Adherence to Treatment and Lifestyle Changes Among People With Cancer

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Research on treatment adherence and health behavior change among people with cancer continues to lag behind that for patients with other serious illnesses or the general population. A large portion of the existing literature related to cancer patients is focused simply on documenting rates of adherence to treatment. Significantly less attention has been paid to variables associated with adherence or to interventions designed to improve adherence. One potential reason for the relative lack of attention to adherence in this population is the widely held assumption that patients facing a possibly terminal illness like cancer should adhere without question to whatever recommendations are made. That is, health professionals have assumed that patients will adhere if they believe that the likely alternative is death. However, comparisons of

adherence rates among patients with diseases of varying severity do not confirm this assumption (DiMatteo, 2004).

Another factor that may contribute to a limited focus on cancer-related adherence is that, until fairly recently, most cancer treatment was administered intravenously (IV) in a hospital or outpatient clinic setting. Specialized skills are required for IV administration, and there was a pressing need for close patient observation to prevent life-threatening side effects or complications. There were simply fewer opportunities for the kind of self-management that characterizes treatment for other conditions. However, improved supportive care (e.g., antinausea medications, white and red blood cell growth factors), reduced insurance coverage for inpatient stays, and the development of numerous oral cancer therapies have changed the cancer treatment landscape considerably.

Treatment advances, in conjunction with improved early detection methods, have significantly improved survival rates for most types of cancers. Even people diagnosed with more advanced disease, such as metastatic breast cancer, are being told that their cancer can be managed as a chronic condition, similar to diabetes. However, cancer is still a serious, often life-threatening, illness. Despite that, DiMatteo's (2004) authoritative review of 50 years of medical adherence research estimated that about one-fifth of cancer patients don't adhere to some part of their prescribed treatment. Such failure can carry high personal costs, such as higher mortality rates, shorter disease-free survival, greater likelihood of cancer recurrence, and the delayed identification of possible complications of treatment (e.g., osteoporosis) (Adsay et al., 2004; Ballantyne, 2003; De Csepel, Tartter, & Gajdos, 2002; Hershman & Narayanan, 2004; McCready et al., 2000; Van Gerpen & Mast, 2004). On the societal level, cancer-related nonadherence can result in the waste of vast amounts of health care resources and can also create misleading or incorrect results from clinical research (Dunbar-Jacob & Mortimer-Stephens, 2001; Farmer, 1999).

This chapter presents an overview of the literature on adherence among people who have been diagnosed with cancer. It is organized as follow. First, we discuss the potential significance of adherence for treatment success. Second, we cover methods for measuring adherence to cancer treatment. Third, we review investigations that have estimated adherence rates for different treatment-related behaviors in an effort to establish the magnitude of the problem of adherence. Fourth, research investigating various determinants of adherence and interventions to improve adherence are examined. We do not address adherence to cancer prevention and screening behaviors among the general population here, as these topics are well covered elsewhere in this book. The chapter concludes with a discussion of future directions for research.

Relationship of Adherence to Treatment Outcomes: Why Study Adherence in Cancer?

Cancer Treatment

The bottom-line significance of adherence to cancer treatment regimens is assumed to be increased likelihood of treatment success, which should translate

into improved physical health and longer survival of the patient. One frequently cited early investigation documented that treatment success was significantly better among patients who received at least 85% of their planned dosages of adjuvant chemotherapy, while disease-free survival was significantly shorter among people who received less than 65% of their planned treatment (Bonadonna & Valagussa, 1981). More recently, a major clinical trial demonstrated a significant survival advantage for people who took tamoxifen for 5 years rather than two or three (Early Breast Cancer Trialists' Collaborative Group, 2005). Although patient adherence was not specifically evaluated, the findings of this and similar dose studies have been generalized to support a role for adherence in treatment outcome. Indeed, a great deal of cancer research is directed toward identifying treatment schedules (e.g., weekly doses rather than every-three-week dosing) and supportive medications (e.g., growth factors G-CSF) that will allow more intense and dense treatment regimens to be administered without intolerable side effects (e.g., Desai et al. 2007; Gridelli et al., 2007). In addition, the dosing schedule is a crucial component of the effectiveness of some medications. Thus, if nonadherence contributes to a patient's receiving less than optimal treatment, such nonadherence may lead to a poorer outcome.

Adherence to recommended follow-up appointments and tests after the conclusion of cancer treatment might be expected to also affect long-term outcome. However, recent research findings are equivocal. Several investigations into the utility of intensive follow-up after cancer treatment have failed to show a benefit to more frequent check-ups (Secco et al., 2000) or the use of state-of-the-art imaging MRI technology in areas where recurrence is most likely (Titu, Nicholson, Hartley, Breen & Monson, 2006). A recent Cochrane systematic review evaluated survival and disease-free survival as they related to the intensity of the follow-up schedule after primary treatment for Stage I–III breast cancer (Rojas et al., 2005). No difference was found for these outcomes in the more than 3,000 women enrolled in these trials.

It is quite difficult to judge the significance of nonadherence, as there are multiple factors that affect outcome, only one of which is adherence. Frequently, the current state of scientific knowledge does not allow an accurate assessment of the impact of treatment. Adjuvant chemotherapy, for example, is given in the absence of any visible evidence of disease. As such, there is no way to reliably monitor the success of treatment, unless the treatment fails and there is a recurrence. Additionally, it is very difficult to specify what a particular patient must do to ensure a response from a treatment: dosage recommendations are made on the basis of group data, and thus any particular individual may need more or less treatment for the cure or control of disease (Barofsky, 1984). Thus, while adherence is likely to play an important role, it is but one of many factors that affect treatment outcomes.

Behavioral and Lifestyle Factors

For many people, a cancer diagnosis is a "wake-up call," motivating them to make long-delayed lifestyle changes. Health care providers are generally in favor of this strategy, making recommendations to stop smoking, eat a balanced diet, increase the consumption of fruit and vegetables, and get regular exercise. Although it's not known whether these behaviors increase the likelihood

of treatment success, they are increasingly recognized for their positive impact on quality of life during cancer treatment. For example, several randomized intervention trials (e.g., Mock et al., 2005) have documented that regular exercise minimizes cancer-related fatigue, a common and debilitating side effect of cancer treatment.

In summary, adherence to cancer follow-up care, medication regimens, and health behaviors has the potential to significantly increase survival time and improve quality of life. The actual size of this effect can be debated, and the applicability to any given individual is unknown. Still, the high stakes of cancer care make it incumbent on researchers to continue to focus on this area.

Methods for Measuring Adherence

There are three general categories of measurement available for assessing adherence (Hays & DiMatteo, 1987). These include self-reports, collateral reports, and objective measures. Each of these has particular advantages and disadvantages when applied to the wide variety of treatment-related behaviors required of cancer patients.

That self-reported treatment adherence is frequently inaccurate has been well documented within a general medical population (Cannell, Oksenberg, & Converse, 1977; Dunbar-Jacob et al., 2000). The few investigations that attempted to validate the self-report of cancer patients by comparing self-report data with data from objective measures have shown equivocal results. A comparison of self-report data and adherence rates obtained from blood levels of a drug treatment suggested that adherence rates derived from blood levels were half the self-reported adherence rates (Levine et al., 1987). However, two measures of smoking cessation, cotinine levels and self-reports, among head and neck cancer patients were in agreement 89.6% of the time (Gritz et al., 1993). One hundred percent agreement between self-report and serum drug levels was reported in a study of children and adolescents (Tebbi et al., 1986).

It is, therefore, possible for patients to be relatively accurate reporters of their own behavior. Nonetheless, the variability in these concordance rates suggests that it is necessary to approach self-reports with some skepticism and to consider the context of the treatment. Sources of inaccuracy in self-report by other medical populations are multiple, including fear of embarrassment or rejection by the health care provider, desire for support and approval, and misunderstandings about treatment recommendations (Hays & DiMatteo, 1987). In addition, self-report does not allow for an assessment of unintentional nonadherence due to forgetfulness or neglect: by definition, people can't self-report about nonadherence of which they are unaware. Although these variables have not been investigated with cancer patients, there is no reason to expect that they would not also operate in this population.

Collateral reports of adherence can be obtained from family, friends, and health care providers. These sources have apparently been little used in the cancer population. In apparently the only study to utilize this kind of data, Dolgin, Katz, Doctors, and Siegel (1986) asked physicians to rate their adolescent cancer patients' treatment adherence and to estimate the threat that nonadherence posed to treatment outcome. However, they did not obtain self-reports of

adherence, so it was not possible to judge the accuracy of the physicians' report. In early work, physicians' estimates of patients' adherence were found to be quite inaccurate (Caron & Roth, 1968, 1971; Davis, 1966).

Chart reviews have been used extensively as a source of objective information on cancer patient adherence to appointments for IV chemotherapy and follow-ups. Another method that is gaining in popularity and feasibility is the use of pharmacy and insurance records to evaluate the adherence of larger patient populations. For example, Silliman et al. (2002) examined the concordance between prescription refills and self-reported adherence to tamoxifen, finding roughly 90% agreement in this cohort of women older than 65 years.

Pill counts, electronic bottles, and urine or blood levels of medication in the patient's body also provide more objective measures, particularly cancer patients' adherence to oral chemotherapy and supportive medications. For example, the presence of 17-ketogenic steroids in urine has been shown to be a reliable indicator of adherence to oral prednisone in pediatric cancer patients (Festa, Tamaroff, Chasalow, & Lanzkowsky, 1992). However, others have questioned whether drug metabolites are really accurate adherence measures in patients for whom a particular treatment is not effective (i.e., biologically active) (Partridge, Avorn, Wang, & Winer, 2002).

Other investigators have also utilized blood serum levels of drugs and their metabolites to measure adherence (Lebovits et al., 1990; Richardson et al., 1987). Differing adherence rates have been found depending on whether the blood level of the parent drug or the metabolite was used. For example, Richardson et al. found that 77% of a sample of cancer patients were nonadherent to allopurinol as measured by the detection of the drug itself in the blood but that only 43.3% of patients would be classified as nonadherent on the basis of detection of oxipurinol, a metabolite of allopurinol. These authors suggest that such different levels might indicate poor or inconsistent medication ingestion. This interpretation has not been tested empirically, and other authors have questioned the value of this method due to individual variability in drug distribution and metabolism (Lee, Nicholson, Souhami, & Deshmukh, 1992).

Another alternative for measuring adherence to oral medication is the use of an electronic pill bottle that can record the times of day that the bottle is opened. This method is a particularly powerful objective measurement tool because it picks up both intentional and unintentional sources of nonadherence: it can also pick up both underadherence and "overadherence," which has been argued to be of potential concern with cancer patients who may think "more is better" when it comes to drugs that are supposed to kill off their cancerous cells (Partridge et al., 2002). Lee et al. (1992) reported the use of such a container with patients receiving oral chemotherapy. They documented almost perfect adherence to the regimen by comparing the number of bottle openings with the number of openings expected if adherence was perfect. In addition, they were able to reveal the pattern of pill taking by noting discrepancies between the time the bottle was opened and the time it was supposed to be opened. Pill bottles were opened the correct number of times on 80.9% of days.

Given the "fallibility" of individual methods, Hays & DiMatteo (1987) advocated the use of a multitrait, multimethod approach to the assessment of treatment adherence. Thus, patients might be defined as nonadherent if their self-report, the report of their physician or their spouse, or serum drug levels

indicated nonadherence to the recommended treatment. The reader is referred to Section III of this book for a more thorough discussion of adherence measurement issues.

Adherence Rates for Cancer Management Behaviors

As with other serious illnesses, the behaviors required for good management of cancer risk and diagnosis are many and varied. For the general population, professional organizations and cancer advocacy groups publish guidelines for screening and early detection tests (Bach, Silvestri, Hanger, & Jett, 2007; Saslow et al. 2007). Although cancer screening and prevention behavior are not covered in this chapter, which is focused on people already diagnosed with cancer, they are a crucial component of the fight against this disease. (See Section II of this book for chapters on health behaviors linked to cancer risk reduction.)

Once a cancer has been diagnosed, additional diagnostic tests may be required to determine if the cancer has spread and, if so, the location of the metastasis. Treatment recommendations will then be presented, and a patient will be asked to adhere to a course that could include surgery, chemotherapy, other anticancer drugs or supportive medications, and radiation therapy. The care regimen may require the patient to attend multiple appointments for treatment and checkups, to take oral or IV medications, to make lifestyle changes, and, finally, to attend specified follow-up visits after treatment completion. In the upcoming sections, we consider various aspects of adherence and self-management in these three categories of cancer-related behavior: cancer treatment, lifestyle changes, and follow-up surveillance to detect possible recurrence or late complications of cancer therapy.

Treatment Refusal

At the far end of the continuum of patient nonadherence is outright treatment refusal. This can be active, with patients informing their physicians that they will not accept treatment, or it may be passive, as when patients simply don't show up for their treatment appointments.

The available data on the prevalence of treatment refusal are fairly limited. Two recent studies retrospectively examined the medical records of women who refused surgical treatment for breast cancer. In one review of 5,339 women in the Geneva Cancer Registry diagnosed with nonmetastatic breast cancer between 1975 and 2000, only 70 (1.3%) women refused the recommended surgery (Verkooijen et al., 2005). Forty-seven percent of those patients opted to receive a different type of therapy, such as hormonal treatment. Surgery is, however, considered to be the mainstay of treatment for early-stage breast cancer. Even controlling for other prognostic factors, those who refused surgery had 2.1 times the chance of dying from breast cancer within 5 years of those on whom operations were performed. Similarly poor outcomes were recorded in a smaller, retrospective chart review study of women who chose to utilize a form of alternative medicine rather than undergo recommended surgery as treatment for their breast cancer (Chang, Glissmeyer, Tonnes, Hudson, & Johnson, 2006).

Treatment refusal is probably more common among people with more advanced cancer. Physicians are also far more likely to support that choice, or at least to voice understanding of it, when a patient appears to have a limited life span. Three recently published studies investigated patient and/or physician perceptions of patients' refusal of cancer treatment. In one study in the Netherlands, interviews were conducted with 30 patients who had refused either a curative or a noncurative treatment, and 16 physicians with experience in this area (Van Kleffens, van Baarsen, & van Leeuwen, 2004). As might be expected, noncurative treatments were more likely to be refused than curative ones. Interestingly, physicians believed that medical information about the disease, treatment, and prognosis was the critical factor in patients' decisions: patients reported that their own, or close other's, experience of cancer and treatment was the single most influential factor in their decision. Taking responsibility for their own bodies and feeling free to make a choice were also critical aspects for patients.

The refusal of treatment for non-small-cell lung cancer was investigated in a sample of nine patients identified through a U.S. Veteran's Administration (VA) hospital (Sharf, Stelljes, & Gordon, 2005). Analysis of the qualitative data suggested that four themes accounted for a large portion of these patients' decision making: self-efficacy, threat minimization, fatalism and faith, and distrust of the medical system. A lack of adequate information, desire to maximize quality of life, and a wish to avoid definitive unpleasant information were additional themes identified in this study. Contrary to the previously discussed study, a great deal of dissatisfaction and distrust with physician and the larger health care system were reported as reasons for avoiding or refusing recommended treatment.

Partial Adherence to Chemotherapy and Other Medical Interventions

The treatment context and demands differ greatly for chemotherapy administered intravenously in an oncology clinic and oral antineoplastic therapies that the patient is responsible for taking on a daily basis. The former is still more common and evokes a traditional image, popular in the medical literature, of a passive patient compliantly receiving treatment. In fact, relatively high rates of adherence have been demonstrated for this form of cancer treatment. This is particularly true for people being treated for early stage cancer. For example, a recent report of a four-arm treatment trial for Stage II and III colon cancer reported that 88.4% of randomized subjects received the treatment as it was specified by the trial (Haller et al., 2005). Importantly, no compliance differences were noted between treatment arms. Differential compliance for different treatments is an important issue, however. For example, Von Minckwitz et al (2006) reported on a trial for early-stage breast cancer. In it, 97.7% of subjects completed the three cycles of a combination chemotherapy, but only 75.4% of subjects completed the other proscribed regimen.

Investigations of adherence to chemotherapy for more advanced cancers have reported significantly higher nonadherence rates. For example, Feld et al. (Feld, Rubinstein, & Thomas, 1994; Feld, Rubinstein, Thomas, & the Lung Cancer

Study Group, 1993) reported on a trial of adjuvant chemotherapy for operable non-small-cell lung cancer. Only 80% of patients enrolled in the trial actually received their first treatment dose, 66% of patients received at least two of the four planned courses of treatment, and only 54% of patients completed all four courses. Another recently reported clinical trial was specifically designed to answer the question of whether the continuation of chemotherapy longer than 12 weeks for late-stage lung cancer resulted in better outcomes (i.e., longer survival, better quality of life) than 12 weeks of chemo followed by monitoring only until relapse (Socinski et al., 2002). There was no difference in survival or health-related quality of life for the two treatment arms, demonstrating that more treatment is not necessarily better in this particularly setting. However, this trial also spoke to the difficulty of adherence to a treatment protocol for patients with advanced cancer: approximately equal numbers of patients on each arm of the trial stopped receiving chemotherapy before 12 weeks. Only 42% of patients actually received more than four cycles of chemotherapy, even though this was the main difference between the two treatment arms. The reasons were varied and included serious treatment toxicity such that the physician deemed the treatment not in the patients' best interests, death, transition to hospice care, and patient choice not to continue the trial often because of worsening illness or significant treatment side effects.

Oral antineoplastic therapies are changing expectations among cancer patients, making them even more responsible for their own care and health than ever before. Nilsson et al. (2006) reported on the use of clinical pharmacy records to obtain the rates at which people with cancer refilled their prescriptions. The majority of these prescriptions were for hormonal antagonist treatments (86%), with the remainder for oral chemotherapies (8.5%) and hormones (5.5%). Of their sample of 141 cancer-related prescriptions, about 14% were filled less than 80% of the recommended times: the authors calculated that those 14% had a median treatment gap of 39 days. Fifty-six percent of prescriptions were filled appropriately, and 30% were actually filled more often than recommended. Contrary to the authors' expectations, these rates didn't differ significantly from refill adherence rates for all other (noncancer) medications.

There is also a growing literature on adherence to tamoxifen and the aromatase inhibitors, which are oral medications usually taken for a period of years to prevent the recurrence of breast cancer. As noted, taking tamoxifen for 5 years provides a significantly greater reduction in risk of recurrence and mortality than does taking it for 1 or 2 years (Early Breast Cancer Trialists' Collaborative Group, 2005). Despite these known benefits, several studies have reported suboptimal adherence rates over a 5 year period. Partridge, Wang, Winer, and Avorn (2003) examined adherence to tamoxifen among 2,378 women beginning tamoxifen for primary breast cancer. Although the percentage of prescriptions filled was relatively high during the first year (87%), the percentage filled decreased to less than 50% of the time by year 4. Another study investigated patterns of tamoxifen use among 516 women with estrogen-receptor-positive breast cancer (Fink, Gurwitz, Rakowski, Guadagnoli, & Silliman, 2004). They found that 17% stopped taking the medication by the second year and that the majority of those who stopped took it less than 1 year. Similarly, Lash, Fox, Westrup, Fink, and Silliman (2006) reported that 31% of their sample of older women diagnosed with stage I–IIIA breast cancer

(N = 462) stopped taking tamoxifen by year 5. A recent study examined tamoxifen use among a cohort of 881 women with stage I or II disease (Kahn, Schneider, Malin, Adams, & Epstein, 2007). Findings indicated that roughly 21% stopped taking tamoxifen by year 4, while 54% of those who stopped did so between the first and third years. Atkins and Fallowfield (2006) interviewed women taking tamoxifen or an aromatase inhibitor in an attempt to distinguish between "intentional" and "unintentional" nonadherence. Of 131 interviewees, 72 (55%) reported occasional nonadherence. Of these, 12 (16.7%) reported that they "chose not to take" their medication on occasion (intentional), while 60 (83.3%) "forgot" to take it (unintentional). These estimates of adherence to oral cancer medication from a number of different samples again suggest rates that are quite similar to those for other serious or chronic conditions. Similar conclusions were reached in a more detailed examination of adherence to oral cancer regimens by Partridge, Avorn, Wang, and Winer (2002).

Adherence to Behavioral Recommendations and Follow-Up

Rates of adherence to behavioral recommendations made during treatment have also been investigated. These recommendations are thought to improve the effectiveness of cancer treatment, decrease the likelihood of relapse, or inhibit the development of other serious health conditions that share common risk factors (Demark-Wahnefried, Peterson, McBride, Lipkus, & Clipp, 2000). Indeed, Denmark-Wahnefried et al. demonstrated strong interest in health promotion programs among a large sample of people who had been recently treated for early-stage breast or prostate cancer. In addition, there was significant variability in the subjects' report of their current level of engagement in healthy behaviors, from a low of 45% who were eating the recommended daily servings of fruit and vegetables to a high of 92% who reported that they did not smoke.

Much higher rates of smoking have been reported among head and neck and lung cancer patients, with estimates of continuing smoking after diagnosis ranging from 23%–35% for the former and from 13%–20% of the latter (Schnoll et al., 2004). In a study that examined rates of participation in a smoking cessation program offered specifically for these patients, 53% of 231 eligible patients declined to participate (Schnoll et al., 2005). Most stated that they intended to quit on their own and did not need additional help to do so. Further work is needed to determine the extent to which this is possible in the midst of intensive treatment.

Behavioral interventions that focus on physical activity and nutrition are far more popular and effective among cancer patients and survivors and are typically well supported by physicians (Brown et al., 2003). Exercise can positively affect psychological, physical, and biological outcomes (Vallance, Courneya, Jones, & Reiman, 2006) that are related to cancer. As with similar programs in healthy populations, adherence to an exercise regimen is moderately difficult for people with cancer. In Mock et al.'s (2005) trial of home-based walking exercise for women with Stage 0–III breast cancer, only 72% of the women were adherent to the prescribed exercise program.

As with other types of treatment-related behaviors, adherence to follow-up visits varies widely. From 77% to 93% of testicular cancer patients kept all of their scheduled follow-up appointments. The actual percentage varied

depending upon the type of previous treatment received (Young, Bultz, Russell, & Trew, 1991). Using a different type of follow-up measure, 84% of colon cancer patients who had been treated with surgery adhered to a fairly intensive follow-up procedure, including three hemoccult tests, a clinical examination, and sigmoidoscopy every 3 months (Crowson, Jewkes, Acheson, & Fielding, 1991). Only 22% of breast cancer patients studied by Tomlin and Donegan (1987) completed all recommended follow-up visits for 5 years or more. However, 100% of a medically indigent population with breast cancer completed 5 years of follow-up after treatment (Smith et al., 1995). Finally, 80% of patients diagnosed with colon cancer returned for at least one follow-up colonoscopy after treatment, although this percentage later dropped, then rose steadily over the 7-year period of the investigation (Eckardt, Fuchs, Kanzler, Remmele, & Stienen, 1988).

In summary, rates of adherence to IV chemotherapy, oral chemotherapy and supportive medications, treatment appointments, behavioral changes, and follow-up visits vary widely. In some cases, such as treatment for early-stage cancer, nonadherence rates are quite low. However, for most others important behaviors, nonadherence rates seem to be comparable to those found in the general medical population. This challenges the widely held notion that people will always be adherent to treatment for life-threatening illness. It also affirms the necessity of investigating sources of nonadherence and potential interventions to improve adherence.

Predictors of Adherence

The primary explanation that is consistently advanced for nonadherence to cancer treatments has been their toxic side effects. Although side effect profiles vary widely, many of these medications produce unpleasant reactions such nausea, vomiting, pain, anemia, diarrhea, alopecia, anorexia, cachexia, loss of taste, and fatigue. In an early investigation, toxicity was cited as the major reason for breast cancer patients' not receiving at least 85% of their planned treatment (Lee, 1983). Similarly, the recent studies of endocrine therapy discussed earlier highlight that side effects that impair quality of life (e.g., hot flashes, night sweats) were the primary reason for temporary or permanent treatment discontinuation (Atkins & Fallowfield, 2006; Grunfeld, Hunter, Sikka, & Mittal, 2005; Lash et al., 2006). Several other cancer treatment variables have been associated with adherence. Treatment length was related to poorer adherence, with fewer patients continuing with longer treatments (e.g., Early Breast Cancer Trialists Group, 2005). The anticipation of longer treatment may be enough, in some cases, to decrease adherence. Rivkin et al. (1993) found that patients assigned to a 2 year treatment were less likely to complete even 6 months of treatment than were those assigned to a 1 year treatment arm. The patient's lack of symptoms, the length and type of treatment, and the complexity of the regimen are additional treatment-related variables known to decrease cancer-related adherence (Dunbar-Jacob & Mortimer-Stephens, 2001; McDonald, Amit, & Haynes, 2002).

The relationship of demographic variables to adherence has also been explored. Younger age has been related to lower likelihood of treatment refusal

after a new cancer diagnosis (Huchcroft & Snodgrass, 1993), greater likelihood of smoking cessation after treatment for head and neck cancer (Gritz et al., 1993), greater tendency to practice breast self-examinations after breast cancer (Taylor et al., 1984) and better appointment attendance (Berger, Braverman, Sohn, & Morrow, 1988). However, younger women may be less likely to adhere to adjuvant endocrine treatment (Atkins & Fallowfield, 2006). Others have found that age does not affect the likelihood of refusing treatment (Moul, Paulson, & Walther, 1990) or completing treatment (Berger et al., 1988; Jehn, 1994). Older patients still tend to receive lower doses of chemotherapy, probably due to fears about tolerance of toxicity or interactions with other medical conditions. However, these concerns are generally thought to be unfounded, as tolerability of chemotherapy seems to be unrelated to age (Cress, O'Malley, Leiserowitz, & Campleman, 2003; Sargent et al., 2001).

Patients' beliefs about their disease and their treatment regimen also appear to play a role in cancer-related adherence. Several recent studies have demonstrated that adherence can be partially predicted by beliefs about the necessity of the medication and influenced also by beliefs about the short- and long-term costs of taking it. Horne & Weinman (1999) assessed subjects with one of four chronic conditions: asthma, renal disease, cardiac conditions, or cancer. Nineteen percent of the variance in patients' self-reported adherence with prescribed medication was predicted by the balance between beliefs about the necessity of taking the medication to control the illness and concerns about the potential negatives about doing so. Patients reported being concerned about potential long-term adverse events and the potential for dependence on their medication. Negative beliefs about the efficacy of tamoxifen (e.g., nothing would be gained by taking it) and increases in negative beliefs over time predicted lower adherence (Grunfeld et al., 2005; Lash et al., 2006). Similarly, adherence to analgesic regimens is influenced by negative beliefs about the potential for addiction to narcotics (Kirsch, Whitcomb, Donaghy, & Passik, 2002) and the likelihood that medication will provide better relief than other pain control methods (Lai et al., 2002). Another cognitive variable, self-efficacy, was associated with a greater chance of quitting smoking (Schnoll et al., 2002) and of regularly attending hospital appointments (Lev, 1997). Adherence to exercise promotion interventions is also predicted by participants' stage of change and level of perceived control (Courneya et al., 2004).

Interventions to Improve Adherence Among Cancer Patients

Although the past 10 years have brought an increase in knowledge about factors associated with greater adherence to cancer treatment, this knowledge has yet to be translated into testable interventions. In a recent chapter, we presented a case-based description of an adherence-promoting intervention on patient, provider, and health care system variables (Victorson, Peterman, & Cella, 2006). This focus on individually tailored changes exemplifies an approach that could be generalized to all patients where appropriate adherence is a concern. In fact, a recent review of interventions to increase adherence to medication regimens across diseases emphasized the complexity of the successful interventions (McDonald et al., 2002). The authors noted the difficulty of disentangling the

necessary from the "nice" components when interventions include multiple appointment reminders, pill counters, and problem solving with trained personnel about barriers to taking medication as prescribed, among others. Although cancer was not one of the diseases for which a randomized intervention trial was described, it is reasonable to assume that these results from other chronic illnesses are generalizable.

Patient navigation is a comprehensive type of intervention that attempts to increase adherence by reducing or removing barriers to quality cancer care (Dohan & Schrag, 2005). Flexibility is a key feature, as the type of provided service differs depending on the barriers identified. Dohan and Schrag's overview of patient navigation programs described a variety of services that are provided in existing programs: improving access to care, including clinical trials, through education and outreach to underserved communities; providing translation services by bilingual, bicultural navigators to minimize communication problems between patients and providers; remedying logistical barriers such as lack of child care during appointments, limited transportation, lack of or insufficient insurance; and addressing systemic barriers such as historical mistrust of health care institutions or the existence of complex, fragmented medical services. The National Cancer Institute recently funded a number of research projects to rigorously examine the impact of patient navigation services in cancer care. To date, reports indicate that the programs are well received and that they increase patient satisfaction (e.g., Steinberg et al., 2006). Data on "harder" outcomes, such as percentage of treatment received or morbidity and mortality rates, are not yet available.

Conclusions and Suggestions for Future Research

Over the past several years, there has been incredible progress in the field of cancer treatment. Improved screening techniques and expanded access to them has allowed the diagnosis of many cancers while still in early, more curable stages. Novel therapies have improved effectiveness while reducing toxic side effects. There is real hope that many cancers can become true "chronic illnesses," rather than imminently life-threatening ones.

The true promise of such scientific discoveries can be enhanced significantly by provider and patient behaviors that support adherence. Clinicians and researchers can look for inspiration in the literature on adherence promotion in other serious illnesses, as well as to the basic cancer research demonstrating the impact of personality, treatment regimen, and patients' beliefs. Thoughtfully designed research will evaluate the utility of patient navigation interventions for improved patient outcomes. If successful, we can begin to untangle the critical components for enhancing adherence and maximizing quality of life and survival.

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Adherence and HIV: A Lifetime Commitment

33

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Since the isolation and identification of HIV in 1983, the number of people living with HIV/AIDS (PLWHA) continues to increase. Fortunately, advances in medical treatments have changed the outcomes for PLWHA for the better. Dramatic improvements in HIV treatment came in 1996 when protease inhibitors (PI) and non-nucleoside reverse transcriptase inhibitors (NNRTI) became widely available and were used as part of highly active antiretroviral therapy (HAART) to suppress HIV viral replication and improve immune function.

The profound impact of HAART was illustrated in the late summer of 1998, when the *Bay Area Reporter* published its now-famous headline "No Obits," commemorating the first time since the beginning of the epidemic that the newspaper received no death notices for a week. These initial reports of the decline in mortality coinciding with the use of HAART were striking. In one

large cohort, the mortality rate fell from 29.4 deaths/100 person years in 1995 to 8.8 deaths/100 person years by mid-1997 (Palella et al., 1998). Since that time, the number of inpatient hospital beds dedicated to patients with HIV/AIDS in the United States has declined, and PLWHA are leading more productive lives for longer periods of time (Crum et al., 2006; Hergenrather, Rhodes, & Clark, 2004, 2006; Schackman et al., 2006).

However, despite advances in treatment, maintaining patient adherence to HIV medications (defined as the extent to which a therapeutic regimen is correctly taken) is challenging, in part because of the complexity of the treatment regimes and side effects. Other challenges to adherence for PLWHA include the need to take other medications, such as opportunistic infection (OI) prophylaxis.

This chapter explores adherence to HIV medications by examining what is currently known about adherence and HIV disease progression; exploring the facilitators of and barriers to adherence among various subgroups of PLWHA, including men who have sex with men (MSM), adolescents, homeless populations, pregnant women, those with comorbidities such as mental illness and substance use and abuse histories, and populations in developing countries; defining and measuring adherence; reviewing the state of interventions developed to improve adherence; and proposing future directions and research needs.

Adherence and Disease Progression and Outcomes

Strict adherence to HAART has been shown to suppress HIV viral loads, increase CD4+ lymphocyte counts and immune system function, improve clinical health, and decrease AIDS-related mortality. However, to maximize its benefit, HAART requires unusually high levels of adherence when compared to other regimens (Paterson et al., 2000). PLWHA taking protease inhibitor-based regimens must adhere to their schedule 95% of the time to achieve an 80% likelihood of having a viral load below the limit of detection. Put another way, they can miss no more than three doses a month of a twice-a-day regimen (Paterson et al., 2000).

With less than 95% adherence, the probability of viral suppression falls dramatically (Paterson et al., 2000; Altice, Mostashari, & Friedland, 2001). Adherence rates between 50% and 80% may promote drug resistance due to ongoing viral replication in the presence of suboptimal drug levels. If adherence falls below 50%, HAART drug levels tend to be too low to affect viral replication.

Suboptimal adherence to prescribed medication is not unique to HAART. Adherence rates ranging from 36% to 70% among various populations of PLWHA have been reported (Arnsten et al., 2002; Heckman, Catz, Heckman, Miller, & Kalichman, 2004). One study of 3,788 young men and women on HAART reported a mean annual adherence rate of 36%, and only 26% of individuals had adherence of 80% or better (Becker, Dezii, Burtcel, Kawabata, & Hodder, 2002).

The success of HAART relies on adherence to potentially complicated medical regimens for extremely long periods of time. Given recent findings that stopping or interrupting HAART can be harmful (El-Sadr et al., 2006), the commitment to staying on HIV medications after starting is likely a lifetime one. Interruptions in medication adherence permit HIV to resume its typical rapid replication of as many as 10^{10} viral particles produced per day (Perelson et al., 1997)

and promote the development of drug-resistant variants of HIV, with potential cross-resistance across entire classes of medications (Hecht et al., 1998). This scenario limits future treatment options for the individual and poses a potential public health risk through the transmission of these strains to others (Friedland & Williams, 1999; McNabb et al., 2001).

Adherence to HAART

Factors associated favorably or adversely with medication adherence in PLWHA can be organized into six domains, as presented in Figure 33.1. Although many of these may provide insight into populations that may benefit from tailored interventions or into potentially modifiable factors for an individual, they are not completely predictive of response to HAART.

Demographic factors associated with decreased adherence in different settings include younger age, African American race, low level of educational attainment, homelessness or unstable housing, and decreased income (Altice et al., 2001; Golin et al., 2002; Kleeberger et al. 2001).

Cognitive and psychological factors that have been found to be associated with decreased HIV medication adherence include having relatively little knowledge about how to take prescribed medications and about the importance of adherence and doubting the efficacy of the medications (Altice et al., 2001; Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000). Compromised cognitive functioning, forgetfulness, and depression are other key factors that adversely affect adherence (Ammassari et al., 2004; Chesney et al., 2000; Golin et al., 2002). An interesting construct that has been identified as a barrier is "seeing positive results" from treatment that in turn leads to the feeling that one no longer needs medication (Adam, Maticka-Tyndale, & Cohen, 2003).

Behavioral factors that have been found to predict decreased adherence include alcohol and substance use and abuse (Ammassari et al., 2004; Hinkin

33.1

Domains affecting adherence to HAART and viral load among persons living with HIV/AIDS.
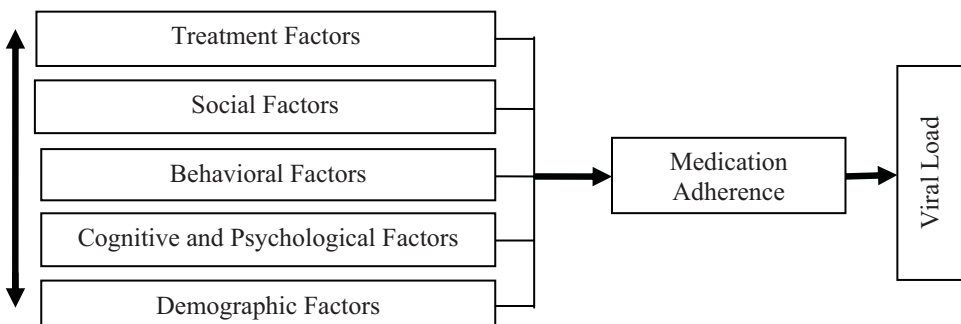
et al., 2007). The use of adherence aids such as pill boxes and timers has been associated with improved adherence to HAART (Andrade et al., 2005; Fogarty et al., 2002).

Provider characteristics have long been associated with health behaviors (Rhodes & Benfield, 2006) and clearly affect adherence to HAART. Reduced adherence among PLWHA is associated with lack of trust in the provider in terms of their skill and their real or perceived abilities to be nonjudgmental and maintain confidentiality (Beach, Keruly, & Moore, 2006; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004).

Social factors also have an influence on adherence. PLWHA who report having less social support and being more socially isolated have lower adherence than those who have increased social support and report not being socially isolated (Catz et al., 2000). Some PLWHA may perceive that taking medications may serve to reveal their serostatus to others, such as coworkers (Meystre-Agustoni, Dubois-Arber, Cochand, & Telenti, 2000).

Finally, the type of treatment regimen is associated with adherence. Complexity and timing of dosing, side effects, food requirements, and how well adherence fits within one's lifestyle can influence adherence rates (Catz et al., 2000; Nieuwkerk, Gisolf, Sprangers, & Danner, 2001). The presence of side effects from medications can be challenging, especially when the benefits of treatment such as delaying disease progression may not have an immediately tangible result.

HAART Adherence Among Subgroups

Certain subgroups of PLWHA have even further challenges to HAART adherence. Economic and social strain and developmental processes experienced by some vulnerable and marginalized populations likely exacerbate adherence issues, since even among affluent and educated populations adherence rates as low as 67% are reported (Deloria-Knoll et al., 2004). Perceptions and beliefs related to efficacy of HAART, the stigma associated with an HIV/AIDS diagnosis, and attitudes toward illness vary by subgroup and can profoundly affect adherence (Parker & Aggleton, 2003).

Men Who Have Sex With Men

Men who have sex with men (MSM) make up a large percentage of the individuals living with HIV/AIDS in the United States and in Europe. Some MSM may not adhere to their treatment regimen because of internalized homophobia, which may lead them to deny their own same-sex behavior. Their infection may present a conflict, since to acknowledge their HIV-positive serostatus may imply that they must acknowledge this behavior. Internalized homophobia also may affect relationships with providers (Klitzman & Greenberg, 2002; Rhodes & Hergenrather, 2002). By not sharing the challenges they face with their providers or other supportive individuals, some MSM may impair their own ability to explore solutions to these challenges. Other complications may include feelings of guilt regarding their HIV-positive status (Madru, 2003).

Just as racism has been identified as a cause for compromised heath outcomes among racial and ethnic minorities (Institute of Medicine, 2003), homophobia

and heterosexism also exist within a broad historical and contemporary context (Rhodes, McCoy, Hergenrather, Omli, & DuRant, 2007; Rhodes & Yee, 2006). MSM may have reduced access to high-quality health services, care, and programs that meet their particular needs (Willging, Salvador, & Kano, 2006). Many providers are uncomfortable discussing HIV or the sexual health of MSM in general, which in turn may discourage disclosures necessary for appropriate care and services (Rhodes & Hergenrather, 2002; Rhodes & Yee, 2006). For example, the provider may fail to engage a same-sex partner in efforts to increase adherence, despite evidence that partner support is beneficial (Power et al., 2003).

To increase HAART adherence among MSM living with HIV/AIDS, providers must: maintain nonhomophobic assumptions and attitudes; distinguish sexual behavior from identity; communicate clearly and sensitively; use gender-neutral terms; and, perhaps most important, recognize how personal provider attitudes affect clinical judgments (Rhodes & Hergenrather, 2002; Rhodes, Yee, & Hergenrather, 2006; Rhodes et al., 2007).

Most of what is currently known about the challenges faced by MSM living with HIV/AIDS came from the early epicenters of the U.S. epidemic, which are large urban areas with long histories of service provision, including treatment, care, and prevention (McKinney, 2002). These epicenters do not fully reflect the unique characteristics of the current epidemic (Rhodes et al., 2007). Those living outside large urban areas are more likely to have providers with less experience dealing with HIV and less opportunity to participate in clinical trials for AIDS treatments (Ellerbrock et al., 2004; Rhodes, Hergenrather, Wilkin, Alegria-Ortega, & Montaño, 2006).

Adolescents

While adhering to HAART is challenging enough for adults, adolescents living with HIV/AIDS face some unique challenges that may make adherence even more difficult. The reasons for these challenges are numerous and overlap to some degree with those already identified. Developmentally, adolescents often feel invincible or immortal. They are prone to live in the moment and may not realize the long-term consequences of their actions (DeWit, Offord, & Wong, 1997). While this way of thinking is beneficial as adolescents try new roles and activities and take healthy risks, adolescents living with HIV/AIDS may not have immediate incentives for maintaining adherence to HAART. Taking the medications often does not make them feel better and can, in fact, make them feel worse. Moreover, they may not feel any worse if they inconsistently take or stop taking their medications, and this lack of immediate negative consequences can reinforce feelings of invincibility. Helping adolescents focus on the long-term health consequences of their adherence choices is a significant but necessary challenge in promoting HAART adherence (Koenig & Bachanas, 2006; Parsons et al., 2006).

Peer acceptance and support during adolescence are important developmentally (Resnick, Harris, & Blum, 1993). Adolescents living with HIV fear rejection, abandonment, and stigma and may not tell their family, friends, and sexual partners of their HIV status. Many adolescents avoid treatment and care, fearing that seeking care will reveal their HIV status (Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007; Steele, Nelson, & Cole, 2007). Their fears are not without reason, as some adolescents with HIV are alienated from their fami-

lies as a result of their HIV status or sexual orientation. Thus, their housing situation is often unstable, increasing the difficulty of making and keeping appointments, refilling prescriptions before they run out, and adhering to HAART. Furthermore, follow-up efforts by clinics (e.g., reminder calls, letters) are problematic when contact information changes or when adolescents have not told family members of their HIV status. Adolescents trying to conceal their HIV status find it difficult to keep medications handy and thus may not remember to take them regularly (Koenig & Bachanas, 2006; Rao et al., 2007).

Psychosocial, mental health, and substance-use problems, common among adolescents with HIV, also make adherence challenging for adolescents. Comparing demographically and socially similar adolescents with and without HIV infection, researchers found that adolescents living with HIV were significantly more likely to have been sexually abused, to have engaged in unprotected sex with causal partners, to have had sex under the influence of drugs, to have engaged in sex for money, to have had another sexually transmitted disease, to have used several types of illicit drugs, to have been incarcerated, to have dropped out of school, to have a history of psychiatric hospitalization, and to not be living at home (Steele et al., 2007). Thus, adherence to HAART is seriously challenged.

Over a quarter of a century into the pandemic, a subgroup of adolescents who are living with HIV/AIDS is emerging: adolescents who were infected through vertical transmission as infants 10–20 years ago. These adolescents may have similar challenges to those infected, but further research is needed to understand their unique adherence needs.

There are few efficacious interventions designed to increase adherence among adolescents living with HIV/AIDS. Promising findings, however, suggest that peer group-level interventions focused on the dynamics of HIV may improve adherence, as may having an understanding of the reasons for adhering to therapies and effective management of side effects, and improved communication with providers (Koenig & Bachanas, 2006).

Homeless Populations

Ensuring proper treatment of HIV/AIDS and adhering to HAART can be extremely difficult for PLWHA without stable housing. Meeting food and shelter priorities often leaves little time for medical appointments. The lack of privacy, risk of physical or verbal abuse, theft of medications, and lack of a secure place to store medications or to lie down during the day compound the discomforts associated with HIV and HAART. Ideally, homeless PLWHA need a stable residence and routine to properly adhere to HAART. Although some transitional housing for HIV-infected individuals exists in larger metropolitan areas, in many communities such individuals face a lack of available housing, long waiting lists, and policies that exclude active substance users or former inmates. Most housing, rehabilitation, or transitional programs available to homeless persons with HIV infection require sobriety for admission or continued residence. Thus, such supports become attainable only when homeless individuals with co-occurring addiction disorders become extremely ill, and typically when HIV disease is advanced (Smith, DeWeaver, & Reece, 2006; Tommasello, Gillis, Lawler, & Bujak, 2006).

Homeless populations also are at risk for discontinuity of care. They often have limited access to health care services, and their utilization of these services

may be infrequent (i.e., only when they require urgent care). Homeless persons tend to have increased rates of arrest and incarceration due to loitering, sleeping, or drinking in public places. These periods of detention or incarceration can interrupt their health care.

A variety of steps can be taken to increase adherence to HAART among homeless PLWHA. For example, written instructions that include simple graphics (for those with low literacy) and color coding have been associated with increased HAART adherence among homeless PLWHA (Conanan et al., 2003). Furthermore, providers who rehearse with homeless PLWHA which drugs to take and when to take them have been successful in increasing adherence (Conanan et al., 2003). Consumer advocates, specifically formerly homeless persons, have increased adherence by navigating the treatment process and overcoming the communication barriers that homeless people sometimes experience in their encounters with health care providers. These advocates know the reality of "living on the street" and may have creative solutions that providers and other caregivers cannot imagine, given their very different frames of reference.

Adherence among homeless populations also has been improved through the implementation of directly observed therapy (DOT; Mitty, Macalino, Taylor, Harwell, & Flanigan, 2003). DOT requires homeless PLWHA to come to a clinic or other location to take their medications. This may be burdensome for clinic staff; however, adherence for indigent PLWHA who use DOT is higher than among those who do not (Santos, Adeyemi, & Tenorio, 2006; Wohl et al., 2004).

Pregnant Women

Worldwide, the number of women infected with HIV/AIDS has grown exponentially, and most women living with HIV are of reproductive age. Without treatment, 15% to 30% of babies born to HIV-positive mothers will be HIV infected (Centers for Disease Control and Prevention, 1994); however, preventive treatment of women during pregnancy combined with short-term treatment of newborns with AZT can significantly decrease perinatal HIV transmission (Centers for Disease Control and Prevention, 1994; Connor et al., 1994). With the progress in HAART and other management strategies, the rate of perinatal transmission of HIV has plummeted in the United States to less than 2% (Centers for Disease Control and Prevention, 2006). Unfortunately, even among those with access to care and treatment, not all pregnant PLWHA adhere to the recommended regimens. Poor treatment of women and racial minorities in the health care system, clients' lack of trust in health care providers, and a lack of accurate information about the treatment and prevention of HIV are barriers to adherence among pregnant women (Sowell, Phillips, Seals, Misener, & Rush, 2001). Furthermore, increased adherence among pregnant women has been associated with women's perception of how strongly their health care providers believe in AZT; social support from family, friends, and peers; and accurate knowledge about HIV, pregnancy, and AZT (Desai & Mathur, 2003; Siegel, Lekas, Schrimshaw, & Johnson, 2001; Sowell, Murdaugh, Addy, Moneyham, & Tavokoli, 2002). Providers' attitudes about pregnancy in women living with HIV/AIDS may greatly impact treatment uptake and clients' adherence to prevent vertical transmission. For example, some providers' attitudes may preclude women who get pregnant or want to get pregnant from having the information they need to make informed decisions and to improve pregnancy outcomes (Sowell et al., 2001).

Finally, despite the fact that AZT is safe for fetuses (Perinatal HIV Guidelines Working Group, 2002; Siu, Yeung, Pang, Chiu, & Lau, 2005), some pregnant PLWHA choose not to adhere to AZT to reduce vertical transmission because they fear that the medication will have unintended and harmful effects on their unborn children (Siegel & Gorey, 1997; Siegel et al., 2001; Sowell et al., 2001).

PLWHA and Comorbidities: Substance Use and Mental Health

It is estimated that nearly 50% of PLWHA receiving care for HIV in the United States have or have had a comorbidity of substance abuse or mental illness within the past 12 months—five to seven times higher than in the general U.S. population (Bing et al., 2001). Substance use negatively impacts adherence to HAART by impairing cognition, judgment, and short-term memory. Factors associated with decreased adherence among PLWHA who use illicit drugs include worries about the possible side effects of illicit drug use in conjunction with HAART. In one study, for example, PLWHA who were using cocaine or heroin and were eligible to take HAART believed that taking HAART while actively using cocaine would harm their bodies; thus, they had very low rates of adherence (Sharpe, Lee, Nakashima, Elam-Evans, & Fleming, 2004).

Nonadherence to HAART has been associated with depression and psychological stress (Elliott, Russo, & Roy-Byrne, 2002; Markowitz et al., 1998; Singh et al., 1996). PLWHA diagnosed with depression are likely to exhibit a general pessimism about the future and have poorer adherence to treatment regimens than do nondepressed PLWHA.

PLWHA with comorbidity of substance abuse and mental illness are likely to face greater morbidity and decreased quality of life and to participate in unsafe sexual and needle-sharing behaviors, leading to HIV transmission and further re-infection. Enabling HIV-infected substance abusers to reduce or end their substance use through treatment programs may produce the best results for medication adherence to HAART (Avants, Warburton, Hawkins, & Margolin, 2000; Boyer & Indyk, 2006; Chander, Himelhoch, & Moore, 2006; Colfax & Guzman, 2006; Kelly et al., 1993; Shapiro et al., 1999; Sherbourne et al., 2000; Willenbring, 2005). PLWHA who are in substance abuse treatment programs are significantly more likely to adhere to HAART (Battaglioli-Denero, 2007).

Interventions designed to increase adherence among PLWHA with a comorbidity of substance abuse and mental illness may include the application of cognitive-behavioral therapy and structured interviewing. These approaches may focus on changing deficiencies in clients' knowledge of HIV diagnosis and of the importance of adhering to the medical protocol and the ramifications of nonadherence; increasing prescribed medication self-efficacy; promoting the management of side effects; using social supports; decreasing perceptions that HAART regimens are too complex; and improving attitudes toward medication and diagnosis. However, these strategies require that public and private options be available for the treatment of mental illness and substance abuse.

Populations in Developing Countries

For PLWHA in developing countries, the fundamental barriers to adherence include limited access to counseling and testing services to determine serostatus

and limited access to HAART. Only 10% of people who need HIV testing in low- and middle-income countries have access to counseling and testing services; thus, most are unaware of their serostatus (Furber, Hodgson, Desclaux, & Mukasa, 2004). Furthermore, the predominant approach to health care and the provision of health care services in developing countries is modeled on acute care—but, for HIV treatment, a chronic disease model is more appropriate. Such a model encompasses regular and ongoing follow-up, data management, and the use of communication tools that are efficient and that protect confidentiality. Access and adherence to HAART are also limited by cost—for PLWHA living in developing countries, paying even modest prices for drugs can be impossible. Criteria for access to subsidized HAART differ profoundly around the world and can be based on social characteristics, level of income, profession, and number of dependents (Desclaux, 2003).

Despite more than 25 years of awareness of HIV/AIDS, the stigmatization of PLWHA and those related to, caring for, and otherwise connected to PLWHA and HIV/AIDS prevention remains strong. Access to antiretroviral drugs may reduce stigma because, as HIV/AIDS is perceived as a chronic but manageable condition, one of the factors that amplify stigma—fear of contagion and inevitable death—is lessened (Hawkins, 2006). However, stigma is also a tool used by cultures to exclude those felt to have broken its rules, and the dominant stereotype of people living with HIV casts them as immoral (Stanley, 1999).

Taking HAART also may be stigmatizing. PLWHA often hide their medicines because relatives and other community members might reject them if they were aware of the PLWHA's medical status (Furber et al., 2004).

Thus, PLWHA in developing countries face fundamental barriers to adherence. First, they must have access to resources for counseling and testing to learn their serostatus. Second, infrastructures must exist to deliver HAART. Currently, more than 95% of PLWHA live in developing countries, and very few within this population have access to HAART. Finally, PLWHA in developing countries face similar but often greater challenges to pay for HAART and have worries about confidentiality and stigma.

Summary

This review of the identified facilitators of and barriers to adherence, while not exhaustive, offers an overview and highlights important considerations in adherence to HAART among populations for whom adherence may pose extraordinary challenges. Of course, these challenges may overlap or be shared by other populations. For example, stigma associated with HIV exists within most populations and is not unique to the challenges of living with HIV within developing countries.

Defining and Measuring Adherence

Valid measures of adherence are key to identifying PLWHA who are not adhering to regimens and to developing and evaluating meaningful interventions designed to increase adherence. However, operationalizing adherence through measurement is problematic. Common methods for measuring adherence to

HAART include drug concentrations in blood and urine, direct observation, pill count, physician ratings, and self-report. Monitoring of pharmacy refills of antiretroviral medications may also be a useful tool for assessing adherence (Gross et al., 2006). Use of medication-event monitoring system (MEMS) caps on drug bottles is the current state-of-the-art method for measuring adherence. MEMS caps have computer chips embedded in them that record the date and time whenever the cap of a medication bottle is opened; however, they are expensive and thus their use is limited (Bova et al., 2005).

Self-report measures are most commonly used because of their relatively low cost, ease of administration, minimal participant burden, flexibility in administration and timing, and potential to yield specific information regarding dosing behavior, such as timing with food (Simoni, Pearson, Pantalone, Marks, & Crepaz, 2006). On the other hand, self-report remains a coarse measure of adherence and is subject to threats such as recall bias and social desirability effects. Self-report of adherence to HAART tends to overestimate adherence and generally does not distinguish individuals by levels of adherence.

Another consideration is that adherence requirements may differ by potency. More potent and more recently developed medications, including nonnucleoside reverse transcriptase therapy (NNRTI) and ritonavir-boosted protease inhibitor therapy, seem to be capable of reliably suppressing viral load in patients at more moderate levels of adherence (King, Brun, & Kempf, 2005; Maggiolo et al., 2005). Moreover, the ability of medication-resistant virus to replicate differs by medication. For example, for single protease inhibitors, drug resistance may occur at adherence levels ranging from 80% to 95%, while for NNRTI, drug resistance may not occur even at adherence levels as low as 2% (Bangsberg et al., 2006). Thus, patterns of adherence may be more critical than overall adherence. Discontinuation of HAART for more than 48 hours is an independent risk factor for NNRTI resistance, even controlling for average adherence over time (Bangsberg et al., 2006; Spacek et al., 2006). As a result, rapid changes in HAART lead to changes in adherence goals. Thus, adherence measurement must include and identify specific levels and specific patterns of adherence that put the health of PLWHA at risk and particular regimens at risk for resistance.

Interventions Designed to Improve Adherence

Studies and intervention strategies have approached improving adherence to HAART from multiple frameworks. These frameworks reflect the array of complex factors that affect adherence, as presented in Figure 33.1. Unfortunately, a lack of consistent predictors of adherence remains (Hill, Kendall, & Fernandez, 2003), and many different measures that may not be directly comparable have been used in adherence studies. Studies differ in design, sample composition, types of adherence measurements, and outcome measures. A quantitative meta-analysis of 19 randomized controlled trials of various adherence interventions using the outcome measures of 95% adherence to HAART or undetectable HIV viral load found that intervention participants were more likely (odds ratio = 1.5; 95% confidence interval: 1.16–1.94) to achieve 95% adherence than those randomized to control groups. Viral load also was positively affected by adherence interventions, although the results were not statistically significant

(Simoni et al., 2006). Interventions studied included counseling (one-on-one or group) provided by health care providers such as physicians, nurses, or mental health counselors. More than half the studies used study staff to deliver interventions, and both the length of time per counseling visit and the number of visits varied considerably. Overall, 62% of those in the intervention groups and 50% of those in the control groups achieved optimal adherence. Although some interventions targeted PLWHA who were at high risk for nonadherence, many were provided to all persons on HAART, conceivably diluting the ability to detect differences in groups (Gordon, 2006). In a similar meta-analysis that included randomized and nonrandomized studies, interventions that targeted PLWHA with known poor adherence had stronger effects than those that had broader enrollment (Amico, Harman, & Johnson, 2006).

A recent trial examined the use of a cognitive behavioral adherence intervention for PLWHA starting or changing HAART regimens. Participants in the intervention groups received five sessions of cognitive behavioral and motivational components (with or without a 2 week trial of placebo medications), while those in the comparison group received usual care (Wagner et al., 2006). Adherence rates in all groups were high with modest treatment effects at week 24 (mean percentage of pills taken 89% in the intervention group and 81% in the control group). Unfortunately, these treatment effects were extinguished by week 48. There were no differences between groups in virologic control. The researchers speculated that a new approach in adherence interventions tailored to the needs of individuals may be necessary.

Another potential strategy for improving adherence among PLWHA is to use a case-management approach. Case management is a client-centered approach that coordinates the provisions of service. It includes intensive, ongoing, individualized counseling, support, and service brokerage by a trained case-management professional. Areas addressed include the relationship between HIV risk (both treatment nonadherence and re-infection) and issues such as substance abuse, treatment for STDs, mental health, and social and cultural factors. A recent study (Kushel et al., 2006), using a nonrandomized prospective observational cohort, reported an association between receiving case management and self-reported adherence in homeless and marginally housed PLWHA. Groups that accessed case management at higher rates had larger increases in CD4+ lymphocyte counts than the groups that did not receive case management. However, no relationship was found between case management and viral load suppression. Case management may be a promising approach for increasing adherence to HAART among PLWHA.

The use of directly administered antiretroviral therapy (DAART) has engendered interest as a strategy to improve adherence. A setting that may be particularly suited for DAART is a structured environment where clients make regular contact with the health care system, such as a methadone clinic. In a recent report, DAART was examined among 82 PLWHA on methadone treatment for injecting-drug use. Clients received a dose of HAART on each morning they received methadone and took prepackaged doses with them for "off" days or evening use. At 1 year, 56% of DAART participants had an undetectable viral load, whereas only 32% in the methadone and non-DAART arms ($p = .009$) and 33% in the no-methadone arm ($p = .001$; Lucas et al., 2006) had such results. A randomized trial that compared (1) daily delivery of prepackaged medications with

extra doses for nondelivery times, (2) intensive adherence case management (weekly individual sessions for 6 months to overcome adherence barriers and self-administered HAART), and (3) standard of care (including quarterly case management visits) found no statistically significant differences in viral suppression or self-reported adherence at 6-month follow-up (Wohl et al., 2006).

Other potentially useful strategies to improve adherence are medication reminder devices such as beepers, pill boxes, and telephone calls. Supportive telephone calls to improve adherence rates in participants were tested in one study; although the intervention did not improve virologic outcomes, an increase in self-reported adherence was found (Collier et al., 2005). The use of a population already enrolled in a clinical trial may have blunted the intervention's potential effectiveness, since participants in clinical trials may be more likely to be adherent than others. Medication reminder devices need to be tailored to individuals and may be most helpful in people with memory impairment (Andrade et al., 2005).

Machtinger and Bangsberg (2007) have proposed a seven-step framework to support adherence, which includes (1) developing patient-centered relationships, (2) using motivational interviewing techniques, (3) addressing the known impediments to adherence, (4) screening regularly for poor adherence, (5) utilizing adherence aids, (6) expanding pharmacy services or directly observed therapy, and (7) creating an adherence program to formalize attention to this issue. Because it is clear that a single approach will not suit each PLWHA, strategies to match adherence interventions to the populations or individuals most likely to benefit from them are needed.

Conclusions and Future Directions

Maintaining health while living with HIV includes adhering to pharmacological treatment regimens, clinical and treatment appointments, and recommendations for safer sex and safer drug use practices. In this chapter, we focused on adherence to pharmacological treatment regimens, specifically HAART. Further research is needed to understand adherence among PLWHA, including adherence to pharmacological treatment regimens, clinical and treatment appointments, and recommendations for safer sex and safer drug use behaviors. Future research also must address a variety of important issues facing adherence, including (1) how to help patients decide when to initiate therapy (e.g., identifying when the patient is psychologically ready to commit to strictly adhering to a potentially lifelong regimen); (2) the rapidly advancing treatment options available to PLWHA and their providers; (3) the evolving technology that can be harnessed via monitoring devices or reminders; (4) the potential benefit of continual or ongoing adherence intervention over the traditional approach of a short-term or limited intervention for the promotion of long-term adherence; and (5) the changing face of HIV/AIDS. In the United States, the epidemic has become more rural and disproportionately affects those of lower social-economic status. Approaches must be developed, implemented, and tested to appropriately meet the needs of these populations. As the HIV/AIDS epidemic continues to evolve and change, adherence research has much to do in order to understand the challenges facing PLWHA, to develop accurate and meaningful measures of adherence, and to increase long-term adherence among PLWHA.

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Lifestyle Change and Adherence Issues Among Patients With Heart Disease

34

Laura L. Hayman

Atherosclerotic cardiovascular disease (CVD) is a major cause of morbidity and premature mortality in women and men in the United States, as well as most of the rest of the developed world, and many developing countries (Rosamond et al., 2007). Accumulated data indicate that atherosclerotic-CVD processes begin early in life and are influenced over time by the interaction of genetic and behavioral factors and environmental exposures. Within the multidisciplinary community of cardiovascular health care professionals, these data have placed emphasis on a life course approach to prevention of CVD with individual and public health efforts beginning early in life (Hayman & Hughes, 2006; Hayman et al., 2007). Similarly, extensive evidence amassed over the past four decades points to established, potentially modifiable risk factors and unhealthy lifestyle

behaviors as important determinants of cardiovascular morbidity and mortality. Central to both prevention and management of CVD are healthy lifestyle behaviors and adherence to therapeutic regimens that emphasize lifestyle change.

This chapter provides an overview of evidence supporting the need for prevention and management of CVD, presents key elements of science-based guidelines and recommendations for lifestyle change for individuals with documented atherosclerotic CVD, and includes strategies to promote adherence that are applicable across health care and community settings. Implications for clinical and public health practice and future research are integrated throughout the chapter and included in the summary.

The Need for Prevention and Management of CVD

In the United States and globally, atherosclerotic cardiovascular conditions, particularly coronary heart disease (CHD) and cerebrovascular disease (i.e., stroke), are leading causes of disability and premature death (Rosamond et al., 2007). In every year since 1900 (except 1918), CVD accounted for more deaths than any other single cause or group of causes of death in the United States. If all forms of CVD were eliminated, life expectancy would increase by approximately 7 years (Rosamond et al., 2007). CVD risk reduction and evidence-based medical therapies play a critically important role in reducing the age-adjusted mortality due to CHD (Ford et al., 2007). Specifically, Ford and colleagues (2007) applied an updated version of the IMPACT mortality model to data for the years 1980–2000 on the use and effectiveness of specific cardiac treatments and changes in risk factors among U.S. adults 25 to 84 years of age. The IMPACT model incorporates major potentially modifiable risk factors for CHD, including smoking, high blood pressure, elevated total cholesterol, obesity, diabetes, and physical inactivity, as well as standard medical and surgical treatments for CHD. Results indicated that approximately half the decline in U.S. deaths from CHD in the period studied may be attributable to reductions in major risk factors, and approximately half is due to evidence-based medical therapies. These results are consistent with earlier U.S. and international studies and underscore the importance of potentially modifiable risk factors and behaviors in preventing mortality from CHD.

The results of the INTERHEART study, a case-control study conducted in 52 countries and designed to examine the effect of CVD risk factors and unhealthy lifestyle behaviors on incident CHD, indicated that nine potentially modifiable risk factors accounted for 90% of the population-attributable risk for incident CHD in men and 94% in women (Yusuf et al., 2004). In part on the basis of these findings, the World Heart Foundation (WHF), the American Heart Association (AHA), and the World Health Organization (WHO) issued a collaborative statement advocating that each country develop and implement plans for prevention and management of CVD, including primary prevention beginning early in life (Smith et al., 2004). In addition to targeting behavioral and lifestyle risk factors for intervention, the recommendations also emphasized the importance of addressing specific cultural, social, and environmental determinants of CVD (Smith et al., 2004).

Disparities in Prevention and Management of CVD

While substantial progress has been made in reducing CHD mortality in the United States over the past three decades, disparities remain pervasive (Bonow, Grant, & Jacobs, 2005; Davis, Vinci, Okwuosa, Chase, & Huang, 2007; Jones, 2007; Mensah, Mokdad, Ford, Greenlund, & Croft, 2005). Many population subgroups defined by race, ethnicity, gender, socioeconomic status, educational level, and/or geography demonstrate an excess burden of CHD and its attendant risk factors (Bonow et al., 2005; Davis et al., 2007; Mensah, 2005). Several national population-based surveys indicate that substantial disparities exist in risk factor prevalence, indices of mortality, and overall quality of life among U.S. adults 18 years of age and older (Mensah, 2005). Specifically, in men, the highest prevalence of obesity (29.2%) was observed in Mexican Americans who had completed a high school education. Independent of educational status, Black women had a high prevalence of obesity (47.3%). Hypertension prevalence was highest among Blacks (39.8%), regardless of gender or educational status. A major independent risk factor for CVD, hypertension has earlier onset, is more difficult to control, and is associated with more end-organ damage among Blacks than among other racial and ethnic groups (Davis et al., 2007).

Consistent with earlier studies, Mensah (2005) and colleagues also documented inverse associations among education, income and poverty status, and ischemic heart disease (CHD) and stroke. Among Medicare enrollees, rates of hospitalization for congestive heart failure hospitalization were higher among Blacks, Hispanics, and American Indian/Alaska Natives than among Whites; stroke hospitalization was highest in Blacks. Hospitalizations for Chronic Heart Failure (CHF) and stroke were highest in the southeastern United States. Finally, Blacks had higher death rates for diseases of the heart at all ages than did Whites (Mensah, 2005).

Intra-individual clustering of CVD risk factors and adverse health behaviors is well documented and known to accelerate atherogenic processes (Grundy et al., 2005; Gustat, Srinivasan, Elkasabany, & Berenson, 2002; Park, Zhu, Palaniappan, Heshka, Carnethon, & Heymsfield, 2003). More recently, attention has focused on racial, ethnic, gender, and geographic differences in multiple-risk-factor clustering (Davis, 2007; Jones, 2007; Mensah, 2005). Similarly, social-ecological determinants of disparities in multiple-risk-factor clustering and comorbid behaviors have emerged as important areas of transdisciplinary inquiry. While more research is needed to guide and inform evidence-based guidelines for prevention and management of CVD, accumulated results support the need for both clinical and public health efforts that target multiple risk factors and comorbid behaviors and that tailor strategies to individuals and families from minority populations.

Evidence-Based Guidelines for Prevention and Management of CVD: Emphasis on Lifestyle Modification

Numerous clinical trials have prompted and informed practice guidelines for primary and secondary prevention of CVD. In this chapter we emphasize recent

recommendations for lifestyle change for individuals with documented athero-sclerotic–CVD, also referred to as secondary prevention. It is noteworthy, how-ever, that heart-healthy behaviors, including patterns of dietary intake, physical activity and smoke-free lifestyles and environments and therapeutic lifestyle change (TLC), are the cornerstone of evidence-based primary and secondary-prevention guidelines, respectively (Kavey et al., 2003; Mosca et al., 2007; Pearson, Blair, Daniels, et al., 2002; Smith et al., 2006).

During the past two decades, practice guidelines for secondary preven-tion of CVD have been issued and updated periodically with recommenda-tions based on evidence generated primarily from clinical trials and systematic meta-analyses. The AHA, in collaboration with the American College of Cardi-ology (ACC) and with the endorsement of the National Heart, Lung, and Blood Institute (NHLBI), recently revised secondary-prevention guidelines classify intervention recommendations on the basis of level of evidence (Smith et al., 2006). Targets for intervention include smoking, blood pressure control, lipid management, physical activity, and weight and diabetes management (Smith et al., 2006). The recent AHA/ACC guidelines (Smith et al., 2006) support and broaden aggressive risk-reduction therapies for individuals with established coronary, and other atherosclerotic vascular disease, including peripheral arte-rial disease, carotid artery disease, and atherosclerotic aortic disease. Indeed, a growing body of evidence confirms that aggressive comprehensive risk-factor management improves survival, reduces recurrent events and the need for in-terventional procedures, and improves quality of life for individuals with estab-lished heart disease (Smith et al., 2006).

The specific pharmacotherapeutic recommendations for secondary pre-vention of CVD are beyond the purpose and scope of this chapter and have been published elsewhere (Braun & Hughes, 2007; Artinian, Yucha, & Dungan, 2007). Lifestyle modification, however, remains a central component of second-ary prevention and is viewed as essential for achieving treatment goals and preventing recurrent events. Importantly, these lifestyle change recommen-dations are consistent with those of the AHA/American Association of Car-diovascular and Pulmonary Rehabilitation (AACVPR), which emphasize that all cardiac rehabilitation and secondary-prevention programs consist of core components that aim to optimize cardiovascular risk reduction, foster healthy behaviors and compliance with these behaviors, reduce disability, and promote an active lifestyle for patients with cardiovascular disease (Balady et al., 2007). They also emphasize theory-based principles of behavior change and patient counseling and encourage clinicians to evaluate and manage psychological fac-tors (i.e., depression, anxiety, anger and hostility, social isolation, marital and family distress, sexual dysfunction and adjustment, and substance use) as part of CVD risk-factor management for individuals with documented CVD. Strate-gies suggested for increasing adherence to lifestyle change are discussed in this chapter and included in Table 34.1.

Adherence Issues Among Patients With CVD

The central and essential role of adherence to lifestyle modification and medication recommendations in preventing recurrent events in patients

34.1 Actions to Increase Adherence to Treatment Recommendations

Actions by patients	Specific strategies
Patients must engage in essential treatment behaviors	
■ Decide to control risk factors and modify adverse health behaviors	■ Understand rationale, importance of commitment
■ Negotiate goals with provider	■ Develop communication skills
■ Develop skills for adopting and maintaining recommended behaviors	■ Use reminder systems
■ Monitor progress toward goals	■ Use self-monitoring skills
■ Resolve problems that block achievement of goals	■ Develop problem solving skills, use social support networks
Patients must communicate with providers about treatment services	
	■ Define own needs and preferences on basis of experience
	■ Validate rationale for continuing to follow recommendations

Actions by providers	Specific strategies
Providers must foster effective communication with patients	
■ Provide clear, direct messages about importance of behavioral change and/or pharmacotherapy	■ Assess patient's health literacy; tailor communication accordingly
■ Include patterns in decisions about treatment goals and related strategies	■ Provide instruction in multiple modes including verbal and written rationale for treatments
■ Incorporate evidence-based behavioral strategies into counseling	■ Develop skills in communicating/counseling
Providers must document and respond to patients' progress towards goals	■ Use tailoring and contracting strategies
■ Create and maintain an evidence-based practice	■ Negotiate goals and plan for treatment
■ Assess patient's adherence at each visit and in telephone follow-up	■ Anticipate barriers to adherence and discuss solutions
■ Develop reminder systems to ensure identification and follow-up of patient status	■ Use active listening
	■ Develop multicomponent strategies (i.e., cognitive and behavioral)
	■ Determine methods of evaluating outcomes
	■ Use self-report or electronic data
	■ Use telephone and other forms of follow-up including e-health technologies

34.1	Actions to Increase Adherence to Treatment Recommendations *(Continued)*

Actions by health care organizations	Specific strategies
Health care organizations must ■ Develop an environment that supports both prevention and treatment interventions with integrated systems of care ■ Provide tracking and reporting systems ■ Provide training and education for providers ■ Provide adequate reimbursement for allocation of time for all health care professionals Health care organizations must develop and implement integrated systems of care including core components of the Chronic Care Model to improve adherence and health outcomes in patients with CVD	■ Develop and implement training in behavioral science and multidisciplinary models of health care delivery ■ Use preappointment reminders ■ Use telephone follow-up ■ Schedule flexible office hours ■ Provide group/individual counseling for patients and families ■ Develop computer-based programs (electronic medical records) ■ Require continuing education courses in communication and behavioral counseling ■ Develop and implement incentives tied to desired patient and provider outcomes ■ Incorporate multidisciplinary models of care including nursing case management ■ Implement pharmacy patient profile and recall review systems ■ Use electronic transmission storage of patient's self-monitored data ■ Obtain patient data on lifestyle behavior before visit ■ Provide continuous quality improvement training

Adapted from Miller, Hill, Kottke, and Ockene (1997) and Ockene, Hayman, Pasternak, Shron, E., & Dunbar–Jacob (2002).

with documented CVD is well established. Consistent with social-ecological models of health, optimal strategies for increasing adherence to preventive and therapeutic regimens consider individual (patient-level), provider, and health care system factors (Miller, Hill, Kottke, & Ockene, 1997; Ockene, Hayman, Pasternak, Schron, & Dunbar-Jacob, 2002).

Individual Factors That Affect Adherence in Patients With CVD

Substantial research attention has focused on individual, patient-level factors and adherence behaviors in both the prevention and the management of

CVD. Systematic reviews of the literature (Burke, Dunbar-Jacob, & Hill, 1997; Dunbar-Jacob, Schlenk, Burke, & Matthews, 1998; Ockene et al., 2002) and evidence-based statements (Miller et al., 1997) point to the importance of considering psychological, cognitive, motivational, somatic, and behavioral factors as individual-level targets for increasing adherence. Research on these patient-level factors, however, has not yielded consistent results across studies.

Depression and depressive symptoms are common in patients recovering from cardiac events (such as acute myocardial infarction) and following interventional procedures such as coronary artery bypass surgery (Ariyo, Haan, & Tangen, 2000; Burg, Benedetto, & Soufer, 2003). Major depression has been observed to develop in 20% of post myocardial infarction patients; approximately 33% of patients have clinically significant symptoms of depression (Ziegelstein, 2001). While some earlier studies did not observe associations between negative affective states and adherence behaviors (Emery, Hauck, & Blumenthal, 1992; Graveley & Oseasohn, 1991; Nelson, Stason, Neutra, Solomon, & McArdle, 1978), others and more recent studies (DiMatteo, Lepper, & Croghn, 2000; Ziegelstein, 2001) suggest that depression and depressive symptoms have a detrimental effect on adherence to recommendations for post-myocardial infarction therapy, including completion rates, and clinical outcomes in cardiac rehabilitation (Caulin-Glaser, Maciejewski, Snow, LaLonde, & Mazure, 2007). In addition, depression has been associated with self-report of medication nonadherence in an outpatient population of patients with documented CHD (Gehi, Haas, Pipkin & Whooley, 2005). Depressive symptoms have also been observed to predict medication nonadherence in heart failure patients (Morgan et al., 2006) and other documented cardiovascular conditions (Bane, Hughes, & McElnay, 2006). The relationship of depression to health outcomes in patients with established CVD, particularly CHD, has been investigated extensively. Recent meta-analyses indicate that there are positive associations between depression and/or depressive symptoms and adverse health outcomes in post-myocardial infarction patients (Barth, Schumacher, & Herrmann-Lingen, 2004; vanMelle, de Jonge, & Spijkerman, 2004) and implicate biobehavioral and biological mechanisms as possible links. As noted earlier, because of the evidence base in this area, depression is included in current practice guidelines as an important target for assessment and management in patients with CVD.

Cognitive variables, including attitudes regarding therapeutic regimens (Fitzgerald & Phillipov, 2000; Frank, 1997) and self-efficacy (the extent to which an individual believes he can change a behavior), have been associated with adherence to a number of CVD-related health behaviors (Burke et al., 1997; Burns & Evon, 2007; Cheng & Boey, 2002; Ewart, Taylor, Reese, & DeBusk, 1983; King, 2001). Because of the extensive database linking self-efficacy and adherence behaviors relevant to CVD, self-efficacy is emphasized in current guidelines as an important target for assessment and intervention.

More recently, attention has focused on health literacy, the knowledge and fundamental ability to manage illness as well as to navigate the health care system (Baker, Wolf, Feinglass, & Thompson, 2008). A study of 3,260 Medicare managed-care enrollees followed for an average of 67.8 months indicated that poor health literacy in elder adults (≥65 years of age) predicts all-cause and cardiovascular mortality (Baker et al., 2008). Specifically, hazard ratios (adjusted for demographic factors, socioeconomic status, and baseline health) for

all-cause mortality were 1.52 (95% CI: 1.26–1.83) for participants with inadequate health literacy and 1.13 (95% CI: 0.90–1.41) for participants with marginal health literacy (Baker, 2007). In addition, risk-adjusted rates of cardiovascular death were higher in participants with inadequate health literacy.

The authors suggest several plausible mechanisms to explain the higher mortality in patients with inadequate health literacy, including less knowledge regarding CVD and poor self-management skills for hypertension, diabetes, and heart failure. While this prospective cohort study did not directly measure adherence behaviors and had some methodological limitations, including a failure to measure confounding variables (i.e., cognitive function), the results point to the need for attention to health literacy in teaching, counseling, and managing chronic disease in patients with CVD.

Health literacy is just emerging as a major patient-level determinant of adherence behaviors, with some research demonstrating an association between inadequate health literacy and low medication-refill adherence in CVD patients (Gazmararian et al., 2006). Considering the complexity of therapeutic regimens for patients with multiple risk factors and CVD, health literacy is an important area of inquiry. Data are lacking, however, on effective interventions for improving adherence to recommendations regarding lifestyle and medication in CVD patients with low health literacy.

Provider Factors That Affect Adherence in Patients With CVD

Substantial evidence indicates that provider interventions have a significant effect on patients' adherence to lifestyle changes in CVD-related health behaviors, including patterns of smoking behavior, alcohol use, and dietary intake (Burke et al., 2001; Fiore, Bailey, & Cohen, 1996; Ockene, Adams, Turley, Wheeler, & Herbert, 1999). Research has demonstrated that brief provider interventions positively influence both initiation and maintenance of such behavior change (Ockene et al., 1999). Unfortunately, as documented in several studies, physician/provider adherence to evidence-based recommendations, including screening for CVD risk factors and behaviors and counseling regarding behavioral change strategies, is much less than optimal (Kim, Hofer, & Kerr, 2003; Pearson et al., 2000; Sueta et al., 1999). A recent online study of 500 randomly selected physicians, including 300 primary-care physicians, 100 obstetricians/gynecologists, and 100 cardiologists, supports the need for educational interventions designed to increase awareness and adoption of CVD prevention guidelines among health care providers (Mosca et al., 2005). Specifically, this experimental case study tested physician accuracy in assessing CVD risk level of high-, intermediate-, and low-risk patients according to evidence-based guidelines. As assessed by the Framingham risk score, all physician groups were likely to assign intermediate-risk women to a low-risk category. It is noteworthy that assignment of risk level significantly predicted recommendations for lifestyle interventions and pharmacotherapy. Importantly, and consistent with results of other studies, physicians did not rate themselves as very effective in their ability to help patients make the therapeutic lifestyle changes necessary for preventing and managing CVD (Mosca et al., 2005). Methodological limitations, including restricting the study to three categories of physicians and low survey response

rate, were acknowledged by the authors; however, the results are consistent with earlier research in this area of provider behavior.

These results suggest the need for interventions designed to increase providers' knowledge and awareness of and adherence to evidence-based guidelines for CVD prevention and management, as well as improvements in physician competencies in behavior-change counseling. As discussed later, they also suggest the need for integrated systems of care that emphasize multidisciplinary team approaches to risk-factor management and encouraging behavioral change in patients with CVD.

System-Level Factors That Affect Adherence in Patients With CVD

In this context, system-level factors refer to both the settings or environments in which patients with established CVD are managed and the processes that influence delivery of care. Substantial research has focused on the influence of such factors on patient adherence to therapeutic regimens, as well as provider adherence to evidence-based guidelines for management of CVD. Institutional or system-level policies establish expectations for care and can facilitate or impede adherence-related activities. For example, as discussed later, systems of care that value, encourage, and reward providers' adherence to evidence-based guidelines normally have mechanisms in place that enable physicians to track patients' risk-factor levels (i.e., lipids, blood pressure, body weight) and monitoring and to follow up until treatment goals are achieved. Robust information technology and integrated systems of care, generally lacking within the current U.S. health system structure, are necessary for effective preventive interventions (including both primary and secondary prevention of CVD) and are likely to enhance patient and provider adherence behaviors. An important additional characteristic of adherence-enhancing health care systems is a multidisciplinary collaborative team approach that optimizes the contributions of professionals from the many disciplines involved in the management of patients with CVD.

Strategies for Increasing Adherence and Improving Outcomes in Patients With CVD

Substantial evidence, including a recent meta-analysis, indicates that multidisciplinary, multicomponent secondary-prevention programs are effective in reducing recurrent acute cardiovascular events and all-cause mortality, and improving health-related quality of life and functional status in individuals with CVD (Clark, Hartling, Vandermeer, & McAlister, 2005). It is noteworthy that almost half (45%) of the 63 randomized trials included in this meta-analysis were identified as nurse-led or nurse-managed programs. As illustrated in landmark and recent clinical and community-based trials, improving adherence and health outcomes in CVD patients from diverse racial, ethnic, and sociodemographic backgrounds is achievable but will require major reforms in current systems of care (Ades et al., 2000; Becker et al., 2005; DeBusk et al., 1994; Fonarow, Gawlinski, Moughrabi, & Tillisch, 2001; Gordon et al., 2002; Haskell et al., 2006;

Vale, Jelinek, & Best, 2003). The key elements of successful secondary CVD-prevention programs identified in this research are consistent with the core components or pillars of the Chronic Care Model as defined by Wagner, Austin, and vonKorff (1996) and Bodenheimer and colleagues (2002), including self-management support, decision support (i.e., evidence-based clinical practice guidelines), computerized clinical information systems, community resources and policies (i.e., linkages between provider organizations and community-based resources), delivery system design (i.e., case-managed, multidisciplinary team approach), and health care organization (i.e., structure, goals, and values of provider organization that prioritize provision of chronic care). More specifically, as operationalized in secondary CVD-prevention programs, essential elements of effective programs include systems for coordination of services with multiple providers (case-managed, multidisciplinary teams); comprehensive lifestyle management programs that incorporate evidence-based principles of behavior change, including self-management support and enhanced social support; clinical information systems (computerized participant management, tracking, reporting, and outcomes analysis systems); and efficient mechanisms for patient follow-up to monitor adherence, safety, and effectiveness of interventions. An essential additional component of effective nurse-led, case-managed programs is the use of evidence-based protocols and algorithms for management of patients with single- and multiple-risk factors (Allen & Scott, 2003; Berra, Miller, & Fair, 2006).

The Stanford Coronary Risk Intervention Project (SCRIP), a landmark clinical trial that included a nurse case-managed, multidisciplinary team approach (and several features of the chronic care model) illustrates the potential of secondary-prevention programs and their core elements to reduce morbidity and mortality in patients with CVD (Haskell et al., 1994). Specifically, SCRIP tested the hypothesis that intensive multiple-risk-factor reduction over a period of 4 years would significantly reduce the rate of progression of coronary artery atherosclerosis in men (n = 259) and women (n = 41) (mean age, 56+/− 7.4 years) with documented coronary artery disease. Participants were randomly assigned to the multicomponent, multiple-risk-reduction intervention that was coordinated by advanced-practice nurses in collaboration with a multidisciplinary team or to physician-delivered usual care (UC). Components included baseline assessment conducted by nurses and dietitians, evidence-based individualized risk-reduction goals, protocol-driven medication algorithms for lipid management, bimonthly clinic visits, and individual follow-up by telephone and/or mail by nurses to monitor participants' progress toward achieving their goals. Strategies for risk- reduction and behavioral change were evidence based, theoretically derived, and individualized, with emphasis placed on helping each participant (in the intervention arm) to reach the best possible outcome (as defined by evidence-based practice guidelines). Intermediate and minimal goals were used selectively to enhance motivation and program adherence. As part of the individualized, risk-reduction behavioral change interventions, participants met with the SCRIP nurse (immediately postrandomization) to develop goals and to design a program that targeted dietary intake, physical activity, weight status, and smoking behavior. Referral and follow-up with members of the multidisciplinary SCRIP team was initiated by the nurse case manager and based on the participant's baseline risk assessment. For example, all participants

in the risk-reduction program (intervention arm) were instructed by a dietitian on how to implement a heart-healthy pattern of dietary intake, with goals set for total fat, saturated fat, cholesterol, carbohydrate, and protein intake. Consideration of the participant's food preferences and resources was an important part of the plan. In compliance with guidelines developed by the SCRIP team for home-based exercise training of cardiac patients, each participant had an individualized physical activity program. Current smokers and those who had recently quit were provided an individualized smoking-cessation or relapse-prevention program by a staff psychologist. Each participant in the risk-reduction intervention arm was provided verbal and written instructions for an individualized risk-reduction, behavioral-change plan; progress toward achieving the goals outlined in those plans was monitored through bimonthly clinic visits and telephone follow-up that also provided opportunity for continued education and counseling.

SCRIP results indicated that an intensive physician-directed, nurse case-managed multidisciplinary, multicomponent, individualized program conducted over a period of 4 years can significantly improve the risk profile in individuals with documented CVD and can favorably alter progression of coronary atherosclerosis (Haskell et al., 1994). Small changes were observed in the UC group, whereas participants in the intervention arm had a 22% reduction in atherogenic low-density lipoprotein cholesterol (LDL-C), a 20% reduction in triglycerides, a 4% reduction in body weight, and a 24% reduction in intake of dietary fat; cardioprotective high-density lipoprotein cholesterol (HDL-C) increased by 12%, and exercise capacity increased by 20%. In addition, the risk-reduction group demonstrated a rate of narrowing of diseased coronary artery segments that was 47% lower than the rate for participants in the UC group, and the intervention group had significantly fewer hospitalizations for clinical events (25 vs. 44) than the UC group.

Building on the SCRIP approach and including other core elements of the Chronic Care Model (described earlier), subsequent clinical and community-based trials were designed to reduce risk factors, adverse health behaviors, and recurrent events in individuals with CVD (Ades et al., 2000; DeBusk et al., 1994; Fonarow et al., 2001; Gordon et al., 2002; Vale et al., 2003). More recently, the effectiveness of multifactor risk-reduction programs has been examined in medically underserved individuals at high risk for CVD (Becker et al., 2005; Haskell et al., 2006). The Heart Disease on the Mend (HDOM) project, for example, was designed to evaluate the effectiveness of a team-based disease-management approach to multifactor CVD risk reduction in patients with limited or no health insurance and low family income. Participants (n = 148; 57% women; 57% Hispanic; 64% uninsured) were recruited from free clinics and hospitals and randomized to UC or UC plus team management. All participants had at least one risk factor for CVD, and 25% self-reported personal history of CVD. The program was physician directed, delivered by nurses and dietitians, and guided by the SCRIP model and included comprehensive lifestyle modifications and pharmacotherapy. Program features included patient counseling, point-of-care lipid and glucose testing, use of existing resources in the community, telephone and mail follow-up, and theory-based strategies for patient self-management. Primary outcomes, LDL-C and systolic blood pressure (SBP), were measured at 12 months; 91% of participants assessed

at baseline were retained through the 12-month data point. Participants in the HDOM disease management program (intervention arm) demonstrated significantly larger decreases in selected risk factors, including the primary outcomes, SBP and LDL-C, than the group receiving UC. In addition, more patients in the disease-management program moved from high-risk to lower-risk categories (as defined by recent guidelines) for selected risk factors, including physical activity and nutrition. While this study was limited to one geographic region and included a small sample, the results indicate the potential of a team-based, multidisciplinary disease-management approach in reducing risk and long-term disease burden in underserved populations.

Taken together, results of clinical and community-based studies demonstrate the promise and potential of innovative multidisciplinary models and integrated systems of care for reducing morbidity and mortality and improving quality of life in diverse populations of patients with CVD. They also underscore the feasibility and effectiveness of the Chronic Care Model and its core components in improving outcomes for individuals with CVD. However, a limitation of most research in this area and a fertile area for future research is assessment and examination of adherence as an outcome. Specifically, a clearer delineation of the relationship between patient adherence to therapeutic regimens and cardiovascular health outcomes, as well as adherence-enhancing multilevel strategies and specific factors that improve adherence behaviors on the individual patient and provider levels, is needed. As presented in Table 34.1 and placed in the context of the evidence accumulated to date, results also reaffirm the need for a multilevel, ecological approach to increasing adherence to lifestyle modifications and pharmacological regimens through efforts that extend beyond the individual patient and include providers, systems of care, and broader socio-contextual factors.

Summary

While substantial progress has been made in reducing CHD mortality in the United States over the past 30 years, cardiovascular diseases remain a major cause of death and disability in men and women. As discussed in this chapter, many population subgroups, defined by race, ethnicity, gender, socioeconomic status, educational level, and geography, demonstrate an excess burden of CVD and its attendant risk factors (Bonow et al., 2005; Davis et al., 2007; Mensah, 2005). Research is needed to inform and guide clinical and public health efforts, as well as multilevel policies designed to reduce the documented disparities in the prevention and treatment of CVD.

Evidence-based guidelines for secondary prevention of CVD (Balady et al., 2007; Mosca et al., 2007; Smith et al., 2006) emphasize therapeutic behavioral- lifestyle change and assessment and management of psychosocial risk factors as part of comprehensive risk-reduction strategies for individuals with established CVD. Indeed, a growing body of evidence confirms that aggressive, comprehensive risk-factor management improves survival, reduces recurrent events and the need for interventional procedures, and improves the quality of life for individuals with established heart disease (Smith et al., 2006). Adherence to lifestyle modification and medication recommendations is

essential to achieving treatment goals and preventing recurrent events. Consistent with social-ecological models of health and behavior, accumulated evidence supports the need and potential for multilevel strategies for increasing adherence to therapeutic regimens. While numerous studies have shown that multicomponent, multilevel interventions result in improved outcomes for individuals with CVD, most studies have neglected to assess either the impact of the intervention on adherence behaviors or the added value of behavioral counseling beyond maximizing the medical management of CVD. In addition, while more research is needed to inform and guide effective strategies at the individual patient, provider, and health care system level, the need to disseminate and apply in practice existing evidence-based, adherence-enhancing strategies is equally as important.

As discussed in this chapter, substantial evidence indicates that multidisciplinary, multicomponent secondary-prevention programs are effective in reducing recurrent acute cardiovascular events and improving quality of life in individuals with CVD. The key elements of successful programs identified in seminal and recent research are consistent with the core components of the Chronic Care Model (Bodenheimer et al., 2002; Wagner et al., 1996) and underscore the promise and potential of innovative models and integrated systems of care for reducing morbidity and mortality and improving quality of life in diverse populations of patients with CVD.

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David L. Mount

Clinical Case Example 1

The patient is a 56-year-old male with a high school education who reports occasional difficulty with mental organization that is most pronounced when he has to listen to multiple conversations. He reports accumulating mild to moderate problems with forgetfulness, concentration, word finding, and irritability. He believes his job is in jeopardy because he is experiencing increased episodic problems with completing work assignments. The patient is concerned that he cannot proficiently comply with medical instructions. He notes forgetting to schedule medical appointments, and his diabetes-related self-care monitoring is highly inconsistent. While he is frustrated with his fluctuating medical status, he denies any significant depression or anxiety. When questioned about his

past history of self-managing health related changes, he states that he is overly compliant with all medical treatments. In fact, the patient notes that he has typically monitored his health and wellness with good vigilance since his family history is significant for diabetes and cardiovascular disease.

The patient reports being diagnosed with Type 2 diabetes approximately 8 years ago. For the past 2 years, he has reported inconsistent adherence to diet, exercise, and other health-protective behavior relevant to achieving glycemic control. The patient reports multiple episodes of errors in medication management, with two related hospitalizations. His mediation regimen for the past 3 years has included oral hypoglycemic and insulin medications, with mixed dosage between lunch and dinner. His medical records indicated that his A1c levels have averaged from 7.8 to 9.2 for the past year. His medical history is remarkable for hypertension for approximately 3 years, and his body mass index is 36. There is no evidence of diabetes-related neuropathy, retinopathy, or nephropathy. His medical history is unremarkable for neuroimaging evaluation, substantiated via medical record review.

The patient denies any prior history of neurocognitive assessment, which is confirmed via his medical record. On a self-report measure of psychological distress, the patient does not endorse symptoms suggestive of psychological distress. On the basis of the patient's age, education level, occupation, and reported history of academic performance, his performance on neurocognitive testing suggests evidence of generally low-average to below-normal abilities in most domains assessed, including memory, speed of information processing, attention and concentration, visual-spatial skills, verbal fluency, and manual dexterity. There is evidence of reduced mental efficiency on tasks requiring complex problem solving and/or multitasking.

From the standpoint of this patient's potential for adhering to a complex medical regimen, his current neurocognitive liabilities warrant concern regarding his ability to effectively self-manage his diabetes-related activities of daily living. It is anticipated that unless cognitive compensatory devices are put in place, his current cognitive resources will adversely limit his potential to adhere to a demanding medical management regimen. This neurocognitive testing provides an objective psychometric understanding of the patient's current cognitive strengths and weaknesses that can inform the tailoring of his medical regimen. It behooves his health care providers to monitor the patient for additional changes in cognitive functioning, particularly given his history of hypertension, which is independently predictive of deterioration in brain functioning, neurocognitive resources, and risk for cerebrovascular event.

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Introduction

The World Health Organization is forecasting that diabetes will afflict 300 million persons by 2025 (King, Aubert, & Herman, 1998). Type 2 diabetes has no cure and is disproportionately prevalent among persons who have family history of diabetes, who are overweight, who are members of a racial or ethnic

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minority, who are of lower socioeconomic status, and who are middle aged or older (Bell & Polonsky, 2001).

Efforts to prevent type 2 diabetes have met with multiple challenges that represent a combination of biological and environmental factors. In efforts to achieve successful management of this chronic disease state, a premium is placed on patients' adhering to medical regimen(s) that work to maintain adequate blood sugar control. Both cross-sectional and well-known longitudinal studies, including the United Kingdom Prospective Diabetes Study, the Diabetes Control and Complications Trial, and the Kumomoto Trial, show evidence that successful glycemic control translates into reduced and/or delayed medical complications, fewer hospitalizations, and decreased medical costs (American Diabetes Association, 2003a; Aring, Jones, & Falko, 2005; Poncelet, 2003; Ratner, 2001; Stearne et al., 1998). It is estimated that the cost for financing chronic disease can increase substantially depending on age, sex, and chronic condition profile (Fishman, Von Korff, Lozano, & Hecht, 1997). Three-year costs for treating adults with type 2 diabetes who also had coronary heart disease and hypertension were more than three times those for treating adults with type 2 diabetes only, that is, $46,879 instead of $14,233 (Gilmer et al., 2005). Past, current, and forecast health care spending suggest a trend toward escalating direct and indirect costs linked to type 2 diabetes (Zimmet, Alberti, & Shaw, 2001).

This existing body of research speaks very little to the intersection of cognitive functioning on adherence to type 2 diabetes regimens. As both human and financial cost projections are being used to understand the impact of diabetes, the ramifications of cognitive dysfunction within this population on adherence to medical regimens has been slowly emerging. Epidemiological studies underscore a connection between diabetes and dementia (Biessels et al., 2006; Boyle, Wilson, Aggarwal, Tang, & Bennett, 2006; Luchsinger et al., 2007; Ott et al., 1996). This chapter seeks to underscore how and to what extent the evidence base supports a diabetes-cognition interaction. The chapter also discusses how acquired cognitive impairments in the type 2 diabetes population might influence adherence. The foundation of this discussion is a review of findings from cross-sectional, meta-analysis, and longitudinal research studies.

Metabolic Control and Adhering to Medical Regimen Components

Type 2 diabetes is a blood sugar dysregulation disorder and is associated with insulin resistance, insulin deficiency, or both. Type 2 diabetes generally has an insidious onset and progresses relatively slowly, and it is estimated that persons can remain undiagnosed for as long as 7 years (Harris, Klein, Welborn, & Knuiman, 1992). When it comes to specifying metabolic control in diabetes, a key benchmark is the hemoglobin A1c value. This value is most clearly associated with likelihood of developing additional medical complications.

A hemoglobin A1c 7% is at present a consensus reference marker for adequate blood sugar control (American Diabetes Association, 2003b; Centers for Disease Control and Prevention Primary Prevention Working Group, 2004). In an effort to achieve metabolic control, physicians may recommend changes in diet, weight loss, medications, or some combination of the three. For people who

are unable to achieve metabolic control using prescribed lifestyle interventions, the next treatment strategy is likely to involve treatment with oral agents (e.g., sulfonylureas, repaglinide, metformin, thiazolidinediones) and/or insulin. More than 50% of persons diagnosed with type 2 diabetes are prescribed exogenous insulin and/or some type of diabetes-related medicine (Harris, Klein, Welborn, & Knuiman, 1992), and this trend is increasing (Austin, 2006; Fan, Koro, Fedder, & Bowlin, 2006; Koro, Bowlin, Bourgeois, & Fedder, 2004; Morris, 2001).

Taking diabetes-related medications as prescribed maximizes clinical benefit; however, the fluctuations in adhering to medical regimen components are an enduring challenge (Dunbar-Jacob & Mortimer-Stephens, 2001; Paterson et al., 2000). Rates of noncompliance for medications range from 20% to as high as 80% (Boccuzzi et al., 2001; Cramer, 2004; Shenolikar, Balkrishnan, Camacho, Whitmire, & Anderson, 2006). Although some components of the medical regimen plan are more difficult to achieve compliance with than others, adherence to prescribed medication protocol is a major deficit area.

Poor medication adherence in diabetes care is associated with increased all-cause mortality (hazard ratio = 1.43; 95% CI 1.13–1.82; P = 0.003) and diabetes-related deaths (1.66; 1.20–2.30; P = 0.002) over a 7-year period after adjusting for relevant confounders (Kuo et al., 2003). When poor medication adherence is a patient-care factor, there is a greater likelihood that such patients will also demonstrate excessive health utilization, ranging from preventable hospitalization to premature mortality due to disease-related complications (Fillenbaum et al., 2004; Ho et al., 2006; Vik et al., 2006). Inadequate metabolic control due to medication nonadherence has an estimated price tag of $100 billion a year (O'Connor, 2006).

Cognitive Functioning and Medical Adherence

Knowledge of a person's cognitive abilities can be useful across a broad range of related activities of daily living. Cognitive functioning represents the capacity for information processing, learning, remembering, analyzing, making reasonable decisions, and executing a plan of action (Baltes, Staudinger, & Lindenberger, 1999; Hultsch, Hammer, & Small, 1993). Our cognitive abilities promote our potential for functional independence and safety in carrying out activities germane to daily living. When cognitive abilities fail, there is increased potential for self-care errors. As shown in Figure 35.1, multiple neurocognitive markers can affect the mental reasoning abilities necessary for tracking details intertwined in the daily disease-management process.

Although the research is primarily correlational in nature, the study of cognitive functioning and components of patient-oriented medical adherence is emerging as a promising and prudent area of scientific inquiry (Cavanagh, Van Beck, Muir, & Blackwood, 2002; Hinkin et al., 2002; Insel, Morrow, Brewer, & Figueredo, 2006; McDonald, Garg, & Haynes, 2002; Okuno, Yanagi, & Tomura, 2001). While health status is a key factor in well-being and cognitive functioning (Morrow-Howell, Hinterlong, Rozario, & Tang, 2003; Small et al., 2006), the relationship between medication adherence and cognitive functioning suggests that cognitive resources are a factor in medication noncompliance (Kalichman et al., 2005). Research shows that lower performance on psychometric tests

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35.1

Neurocognitive markers of everyday functioning.
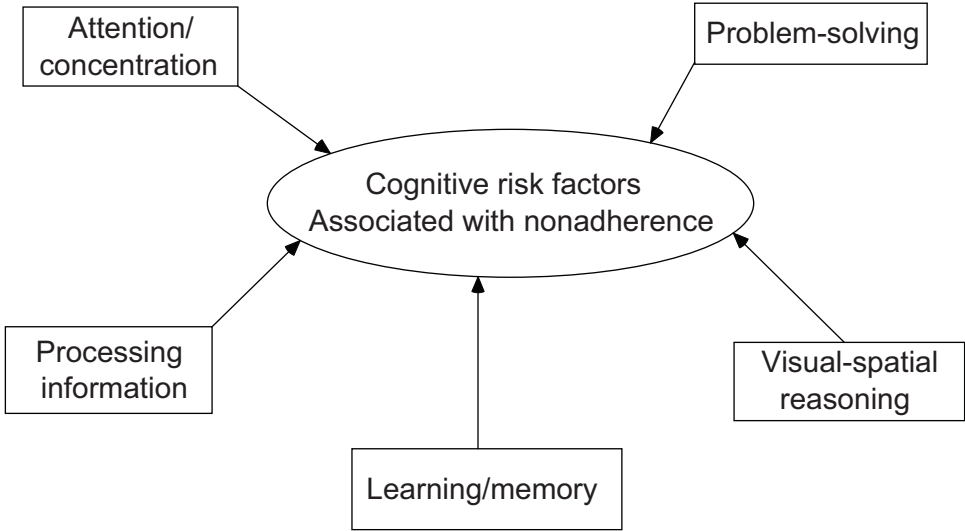
of cognitive abilities, as well as low literacy, is inversely related to medication adherence (Hutchison, Jones, West, & Wei, 2006; Kripalani et al., 2006; Maddigan, Farris, Keating, Wiens, & Johnson, 2003). In 2001, Salas and associates published data from the Rotterdam Study in which the researchers related impaired cognitive function to adherence to antihypertensive drugs in older adults. After adjustment for age, sex, education, income, living situation, and smoking, the findings indicated that persons who were cognitively impaired were twice as likely to have adherence problems with antihypertensive medicine as were persons without cognitive impairment. In addition, persons living alone were approximately three times as likely to be medication nonadherent.

For persons suffering from diseases of the immune system (i.e., HIV-infected persons), a trend toward lower medication adherence increases as patients are expected to cope with complex medication regimens (e.g., taking multiple medications and adhering to food requirements). Persons at higher risk for medication nonadherence have been shown to demonstrate cognitive deficits including problematic information processing sequencing, slowed problem solving related to how to self-management variability in medical symptoms, and fluctuation in memory functions (Hinkin et al., 2002).

Other factors such as psychiatric illness (Jeste et al., 2003; Piette, Heisler, Ganoczy, McCarthy, & Valenstein, 2007), environmental demands (Martin & Park, 2003), and age-associated cognitive changes (Insel, Morrow, Brewer, & Figueredo, 2006) are shown to increase medication-taking errors and risk for failure to take medicines as prescribed. These risks are also elevated in persons who have undergone changes in higher-order thinking skills, particularly memory. Although the literature regarding type 2 diabetes populations is not well developed or understood, it is nevertheless possible to speculate, on the basis of

findings on adherence among those with other chronic diseases, findings that are traditionally understood to have neurocognitive connections.

Risk for Cognitive Decline in Type 2 Diabetes

Although study findings are not complete or always consistent, there is growing speculation that individuals diagnosed with type 2 diabetes can carry an elevated risk for cognitive decline. Some of the earlier reports noted that memory problems seemed to emerge in persons experiencing type 2 diabetes-related complications of peripheral neuropathy and/or elevated A1c levels (Perlmuter et al., 1984). Just over a decade later, Strachan and colleagues (1997) published findings that validated the observations of Perlmuter and associates. In their meta-analysis approach, and on the basis of research published between 1980 and 1995, Strachan and colleagues found that, indeed, there was a connection between a vulnerability in verbal memory and type 2 diabetes.

Supplementing these findings, multisite longitudinal studies, including the Rotterdam Study (Ott et al., 1996), the Honolulu-Asia Aging Study (Peila, Rodriguez, & Launer, 2002), and the Epidemiology of Vascular Aging Study (Fontbonne, Berr, Ducimetiere, & Alperovitch, 2001) have also found that risk to cognitive functions are increased in type 2 diabetes. Verbal memory is one particular cognitive asset that is at risk in type 2 diabetes. This memory process refers to the ability to remember words, narrative passages, and verbal items. This ability can be evaluated by asking the patient to recall information from a short story or a set of items from a word list.

Older cohorts have been the focus of choice when investigating the risk for non-age-related cognitive changes in type 2 diabetes. When studying younger type 2 diabetes cohorts, non-age-related changes in information processing speed are observed. The work of Ryan and Geckle (2000), for example, employed a cross-sectional methodology investigating differences in cognitive functions in 50 persons ranging in age from 34 to 65 years old with type 2 diabetes. This study highlighted cognitive deficits in psychometrically estimated information-processing reaction time. Information-processing speed is a cognitive asset thought to be correlated with global cognitive capacity. This cognitive skill can be stratified into several tasks: simple reaction time tasks (all stimuli require a response), recognition reaction time tasks (patients must discriminate using what was learned), and choice reaction time task (patients are required to respond to only one of the two possible stimuli). Whereas speed of information processing is a strong neurocognitive asset in younger years, the ability to handle situational tasks requiring quick acquisition of information, multitasking, or efficiency in the mental manipulation of multiple pieces of information declines with advancing age (Alloway, Gathercole, & Pickering, 2006; Miyake, Friedman, Rettinger, Shah, & Hegarty, 2001; Park et al., 2002).

In a middle-aged cohort from the Whitehall II study, Kumari and Marmot (2005) compared cognitive performance among three groups: those with diagnosed Type 2 diabetes, those with diagnosed impaired glucose tolerance, and persons with euglycemia. They found that persons with diabetes performed poorer on cognitive measures (men: OR, 2.45; 95% CI, 1.77 to 3.38; women: OR, 1.83; 95% CI, 1.09 to 3.08). In an earlier case-control study focused on persons

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younger than age 55 years with type 2 diabetes, Dey and colleagues (1997) found that those with diabetes had suboptimal performance on neuropsychological tests measuring attention, repetition, and memory. However, no differences between those with diabetes and controls were observed for other measures of neurocognitive functioning (e.g., tasks of comprehension, visual naming, visual-spatial ability, or math skills).

As noted in their published findings on the Atherosclerosis Risk in Communities cohort, a large biracial, multisite, longitudinal investigation of middle-aged individuals, Knopman et al. (2001) observed that persons with type 2 diabetes demonstrated problems with language-skills tasks, specifically word fluency, which measures the speed and flexibility of verbal thought processes, as well as assessing an individual's ability to generate as many words as possible within a fixed time limit.

The type 2 diabetes population is not a homogenous population. When persons with well-controlled type 2 diabetes are compared with relatively healthy individuals without diabetes, there are practically no discernable differences between them on behavioral tasks that measure verbal memory, except when duration of diabetes is considered (Cosway, Strachan, Dougall, Frier, & Deary, 2001). Duration of diabetes as a brain-cognition threshold marker is reported in the literature (Stewart & Liolitsa, 1999). Similar findings were reported from a sample of 16,596 women ages 70–81, with and without type 2 diabetes. In this study, the odds that a study participant would have poor cognition were approximately twice as great for those persons with longer duration of type 2 diabetes (Logroscino, Kang, & Grodstein, 2004).

Physiological Markers and Brain Functioning

Some biomarkers are reported to drive the relationship between diabetes and brain function more than others. Type 2 diabetes is largely a disease of the aging process; however, one must keep in mind that there are various types of aging, including chronological aging, physiological aging, and mental aging. It is generally accepted that chronic stress and chronic physical diseases accelerate physiological changes in multiple organ systems independent of age (Roth et al., 2004; Sieck, 2003). As some brain functions are more sensitive to the effects of aging than others, neurobiological and contextual factors such as environmental demands and cultural experiences independently and simultaneously influence underlying neural circuits that activate and deactivate cognitive processes (Baltes, Staudinger, & Lindenberger, 1999; Park & Gutchess, 2006; Salthouse, 1996; Von Dras & Blumenthal, 2000).

The poor supply of glucose to the brain can also cause neurological symptoms such as drowsiness, confusion, loss of consciousness, seizures, and permanent brain damage. Elevated blood glucose levels can damage small blood vessels (microvascular disease) that in turn affect the eyes (diabetic retinopathy), kidneys (nephropathy), and nerves (neuropathy). Elevated blood sugar or hyperglycemia is a significant complication experienced in type 2 diabetes. Elevated blood sugar is shown to decrease acetylcholine synthesis in rat brain (Welsh & Wecker, 1991). Acetylcholine is a neurotransmitter that appears to be involved in learning and memory and is severely diminished in the brains of persons with Alzheimer's disease.

As diabetes is a constellation of signs and symptoms, a salient feature of poor glycemic control is increased risk for atherosclerosis. Atherosclerosis, a disease of vessel wall thickness and plaques of the carotid arteries, is a risk factor for non-age-related changes in brain functioning (Hofman et al., 1997) and a consequence of several lifestyle factors (e.g., cigarette smoking, sedentary lifestyle, obesity). Reporting on their findings from the Rotterdam Study, Hofman and associates found that atherosclerosis is associated with dementia, and the odds ratio for Alzheimer's disease in those with severe atherosclerosis compared with those without atherosclerosis was 3.0 (95%, CI 1.5–6.0; p = 0.001).

Similar to atherosclerosis, hypertension is shown to alter brain functions (den Heijer et al., 2005; Kilander, Nyman, Boberg, Hansson, & Lithell, 1998). Variables that may alter (i.e., moderate) the relationship of hypertension to brain functioning include age, education, several characteristics of elevated blood pressure or hypertension, and the presence of concurrent diseases (Waldstein, 2003). The data suggest that while hypertension is a risk for cerebrovascular health independent of type 2 diabetes, the joint contributions of both diseases elevate stroke mortality (Hu et al., 2005).

Cognitive Functioning and Patient Care Planning

Verbal Fluency

Changes in any of these cognitive domains can have adverse consequences for following a diabetes regimen. Mild word generation problems can affect social processes. Verbal fluency deficits in diabetes can affect spontaneous speech. This issue is most problematic when the primary-care team has a short window to collect information from patients during follow-up visits. Some patients become relatively skilled at masking this problem. A consequence of verbal fluency deficits is that patients will likely have problems generating accurate representations of their diabetes self-management. If health care providers are unaware that such problems exist, the patient-provider interface will have multiple challenges, including the belief that the patient is unmotivated and not interested in talking with members of the health care team.

Verbal fluency problems may also cause the patient to be perceived as depressed. This misjudgment will unfortunately cause a strain in the relationship between primary-care providers and the patients they care for. As patients are likely to feel misunderstood, there is the potential that the diabetes care recipient will become uninterested in his own care and will resist complying with medical recommendations. When patients are unsuccessful in achieving stable diabetes control, consultation with a health care professional specializing in diabetes and neurocognitive functioning can provide an opportunity to rethink the existing diabetes care regimen. Such professionals should be knowledgeable about psychometric measures that are sensitive to changes in neuropsychological functioning within this chronic disease population.

Information Processing Speed

Cognitive reaction to information can alter a patient's ability to understand information presented through either an auditory or a visual medium. The

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primary care environment generally makes an assumption that patients have relatively equivalent information-processing efficiency. This belief represents a ubiquitous process operating throughout health service delivery. In the event that information is presented at a rate faster than the patient's neurocognitive processing can encode and organize it, it is highly likely that the patient will not remember what has been discussed. The primary care team will want to intervene around this issue by attending to the accuracy of each patient's understanding of the information presented. It is estimated that 50%–80% of persons with type 2 diabetes have knowledge and skill deficits in self-care–related activities and experience a significant relapse in self-management adherence 6 months after receiving initial treatment instructions (Norris, Engelgau, & Narayan, 2001).

While skill deficits in diabetes care may be unrelated to challenges in cognitive processing, investigating the influence of such a process on the acquisition of care skills is in many cases warranted. A key to assisting patients with below-average information processing speed is allowing them an adequate amount of time to process information. An additional strategy is to repeat information and verify that the patient has correctly understood the instructions.

Cognitive impairment in type 2 diabetes is not commonly understood or recognized and is likely to be missed during primary care clinic visits. With the proportion of adults with type 2 growing and the rates of nonadherence to diabetes medical regimen rapidly increasing in the United States, the number of persons living with both type 2 diabetes and cognitive impairment is expected to present a massive public health problem. The demand for translational science has pushed basic science, epidemiological, and clinical trial researchers to think more broadly about the bidirectional pathways of diabetes on body, brain, and society. A type 2 diabetes body-mind paradigm on adherence has the potential to provide a platform that models and investigates the underlying differences in patient outcomes, particularly given the body of research emerging in the study of neurobiology and cognitive function, with particular attention to brain plasticity, cognitive health, culture, and successful mental aging (Chua, Chen, & Park, 2006; Gutchess et al., 2006; Park & Gutchess, 2006).

Implications From the Clinical Case

The case presented at the beginning of this chapter has multiple implications that might shed light on the cognitive mechanisms potentially connected to an individual's ability to develop and maintain self-care skills, to benefit from diabetes-related education, and to follow a prescribed treatment regimen. When cognitive functions become unstable or specific neurocognitive abilities start to diminish, it is important that health care providers tailor the medication regimen to patients' cognitive strengths and weaknesses, taking into account the complexity of the medication regimen.

Diabetes care is heavily language driven. When persons present for a medical visit, the majority of the interface is verbally driven, and patients' ability to understand the information discussed with the provider has implications for their ability to execute self-care skills after the medical visit. Since face-to-face contact time with health care providers is limited, problems with verbal fluency may hinder individuals' ability to effectively communicate issues that

might place them at further safety risk with regard to self-management of their diabetes. Patients with diabetes can experience deficits in new learning and memory functioning that can affect diabetes education as well as their ability to remember what is discussed during a clinic visit. Peoples with diabetes can also experience deficits in higher-order cognitive functions. Such patients may evidence weaknesses in their ability to process and respond to verbal instructions of increasing complexity. Deficits in higher-order cognitive functioning are hallmarks of problems in planning, self-monitoring, self-regulating, flexibility in mental processing, and problem solving. As with other chronic diseases that have a neurological connection, the signs and symptoms of type 2 diabetes-related neuropsychological disturbance vary in the rate at which they progress and can range from deficits in concentration, declarative memory, visual understanding, acquisition of new information, and word finding to deficits in ability to remember vital information, mental agility, and emotional stability.

The development of strategies to improve how patients learn health information are of particular interest in the management of chronic disease (Rogers, Wallace, & Weiss, 2006; Safeer, Cooke, & Keenan, 2006; Schillinger et al., 2002). This suggests that benefits from health education are generally influenced by a combination of cognitive factors, including risk perception, motivation, self-efficacy, reasoning, knowledge, and general intellectual functioning (Bandura, 1998; Whitehead, 2001). However, health care providers need to be aware that the potential for completing tasks of relatively moderate to high complexity is reduced when cognitive agility or cognitive efficiency is compromised (Perneczky et al., 2006; Tabert et al., 2002). As noted by Lezak (1995), brain-behavior relationships have implications for proficiency in activities of daily living. Self-managing a diabetes regimen involves performance of a complex variety of functions related to filtering, selecting, focusing, shifting, and tracking information. Since there is typically a huge amount of available information to attend to, a person must be able to filter this potential information and attend to only the most relevant sources.

Discussion

Diabetes control is a unifying goal of care, but many elements weigh in on the achievability of diabetes control, including who is receiving the care and who is delivering the care. Poor diabetes management increases risk for secondary medical complications ranging from heart disease, erectile dysfunction in men, and polycystic ovary disease in women to blindness, stroke, end-stage renal disease, and lower-extremity amputations, polypharmacy, and premature death. The rate of complications associated with type 2 diabetes nonadherence places increasing demands on health care providers at all levels.

Diabetes Adherence and Cognitive Functioning

Type 2 diabetes is a regimen-intensive disease that requires an assortment of complex mental skills. Cognitive problems in diabetes may affect the patient's ability to correctly identify appropriate medications, awareness of physiological responses to self-care behaviors, ability to remember to take medications

at scheduled times, and ability to fill prescriptions in a timely manner. The evidence base for type 2 diabetes-related cognitive dysfunction and adherence capacity is relatively sparse at this time, and future research will be needed to fill this gap while simultaneously educating providers of direct-service care about the patient self-management challenges associated with alterations in cognition. Effectively matching a patient's cognitive strengthens and weaknesses with patient care regimen planning is a promising and innovative strategy for reducing problematic nonadherence.

Conclusions and Future Implications

The risk for dementia appears to be significantly greater for persons diagnosed with type 2 diabetes than in the general population. However, correlation does not warrant a conclusion of causation. While the literature does not fully support the proposition that all persons diagnosed with type 2 diabetes experience cognitive impairment, or that all cognitive abilities are affected equally, it is worth reiterating that diabetes self-management can place demands on a variety of cognitive resources.

Persons treated for diabetes require care from primary-care physicians and various allied health professionals, including diabetes educators, nurses, pharmacists, and physical activity specialists. The patient-oriented diabetes regimen is a full-time job that requires, among other activities, keeping vaccinations up to date; checking feet every day; taking daily aspirin and other prescribed medications; monitoring blood pressure; managing stress; and planning ahead for health care visits.

In summary, adherence to diabetes-related therapies is a major issue in diabetes care, and strategies for improving adherence are desperately needed. Cognitive functioning in diabetes has an impact on medical regimen planning, tailored intervention programs, lifestyle management, and health behavior practices. It seems highly important for science to determine whether differences in diabetes care outcomes are influenced by a set of cognitive skills such as attention to details, multitasking, complex problem solving, and remembering information and how these affect self-care behaviors, particularly checking blood sugar, taking medicines, and following up on medical appointments. Elucidating the mechanisms by which cognitive dysfunction is a barrier for diabetes-related adherence would provide insight as to what cognitive remediation strategies are needed and how technological innovations might be employed to strengthen adherence behavior.

Given the cost of diabetes care, shifts in philosophy from a focus on intervention to one on prevention, and the burgeoning interest in pay-for-performance, it is imperative that a fuller picture be developed of diabetes-related medical adherence. It is anticipated that, as the body of evidence grows in type 2 diabetes adherence research, brain-behavior research will add to the process of tailored intervention planning to reduce risk for nonadherence to medical regimens. A potential barrier in coordinating diabetes and neurocognitive care will involve restructuring the traditional primary-care team. Health service providers will find that holistic management of patients with type 2 diabetes supports a realistic chance to effectively close gaps in disparate adherence to diabetes regimens.

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Lifestyle Change and Adherence: The Broader Context

Section 7

Sally A. Shumaker
Editor

As discussed throughout this volume, obstacles to adherence may arise from a number of factors, including individual differences; the complexity of a particular regimen; behavioral or biological disincentives to changing behaviors; poor communication between individuals and their health providers; public policies and social contexts that reinforce negative health behaviors; and the complex needs of specific populations. Furthermore, though improving, there is a persistent inadequacy in the theoretical models used to help investigators frame questions and to assist them in better understanding adherence and behavior change. Also, defining, measuring, and interpreting information about adherence continues to be a formidable challenge for both researchers and health

providers. In spite of these problems, however, there is an implicit assumption throughout this book that better adherence is almost always worth pursuing and will usually result in improved health outcomes for most individuals. Thus, our focus to this point has been on identifying and pursuing methods to enhance adherence and the adoption and maintenance of healthy behaviors.

In this final section—expanded from the earlier edition—the authors step back from the assumption that adherence is prima facie good and should be relentlessly pursued by both consumers and health care providers. They consider the possible unintended consequences of good adherence, who in society is ultimately responsible for health behavior changes, the underlying ethical issues inherent in the contracts between health providers and their patients, how much adherence is actually enough, and, after several years now of investigating interventions to enhance adherence, what we have actually learned.

Updating their chapter from the earlier edition, Czajkowski, Chesney, and Smith discuss the potential consequences of adherence in experimental studies that include placebo and treatment groups in the chapter "Adherence and the Placebo Effect." They consider how various factors, including one's belief in the efficacy of treatment, can produce treatment-like effects in the placebo condition. Further, this placebo effect is strengthened by adherence. These authors suggest that as long as the placebo effect is treated as a nuisance variable rather than as a real phenomenon worthy of study in its own right, differences in adherence rates between treatment and placebo groups may lead to incorrect interpretations of data and, ultimately, inaccurate recommendations for clinical care. Health care providers may be underutilizing the strength of personal commitment embodied in the placebo effect to improve health. Czajkowski, Chesney, and Smith describe several models to explain the placebo effect and discuss its implications for clinical research and for assumptions regarding treatment efficacy.

In "Collaboration Between Professionals and Mediating Structures in the Community: Social Determinants of Health and Community-Based Participatory Research," Cashman and Forlano provide an updated and expanded perspective from the chapter in the earlier edition by Ribisl and Humphreys. In the earlier chapter, Ribisl and Humphrey described a "third path" between individual and social responsibility for health status in which collaboration with organizations and institutions is critical. Cashman and Forlano build on this framework and consider the powerful means for effecting change embodied in taking into account the social determinants of health (SDOH), coupled with the methods available within community-based participatory research (CBPR). The authors argue that SDOH provides a philosophical underpinning for action that is directed toward transforming power relations from ones that permit inequity and injustice to ones that promote equity. In the section on SDOH Cashman and Forlano provide a definition of the concept and supporting evidence of its impact on health behaviors. In addition, they consider how SDOH can influence inequalities in health care, and they update the reader on current research, barriers to investigating and impacting SDOH, and actions that can be taken within this area. Complementing SDOH, the authors describe CBPR as a method that can be used to build productive partnerships. They provide a current definition of this concept and the methods implied in conducting research from a CBPR perspective. In addition, they consider the relative strengths of CBPR, the limits

and challenges to applying it to health related research, and how CBPR can be used to enhance sustained health behavior changes. The authors provide a compelling and innovative approach to the complex systems in which health behaviors exist—a natural addition to the several chapters within the volume that approach adherence and health behavior change and maintenance from a systems or social ecological model.

In her chapter on "Ethical Issues in Lifestyle Change and Adherence," King expands on and updates the chapter by Faden in the earlier editions of this book. Providing an in-depth and critical analysis of the degree to which ethics help frame the factors that underlie adherence and health behavior change, King examines issues in lifestyle change and adherence from the perspective of normative ethics—the moral theory addressing the way individuals, institutions, or societies ought to act. She discusses the key moral issues related to lifestyle change and adherence in each of four relationships, and describes the emerging relevant principles and rules as each relationship is discussed. These relationships include the ethics of the health professional-patient relationship; the ethics of the researcher-subject relationship; the ethics of the government-citizenry relationship; and the ethics of the payer-client relationship. Finally, King cautions the reader about the critical distinction between adherence in the clinical setting versus lifestyle changes for the general public, and the blurring of these two heretofore clearly distinct domains as the tendency to medicalize nondisease states (e.g., prediabetic, estrogen deficient) is becoming a more common strategy used to persuade healthy individuals to change behaviors or take preventive medications. This chapter underscores the complex ethical aspects that are critical to our consideration of how and when we attempt to alter human behavior, and what defines good for the individual and the society at large.

In a new chapter to this third edition of the book, Haskard, DiMatteo, and Williams ask the provocative question "Adherence and Health Outcomes—How Much Does Adherence Matter?" In addressing this question, the authors consider what they define as the ultimate issue regarding the efficacy of adherence—does it improve health outcomes? They then provide a critical review of the evidence linking adherence rates to health improvements across a number of diseases and conditions including CVD, cancer, HIV, diabetes, transplant patients, and depression. Further, they explore differences in the link between adherence and health status among adults and pediatric populations. Haskard et al. review the methodological issues, mediating factors, and various interventions to enhance adherence as they explore the fundamental issue of whether or not adherence enhances health. In general, they provide convincing data on the basic premise that people do better when they adhere to pharmacological and behavioral treatments. However, as noted by the authors, optimum rates of adherence with specific conditions are less clear, thus leading to ambiguity regarding ideal treatment protocols and clinical care recommendations. This chapter provides an excellent grounding in the key meaning of adherence and brings the reader back to some fundamental questions in this area of research.

Since the previous edition of our book, a number of efforts have been undertaken to enhance treatment adherence and health behavior change, with varying degrees of success. In this final and new chapter, Bowen and Boehmer consider the "Lessons Learned: What We Know Doesn't Work and What We

Shouldn't Repeat." They divide their chapter into two sets of "don'ts." The first set relates to what has been learned within specific lines of research. Through specific examples from research, they consider issues such as focusing too much on the individual and not enough on the environment, overgeneralizing from one group to another, making assumptions about mechanisms without the support of science, and the critical differences between changing and maintaining behavior. In the second set of "don'ts," Bowen and Boehmer consider issues related to the process of doing research. Here they provide provocative evidence of the consequences that occur in terms of compromised science when health behavior researchers enter a study as an afterthought. In addition, they provide several vivid examples of the contradictions that occur between public policy and evidence-based health care practices—a fitting cautionary end note to the complex arena embodied in this text on health behavior change and maintenance.

Adherence and the Placebo Effect

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Susan M. Czajkowski,
Margaret A. Chesney,
and Ashley W. Smith

Traditionally, adherence has been viewed as a critical element in the success of a treatment or health regimen, for without it patients may not receive the full benefits of treatment. Given the importance of adherence to treatment success, other chapters in this volume focus on factors that *predict* or influence adherence to a specific treatment and on strategies for increasing adherence. In contrast, in this chapter we consider adherence from another perspective: the potential *effects* of adherence on treatment effectiveness and health outcomes.

A series of studies has found that, across a range of diseases and treatments, patients who demonstrate better adherence to *either* an active treatment *or* to a placebo have better health outcomes and, in particular, lower mortality, than those who have poorer adherence. The mortality benefits associated with adherence to placebo have been explained in two ways: first, as resulting from

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biases inherent in performing analyses based on patient responses (such as adherence) in randomized clinical trials, and, second, as reflecting a "healthy adherer" effect in which the act of adherence is a marker for a set of healthy behaviors, such as healthy diet, physical activity, and adherence to other medications and regimens, that are themselves responsible for the lower mortality risk. While acknowledging the merit of these explanations, we propose an additional explanation for the consistent finding of an placebo adherence-mortality relationship: that, in addition to its role in maximizing the *active, specific* effects of the treatment, adherence may also increase treatment effectiveness by activating nonspecific or *placebo* effects that influence treatment success. Thus, the mere act of adhering to a treatment regimen may in itself produce positive health outcomes, regardless of the actual efficacy of the intervention, because of a placebo effect.

We begin with a brief review of studies documenting an association between adherence to treatment and health outcomes. We then outline a hypothetical model of the role adherence may play in enhancing the nonspecific, or placebo, effects of an intervention and thus in affecting treatment outcome. A brief overview of placebo effects is presented, including a discussion of possible mechanisms through which placebos exert their influence. Applying the model, we then suggest an explanation for why adherence to a treatment may enhance a placebo response and, finally, discuss implications of the model for both clinical applications and research.

The Relationship of Adherence to Treatment Outcome

A number of studies have now documented an association between adherence, to either active treatment or placebo, and health outcomes. Good adherence to either treatment or placebo has been associated with benefit, and poor adherence with negative effects, in studies of treatments for myocardial infarction (Coronary Drug Project Research Group, 1980; Verter & Friedman, 1984; Horwitz et al., 1990); congestive heart failure (Granger et al., 2005); arrhythmias (Irvine et al., 1999); cancer (Dolin et al., 1982; Pizzo et al., 1983); and schizophrenia (Pledger, 1992), as well as in studies of preventive therapies for cardiovascular disease and cancer (e.g., the Physicians Health Study, a primary prevention trial of aspirin alternating with beta carotene; Glynn, Buring, Manson, LaMotte, & Hennekens, 1994). A recent meta-analysis of 21 studies (46,847 participants) that included eight clinical trials with placebo arms (19,633 participants) showed that good adherence to placebo was associated with lower mortality (odds ratio 0.56, 95% confidence interval 0.43 to 0.74) than poor adherence to placebo, as was good adherence to beneficial drug therapy (0.55, 0.49 to 0.62; Simpson et al., 2006).

In one of the earliest studies to document this effect, the Coronary Drug Project (CDP) (Coronary Drug Project Research Group, 1980), male patients who had experienced a myocardial infarction within 3 months of study entry were randomly assigned to either a condition in which they received clofibrate or to a placebo control group. The results showed no significant difference in 5-year mortality between the two groups: for the 1,103 men treated with clofibrate,

36.1	The Influence of Adherence on 5-Year Mortality Rates in the Coronary Drug Project

	Treatment group	
Adherence	Clofibrate	Placebo
Good adherers (> 80% adherence)	15.0% (15.7)[a]	15.1% (16.4)
Poor adherers (< 80% adherence)	24.6% (22.5)	28.2% (25.8)

Note. From "Influence of Adherence to Treatment and Response of Cholesterol on Mortality in the Coronary Drug Project," by The Coronary Drug Project Research Group, 1980, *The New England Journal of Medicine, 8,* pp. 1038–1041. Copyright 1980 by The Massachusetts Medical Society. Reprinted with permission of The Massachusetts Medical Society.
[a]The figures in parentheses are adjusted for 40 baseline characteristics.

5-year mortality was 20%; for the 2,789 men given placebo, it was 20.9%. Further analyses performed to determine whether adherence to clofibrate influenced 5-year mortality showed that good adherers (defined as patients who took 80% or more of the drug during the 5-year follow-up period) had a significantly lower 5-year mortality (15%) than did poor adherers (24.6%). However, this was true for those receiving the placebo as well; good adherers to placebo had significantly lower mortality than poor adherers to placebo (15.1% for good adherers and 28.2% for poor adherers). Furthermore, this effect held even when multivariate statistical methods were used to adjust for baseline differences between the two groups on 40 variables that were related to 5-year mortality (e.g., indices of disease severity, use of hypertensive medication; see Table 36.1).

In the CDP, flaws in the way adherence was measured may account for the relationship found between adherence and mortality. Adherence was determined by physician estimates of the number of pills taken by patients each day. These estimates were based not only on the number of pills returned by patients at their clinic visits but also on physicians' interviews in which patients were questioned about problems with the medication, including side effects, that may have affected adherence to the regimen. Because of the subjective nature of the latter measure of adherence, assessments of patients' adherence may have been influenced by physicians' assessments of the health of individual patients. Thus, the healthier patients may have been assigned to the high-adherence group, and their lower mortality rate may have simply reflected this bias in assignment to the adherence "condition."

However, similar results have been found in other studies using more objective measures of adherence. For example, in the Aspirin Myocardial Infarction Study (AMIS), in which adherence was assessed using three different measures (pill count, urine salicylate, and platelet aggregation), lower mortality rates were found for good adherers to the aspirin treatment (6.1%) and to placebo (5.1%) than for poor adherers to either aspirin (21.9%) or placebo (22%). An analysis of the relationship of adherence to mortality in the Beta-Blocker Heart Attack Trial (BHAT) also found good adherers to have better health outcomes than poor adherers: patients who demonstrated poor adherence, whether assigned to

treatment or placebo, were twice as likely to die within 1 year of follow-up as patients with good adherence (Horwitz et al., 1990). Other studies demonstrating this effect include trials of antibiotic prophylaxis to reduce fever or infection in cancer patients (Dolin et al., 1982; Pizzo et al., 1983) and a trial of chlorpromazine versus placebo in schizophrenic patients (Pledger, 1992).

These results have most often been used to demonstrate the problems associated with analyzing clinical trial data on adherence using subgroups on the basis of patient responses, since individuals who demonstrate good adherence may differ from poor adherers on any number of variables that may also cause differences in mortality (Coronary Drug Project Research Group, 1980; Friedman, Furberg, & DeMets, 1996). Perhaps the healthier patients in these studies were better able to tolerate the medication and so adhered better to it, while the sicker patients were less able to tolerate it and so discontinued using it. Alternatively, the results of these studies have been explained as reflecting a "healthy adherer" effect, in which good adherence is considered a marker for an overall healthy lifestyle and poor adherence may reflect adverse health behaviors, habits, or characteristics (Simpson et al., 2006). For example, the poor adherers in studies such as the CDP may have been individuals who exhibited some unmeasured (and therefore unadjusted for) adverse behavior or characteristic (e.g., psychiatric conditions, drug or alcohol abuse) that caused them to be negligent about taking their medication. If these individuals were also less healthy than adherers, which might be expected, their survival rates over the 5-year follow-up period would be lower than those in the "high-adherence" group. In this case, both adherence and mortality would result from a third, unmeasured variable—such as psychiatric condition or alcohol/drug abuse—and would actually be unrelated to each other when that third variable was controlled.

Many of the studies cited here used multivariate analyses to control for sociodemographic, medical, psychosocial, lifestyle, and other health-related factors that might account for the adherence-mortality relationship in an attempt to determine the variable or variables that underlie this relationship (Coronary Drug Project Research Group, 1980; Glynn et al., 1994; Granger et al., 2005; Horwitz et al., 1990; Irvine et al., 1999). Adjustment for these variables, including medical history, various indices of disease severity, psychosocial factors such as stress, and unhealthy behaviors such as smoking and alcohol use did not appreciably weaken the adherence-mortality association. Nevertheless, it is possible that some key explanatory variable was not measured and therefore not able to be used in the adjusted analyses. For example, Kellet (1990) suggests that depression, which has been independently associated with mortality in coronary artery disease and myocardial infarction patients (Barth, Schumacher, & Herrmann-Lingen, 2004; Carney & Freedland, 2003; Frasure-Smith, Lesperance, & Talajic, 1993; Glassman & Shapiro, 1998; van Melle et al., 2004) and with adherence to cardiovascular treatment regimens, cardiac risk factor modification, and cardiac rehabilitation (Blumenthal, Williams, Wallace, Williams, & Needles, 1982; Guiry, Conroy, Hickey, & Mulcahy, 1987; Kronish et al., 2006; Rieckmann et al., 2006), may have contributed to both low levels of adherence and higher mortality in the heart disease treatment trials (AMIS, CDP, and BHAT).

A recent study calls into question the extent to which a "healthy adherer" effect is responsible for the relationship between adherence (whether to active drug treatment or placebo) and positive health outcomes, including

survival (Rasmussen, Chong, & Alter, 2007). In this longitudinal study of a large (N = 31,455) cohort of elderly patients with acute myocardial infarction (MI), adherence to evidence-based therapies for MI (based on pharmacy refill records) was associated in dose-response fashion to mortality, with high adherers to beta-blockers and statins at lowest risk for mortality, moderate adherers to these drugs at higher risk, and low adherers at greatest risk. However, this graded relationship was not found for calcium channel blockers, which have not been shown to improve post-MI survival. One might expect that, if a placebo-adherence relationship exists, adherence to a non-evidence-based (and therefore, presumably, noneffective, at least in terms of mortality) therapy would show the same kind of graded, dose-response relationship with mortality as would adherence to a biologically active therapy. However, there are several differences between the Rasmussen et al. (2007) study and the placebo-controlled trials finding placebo-adherence effects. The main difference is that the Rasmussen et al. (2007) study is a longitudinal cohort study of a group of elderly patients seen in clinical practice settings, rather than a placebo-controlled trial. There are many differences between patients who volunteer to participate in a clinical trial and those being seen in clinical practice that may account for the discrepant findings, including health status, health-related behaviors, and even expectations about treatment effectiveness. Other differences include the use of pharmacy refill data in the Rasmussen et al. (2007) study (rather than pill counts, which are the primary adherence measures used in the clinical trials) and analyses using survival curves in the Rasmussen et al. (2007) study (rather than simple percentages of patients who survived in the active treatment and placebo groups in the studies that showed a placebo-adherence effect). Thus, while the Rasmussen et al. (2007) findings raise questions about healthy adherer effects and placebo-based adherence, too many methodological and analytic differences exist between their study and the clinical trials that find such placebo-adherence effects to rule out the existence of either of these phenomena.

Of clinical trials, however, at least two studies have failed to find a relationship between adherence to placebo and health outcomes. In the Lipid Research Clinics-Coronary Primary Prevention Trial (LRC-CPPT), a primary prevention trial of cholesterol lowering as a way to reduce coronary heart disease risk, no evidence of a relationship between adherence to placebo and fatal or nonfatal MI (the primary outcome) was found after adjustment for baseline measures of risk, including serum lipid levels (Lipid Research Clinics Program, 1984). And no relationship between placebo adherence and arrhythmic mortality was found in the Cardiac Arrhythmia Suppression Trial (CAST), a three-arm, double-blind, placebo-controlled randomized clinical trial of two anti-arrhythmic agents in patients with ventricular arrhythmias following MI. The trial was stopped early due to increased mortality in the active-treatment arms (encainide and flecainide), and, as expected, adherence to treatment was associated with increased arrhythmic mortality in the active treatment arms, but no association was found for the placebo group (Oblas-Manno et al., 1996). Questions have been raised about the CAST placebo adherence findings, due to problems such as low power (analyses were based on only nine arrhythmic deaths) and the limited nature of the adherence data used (only pill counts from the first follow-up visit were used; Avins, personal communication). In addition, it is interesting to note that of the seven clinical trials that have investigated the association

between adherence to placebo and health outcome, the two that did not find an effect were the only trials that did not use total mortality as the primary outcome and the only two to analyze adherence as a continuous variable (Avins, personal communication). Secondary analyses of data are currently under way to examine these and other differences between studies that found the effect and those that have not and to better understand the basis for the relationship between placebo adherence and mortality found in most of the studies.

Apart from their value in justifying intent-to-treat approaches to data analysis in clinical trials, some have argued that the finding of a relationship between placebo adherence and mortality reflects an interesting phenomenon that deserves study in its own right—that the act of adherence itself may enhance psychosocial characteristics or qualities that generate positive health outcomes (Epstein, 1984; Horwitz & Horwitz, 1993). Epstein (1984) raises the possibility that patient expectations about the efficacy of treatment may play a role in the relationship between adherence and health outcomes found in these studies. Horwitz and colleagues (Horwitz & Horwitz, 1993; Horwitz et al., 1990) suggest that adherence may be a marker not only for a healthy lifestyle but also for a variety of psychological, social, and behavioral variables that may affect the outcomes of treatment (e.g., a patient's ability to control aspects of life that affect disease progression; optimism or resilience in the face of adversity) and recommend further research using more extensive and refined measures of psychosocial and behavioral factors.

We agree that the relationship between adherence and placebo found in these studies may be attributable to bias or to adherence acting as a surrogate for healthy lifestyle behaviors. However, in this chapter we explore the possibility that the act of adherence may affect health outcomes by activating the nonspecific or placebo effects of an intervention. In the next section, we propose a hypothetical model that demonstrates the ways in which adherence might influence treatment outcome via nonspecific effects.

Model: The Nonspecific Effects of Adherence

The model proposed here is one in which adherence to an intervention is seen as enhancing not only the effects of active treatment components but also the effects of nonspecific components of that intervention. Specifically, the model suggests that adherence enhances the following nonspecific components that can influence intervention outcomes: (1) patient and provider *expectancies* of the intervention's success, and (2) the *social support* available to the patient from the provider and others in the patient's environment.

In several chapters in this volume, expectancies and social support have been described as predictors of adherence. The model presented here suggests that these factors may also be "effects" of adherence. Adherence influences the expectancy of treatment success to the extent that patients who follow an intervention develop the expectation that they will experience positive health outcomes. Conversely, patients who do not adhere should have a diminished expectancy of positive outcomes from the intervention. Patient adherence also impacts provider expectancies regarding the outcome of the intervention. For example, a physician is more likely to expect lower serum cholesterol levels in

a patient who is adhering to a prescribed low-fat diet than a patient who continues to eat a high-fat diet. Patient adherence may also influence the amount of social support extended to patients by providers and others in the patient's social network, since adhering to a prescribed medical regimen is likely to be rewarded by positive responses from family, friends, and caretakers.

As portrayed in the model, the relationship between adherence and the nonspecific components of treatment is a reciprocal one. Expectancies and social support are affected by adherence and, in turn, influence subsequent adherence. For example, the patient who adheres to the low-fat diet and meets with a physician who expresses a positive expectancy for lower cholesterol levels and praises the patient for adhering is more likely to continue adhering to the prescribed diet.

In the model, expectancy and social support are considered not only in terms of their relationship to adherence but also in terms of their roles as nonspecific factors influencing treatment outcomes. This aspect of the model is based on evidence that these two variables are important in influencing health outcomes (Agras, Horne, & Taylor, 1982; Berkman, Leo-Summers, & Horwitz, 1992; Hovell et al., 1986; Williams et al., 1992). Thus, the perspective added by this model is that the expectancies and social support fostered by adherence may have an affect on health that is independent of any active treatment the patient may receive.

Finally, the literature indicates that nonspecific effects are influenced by some of the same factors known to influence adherence. These factors include patient characteristics (e.g., attitudes toward the provider, self-efficacy, and positive expectancies) and intervention characteristics (e.g., therapeutic setting, provider characteristics, treatment cost, and method of treatment delivery). Figure 36.1 shows these characteristics as having effects on adherence and on nonspecific treatment components; in addition, patient characteristics can directly influence specific treatment effects (e.g., due to individual differences in sensitivity to the therapeutic agent).

Overview of the Placebo Effect

Shapiro and Shapiro (1984, p. 372) define a placebo as "any therapy or component of therapy that is deliberately used for its nonspecific, psychological, or psychophysiological effect, or that is used for its presumed specific effect but is without specific activity for the condition being treated." A placebo effect is defined as "the psychological or psychophysiological effect produced by placebos" (Shapiro & Shapiro, 1984, p. 372). This definition implies that active treatments may have placebo components and that the effects of specific therapies (i.e., nonplacebos) are often due to both placebo and nonplacebo effects (Shapiro & Shapiro, 1984).

Historically, the term "placebo" has referred to inactive pills or tablets given to control subjects in drug trials. Over time, however, the term "placebo effect" has come to refer to a variety of nonspecific effects on health outcomes that are integrally related to the delivery and monitoring of treatment but that are not attributable to the specific therapeutic agent under study. In this chapter, the terms "placebo" and "nonspecific" are used interchangeably.

36.1

The effects of adherence on health outcomes.
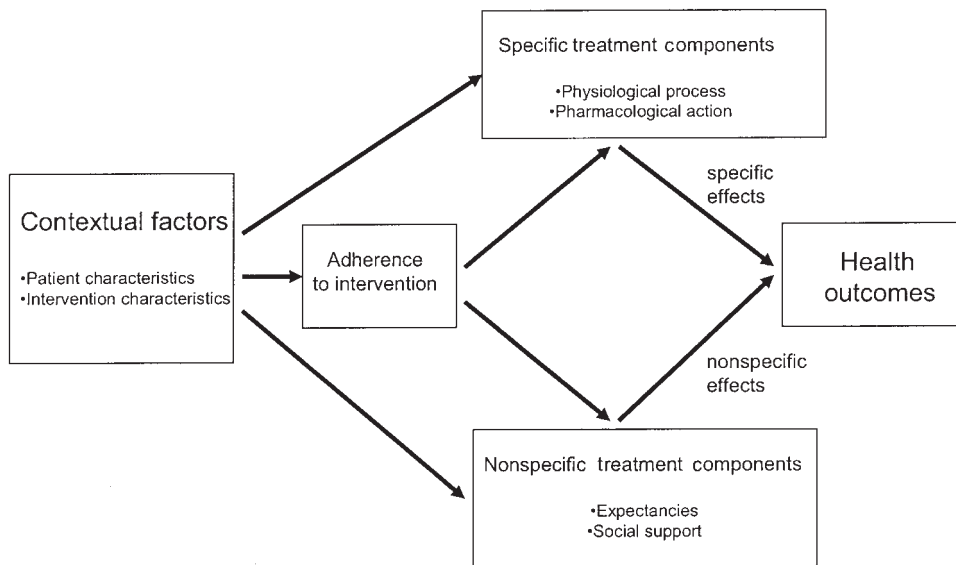
The nonspecific effects of treatments are well documented in the literature on medical and behavioral interventions. Placebo effects have been studied in medical conditions as diverse as pain (Peck & Coleman, 1991); ulcerative colitis (Meyers & Janowitz, 1989) and irritable bowel syndrome (Dobrilla, Imbimbo, Piazzi, & Benzi, 1990); and congestive heart failure (Archer & Leier, 1992; Packer, 1990). Beecher (1955), in his classic review of placebo responses in patients suffering a wide variety of illnesses, found that in 35% of patients (averaged across the studies), symptoms were "satisfactorily relieved" by the placebo.

Placebo effects have received increased attention in clinical trials that have found greater than expected improvements in the health of participants in placebo control groups, in some cases equivalent to or greater than those observed in participants receiving active treatment. In the area of hypertension control, for instance, a number of studies, including the Multiple Risk Factor Intervention Trial (Multiple Risk Factor Intervention Trial Research Group, 1982), the Hypertension Detection and Follow-up Program (Hypertension Detection and Follow-up Program Cooperative Group, 1979), and the Australian National Blood Pressure Study (Management Committee, 1980), found significant and persistent reductions in blood pressure in usual care or placebo control groups. Similar results have been reported in several other studies that compared the effects of behavioral treatments for hypertension (e.g., relaxation training, biofeedback, cognitive restructuring) with the effects of placebo treatment (e.g., flexibility training) or blood pressure monitoring alone (Agras, Taylor, Kraemer, Southam, & Schneider, 1987; Chesney, Black, Swan, & Ward, 1987; Jacob et al., 1986; Ward, Swan, & Chesney, 1987). The results of these studies stimulated inquiry into possible explanations for the significant improvements or changes found for control groups and focused attention on the impact of nonspecific

and behavioral factors on control groups in clinical trial research (Kramer & Shapiro, 1984).

It is important to note that in the clinical trials mentioned here, as well as in other studies, nonspecific effects have been demonstrated to involve not only improvements in subjective symptoms but also objectively measured cardio-vascular risk factor and end organ changes (Gould, Davies, Mann, Altman, & Raftery, 1981). Indeed, the physiological effects of placebos are acknowledged as being very powerful: placebos can induce addiction and have been reported to be more effective than, or even to reverse the effects of, some pharmacologic agents (Shapiro & Shapiro, 1984). In addition, the range of physiological processes that have been shown to exhibit placebo effects are very broad and include inhibited gastric acid secretion, reduced adrenocortical activity, and decreased serum lipoproteins (Bush, 1974).

Mechanisms of the Placebo Effect

The recognition that nonspecific treatment components may influence health outcomes raises questions regarding the mechanisms underlying these effects. Placebos are thought to exert their effects through both *psychological* and *biological* mechanisms (Wilkins, 1985).

Psychological Mechanisms

Models that focus on the psychological mechanisms underlying the placebo effect fall into two categories: (1) *learning theory* models, which explain placebo effects as classical conditioning phenomena, and (2) *cognitively oriented* models, which emphasize the role of mental processes, such as expectancy.

Learning Theory Models

Models based on a learning theory approach focus on the placebo effect as a *conditioned response.* According to this explanation, the complex of stimuli surrounding the administration of a drug (e.g., taking a pill) become conditioned stimuli because of their repeated association with drug administration and relief from suffering during the person's developmental history (Wickramasekera, 1985). For example, a patient who derives pain relief from aspirin may eventually respond in a similar fashion to medications with similar characteristics (e.g., small, white pills). Support for the learning theory model involves mostly animal research, which has confirmed the conditioning of physiologic and pharmacologic responses as an important element in placebo phenomena (Ader, 1985). This model is useful in explaining placebo effects associated with the administration of drugs; however, it is less applicable to situations involving nonpharmacologic treatments, such as behavioral or lifestyle interventions.

Cognitive Models

Currently, the most widely accepted cognitively based explanation for the placebo effect is that it is based on people's expectations of therapeutic benefit or success. The expectancy model of placebo effects is similar to an early

cognitively based hypothesis that postulated a relationship between people's response to placebo and their suggestibility. However, although it is commonly believed that individuals who score high on measures of suggestibility are more prone to the placebo response, no consistent relationship has been found between this response and either suggestibility or hypnotizability (Evans, 1985).

Another early cognitive model of placebo effects involved anxiety reduction, resulting from an individual's belief in the pain reducing effects of a treatment. According to this model, placebo effects are attributable to decreased perceptions of pain and distress associated with anxiety reduction. This hypothesis was supported by studies showing that for chronically anxious individuals, feelings of reduced anxiety following placebo ingestion lead to a significant increase in pain tolerance (Evans, 1985). While the anxiety-reduction hypothesis addresses the effects of placebos on pain, it does not generalize easily to the many other physiological processes affected by placebos.

More recently, studies have shown that individuals' expectations regarding the effects of a drug or treatment influence their responses to placebo treatments. For example, study participants who received a caffeine placebo and were led to expect improved performance on a psychomotor task showed improved performance relative to participants who received the caffeine placebo and were told they could expect impairment (Fillmore, Mulvihill, & Vogel-Sprott, 1994). Similarly, the belief that alcohol has been consumed and expectations about the effects of alcohol have been shown to influence a variety of responses to consumption of nonalcoholic beverages, including pain reduction (Cutter, Maloof, Kurtz, & Jones, 1976) and alcohol craving (Ludwig, Wikler, & Stark, 1974). Study participants given placebos that were described as analgesics have also reported less pain than no-treatment controls (Liberman, 1964; Gelfand, Ullman, & Krasner, 1963), and the content of placebo instructions has been found to be a powerful influence on study participants' responses to dental pain (Gryll & Katahn, 1978). Other studies have demonstrated changes in physiological responses such as blood pressure and pulse rate based on participants' expectancies about the effects of the placebo being administered (Kirsch & Weixel, 1988). Ross and Olson (1981), in an examination of double-blind drug outcome studies, conclude that participants' expectancies are key determinants of placebo responses and that participants provided placebos will respond in ways that are congruent with expected symptoms or physical responses.

Studies in clinical settings have also shown that responses to treatment are mediated by patient expectancies generated within the therapeutic relationship. In one study, students who expected a relaxation procedure to produce an immediate lowering of blood pressure had significantly lower systolic blood pressures immediately following the procedure than did a group of participants who were led to believe that the relaxation training would produce a delayed effect (Agras et al., 1982). In contrast, Wadden (1984) found no differences in blood pressure reduction between participants assigned to a cognitive therapy condition, which involved a positive expectancy of blood pressure change, and those assigned to relaxation therapy. Results from several other studies, however, suggest that the effects of relaxation therapy may be primarily due to nonspecific factors, such as positive expectancy or social support (Brauer, Horlick, Nelson, Farquhar, & Agras, 1979; Luborsky et al., 1982).

Evidence suggests that the placebo effect is influenced not only by patient expectancies but also by doctor or experimenter expectations. For example, when the physician believes a powerful drug is being used in a double-blind study, the placebo effect is stronger than if he or she believes the medication is less effective (Evans, 1985). Thus, the physician's belief about a drug's efficacy may be communicated to the patient and appears to mediate treatment effectiveness.

An individual's expectations about treatment success may be influenced by a variety of factors. For example, the social support received from family, friends, and health providers may enhance patients' beliefs or expectations about the efficacy of therapy. When a spouse is supportive of the patient's receiving a specific form of therapy, the patient may come to believe that such therapy will be beneficial. The effect of social support from members of a patient's network can be especially powerful when those others are seen as credible sources of information and when the patient has a great deal of faith in them. Plotkin (1985) emphasizes the impact of the patients' faith in the therapist as an important condition for behavioral change to occur in therapy.

The powerful influence of social support on health outcomes, including morbidity and mortality, is now well documented (Berkman et al., 1992; Williams et al., 1992). Given these effects, one might expect that supportive interactions with health care personnel might influence response to treatment. One study demonstrated a positive effect for personalized care, operationalized as greater personal attention and warmth shown to the patient, on blood pressure reduction in hypertensives (Hovell et al., 1986). In this study, patients receiving personalized care differed significantly in the magnitude of their blood pressure reductions from those receiving usual care. Several other studies have documented similar differences in the effects of personalized and usual care, although the mechanisms for such effects remain unknown (Dunbar, Marshall, & Hovell, 1979; Finnerty, Mattie, & Finnerty, 1973). Hovell et al. (1986) have speculated that personalized care may evoke a generalized relaxation response and suggest that future research is needed to determine the mechanisms underlying the effects of social support on blood pressure reduction. One mechanism through which social support may affect cardiovascular health, including the development of hypertension, is through effects on biological processes, such as neuroendocrine or hemodynamic functioning. This hypothesis has received support from a series of studies that have shown that interpersonal support, characterized by the presence of a friend or supportive other during a challenging experimental task, reduces blood pressure reactivity to stress (Christenfeld et al., 1997; Edens, Larkin, & Abel, 1992; Fontana, Diegnan, Villeneuve, & Lepore, 1999; Gerin et al., 1992; Kamarck, Manuck, & Jennings, 1990; Lepore, Allen, & Evans, 1993).

Neurobiological Models

Developments in recent years, particularly in neuroscience and biochemistry, including new tools such as functional magnetic resonance imaging (fMRI) and positron emission tomography (PET), have provided new insights into pathways by which placebos may exert effects. A detailed review of the full range of potential neurobiological mechanisms of the placebo effect that are currently

being proposed is beyond the scope of this chapter. Among those most relevant to the issue of adherence and the placebo effect is the evidence that the placebo may activate the endogenous opioid system and the neural circuitry underlying reward mechanisms (Benedetti et al., 2005; Benedetti et al., 2008).

In their original research on placebo analgesia, Levine, Gordon, and Fields (1978) hypothesized that placebo effects resulting in pain reduction are based on expectancies that activate the endorphin system. There is substantial evidence from studies of both clinical and experimentally induced pain that administration of placebo with the expectation of analgesia is associated with reduction in reports of pain that are reversed by either hidden or open administration of naloxone (see Amanzio and Benedetti, 1999; Benedetti, 1996).

The endogenous opioid system and its activation of μ-opioid receptors is thought to be important in animal and human responses to novel and potentially threatening environmental stimuli (Filliol et al., 2000; Zubieta et al., 2003). This neurotransmitter system is implicated in the regulation of neuroendocrine functions, stress responses, emotional states, and pain. (Akil et al., 1984; Sora et al., 1997; Zubieta et al., 2001, 2003).

Using fMRI, researchers found that placebo administered under the condition of expectancy (for pain relief) was associated with reductions in activity of regions of the brain known to be pain-responsive (the rostral anterior cingulate, the insular cortex, and the thalamus) (Wager et al., 2004). Using PET and molecular imaging techniques, Zubieta and his colleagues examined the effects of administration of placebo with expectancy on the activity of the endogenous opioid system on μ-opioid receptors in healthy human volunteers who were exposed to deep sustained muscle pain (Zubieta et al., 2005). To circumvent the activation of antinociceptive (pain-inhibiting) responses to sustained pain, which could interfere with the placebo responses, this team of investigators used an adaptive system that maintained the pain over time by increasing the pain stimulus as volunteer ratings of the pain declined. With this experimental procedure, Zubieta and his research team observed, for the first time, significant placebo-induced neurotransmission in both higher and subcortical brain regions that was mediated by the μ-opioid receptors. This work "takes the investigation of placebo effects directly into the realm of human brain neurotransmission, addressing the function of a single neurotransmitter system" (Zubieta et al., 2005, p. 7759). As noted earlier, the μ-opioid receptor-mediated neurotransmission system is implicated not only in the modulation of pain but also in emotional responses (Zubieta et al., 2003) and stress responses, including those on the cardiovascular system (Akil et al., 1984).

Among the brain regions involved in the μ-opioid receptor-mediated neurotransmission are the pregenual and subgenual rostal anterior cigulate, the dorsolateral prefrontal cortex, the insular cortex, and the nucleus accumbens. This latter region, the nucleus accumbens, responds to anticipated rewards in studies conducted in nonhuman primates and in rodents. It is also a region potentially implicated in the placebo effect in Parkinson's disease, which is thought to be related to placebo-activated dopamine release (de la Fuente-Fernandez et al., 2002, 2004).

On the basis of observations in Parkinson's Disease, de la Fuente-Fernandez and his colleagues proposed the hypothesis that the placebo effect is mediated by activation of the brain circuitry underlying reward mechanisms and linked

to the expectation of therapeutic benefit (de la Fuente-Fernandez et al., 2001). Confirmation of this hypothesis is provided by Scott, Zubieta, and their colleagues who, using functional molecular imaging, demonstrated that not only is activation of dopamine release in the nucleus accumbens observed in response to placebo administration but there are individual differences in neurochemical responses (e.g., dopamine release) and psychophysiological responses (pain ratings) that are associated with individual differences in reward expectation processing (Scott et al., 2007).

Returning to the issue of adherence and the placebo effect, participants in trials or patients in clinical practice who adhere to placebos may be more likely to develop greater "reward expectancies" than those who are aware of their own nonadherence. These patients would therefore have greater placebo responses. The earlier discussion suggests that the placebo effect is mediated by neural reward mechanisms and the μ-opioid receptor-mediated neurotransmission system. This neurotransmission system is involved in behavioral and physiological responses to the environment, including the modulation of pain, emotional responses to events, and both psychological and physiological responses to stress. Thus, this proposed mechanism may at least in part explain some of the health-related changes associated with adherence to placebos discussed in this chapter.

Adherence and the Placebo Effect

Returning to the thesis outlined earlier that adherence may activate or enhance placebo effects, how might adherence influence these effects? There are two leading explanations: (1) adherence per se activates nonspecific components of treatment, and (2) certain characteristics of individuals who adhere to a treatment enhance the nonspecific components of treatment.

With the first explanation, given the hypothesis discussed in the previous section that expectancies of therapeutic benefit or success activate placebo effects, then any factor in a therapeutic situation that enhances such expectancies would indirectly influence placebo effects, as well. Adherence to treatment may be one such factor, since adherence is integrally related to patient expectancies in a therapeutic situation.

Patient adherence to treatment is influenced by the expectation that the treatment will produce the desired effect (e.g., lower cholesterol, reduced weight). For example, individuals will be more likely to adhere to a low-calorie diet if they believe that doing so will be effective in producing weight loss *and* if they see themselves as capable of adhering to the diet. Bandura (1977) refers to the former belief as an outcome expectancy (the belief that a given behavior will lead to a particular outcome) and the latter as an efficacy expectation (the belief that "one can successfully execute the behavior required to produce outcomes"). According to Bandura (1977), success in a therapeutic situation is based on the acquisition of expectancies of increased personal effectiveness, or efficacy expectancies. High-efficacy expectancies are related to perseverance at a task (e.g., adherence) and thus to maintenance of therapeutic improvement.

Expectations about treatment effectiveness and one's ability to comply with a treatment are thus important determinants of actual adherence to treatment.

However, as noted earlier, the relationship is reciprocal, since expectancies of success can also be a consequence of complying with treatment: the more one adheres to the treatment regimen, the more likely one is to expect treatment success. By complying with treatment, the patient enhances the expectation that the treatment will work. Adherence may also affect patients' generalized feelings of well-being and increase their expectations that they can control other aspects of their lives, such as health-related behaviors (Epstein, 1984), ultimately leading to changes in these behaviors (e.g., quitting smoking, adhering to other medications, and adopting healthy dietary and exercise regimens). While there are cognitive and social reasons for expecting health behaviors to cluster, few studies have found significant associations among health behaviors, with the exception of the documented link between smoking and alcohol consumption. National and health-plan level data suggest that a very small percentage of the population meets multiple recommended levels of positive health behaviors at once (e.g., Pronk et al., 2004; Berrigan, Dodd, Troiano, Krebs-Smith, & Barbash, 2003). However, there is some evidence that changing one behavior has implications for other behaviors. For example, intervention research has shown that having a more fit lifestyle is associated with improvements in diet (O'Halloran et al., 2001). Similarly, research by King and colleagues (1996) showed that reduced smoking behavior is associated with increased physical activity and that self-efficacy for smoking cessation was significantly associated with self-efficacy for increasing physical activity. It is possible that perceptions of control and more generalized self-efficacy are important mediators of positive health behavior adoption (i.e., change). Expectancies of change and improvement may therefore be important as both antecedents and consequences of adherence.

If this is true, then efforts to increase adherence (especially by enhancing expectancies of treatment success) may increase treatment effectiveness not only because they maximize the extent to which the patient receives active treatment but also because these adherence-induced expectancies activate placebo responses to treatment. In the same way, social support may influence patients' beliefs or expectations about the efficacy of treatment and thus influence nonspecific treatment responses.

The second explanation of how adherence influences placebo effects, that there are certain characteristics of adherers that activate nonspecific components of treatment, may also be based on an expectancy effect. For example, if adherers are more likely to have an enhanced sense of control over events in their lives and are therefore more likely to believe that they can affect their health positively by complying with treatment recommendations, then treatment effectiveness may result primarily from the greater expectancies for treatment success held by these individuals, rather than from the treatment itself. This may be true of behavioral treatments, as well as medical treatments. For example, one recent randomized study showed that the perception of adherence to healthy exercise levels (in the absence of increased workloads) predicted weight loss and other health benefits (Crum & Langer, 2007). In this study, female hotel workers were given information about the benefits of exercise on their health and were then randomized to one of two conditions: one group was told that their housekeeping work satisfied the CDC's recommendations for physical activity, while the other group was not told that their work was good exercise. Those who

were told that their work satisfied recommended physical activity levels had improved outcomes (greater weight loss, improved body composition, and reduced blood pressure) after 4 weeks than did the women who were not told this information. The study authors attributed this change to a placebo effect—that increasing the *perceived* level of exercise alone resulted in health benefits.

While the results of this study are intriguing and merit further investigation, the authors fail to control for or measure differences in the *actual* levels of physical activity of the two groups, which could be the source of the differences found in health benefits between the groups. The authors state that hotel managers reported no alterations in housekeepers' workloads over the 4-week study, but it is possible that the information provided to the "informed" workers, that housekeeping is good exercise, stimulated them to alter the *intensity* of their physical activity while working; perhaps applying the label "exercise" to the work they were performing caused them to more vigorously perform that work, resulting in the health benefits that were found. To explore this possibility, the use of accelerometers or other devices to monitor the intensity of workers' physical activity, as well as measurement of fitness level before and after the study period for both "informed" and "control" groups, would be required.

Other characteristics that differentiate adherers from nonadherers (e.g., "hardiness" or greater resiliency under stress, optimism) may also be important determinants of treatment success to the extent that they influence patient expectations regarding treatment outcomes. More adherent individuals may also be more likely to engage in a variety of health-related behaviors, such as adopting healthier diets and exercise regimens and avoiding stressors, than nonadherers. Adoption of these behaviors, which may increase expectations of better health, may also contribute to better medical outcomes in these individuals. These may have implications for mental health, as well as physical health. For example, one recent intervention among breast cancer survivors found that both a nutrition intervention and a psycho-educational intervention resulted in better physical functioning and fewer depressive symptoms than were found in a group that received standard care (Scheier et al., 2005). The effects of the nutrition intervention were mediated in part by self-efficacy expectations.

Finally, Horwitz and Horwitz (1993) suggest that in individuals with chronic disease, adherence may reflect better adaptation to the stress of illness and an enhanced capability to respond to such stress. This enhanced adaptive response may itself generate both positive health-related behaviors and increased expectancies for treatment success, both of which may result in improvements in health.

Implications and Research Directions

There has been no research to date that adequately tests the model proposed in this chapter concerning the role that adherence may play in enhancing nonspecific treatment effects. This may be partly because of the lack of attention paid to nonspecific treatment components in health research. Although placebo effects are acknowledged as being of sufficient importance to necessitate the inclusion of placebo controls in most studies of medical or behavioral interventions, biomedical researchers have not made use of the placebo condition as an

opportunity to examine and better understand the nonspecific effects of treatment. Instead, placebos have traditionally been viewed as nuisance variables to be controlled for, rather than as variables that are important for study in their own right or as important adjuncts to active treatment (Evans, 1985). This is in contrast to the emphasis on nonspecific factors in psychotherapy outcome studies (Frank, 1971; Garfield, 1980, 1982; Smith, Glass, & Miller, 1980; Stone, Imber, & Frank, 1966). In this literature, psychotherapy researchers have identified a number of nonspecific factors, or "common ingredients," as being important contributors to positive therapy outcomes, regardless of the particular mode of therapy used (Garfield, 1982). The nonspecific factor thought to be most central to therapeutic outcome is the patient's expectation of benefit (Frank, 1961, 1983; Garfield, 1982; Goldstein, 1962), which has also been implicated as an important mechanism underlying placebo effects.

The model presented in this chapter suggests that adherence to treatment may affect health outcomes by enhancing or activating nonspecific effects of treatment (e.g., expectancies, social support). This has important implications for clinical trials and other research studies involving interventions, since there are several situations in which such adherence-induced placebo effects could lead to inaccurate conclusions about treatment efficacy.

As stated earlier, secondary analyses of data by Avins et al. (personal communication) are being conducted to confirm the placebo-adherence effect, to determine conditions under which this effect is likely to occur, and to better understand the basis for the relationship between placebo adherence and mortality that has been found. The results of these analyses should provide important information concerning the existence and nature of this effect.

While placebo control conditions are commonly used in studies involving the evaluation of drug therapies, studies evaluating other types of interventions (especially behavioral or lifestyle interventions) often do not use placebo conditions or use inadequate placebo controls. This is a result of the difficulty of designing a placebo control condition when the treatment is behavioral in nature. When the treatment is pharmacological, it is possible to manufacture a pill that is identical in every respect (e.g., in appearance) to the pharmacological agent being used. But it is often difficult to devise a placebo for a behavioral treatment that is identical to the treatment itself in every way except that it has no active component (Buck & Donner, 1982). Clearly, given the possibility that adherence to an intervention may affect the evaluation of a treatment's effectiveness, the design of placebo conditions for all studies involving patient adherence to some intervention, whether behavioral or pharmacological in nature, should be given serious consideration.

Problems may arise even when adequate placebo controls are used if adherence rates differ between the treatment and the control groups. One reason for different adherence rates that could influence patient expectations regarding treatment success (and therefore affect treatment effectiveness through those expectations) is that some patients receiving treatment who are particularly sensitive to physiological cues and sensations might interpret the presence or absence of such sensations as indicating whether or not they are receiving the active treatment (Wilkins, 1985). Because patients in the active treatment group would be more likely to become "unblinded" in this way, and therefore more likely to adhere to treatment and to expect a successful outcome, it would be

difficult to pull apart the actual treatment effect from an expectancy-induced effect. In this case, a more positive outcome for the treatment group could be inaccurately attributed to treatment efficacy when it was actually due to increased expectations of treatment success. This suggests that adherence rates in the treatment and the placebo conditions should always be assessed to rule out the possibility that adherence-induced placebo effects are responsible for any effects found.

The model presented in this chapter has implications not only for the internal validity of studies that involve adherence to interventions but also for the generalizability of such studies. For example, one disadvantage of prerandomization screening (also known as the "run-in" phase of a clinical trial) is that by screening out nonadherers, any effects found for a particular treatment can be generalized only to those individuals who are likely to adhere to a treatment regimen. Since these individuals may have certain psychosocial characteristics that affect their adherence behavior (e.g., high self-efficacy) and that may also affect treatment success, the finding of a treatment effect would be applicable only to a narrow subgroup of patients, those who adhere to treatment. More studies are needed of the characteristics of nonadherers and the ways in which they are similar to or differ from good adherers to determine whether the results of studies using "run-ins" can be generalized to those individuals who are typically less adherent.

Future research should attempt to (1) determine whether adherence-induced expectations do in fact activate placebo effects, and (2) identify and evaluate aspects of the act of adherence or characteristics of those who comply that may enhance placebo effects. Furthermore, clinical trials and other studies that evaluate the effects of interventions should use designs that allow researchers to distinguish between or control for these effects. Rosenthal (1985) and Ross and Buckalew (1985) suggest experimental designs that can be used to better understand how nonspecific effects may impact evaluations of treatment effectiveness. A method that may help clarify whether or not patient expectancies are mediating the effects of adherence on mortality and morbidity is a causal modeling approach that tests the effect of adherence on health outcomes directly and indirectly (via expectancy as a mediating variable). Aspects of the model presented in this chapter can also be tested experimentally. Examples of this approach include laboratory studies in which participants' expectations about the effects of a particular treatment are manipulated (see Agras et al., 1982; Fillmore et al., 1994; Kirsch & Weixel, 1988). A classic design in this regard is the balanced placebo design proposed by Marlatt and Rohsenow (1980), which allows independent evaluation of drug effects, expectancy effects, and their interaction. Design of studies to include a placebo and nonplacebo control group may also clarify expectancy effects.

Some behavioral and biomedical researchers have called for increased attempts to understand and harness the power of the placebo effect to benefit patients in clinical practice settings (Benson & Friedman, 1996; Chaput de Saintonge & Herxheimer, 1994; Connelly, 1991). Clearly, more attention should be focused on the role of nonspecific factors in health-related research, similar to the prominent role given to such factors in psychotherapy outcome research (Garfield, 1982). Perhaps certain components of health care interventions, such as enhanced expectations of benefit or perceived social support available from

the health care provider, are "common ingredients" that enhance health-related outcomes regardless of the treatment or disease process involved. Future research should focus on identifying such common ingredients and using them to increase the effectiveness of health-related interventions.

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Collaboration Between Professionals and Mediating Structures in the Community: Social Determinants of Health and Community-Based Participatory Research

37

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With a focus on identifying ways in which providers and colleagues can help individuals develop healthier lifestyle practices, many chapters in this book emphasize micro-level analyses and provide rich information about effective interventions for behavior change. This micro focus represents a necessary but not sufficient approach to the goal of improving health. In this chapter, we consider social determinants of health (SDOH) and community-based participatory research (CBPR). Both are powerful means for effecting change. SDOH provides a philosophical underpinning for action aimed at transforming power relations from ones that permit inequity and injustice to ones that promote equity. CBPR offers a method for building and capitalizing on productive partnerships that result in empowered communities acting to improve health.

Together, these two approaches help frame a language of health behavior that more clearly articulates the values of equity, social justice, and the common good. (See also chapter 38, "Ethical Issues in Lifestyle Change and Adherence," for a further discussion of equity framing in adherence research.)

When the second edition of this volume was published a decade ago, this chapter addressed "whether health is primarily a personal responsibility or a societal obligation" (Ribisl & Humphreys, 1998, p. 535). In laying out their thesis, the chapter's authors presented strengths and weaknesses of the individual as well as the paternalistic approaches to health and suggested a "third way" that would highlight the advantages while reducing the disadvantages of each approach. This "third path" consisted of collaboration with mediating structures, defined as organizations and institutions (e.g., churches, families, voluntary associations, and neighborhoods) that "stand between individuals' private lives and the larger public domains" (Ribisl & Humphreys, 1998, p. 539). In suggesting that collective approaches are based on "doing with" rather than "doing for" or "doing to," the authors concluded that health promotion and behavior change initiatives could be most effective if they adopted a collaborative or partnership model and took advantage of the best elements that community control and decision making offer. In this chapter, we build on these ideas and advance the need to address social determinants of health and consider community-based participatory research.

Increasingly, models of health use ecological approaches that recognize the interconnectedness of individuals and the context of the communities in which they live (Wilcox, 2007). Yet, despite the development of these models and the knowledge that many advances in the conquest of diseases have come from structural approaches and macro interventions such as environmental and policy changes that alter the norms in which we live, a preponderance of health promotion activities continues to be directed toward encouraging individuals to adopt healthier approaches to living. In focusing the majority of our efforts on the individual, we risk failing to attain our full potential for improved health (McKinlay, 1998). We must use our understanding of SDOH and the potential of CBPR if we are to make meaningful, lasting changes (Navarro et al., 2006).

The Ecological Approach

The choice of language and how we elect to frame issues are powerful influencers of action (Hofrichter, 2003; Leichter, 2003). For example, it is widely stated that the factors affecting an individual's health status include genetic make-up, environment, and medical care, as well as lifestyle and health behaviors (McGinnis, Williams-Russo, & Knickman, 2002; O'Hara, 2005). With lifestyle and behavioral factors accounting for approximately 50% of an individual's health status (Regan & Brookins-Fisher, 1997), policymakers suggest that we need to pay more attention to *individuals*' lifestyle "choices" and behaviors (McGinnis et al., 2002). Placing the majority of our efforts at this level, however, ignores the power of context in which individuals live and work. The decrease in tobacco use provides a good example of context, as behavioral change did not reach significant levels until laws, regulations, social norms, taxes, and other societal factors were implemented in conjunction with individually focused aids for quitting and for avoiding initiating tobacco use (Schneider, 2006).

Almost 30 years ago, in an essay about health care in America, Crawford (1979) challenged what he saw as the then prevailing victim-blaming approach to health promotion. He asserted that this focus substituted an ideology of individual responsibility for an understanding of the complexities of social causation of disease and disability and suggested that the individual approach "ignored what is known about human behavior" and minimized "the importance of evidence about the environmental assault on health." Crawford lamented the fact that individuals were being held responsible for achieving a level of health that was influenced by environmental factors beyond their control and castigated those who asserted that, while environmental factors might be relevant, there was little that could be done to effect change at this level (Crawford, 1979).

Writing at about the same time, Brofenbrenner (1977, 1979) proposed an ecological perspective on health in which behavior was viewed as simultaneously being affected by and affecting multiple levels of influence. In dividing environmental influences on behavior into micro-, meso-, exo-, and macro-systems, he reinforced the importance of addressing the SDOH as a means of achieving meaningful change and noted that ecological models view behavior and the social environment as inextricably intertwined. Consequently, to improve health, SDOH need to be addressed, with actions and interventions complementing one another and occurring simultaneously on all levels.

In 1988, McLeroy and colleagues (1988) proposed an ecological model for health promotion that specified patterned behavior as the outcome of interest, with behavior determined by intrapersonal factors; interpersonal processes and primary groups; institutional factors; community factors; and public policy. This model extends Brofenbrenner's by dividing the macro-system into community factors and public policy. Both are relevant to health promotion and behavior change. McLeroy et al.'s ecological model offers a comprehensive approach that captures a wide range of strategies available for health promotion interventions and programs and, again, reminds us of the importance of focusing on SDOH and on working at multiple levels simultaneously.

While applying the ecological model has been shown to be effective in identifying environmental causes of behavior and suitable environmental interventions, using this model can result in charges of coercion, paternalism, and invasion of privacy (McLeroy, Bibeau, Steckler, & Glanz, 1988). To avoid these charges and to maximize the model's effectiveness, the active involvement of communities in defining issues and selecting foci of change with accompanying appropriate interventions, implementation, and evaluation is needed. While not a panacea, the process of engaging in community consensus building around health concerns and issues initiates needed consciousness raising regarding causes and responsibilities for health and illness (Wallerstein & Bernstein, 1988).

Social Determinants of Health (SDOH)

Definition and Background

The social determinants of health (SDOH) are defined similarly but with nuanced differences by various theorists and researchers. Synthesizing these definitions, Raphael (2007) concluded that SDOH represent the "economic and

social conditions that influence the health of individuals, communities, and jurisdictions as a whole." These determinants influence an individual's health directly, as well as indirectly, through the extent to which a person has access to the physical, social, and personal resources to identify and achieve personal aspirations, satisfy needs, and cope with the environment. Thus, SDOH is about the "quantity and quality of a variety of resources that a society makes available to its members" (Raphael, 2007). In short, SDOH captures elements related to the social gradient, stress, early life, social exclusion, work, unemployment, social support, addiction, food, and transport (Wilkinson & Marmot, 1998).

Engels (1845/1987), and Virchow (1848/1985), two prominent figures in health and medicine, reported that factors related to a society's structure, such as political, economic, and social forces, exerted important influences on health. After investigating a typhus epidemic in Upper Silesia, Virchow did not recommend that the region adopt a behavioral model of health. Rather, he risked his career by asserting that unfair social structures that included tax policies and feudalism were responsible for residents' unsanitary conditions and poor diet and that it was these factors that had been a catalyst for the epidemic. He challenged the power structure by asking, "Do we not always find diseases of the populace traceable to defects in society?" and encouraged physicians to become advocates for the poor, working for change at the level of social structures.

The World Health Organization's (WHO) constitution states that health is "a state of complete physical, mental and social well-being" (World Health Organization, 1948). Premising its view of health on this definition, 40 years later, in 1986, the First International Conference on Health Promotion drafted what has become known as the Ottawa Charter. Based on strong principles of equity, the Charter identified the prerequisites of health as peace, shelter, education, food, income, a stable ecosystem, sustainable resources, social justice, and equity. Despite that Charter's principles having been reaffirmed at subsequent international meetings, in the United States, however, the major focus of health promotion has been on lifestyle approaches associated with behavioral change, rather than on society's larger structural elements (Baum, 2007; Raphael & Farrell, 2002). Nevertheless, local efforts that engage community voices have identified governmental and other institutional decisions as appropriate areas of activity for improving health (Minkler, 1997; Minkler & Wallerstein, 2003). Moreover, the U.S. blueprint for improving population health states that "communities, states, and national organizations will need to take a multi-disciplinary approach to achieving health equity—an approach that involves improving health, education, housing, labor, justice, transportation, agriculture, and the environment" (U.S. Department of Health and Human Services, 2000, p. 16; Metzler, 2007).

In the United Kingdom, two reports, the Black Report (1980) and the Health Divide (1992), have energized the SDOH approach by keeping the influence of social structures in the purview of policy makers. These reports described how members of the lowest employment-level groups were more likely than those at higher levels of employment to experience a wide range of diseases and premature death from illness and injury throughout the life cycle (Townsend, Davidson, & Whitehead, 1992). The authors reported health differences in a step-wise progression across the socioeconomic range, with professionals having the best and manual laborers the worst health. The researchers concluded that material conditions such as income, working conditions, and quality of food

and housing were the primary determinants of outcomes and noted that health inequalities were socioeconomically driven. The significance of these two reports cannot be understated—they mark the first time that the government of a Western industrialized nation acknowledged that a wide range of social policies influenced levels of health and that these policies were deemed appropriate for government action (Benzeval, 2002).

Evidence Supporting SDOH

In the past century, industrialized nations witnessed significant improvements in health status on a wide range of measures. While access to medical care and changes in individual behaviors are responsible for part of these improvements, the main contributors to increased longevity and decreases in morbidity are improvements in material conditions, including more widespread education, safe food, improved housing, and better sanitation. In a recent seminal study of the macro-economic determinants of health, researchers concluded that the "empirical evidence is overwhelming that poverty, measured at the levels of societies as well as individuals, is causally related to poor health of societies and individuals, respectively" (Subramanian, Belli, & Kawachi, 2002, p. 287). There are multiple ways in which poverty can affect health. Income provides the ability to purchase shelter, food, and warmth and, in many instances, the ability to participate in society. Poverty is stressful and frequently results in heightened levels of anxiety that can damage health. Additionally, a low income limits a person's choices and represents a major barrier to healthful behavior changes (Benzeval, Judge, & Whitehead, 1995). It is estimated that the cumulative effect of income-related exposures may mean that the highest 5% of income earners live approximately 25% longer than the bottom 5% (Rogot, 1992) and that an individual 18 years of age or older who lives below the poverty threshold can expect 8.5 fewer health-adjusted life years than a person of the same age who lives above that threshold (Muennig, Franks, Jia, Lubetkin, & Gold, 2005).

Writing in 2002 under the auspices of the Center for Social Justice Foundation for Research and Education and focusing on social exclusion, Raphael concluded that while "an unhealthy material environment and unhealthy behaviors have direct harmful effects, . . . the worries and insecurities of daily life and the lack of supportive environment also have an influence" (Raphael, 2002, p. xi). The concept of social exclusion helps us understand the interrelationships among three important and influential aspects of low-income people's lives: material disadvantage, excessive psychosocial stress, and unhealthy behaviors (Raphael, 2002). "Social exclusion is defined as a multi-dimensional process, in which various forms of exclusion are combined: participation in decision-making and political processes, access to employment and material resources, and integration into common cultural processes. When combined, they create acute forms of exclusion that find a spatial representation in particular neighborhoods" (Raphael, 2002, p. 30).

Examining cardiovascular disease and noting that only a small proportion of the variation in incidence of heart disease is explained by medical and lifestyle risk factors, animal researchers have identified the biological and psychological mechanisms by which chronic stress and hierarchy create illness (Sapolsky & Share, 1994; Shively, Laird, & Anton, 1997). These stress models reflect the

experience of life lived on a low income and help explain the relationship between low income and cardiovascular as well as other diseases. "Chronic anxiety, insecurity, low self-esteem, social isolation, and lack of control over work appear to undermine mental and physical health" (Brunner & Marmot, 1999, p. 41). It has been posited that, by disturbing the usual homeostatic equilibrium by repeated activation of the related "fight or flight" response, social differences affect neuroendocrine, physiological, and metabolic variables—the precursors of ill health and disease (Brunner & Marmot, 1999; Kunst, Groenhof, & Mackenbach, 1998; Stansfield & Marmot, 2002). Additionally, stress has been shown to be associated with changes in allostatic load, resulting in bodily wear and tear (McEwen, 2003), as well as higher levels of cortisol excretion, leading in time to excess weight gain (McEwen, 1998a, 1998b). Furthermore, adding to this toll on the body is the positive association between the psychosocial stress of living in poverty and the likelihood of adopting behaviors such as tobacco use and lack of physical activity that are related to poor health (Wardle & Gibson, 2002). Individuals who have adequate coping mechanisms, coupled with opportunities to control their environments, are better able to return rapidly to a resting level and thus resist stress-related conditions (Marmot & Wilkinson, 1999).

Ten years ago, researchers concluded that there was a body of evidence that demonstrated the accumulating effect of a lifetime of poor socioeconomic conditions on adult health outcomes. It is now understood that an early life spent in adverse socioeconomic conditions can result in lasting increases in the risk of cardiovascular disease, respiratory disease, diabetes, and some cancers (Smith, Hart, Blane, Gillis, & Hawthorne, 1997). Without structural changes that address the social determinants of health, encouraging the adoption of healthy lifestyles and behavior change to reduce risk may simply be too little, too late. Moreover, focusing exclusively on individual behavior change may set people up to fall short of their goals and possibly even exacerbate the ill effects of a life characterized by high stress levels. In contrast, behavior change developed through using approaches focused on SDOH and associated with community-based participatory research (CBPR) engages people at the level of their primary concerns and marshals the community's energy and creativity to develop structures and systems that encourage the desired changes. Ultimately, understanding the SDOH is essential "because the health gradient [cannot] be attributed, in the main, to differences in diet, smoking or other aspects of 'lifestyle'" (Marmot, 2004, p. 241; see also Dovell, 2006). To improve health status through effecting behavior change, a community-engaged SDOH approach that incorporates multiple strategies and interventions and includes cross sector collaborations is needed.

Inequalities in Health Contributing to Evidence of SDOH

While empirical evidence related to the effect of a society's income distribution on population health suggests that income inequality is related to health levels (Kawachi, Kennedy, & Wilkinson, 1999; Ram, 2005), studies of economic inequality and health have found the effects of income inequality to be inconsistent or relatively small. As a consequence, researchers continue to debate the degree to which income inequality per se affects population health (Abbott, 2007). One hypothesis drawn from this body of research is that the relationship between

income inequality and poor health is not universal. Rather, it may depend on a government's social policies and the effect of those policies on reducing the impact of economic inequalities (Kawachi et al., 1999), as well as on the specific mechanisms by which income inequality is hypothesized to affect health (Subramanian et al., 2002). This hypothesis is consistent with evidence offered by SDOH researchers who have concluded that the most important social determinant of health is income inequality (the actual income gap between people), rather than absolute income. Indeed, evidence of differences in health status across an entire socioeconomic gradient, not just between rich and poor, demonstrates that the larger the gap, the lower the health status of the overall population (Marmot & Wilkinson, 1999).

Inequality is affected by government policies that focus on tax structure; education and job training; investment in children, particularly their education and their early developmental years; transfer payments; minimum wages and benefits; and availability of capital. An inverse relationship characterizes the degree of inequality within a geographic area and the amount of resources invested in social infrastructure and social safety net organizations. Ramifications of this inverse relationship are not reserved for the less well off exclusively; the well off in economically unequal communities have greater rates of health problems than their counterparts in communities characterized by relative economic equality (Lynch et al., 1998).

Current Activity Related to SDOH

Recognizing that in the later decades of the 20th century the world had largely moved away from action on the social determinants, early in the 21st century, the WHO committed to returning to its original concerns. To refocus activity on the social roots of ill health and health inequality, in 2005, the WHO constituted a global Commission on the Social Determinants of Health (CSDH). The Commission's charge is to catalyze policy and institutional change that addresses social determinants of health within countries, among institutions working in global health, and within WHO itself (Irwin et al., 2006). Knowledge Networks comprised of scientists and practitioners have been established and charged with compiling evidence related to policies and interventions to eliminate social barriers to health. In a recent report to the Commission, authors concluded that to effect change, "political will combined with the evidence offers the most powerful response to the negative effects of social determinants" (Kelly, Morgan, Bonnefoy, Butt, & Bergman, 2007, p. 7).

In the United States, the National Association of County and City Health Officials (NACCHO) has taken a strong SDOH approach to recommendations for future public health activity. In a book entitled *Health and Social Justice* (Hofrichter, 2003), the editor quotes Beauchamp (1988, p. 14) as stating that, to reclaim its historical focus on "collective control over conditions affecting the common health," public health must return to a focus on broad-based social reform. Several premises, including the belief that health is a "collective public good, actively produced by institutions and social policies," that "population health outcomes are primarily the result of social and political forces, not lifestyles or behavior," and that "an accumulation of negative social conditions and lack of fundamental resources contribute to health inequalities,"

frame NACCHO's recommendations for how local health departments might tackle health inequities. Thus, rather than simply asking why an individual uses tobacco products, the question should be more broadly framed so that it asks, "What social conditions and economic policies, along with systematic practices of tobacco companies, predispose people to the stress that encourages smoking?" In order to effect change, public health is being encouraged to move away from accepting social conditions without exploring how they have developed and to question how behavior is linked to and affected by the socioeconomic context and conditions in which it occurs.

Barriers to Employing the SDOH Approach

Despite accumulating evidence and extensive discussion in the literature regarding the social determinants of health and their influence on health status and rising medical care costs, little attention has been paid in the policy arena to effecting change in these determinants. While public health has long been noted for its efforts to focus activity and change upstream rather than downstream, even public health as a profession and as a movement has been noticeably absent from identifying effective policy levers related to making change at the level of the SDOH. Why is that?

Several barriers to working at the level of the SDOH pose significant challenges to public health. They include (1) ideological issues related to an ongoing debate about the relative contribution of medical, lifestyle, and societal explanations for health; (2) political issues that are raised when health workers are employed by the very governments whose policies may compromise health; (3) institutional issues that result in workers electing the course of least resistance, thus choosing to focus activity at the level of lifestyle change, rather than at the level of social conditions and institutional policies; (4) personal issues of knowledge and competence that result in workers remaining in the domains of medical treatment and lifestyle change, rather than those of community organizing and development; and (5) attitudinal and motivational issues that render issues of poverty too overwhelming to tackle, thus keeping health workers in arenas that seem to offer more control, even though they may not be particularly effective (Raphael, 2004). Together, these challenges represent significant barriers to improving health through an SDOH approach.

Recommendations for Action

The strong associations between people's material circumstances and their health, coupled with the importance of one's relative position in the social hierarchy, suggest a need to focus on the fundamental structural determinants of the social environment (Marmot, 2007; Wilkinson, 1999). Moreover, correcting social inequalities has been shown to improve the health of whole populations (Navarro, et al., 2006). Unlike policies related to modifying individually oriented risk factors that lie between distal causes and disease, approaches based in population health focus on developing healthy public policies that call for governmental, institutional, and organizational action (McKinlay, 1998). They require intersector cooperation (Murphy, 2004) and focus on reducing the burden of disadvantage,

particularly related to employment, income, and education (Wilkinson, 1999). In a recent discussion on promoting population health and reducing disparities, policy researchers recommended approaches that (1) benefit individuals regardless of their own resources and actions; (2) target special needs of resource-poor groups that may face barriers to implementing recommended interventions; and (3) promote policies that increase socioeconomic resources that are available to resource-poor groups (Link & Phelan, 2005).

At the global level, the slow uptake of activity aimed at policy change has led the WHO European Regional Office (The International Centre for Health and Society at the University College of London) to compile evidence on the social determinants of health in a way that policy makers can find helpful. The resulting document, *The Solid Facts,* summarizes SDOH in 10 messages and is being used to formulate health policy (Wilkinson & Marmot, 2003). In addition, WHO leaders have called for the development and implementation of pro-equity health policies that go beyond a focus on income by addressing "systematic disparities in health between more and less advantaged social groups" (Braveman, Starfield, & Geiger, 2001, p. 679) and by intervening in the social factors that influence health (Baum, 2007; Vega & Irwin, 2004). At the municipal level, this approach has been captured in the Healthy Cities movement, which promotes initiatives aimed at improving health by changing local social structures and environments. Incorporating elements of the community-based participatory research approach, Healthy Cities calls for including community members' voices in identifying community issues (Blackwell & Colmenar, 2000; Norris & Pittman, 2000; Raphael, 2003). This pro-equity approach requires intersectoral cooperation—even in the face of administrative and budgeting structures in the public sector that make such collaborative action difficult. Addressing health and health inequities at this level will likely remove the veil that has shielded health from the political arena and presented it as an apolitical entity. The need to develop a "politics of health" and to acknowledge the profoundly political nature of health was posited recently by a team of academics from the United Kingdom (Bambra, Fox, & Scott-Samuel, 2005). They suggest that failing to see the political nature of health policy results in a lack of understanding of the degree to which the political context affects how health policy is formulated. Furthermore, individuals and groups with the greatest power have a vested interest in maintaining this failure of understanding.

Building a more inclusive society (Schulz & Sankaran, 2006) is suggested as a way to address the social determinants of health and thus improve health status. The need to rethink health policy at the macro as well as the micro level has also been recommended. In the United States, the Department of Health and Human Services (DHHS) recommended that a Federal Leadership Council be created under its auspices. This Council would leverage government-wide resources to improve health and reduce inequities (Hofrichter, 2006). Coordination among departments, including labor, education, defense, justice, energy, and transportation, would occur at the regional and local levels; strategies have been identified at the political, professional, and organizational levels to address the multiple barriers to such intersectoral collaboration (Syme, Lefkowitz, & Krimgold, 2002). In Canada, a resource for health professionals, lay workers, volunteers, and activists provides a primer for action on SDOH (Ontario Prevention Clearinghouse, 2007).

A further initiative that could increase the likelihood that the SDOH would be incorporated into policy changes focuses on educating the polity about the consequences for all of increasing inequality and poverty on health. One example in the United States is the *Guide to Community Preventive Services,* an evidence-based review of interventions that have been shown to be effective at a community level (Zaza, Briss, & Harris, 2005). For example, the Task Force "highly recommended" an increase in housing vouchers and center-based child care for low-income children from birth to age 3. Educating the public using the vehicle of a Surgeon General's report on the SDOH could also have a powerful effect on policies that would improve health. The high profile that these initiatives have garnered indicates that such a report would feature the important role that SDOH plays, thereby stimulating action (Lurie, 2002).

Complementing the idea of a Surgeon General's report on the SDOH is the *Index of Social Health* that the Fordham Institute for Innovation in Social Policy has published since 1990 (Miringoff & Miringoff, 1999). Consisting of 16 health and well-being indicators, the Index captures elements of SDOH that include availability of affordable housing, rates of unemployment, average weekly wages, inequality, child poverty, and violent crime. Additionally, Health Impact Assessments (HIA), defined as "a combination of procedures, methods and tools by which a policy program or project may be judged as to its potential effects on the health of a population and the distribution of those effects within the population" (European World Health Organization, 1999, p. 4), are suggested as a mechanism for developing healthy public policies. A goal of HIA is the integration of diverse assessment methods that use health promotion as a unifying lens (Bhatia, 2003). With an emphasis on the social, economic, and environmental conditions that influence health (Kemm, 2001), health equity is frequently an underlying value of HIAs (Parry & Stevens, 2001). As demonstrated by one recent example of a community participatory research approach in developing a health impact assessment, the significance of the HIA is in its joining diverse disciplinary interests and practices that value experiential and intuitive knowledge. Moreover, as a mechanism for promoting political accountability and community capacity development, the HIA process can result in the development of political analysis tools that reflect community values and needs, thus supporting the participation of lay people in ensuring institutional accountability (Bhatia, 2003).

Progress on building the science base for interventions in the SDOH has been made. Nevertheless, we continue to know too little about the mechanisms through which nonmedical determinants affect health. This is particularly true in the case of socioeconomic status and a range of social conditions. Research into causal mechanisms is needed to ensure that our policy interventions are evidence based (Lurie, 2002) and that they derive from the perspective of a "critical social science" (Fay, 1987). Examples of areas where such research could be particularly effective are in the health consequences of tax and income transfer policies, labor market policies, and social service policies. Concomitantly, we must change our language to embrace SDOH and social justice. In the interim, using the CBPR approach—which by definition engages communities and works with them to effect needed structural changes—can result in modifications in community structures that not only permit but also encourage healthier behaviors.

Community-Based Participatory Research (CBPR)

Given the complexities related to individual behavior change and the social determinants of health, it is reasonable to question how one might integrate the two approaches. Furthermore, the important question regarding how to most efficiently and effectively investigate health behavior change within an ecologic context remains. While traditional research methodology serves a valued and important purpose, when researching multifaceted issues such as the nuances of human behavior, health disparities, and how the complexities of the communities in which people live might affect behavior, a different research approach is warranted. More important, traditional research approaches that focus only on individual-level behaviors risk preventing recognition of the broader context of health and disease and ignoring the roles of social and environmental factors (Israel, Schulz, Parker, & Becker, 1998). In contrast, participatory research "ensures that research results may in fact address real needs and will actually be used" (Green and Mercer, 2001, p. 1926).

Definition of CBPR

"CBPR is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change" (Viswanathan et al., 2004, p. 77). CBPR encompasses the concepts of co-learning, shared decision making, and mutual ownership of the research and its products (Viswanathan et al., 2004). It is intended to intimately involve communities in the research process so that the resulting knowledge reflects their needs. This approach is particularly well suited to the area of health behavior change, as it allows for the design of interventions that consider the unique qualities of the community in which the interventions are to be implemented. Consequently, CBPR is intended to foster sustained health behavior change by focusing on an ecological approach that includes political change.

Israel and her colleagues shed light on CBPR by describing it as "a partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process" (Israel, Engels, Schulz, & Parker, 2005, p. 5). In identifying key elements of participatory research, the importance of participation, influence, and control of nonacademic researchers in the process of creating knowledge and change is emphasized. Israel also calls upon health behavior researchers to recognize the community as a social and cultural entity by actively engaging the community in the research process.

Cornwall and Jewkes (1995) elaborate on the definition of participatory research when they describe the CBPR process as a series of reflections and actions, carried out "*with* local people rather than *on* them" (p. 1667, italics added). Traditional research studies rarely include the participants in most aspects of the research design, analysis, and implementation. Some traditional researchers may believe that a participatory approach is incompatible with "real" or "rigorous" research. This attitude accompanies the intention of removing bias

from the study. Nevertheless, there is growing acceptance of inclusive participatory methods that render a study's results more applicable and pertinent to the targeted participants. Rather than serving the needs of academic researchers, participatory research reminds us of the goal of research: to serve and improve the health and well-being of the people and communities being studied. As research in the field of behavior change explores the motivations and challenges inherent in behavior, it must also address the ecological context discussed earlier in this chapter by including the broader aspects of the community environment and social factors that inevitably affect behavior. For behavior change promotions and interventions to be successful, the workings and structures that currently (or could in the future) influence behavior change in individuals within the community must be considered.

The CBPR Approach

CBPR is an approach that draws upon the full range of research designs and can include qualitative and quantitative data collection and analysis. It is used in developing health promotion interventions (Lantz, Israel, Schulz, & Reyes, 2006) and has been shown to be beneficial in developing policy processes and environmental change (Vasquez, Minkler, & Shepard, 2006). The CBPR approach is strongly linked to individual behavior change through the context of community-based interventions that address the SDOH. Thus, CBPR considers address the broader context of health, environment, culture, and community, thereby making behavior change more approachable and feasible for individuals. CBPR enhances research relevance by involving the knowledge and experience of people with relevant lived experience, rather than relying on outside researcher input alone (Altman, 1995). Developing partnerships and community assessments are initial elements of CBPR. The community context is used to define research questions and, eventually, interventions such as health promotion campaigns or behavior change strategies. Research products are shared equally and focus on effective program and policy changes that will produce lasting health behavior change and sustainable positive health outcomes (Israel et al., 1998).

The development of partnerships is a key component of CBPR and serves a significant purpose in relation to health behavior change and health promotion. In its attempt to reach the heart of the community and to benefit from community knowledge and expertise, CBPR is unique in its emphasis on relationships with nontraditional public health partners and reaches past barriers to partners and relationships that were previously out of reach. Adhering to the principles of good participatory research means that "activities critical in partnership development include sharing decision-making, defining principles of collaboration, establishing research priorities, and securing funding" (Metzler et al., 2003, p. 804).

Partnership building in and of itself can lead to positive actions related to health behavior change. Partnerships created via participatory research strategies often result in relationships that facilitate significant collective action. Developing partnerships constitutes an integral step in the process toward social action and community empowerment through the development of networks of organizations and individuals.

In its partnership-building process, investigators associated with The Healthy Neighborhoods Project in West Contra County, California, discovered that the community had much to offer to the health promotion and research projects targeting its residents. The project used a community-organizing approach and created an authentic partnership between residents, community-based organizations, the health department, and often others, such as the housing, crime and safety, business, and transportation sectors (Minkler, 2000). Through the participatory research processes of this project, among other results, transportation services were improved and security measures for high-risk neighborhoods increased. The community-wide changes that took place through the Healthy Neighborhoods Project demonstrated how CBPR engages communities to address the social determinants of health, thereby improving the likelihood that health behavior change will result. Without community engagement, it is possible that these key factors could be missed and change would be impossible, regardless of the theoretical efficacy of any given health promotion intervention.

One of the most critical junctions of the research process is the development of the research question. Traditionally, in health promotion and behavior change, the question is developed by hypothesizing the reasons for a specific disease state in a certain population. Researchers then work from this hypothesis to develop an intervention that they theorize will encourage and inspire change in a certain health behavior, such as physical activity, sexual practices, or tobacco use. While this is obviously a well-tested approach to research, CBPR adds an additional component to crafting the research question, or the definition of the problem to be addressed: community members are involved in the discussions. "With the community playing a key role, epidemiologists may have to put aside their topic of interest and predetermined methods so that the community can help determine the issue and how it is to be investigated, as well as toward what ends" (Leung, Yen, & Minkler, 2004, p. 501). Leung argues that involving community members in the development of the research question strengthens researchers' ability to learn about community networks and therefore their ability to write informed hypotheses and collect data.

Strengths of CBPR

While the benefits of using the CBPR approach must be balanced by the challenges that accompany its use, CBPR is gaining acceptance as a valid research approach. The strengths of CBPR lie in its ability to address a broad context, value local resources, develop collaborative and trusting relationships with communities, build capacity, and effect policy change.

Broad Context

Working with community members to define the research question or issue can be a means to the end of addressing the broader context of health promotion and disease prevention. In East Harlem, New York, a community coalition that included care providers, community-based organizations, and community members was created in order to conduct a survey research study in a population with an exceptionally high prevalence of diabetes (Horowitz, Williams, &

Bickell, 2003). Before health behavior change researchers could design inter-ventions to encourage individual-level behavior change, they acknowledged that gaining a broad community-level picture was an important part of the initiative. This study found that most residents of this community had the knowledge they needed regarding their medicines but that underlying condi-tions were preventing them from attending to their personal diabetes care. Factors such as transportation and financial challenges ranked high on their lists of concerns (Horowitz et al., 2003). Without the use of participatory community-based research, these underlying social and economic factors might not have been identified and incorporated into the overall intervention design and solution.

Without community participation, health promotion interventions can sometimes miss the mark. An example is seen in the Community Intervention Trial for Smoking Cessation (COMMIT). This large project had modest success in changing the behavior of light to moderate smokers but had no marked effect on the higher risk heavy-smoker group. A community-based intervention in sev-eral matched communities, COMMIT did not permit flexibility in intervention design between and among communities. While this consistency across settings serves the purpose of testing the same intervention, it necessarily ignores the unique underlying social factors in each community. At the study's conclusion, the authors agreed that "the standardized protocol may have constrained some communities from undertaking activities that might have had greater impact" (COMMIT Research Group, 1995, p. 190). In addition, they "felt that the proto-col did not permit emphasis on some kind of policy or environmental changes that might have been quite powerful" (COMMIT Research Group, 1995, p. 190). While it is challenging to attain the rigor of traditional scientific design with community-based approaches, the strategies proposed in CBPR can combine the two and, in the end, strengthen the results.

Valuing Local Resources and Community Collaboration

A reward of partnerships built through CBPR is the multitude of skills and knowledge gained from the involvement of individuals and community organi-zations. Participatory research emphasizes the role of communities as collabo-rators in research. It involves communities and aims to support the structures of those communities in order to improve their health (Israel et al., 1998). Minkler (2005) discusses the strengths of this approach and notes that "by deeply valuing lay knowledge, CBPR can uncover hidden contributors to health and social problems" (p. 6).

The Kahnawake schools diabetes prevention project is a good example of utilizing local resources and community collaboration in a health promotion project (Macaulay et al., 1997). It also demonstrates the importance of this com-ponent in a population not traditionally involved in research. This project was implemented in a Canadian Mohawk community, one with a long-term goal of primary prevention of type 2 diabetes. Kahnawake is represented through a community advisory board of 25 volunteers from the health, educational, political, recreational, social, spiritual, economic, and private sectors and the full-time project staff (Macaulay et al., 1997). Researchers noted that the community

members' "collective wisdom adds a perspective that broadens interpretations, increases the project's effectiveness, helps to decrease harm and improves the credibility of oral and written results, which saves the community from potential stigmatization" (Macaulay et al., 1997, p. 779). The community members involved in the project's design and implementation were able to give researchers their perspectives on critical aspects of the project, such as the population to be targeted, advocating for respect for community acceptance of interventions and reminding the research team of relevant local customs and practices. These were integral parts of the overall research plan and led to a successful outcome. Although not all the targeted health outcomes were reached, community collaboration and empowerment were certainly increased. These are welcome secondary outcomes of participatory research and are often the precursors of behavior change.

Establishing Trust

Participatory research has been said to be more inclusive of communities that are more often marginalized in traditional research, partly because of the ability of the CBPR approach to foster trust through collaboration. Populations that have previously been taken advantage of in research studies are historically skeptical of researchers, questioning their motives and approaches. This historical lack of trust can make it difficult to recruit and retain participants from these populations for research studies. Attributing the culture of distrust to such grievous violations such as the Tuskegee syphilis study, researchers have found that, for example, African Americans have a marked distrust of the medical community and that this is a prominent barrier to participation in research (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999).

Practiced ethically and with adherence to CBPR principles, community-based research can involve community members and their representatives in all phases of the research project—from defining the research question to owning and implementing the results (Cashman, et al., 2008). Participatory research, with its more inclusive and transparent methodology, may well alleviate some of the trust issues previously seen in traditional research methods. In their review of three urban health promotion projects, Metzler et al. (2003) determined that the "challenge of community-based research partnerships is to overcome historical breaches of trust and discrepancies in power to build relationships across boundaries of race and class" (p. 809). The projects reviewed in this study did indeed have some success in combating these challenges.

Research to Action—Relevance

A common criticism of public health research is its limited ability to translate into realistic, effective action. The CBPR approach challenges some of this criticism through its goal of effecting social action and environmental change. By the very nature of its participatory paradigm, CBPR increases the relevance of resulting recommended interventions and therefore translates more easily into realistic practice.

Limitations and Challenges of CBPR

Criticisms of CBPR focus on the extent to which the CBPR approach embodies scientific rigor. Additionally, some researchers question the ability of CBPR to identify causes and determine the effect of an intervention. Even those who advocate for CBPR as a research approach and who value its contributions to health promotion and disease prevention recognize that it is challenging to implement. Challenges arise in three areas (1) Institutional Review Board human subjects protocol approval (Malone, Yerger, McGruder, & Froelicher, 2006); (2) obtaining funding (Minkler, Blackwell, Thompson, & Tamir, 2003); and (3) balancing pressures from both academic researchers and community members in adhering to CBPR principles and practices (Green & Mercer, 2001).

Logistical obstacles also arise when trying to maintain full community participatory status, as often the community members are contributing as volunteers. Additionally, given the time needed to focus on process, it can be challenging to maintain community members' interest, and community champions may move on. Furthermore, priorities may change in a community during the time that the research project is being carried out, and motivation to remain involved may wax and wane. Expectations for community-based projects may be set too high, with timelines that are unrealistic given the need to change long-standing social and environmental contexts and practices. Yet, the results of community-based research often lay the groundwork and develop the supporting structures needed to facilitate change.

When addressing specific health outcomes as results of behavior change, community-based programs may not show immediate results. Outcomes such as changes in body mass index for physical activity promotions or glycated hemoglobin levels for diabetes prevention programs, for example, may not occur within the time frame of the research project, as these particular outcomes require longer timelines for measurable change (Daniel et al., 1999).

Relating CBPR to Behavior Change

Through the CBPR approach, research on behavior change within the community context can flourish. Because CBPR allows for more inclusive approaches that often result in addressing social determinants of health and environmental factors that affect community and individual health, it ultimately leads to more effective programs and interventions to support behavior change. The collaborative, community-engaged approach serves as a conduit, linking individual and population-based approaches to health promotion. The development of partnerships and collaborative structures in communities is a fundamental building block of CBPR; relationships that develop through these partnerships assist in health behavior change efforts by focusing on underlying causes and striving for social justice.

Schulz and her colleagues (Schulz et al., 2002) investigated these principles through their work in the East Side Village Health Worker Partnership. They found that interventions that consider the local perspective can serve a dual purpose of meeting local community priorities for change (more police presence, adequate street lighting) and addressing fundamental, structural issues

that shape behavior (e.g., housing, poverty) and that may be of more immediate concern to the academic partners. This dual purpose of CBPR can in turn affect the likelihood that healthy behavior changes will occur. While behavior change takes place at an individual level, individuals are part of a larger community; they influence community norms and customs while in turn being influenced by them.

Laverack and Labonte (2000) offer a description of the differences between initiatives that work within communities and those that work on communities. The former describes an approach that engages communities in the very early stages of disease prevention, in defining the issues and priorities that are most important to the people actually living in the community itself. This approach, which characterizes the CBPR strategy, can result in increases in community capacity and power; these increases in capacity are themselves a desired outcome of the intervention. It follows, therefore, that from this increased capacity is born an environment that is more amenable to behavior change outcomes. The second approach refers to health promotion programs designed primarily by outside agencies, with little regard for community interests or priorities. This approach more often targets particular health behaviors as the desired health outcome. One approach is not necessarily always more successful than the other. However, interventions that begin within and engage communities create a sense of ownership in the problem and the solution. This approach often results in more sustainable positive healthful changes, while simultaneously creating a stronger community network.

The work of the Chicago Southeast Diabetes Community Action Coalition is a good example of this concept of community capacity building (Giachello et al., 2003). While traditional health promotion activities to combat diabetes usually rely on health education to change individual lifestyle practices, the CBPR approach will often address components that contribute to problems such as diabetes in struggling communities. The researchers in the Chicago project utilized CBPR to engage the community in identifying the root causes and social determinants of their priority health issues. As part of their research process, local community members interested in diabetes were offered training sessions that provided information about the disease, approaches to community building, and methods of research. This reduced the "gap" between outside researchers and community lay persons, while affording the community an opportunity to build upon its own strengths and to utilize those strengths for future projects.

Communities can also use skills fostered through those developing CBPR partnerships to advocate for policy and environmental changes that support health promotion efforts. In the Chicago diabetes project, the collaborative team recognized that "health education and increased surveillance in a system without reform will only serve to further frustrate a population that has few options in general" (Giachello et al., 2003). While healthy lifestyles are indeed worthwhile goals, many residents of high-risk communities cannot adopt these healthier practices. In many cases, they have no healthy options. Using CBPR as a basis for health behavior change, researchers found that the primary vehicles for health promotion and health behavior change resided in building community control, resources, and capacities toward economic, social, and political change (Laverack & Labonte, 2000).

Summary

Community-based participatory research is becoming an increasingly valued approach to behavior change and health promotion research. This methodology contributes to the field of health behavior change by providing a means of examining the larger, contextual setting of human behavior that exists beyond the individual. The social determinants of health and the ecological perspective are vital aspects of health promotion activities. Without considering these perspectives and building on the insight they provide, interventions from health promotion initiatives can miss key elements contributing to the health issue addressed. CBPR gives us a way to investigate these crucial elements, while still maintaining scientific quality and relevance. This participatory approach increases the value of health promotion research, while simultaneously helping a community build its own capacity to address public health challenges that stem from any of the array of social determinants of health. It also allows us to consider the broader context of health and disease, place value on local resources, increase community capacity, and enhance the relevance of the research. Remarkably, studies that incorporate a community's view of its health needs frequently find that community-driven concerns are consistent with the view that societal factors are the primary driving forces affecting health (Raphael, 2001).

The strength of the CBPR approach, combined with efforts to trace the causes of poor health encompassed in SDOH, allows communities and researchers alike to aim for a more effective translation of research into public health practice that includes social and political change. With the power of research, communities can feel more confident in advancing their struggle to meet basic needs, such as transportation, housing, job security, access to healthy foods, and physical safety. The use of CBPR allows us to consider behavior change at the community and population level, set within the context of social determinants of health. Combining strategies that encompass individuals and the communities in which they live and work results in health promotion efforts that bring about measurable improvement.

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Ethical Issues in Lifestyle Change and Adherence

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In this chapter, I examine issues in lifestyle change and adherence from the perspective of normative ethics—that is, moral theory that addresses the way individuals, institutions, or societies ought to act. Moral deliberation and justification in normative ethics ordinarily rest on action guides. These action guides are often expressed as rules or principles; in addition, however, ethical analysis may be based on rights theory, which requires an examination of reciprocal rights and duties within a relationship, or on virtue theory, which employs considerations of moral character.

These action guides serve as the centerpiece of modern ethical theory. They do not stand alone, however. Moral analysis requires choosing which action guides to employ, as well as considering the relationships among those chosen,

in addition to applying them to particular circumstances. Each of these analytical steps is subject to controversy and disagreement (Beauchamp & Childress, 2008). Perhaps most important, human moral agency may only rarely fit neatly into a single model of moral reasoning. It is likely that people think through moral choices more by using "moral eclecticism"—that is, the propensity to mix and match different kinds of moral considerations and analyses—than by applying a single philosophical model (Churchill, King, & Schenck, 2005). The universe of available moral action guides among which to choose has also been expanded by inclusion of models reflecting a diversity of cultural and religious perspectives (Guinn, 2006; Prograis & Pellegrino, 2007).

Structures of principles and rules, rights, and virtues can be used to analyze questions of morality in particular concrete situations and arenas of social life. Often, such analysis is referred to as "applied ethics." Numerous areas of applied ethics have been identified, such as business ethics, journalism ethics, and health care ethics.

Four areas of applied ethics with particular relevance to the themes of this volume are the ethics of the health professional-patient relationship; the ethics of the researcher-study participant relationship; the ethics of the government-citizenry relationship; and the ethics of the payer-client relationship. This chapter considers the key moral issues related to lifestyle change and adherence in each of these relationships. Relevant principles and rules emerge as each relationship is discussed.

Two distinct but related questions of adherence are considered in this volume: adherence in a clinical context and questions of lifestyle change for the general public. The ethical issues raised by adherence to prescribed medical regimens for the clinically ill may often be substantively different from the issues raised by adoption of recommendations of the Surgeon General or the American Heart Association regarding healthy lifestyles. And, although such differences seem stark, the distance between the "well" and the "ill" can be minimized rhetorically by the process, increasingly common in health care, of "medicalization." Medicalization is the tendency to label nondisease states, including risk factors for the development of common disorders, as medical conditions. For example, it has become commonplace to use labels like "prediabetic" to persuade asymptomatic individuals to adopt lifestyle changes and sometimes even to penalize physicians who fail to so counsel such patients. Increased knowledge about genetic contributions to common multifactorial disorders can also "medicalize" a healthy individual's genetic heritage, as a result of identifying in that person an increased likelihood of developing a disorder. Sometimes medicalization increases recognition of the risks to health posed by some nondisease states; the metabolic syndrome might be one example. Other instances of medicalization may be premature or counterproductive. It is important to consider possible differences in lifestyle change and adherence for different populations in the discussion that follows and to note how these differences can become blurred, although a full exploration is beyond the scope of this chapter.

The Clinician–Patient Relationship

Much of the emphasis in this volume is on adherence and lifestyle issues in health care services and the clinical encounter. Chapter 6, for example, considers

how different models of the provider-patient relationship affect adherence. Medical ethics also considers different models of the doctor-patient relationship. One such approach argues that the doctor-patient relationship in particular, and all health professional-patient relationships generally, are dominated by two competing models of moral responsibility—the beneficence model and the autonomy model (Beauchamp & McCullough, 1984). Discussion of the conflict between beneficence and autonomy dominated early thinking in bioethics. Since then, analysis and application of these two models has become far more nuanced, and both their interdependence and their complementarity with other models are more fully recognized (Beauchamp & Childress, 2008). For the purposes of this chapter, however, it is useful to begin with a rather broad description of each.

According to the beneficence model, the primary obligation of clinicians is to seek the best balance of good over harm for their patients. Goods and harms are understood in medical terms: the chief goods are health, the prevention or elimination of disease and injury, relief from pain and suffering, the amelioration of disabilities, and the prolongation of life. The principal harms at issue are death, disease, disability, pain, and suffering. In the autonomy model, the values and beliefs of the patient and the patient's own assessment of what is in his or her best interests become the primary moral considerations. If the patient's values conflict with the values of medicine, the clinician's primary moral obligation is to respect and facilitate the patient's preferences. Both models speak to important moral truths about the health professional-patient relationship. However, when starkly drawn, their requirements can conflict, and it becomes necessary to bring them into balance by identifying the limits of each in a particular context.

The perspective of the beneficence model can provide strong moral support for adherence interventions in clinical settings. Under this model, clinicians have a moral obligation, an affirmative duty, to take actions that will preserve the health of their patients and protect them from disease and injury. Thus, clinicians who do not take seriously their obligations to secure the adherence of their patients to medically indicated regimens are morally blameworthy. This moral obligation was given legal force in a California case in which a physician was held liable for not adequately informing his patient of the risks of failing to have a Pap test (*Truman v. Thomas,* 1980). Nonetheless, there are legal, moral, and practical limits to the clinician's obligation to act to secure patient adherence. Even in the court decision just mentioned, the physician's responsibility was limited to adequately informing the patient so that she would be equipped to decide for herself whether to take his advice.

If it is not reasonably possible for clinicians to implement adherence interventions or otherwise secure adherence, they have no obligation to do so. As discussion throughout this volume demonstrates, clinicians' abilities to secure adherence depend on a host of factors, including the amount of time and the kinds of skills needed to be successful in promoting adherence in clinical contexts. Similarly, assessing the clinician's obligation to secure adherence also requires considering the relative moral priority of competing clinical duties in a context of limited resources. When the amount of time and dollars to be spent on clinical encounters is limited, what priority is to be placed on activities that can cure disease and allay suffering, rather than those that can prevent deterioration or promote health? Although clinicians may have a prima facie obligation to seek adherence to medical regimens and lifestyle recommendations,

these obligations may be less weighty than other duties that compete for the clinician's attention. The strength of the clinician's obligation further depends on the strength of the evidence that, in given circumstances, adherence improves health outcomes; this requires not only knowledge of the epidemiologic literature but some application of that evidence to the individual patient. Thus, determining what steps clinicians should reasonably be expected to take to promote lifestyle change and adherence in patients is an important inquiry that depends both on particular circumstances and on continued developments in the rapidly changing health care environment.

The most important limit on the clinician's duty to "secure" adherence is the role of the individual whose adherence is sought. The autonomy model does not provide clinicians with a direct moral warrant for securing adherence to medical recommendations. According to the autonomy model, if the patient's values do not include improving his health prospects by altering lifestyle or adhering to medications, then the clinician is obligated to respect that value preference. This is not to say, however, that the autonomy model releases clinicians from any obligation in relation to adherence and lifestyle change. At minimum, respect for the patient's autonomy requires the clinician to ascertain the basis for the patient's position and, in particular, to establish whether the patient's rejection of the clinician's recommendation is based on an adequate understanding of what is at stake. The *Truman v. Thomas* decision can thus be interpreted as a reflection of the autonomy model, as well as the beneficence model. The physician in the case admitted that, although he repeatedly recommended a Pap smear and his patient repeatedly refused, he never probed beyond her refusal to determine whether she understood its consequences.

It cannot be assumed that laypersons' understandings of disease conform to medical understandings; therefore, laypersons and clinicians will not necessarily agree about the importance of medical recommendations for disease prevention. Moreover, even when their understanding is similar, it cannot be assumed that laypersons and clinicians place similar weight on what the clinician identifies as in a patient's medical best interests in relation to that person's other life priorities. Indeed, it is now widely recognized that informed decision making is best understood as a process of mutual learning in the clinician-patient relationship, whereby both clinician and layperson come to appreciate the other's reasoning and perspective and seek the best course of action for the patient under the circumstances. Discussions throughout this volume of the health beliefs model, including its dimensions, strengths, and limitations (e.g., chapters 2, 3, & 28), parallel this ethical analysis of autonomy by recognizing that decision making about adherence is a complex calculus of preferences, perceptions, priorities, and circumstances. The contribution of ethics to this increasingly nuanced understanding of health behavior change is simply the recognition that the physician's duty to support and enhance the patient's autonomy (Faden & Beauchamp, 1986) may require addressing these differences in viewpoint as part of the decision-making relationship.

What if the clinician ascertains that the patient has a correct understanding of what is at stake in refusing to adhere to medical recommendations and still wishes to ignore them? Both beneficence and autonomy suggest that the clinician is required to attempt to persuade the patient to change her position.

The obligation to promote the patient's good requires the clinician to attempt to persuade the patient that she will benefit from adherence. Persuasive interventions, properly constrained, do not violate obligations to respect patient autonomy (Faden & Beauchamp, 1986)—to the contrary, they often promote autonomous decision making by providing necessary information. However, if, after reasonable attempts at persuasion, the patient's decision remains unchanged, it must be respected.

It is essential to distinguish persuasion—defined as using reason to convince the patient to adopt the clinician's viewpoint as her own—from manipulation and coercion, which can appear similar (Faden & Beauchamp, 1986). Manipulation can be defined as using means other than reasoning, such as emotional appeals (for example, to fear), to bring the patient to a particular decision. Manipulation may or may not be morally permissible; that determination depends on the circumstances. Advertising campaigns often make use of manipulation, and the techniques of advertising (for example, music, imagery, and the addition of emotion to information) are often used to promote lifestyle changes such as exercise, smoking cessation, and diet modification. In such contexts, manipulation can be morally acceptable. In contrast, a classic example of manipulation that may be morally unacceptable is a physician's informing a smoker that something suspicious has been seen on a lung X-ray, intentionally misreading a benign finding in order to frighten the patient into quitting smoking (Smith & Churchill, 1986). Coercion—that is, seeking to achieve a given outcome by force or threat—is always and by definition morally illicit. An example might be a clinician's refusal to continue providing health care to a patient who does not give up smoking.

While it is morally necessary to distinguish among persuasion, manipulation, and coercion, it is not always easy to do so. Clean distinctions—especially between manipulation and persuasion and between acceptable and unacceptable manipulation—depend on the totality of circumstances and can be elusive. To help determine whether a given action is ethically permissible, the clinician should consider whether its goal is to ensure the patient's adherence or to ensure that the patient is well equipped to assess his own benefit and make his own choices, assisted by the clinician's education, advice, and support.

Increased recognition of the need to promote and support individuals' autonomy has been reflected in the adherence literature over time. What was once referred to as the problem of "compliance with doctor's orders" has become the problem of "adherence to the recommendations of professionals." Yet, even this second adherence formulation is not wholly satisfactory. A more desirable formulation would be something like "helping individuals make informed and reflective choices about whether to adopt or reject professional recommendations." Progress has also been made in expanding clinicians' views of what can be in the patient's best interests beyond a strictly medical perspective. Finally, both beneficence and autonomy find common cause in the recognition that neither can be adequately promoted by examining the clinician-patient relationship in isolation. Bioethics has moved beyond an exclusive focus on decision-making dyads to examine the roles and responsibilities of institutional actors (Henderson et al., 2005; Institute of Medicine, 2002). As is discussed extensively in this volume (e.g., chapters 2, 3, & 37), it is now also necessary to consider

how the wider web of social structures, networks, and relationships supports or impedes individual lifestyle change.

As noted, although contrasting the beneficence model of professional-patient relationships with the autonomy model helps highlight the central moral issues raised by adherence and lifestyle interventions in clinical settings, this approach draws too stark a contrast between competing moral principles and fails to capture much of the contextual richness of the clinician-patient relationship. An alternative approach in moral theory, frequently referred to as the care perspective, draws attention to issues of responsiveness and compassion in the moral life, including the need to respond to that which is unique and particular about the other in a moral relationship (Areen, 1988; Hanen & Nielsen, 1987; Noddings, 2002). The care perspective reminds us to refrain from being formulaic in our approach to moral issues. In clinical encounters, each patient brings a unique history and life experience. From the care perspective, helping individuals make informed and reflective choices about medical regimens or lifestyle changes requires compassionate attention to the needs of the patient as a unique individual.

Uncertainty also plays a critical role in the ethics of adherence in the physician-patient relationship. The recent explosion in empirical data relating to health behavior and lifestyle has also led to greatly increased awareness of the gaps, ambiguities, and uncertainties inherent in those data, their interpretation, and their application. In providing decision-making assistance, professionals should recognize that there is genuine epistemic uncertainty about the value of many medical recommendations for lifestyle change. Challenges to the validity of medical knowledge, opinions, and recommendations almost always have a legitimate basis and should be taken seriously. As many recent examples have shown, and as other chapters in this volume describe in more detail, the medical community has a notable history of being wrong in its predictions and recommendations regarding both health risks and protective behavior (see, e.g., chapter 40). Patients of the past who refused to increase their consumption of eggs and who refused to take swine flu shots were at the time considered to be "noncompliers" who held "false beliefs" by contemporary medical standards. And medical recommendations about a variety of preventive regimens, such as postmenopausal hormone therapy for women, the best diet for weight control, and the type of exercise regimen best calculated to maintain physical function, have undergone recent and repeated revisions, leading to understandable public confusion and even disillusion.

To a significant extent, this sort of disagreement between patient and physician is an epistemic problem about the nature of medical knowledge and its evidentiary base, in a context of ever-evolving scientific theories of disease and illness. At stake is whether physicians can offer anything stronger than medical opinions, a far cry from traditional "doctor's orders." In addition, these disagreements reflect the changing social context of medical science and are resolved not only by the acquisition of better data but also by the recognition that successful lifestyle change depends on much more than convincing data: not only on medical opinion but on a supportive relationship that places adherence in the context of the life and needs of each individual.

The Researcher–Study Participant Relationship

The ethics of the researcher-study participant relationship has a different tradition and a different social imperative from that of the physician-patient relationship. In the clinical context, ethics is guided, at least in part, by the assumption that both clinician and patient share the goal of seeking to improve the patient's welfare. By contrast, in research the primary goal is not to benefit the study participant but to produce generalizable scientific knowledge. Because the welfare of the study participant is not central to the research enterprise, there is no beneficence model in research ethics corresponding to that in clinical ethics. As a result, overriding the obligation to respect the autonomy of study participants is extremely difficult to justify, even by appeal to arguments grounded in beneficence or conceptions of the public good.

The implications of this understanding for considering adherence issues in research are fairly straightforward. In general, it is morally impermissible for researchers to fail to fulfill their obligations to (1) seek valid informed consent from study participants, and (2) respect potential participants' decisions to refuse to participate or to drop out of studies—even when honoring these obligations compromises the scientific integrity of their research. When tensions arise between respecting the refusals of study participants and promoting their cooperation, the interventions of researchers should be restricted to persuasion and to inducements that do not substantially undermine the voluntariness of study participants' decisions.

Although researchers are not generally viewed as having an obligation to promote study participants' good, they are nonetheless increasingly viewed as having a related but distinguishable obligation to minimize harms to study participants arising from their research participation. This "nonmaleficence" obligation has been seen as underpinning the researcher-study participant relationship since the beginning of research ethics in the United States (National Commission, 1979) but has recently taken on special force in instances where research participation has the potential to disadvantage study participants.

Two examples are relevant to prevention research. First, in the Kennedy-Krieger Institute decision, researchers who were testing different lead abatement strategies in Baltimore low-income housing were held to have a responsibility to the welfare of resident children whose blood lead concentrations, measured for study purposes, exceeded safe levels (*Grimes v. Kennedy Krieger Institute, Inc.,* 2001). The court's reasoning is controversial and the decision's applicability is limited, but the case has reawakened vigorous discussion of the researcher-study participant relationship.

Second, since, as noted, the evidentiary support for many preventive regimens can be flawed or lacking, randomized controlled trials can provide a useful way to assess the effectiveness of preventive health care. Comparisons between the long-term health of study participants who practice preventive regimens and that of those who do not is usually more accurate if participants are randomly assigned, and even more accurate if the assignment can be blinded—which can be easy to do with some preventive drug regimens but impossible with other behavior-based regimens, like diet and exercise.

For a potential participant, the challenge is to understand and agree to take the chance that a prophylactic regimen in which he believes strongly may be safely forgone for what may be a long period of time. For researchers and oversight bodies, the challenge is to ensure clarity about the nature of the evidence that exists and that is needed to justify research to determine the efficacy of what may have come to be common practice. Even research that poses few risks of harm to well-informed participants can be unethical if the trial design cannot answer the question asked or if the study data cannot be meaningfully analyzed—that is to say, it is not fair to subject study participants even to inconvenience if there is little or no chance that their inconvenience will benefit science (Emanuel, Wendler, & Grady, 2000). Large-scale epidemiologic studies of preventive interventions may be more likely than other randomized trials to pose these kinds of ethical challenges because of their design complexities.

Imagine translating the recent controversy over the short- and long-term effects of the Atkins diet into a randomized trial of different Atkins-type diets and trying to monitor weight, serum cholesterol, body fat percentage, disease outcomes, and other measures over time. How should the risks of harm and potential benefits of such a study be described for potential participants? How can the conduct of the study be adequately monitored? How should it take account of changing information about the safety and effectiveness of the Atkins diet? Randomized controlled trials that involve behavior-based interventions and seek to measure disease-related outcomes can require following the cohort for a very long time, as the expected effect sizes may be quite small and event rates are often low. Replacing a clinical outcome with a surrogate measure can shorten the duration of a trial but may also weaken the significance of the data. Moreover, there is considerable evidence that adherence to the placebo arm in a trial can sometimes improve health outcomes significantly, which signals the existence of considerable uncertainty about the relationship between adherence and health outcomes generally: is it causal, only an association (see chapter 40)? This combination of complexities in prevention research helps to explain why large studies are not undertaken more often. The result, of course, is continued uncertainty, smaller studies, persisting gaps in the evidence base, and decision making based on limited evidence. This example is just one illustration of how complex the ethical and social context of prevention and prevention research can be.

The Government–Citizenry Relationship

That government has both the obligation and the right to protect the public health is clear. What is less clear is the scope of this government obligation. What kinds of threats to health are covered under this government obligation? What means should the government use to control these threats?

The answers to these questions turn on a complex of principles and values, including, most prominently, respect for autonomy, justice, public welfare, and utility. How the demands of these principles are to be balanced or blended depends critically on one's theory of the state—in this instance, on one's theory of the liberal state in a democratic society.

In the government-citizenry relationship, the counterparts of the benefi-cence and autonomy models have been described as the paternalism model and the "rugged individual" model (Ribisl & Humphreys, 1998) or the "public inter-est viewpoint" and the "libertarian viewpoint" (Callahan, 2000). Paternalism is defined as the overriding of autonomous choice for beneficent reasons, that is, the determination that someone other than the affected individual—in this case, the government—knows what is best for the individual. Bioethics scholars have expressed concerns about paternalism in health education efforts, while at the same time advocating for restrictive government regulatory action where appropriate (Faden, 1987). Bioethics scholars have likewise expressed concern about the increasing focus on personal responsibility for health, while at the same time seeking to protect decisional autonomy (Minkler, 2000). What may at first appear to be contradictory in such arguments is rather an acknowledgment of different decision-making contexts, as well as the articulation of a model in-termediate to the extremes of paternalism and individual self-sufficiency.

Strong state action is most clearly morally demanded when the health of innocent parties is placed at risk by the actions of others and there is a feasible way to remove the risk through regulation or environmental control. Classic examples include asbestos and lead exposures in the workplace or the home, unsafe appliances, and carcinogenic food additives. Many expressions of the type of state action discussed here are, by nature, coercive—that is, designed to change behavior by threat of legal sanction. In the government-citizenry rela-tionship, legal coercion is morally acceptable when it reflects the appropriate workings of the democratic process.

State action is demanded in these cases by a complex of principles, includ-ing justice and utility. It should be noted that these cases do not raise relevant autonomy issues: that is, there is no substantive conflict, in these examples, between the demands of justice and obligations to respect autonomy. (To be facetious, one rarely asserts a liberty right to be exposed to lead or asbestos.)

It is also significant that lead and asbestos exposure represent classic examples of the victim-blaming scenarios that appear frequently in the health behavior change literature. Interventions designed to change indi-vidual behavior, rather than the use of state action to change the root causes of exposure, often focus attention on the wrong end of the equation. Health education interventions to promote the wearing of respiratory protective gear among workers in inadequately ventilated plants, to encourage more vigilant behavior among tenants in lead-contaminated apartments, or to train migrant workers to wear gloves while using pesticides in the fields are morally sus-pect, if not unconscionable, when governmental action is possible, more ap-propriate under the circumstances, and likely to be more effective. In these examples, government is in a position to improve ventilation in the workplace, to require lead abatement in rental housing, and to ban highly toxic pesticides and to mandate the availability of protective gear and shower facilities for farmworkers, making it unjust to rely on individual action alone (chapter 37; Steinbrook, 2006).

The moral issues are somewhat more complicated when we move to cases where there are plausibly some autonomy interests at issue, but no weighty liberty values. Classic examples are the controversy over seat belts and air bags

in automobiles and the freedom of motorcyclists to forgo wearing helmets. To put the argument somewhat simplistically, those opposed to compulsory seat belt or helmet legislation claim, among other things, a liberty right to drive unharnessed. Those opposed to mandatory air bags claim, among other things, a liberty right to decide whether they wish to pay the additional costs of air bag installation, which are passed on to consumers.

The position one takes in relation to these controversies depends to a significant extent on the value one places on these particular liberty interests in comparison to the value placed on other principles. (In the case of helmets and seat belts, for example, it is reasonable to consider whether society should share the increased costs of medical treatment when those not wearing seat belts or motorcycle helmets are injured.) Whether media campaigns or other forms of behavioral interventions are morally preferable or morally questionable alternatives to regulation turns on a complex balancing of these competing values and principles.

Of course, all health issues do not entail strong arguments for coercive state action. Individual autonomy may outweigh other considerations; effective technological or regulatory solutions may not exist, or, if they do, they may be inadequate to the problem. In such instances, behavioral interventions directed at individuals by governmental entities are appropriate. Examples include governmental promotion of oral hygiene, breast self-exam, safer sexual practices, and exercise.

As in the clinician-patient relationship, in the government-citizen relationship when autonomy interests are strong it is important to evaluate behavioral interventions in terms of their effects on autonomous choice. However, it is not always possible to reach consensus about which health issues entail strong autonomy interests, in part because of fundamental disagreements about the role of social and cultural influences on individual choices and actions (chapter 2; Steinbrook, 2006). The classic lifestyle issues of diet and exercise may fall into this area of disagreement. Consider, for example, the difference between a governmental requirement that the amount of trans fats be listed on all food packaging and a ban on trans fats in prepared and packaged foods. The former requirement provides the citizenry with the information needed to make healthier food choices but does not in itself ensure that healthier choices are available. The latter requirement ensures the availability of trans fat-free food choices, but at the expense of individual autonomy.

Finally, any evaluation of the ethics of government lifestyle change and adherence interventions must recognize that there are instances in which regulatory or environmental intervention is morally preferable but politically inadvisable or impossible. How government officials and researchers ought to proceed under such circumstances is difficult to stipulate in the abstract. As other chapters in this volume make clear, circumstances are likely to arise in which interventions directed at individuals are morally permissible as the only available strategy for dealing with a health problem. Increasingly, however, health promotion and disease prevention has taken on an ecological perspective (chapter 37), acknowledging the connections between individual actions and their social context and recognizing that institutional and society-wide changes, including regulatory changes, may be imperative.

The Payer–Client Relationship

In addition to the aforementioned relationships, the relationship between health insurers (or other payers) and their clients is increasingly important in the arena of health behavior change, for two reasons. First, discussions about whether and when to pay for prevention and health maintenance are becoming more common. In addition to familiar preventive services such as Pap tests and mammograms, many insurers pay for other services, as well, both for healthy clients and for clients with chronic diseases such as diabetes. Second, as health insurance moves further away from community rating and experience rating becomes ever more elaborate, insurers and other payers are more likely to increase health insurance premiums for individuals identified as being at increased genetic or behavioral risk (Stone 1990) and to lower premium costs only upon demonstration of successful behavior change, such as smoking cessation, weight loss, or blood pressure control (Mello & Rosenthal, 2008; Morreim, 2000; Steinbrook, 2006). The relationship between payers and clinicians may similarly be affected by patients' success, or lack thereof, through payer-imposed reporting requirements (Bishop & Brodkey, 2006) and "pay-for-performance" programs (AMA Council on Ethical and Judicial Affairs, 2005), detailed discussion of which is beyond the scope of this chapter.

The payer-client relationship implicates the same tensions between beneficence and autonomy that arise in the relationships already discussed, with several important differences. First, this relationship may be clearly contractual, or individuals may be the direct beneficiaries of a contractual relationship between the payer and their employer. Second, individuals may or may not have the ability to choose other health insurance plans. Thus, the responsibilities of the payer may depend on the freedom of the client. When the payer is governmental—as is the case for Medicare and Medicaid—individuals' choices may be especially constrained by their circumstances, but the stakes for payers grow higher as the costs of chronic disease-related health care increase.

For these reasons, another important difference lies in the way that payers make use of information. Whether the payer's goal is to benefit patients by offering incentives for behavior change or to benefit stockholders by saving money and increasing profitability is often an open question. Positive incentives, such as insurer coverage for preventive services, are more likely to have beneficent intent than are negative incentives, such as increased premiums for failure to change behavior (or for failure to demonstrate the effectiveness of behavior change). Even so, it is not clear how the information payers might use to assess premiums should be interpreted. Whether prevention is effective and whether various payer incentives to practice prevention are fair and reasonable are empirical questions that merit careful investigation, especially in the rapidly changing health insurance market.

Finally, as Morreim has noted, the task of determining how to apply these kinds of incentives is morally problematic in yet another way. Meaningfully measuring adherence is potentially very intrusive upon individuals' privacy, while refraining from intrusion is likely to reward deception (Morreim, 2000). Indeed, the very ability to ascertain whether adherence improves health or

saves money requires a significant privacy tradeoff—one that is largely familiar and accepted in prevention research but that is far more sensitive outside the research context.

Common Issues Across Relationships

Discussion of these four relationships—physician and patient, investigator and study subject, individual and government, payer and client—reveals some important common issues. First, the process of assessing the respective responsibilities of the parties to each relationship necessitates the same comparison and balancing of principles, though in each case the context and conclusions will differ. Second, in each relationship, several considerations are key, most notably the empirical question of uncertainty regarding the evidence available to prove or disprove the effectiveness of lifestyle change in improving health and the concomitant normative question about what counts as effectiveness in health behavior change. Is it improved health—measured by fewer illness episodes, or decreased need for treatment interventions, or in some other way? Is it longer life? Is it lower health care costs over a person's lifetime? Is it better quality of life, by self-report or by some other measure? Third, each relationship embodies a tension—albeit a productive and necessary tension—between autonomy and beneficence.

An emerging issue held in common across each of these relationships is the significance of the genetic contribution to health. As has been extensively debated in the literature, the current trend toward the "geneticization" of health behavior and the concomitant search for genetic predispositions, gene-environment interactions, and the genetic contributions to common multifactorial disorders and conditions has important implications for how society views individual autonomy in health behavior change.

If individuals are considered able to effect change, then persuasion will take on a more significant role. If, however, individuals' health is viewed as determined by genetic risk factors, then interventions that place less emphasis on individual choice—such as regulation and coercive sanctions—could become more common. The geneticization of health behavior could reduce the tendency toward victim blaming, but at considerable expense, by unduly downplaying the capacity of individuals to effect behavior change and thereby improve their health. Moreover, this trend could exaggerate the role of the genetic contribution to health and deemphasize inherent uncertainty about the significance of genetic information for individuals (Koenig & Stockdale, 2000). If lifestyle change is achieved by prematurely labeling people with new diagnoses solely on the basis of their genetic heritage, then that achievement may come at some moral cost. The possible costs include issues discussed throughout this volume: stigmatization, guilt, the inappropriate manipulation of information necessary for informed decision making, and a focus on individual behavior to the exclusion of attention to the social and cultural determinants of health behavior change.

Finally, perhaps there is yet another common tension, at the policy level, between the costs of prevention and its goals. Effective promotion of health behavior change—efforts that address the social, cultural, economic, and political context in which individuals act and live—may not only be expensive but also may involve sometimes-profound changes in the communities in which we

live and work (chapters 2 & 37) and invoke important social values. Some deep changes may be welcome; others will certainly not be; all are likely to foster public debate and discussion.

The Social Context of Ethics in Health Behavior Change

This chapter focuses on traditional moral principles, most notably beneficence, justice, and autonomy, as they relate to lifestyle change and adherence. One variant of the justice and autonomy themes not yet discussed is the morality of devoting significant attention to promoting healthier lifestyles while at the same time millions of Americans lack access to basic health services. Any thorough examination of the ethics of lifestyle change and adherence must address not only whether the characteristics of specific interventions conform to our moral obligations, narrowly construed, but also whether the resources needed to mount these interventions have been fairly allocated in a broader sense.

A rich understanding of autonomy includes recognition that decision-making relationships in health care should support and facilitate autonomous decision making by individuals. Thus, addressing the social and structural determinants of health is both a way to avoid the victim blaming of individually focused responsibility for health behavior change and a means of identifying additional levels of responsibility for making more choices available and fostering more fully informed decision making. Understood in this way, the ethics of health behavior change must not fail to take account of the system of health care delivery, of which prevention and lifestyle change form one part.

The ethics of lifestyle change and adherence must also consider the goals of an intervention and how the intervention's success is measured. If the objective is to encourage people to make informed and voluntary decisions regarding their health, then the primary evaluation criterion should be the quality of the choices made by those at which interventions are aimed, more than the choices themselves. The correct evaluation criterion, then, is not how many subjects stayed in the trial but how well they understood what was involved in participating in the trial, regardless of whether they consented or refused, stayed in or dropped out. The issue becomes not how many individuals with hypertension took their medications according to directions but how many made an informed, reflective decision about whether they wanted to take the medication as recommended.

In other words, morally sound evaluation of the success of health behavior change should include mutual, ongoing education about what constitutes good decision making about health and about how health behavior is integrated into the lives of individuals, cultures, and communities. Patients, the public, and health care professionals must learn from one another what works and does not work and why, so that progress in the field is built on using sound data to develop interventions that are both effective for and respectful of all concerned.

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Adherence and Health Outcomes: How Much Does Adherence Matter?

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Patient adherence (also known as patient compliance) involves the degree to which patients follow their medical provider's recommendations for varied health regimens, including taking medications, making changes to diet, exercising, attending follow-up appointments, completing screenings, and attending to a host of lifestyle changes and treatment activities. Rates of nonadherence vary widely across disease conditions and treatment requirements, but, on average, at least a quarter of patients are nonadherent (DiMatteo, 2004a). Average rates of

nonadherence in the treatment of various common conditions include 20.9% for cancer, 32.5% for diabetes, 30% for end-stage renal disease, and 34.5% for sleep disorders (DiMatteo, 2004b).

Patients may have numerous reasons for their nonadherence. Ickovics and Meisler (1997) described patient, regimen, clinical setting, disease character-istics, and the provider-patient relationship as broad categories of factors that affect adherence. Nonadherence has economic outcomes, such as unnecessary hospitalizations, wasted medical visits, and unused prescriptions, to name a few. Nonadherence also diminishes the quality of the physician-patient relationship, as trust deteriorates and physician and patient frustration intensifies.

Ultimately, outcomes of health and disease management serve as the most important endpoints in determining the value of adherence. For example, the efficacy of medication adherence can be determined by several outcomes, in-cluding reduction of symptoms, alteration of disease course, decrease in pain, improvement in functioning, and even increase in life expectancy. Answering the important question of whether patient adherence "matters" is the purpose of the current chapter. This chapter addresses disease-specific evidence from studies describing the relationship between treatment adherence and relevant outcomes and presents broader evidence from qualitative and quantitative re-views that address this issue. The role of adherence in the outcomes of placebo treatment is also considered, as the beneficial effects of adhering to a placebo introduce consideration of possible psychosocial and biological mechanisms in the adherence-outcomes relationship. Finally, we examine the role of inter-ventions to improve adherence in terms of their potential to improve patients' health outcomes.

Adherence-Outcome Relationship Across Diseases

The relationship between patient adherence and treatment outcomes is criti-cally important to examine in a range of disease realms, where the requirements of adherence and the potential for its benefit vary widely. Studies of heart dis-ease and myocardial infarction (MI), for example, point to a strong relationship between adherence and mortality risk. Specifically, patients whose adherence to the medication clofibrate was at least 80% had a lower risk of death over the ensuing 5 years. In this study, as is examined in more detail later, patients who were adherent to a placebo also had a lower risk of death than did those who were nonadherent to a placebo (Coronary Drug Project Research Group, 1980). The Beta-blocker Heart Attack Trial demonstrated that men whose medication adherence was less than 75% had two and a half times the likelihood of dying in the year after experiencing an MI of those with better adherence. This result occurred even when psychosocial factors, including social support and stress, which may independently affect mortality, were controlled for (Horwitz et al., 1990). In other research, women with heart disease who were poorly adher-ent to propranolol had three times the risk of dying over a 25-month follow-up period than did those with good adherence (Gallagher, Viscoli, & Horwitz, 1993). Hypertension patients have better control of their blood pressure when they are more adherent. Comparisons of hypertensives with low (<50%), me-dium (50%–79%), and high (≥80%) adherence revealed significantly greater

blood pressure control in the highly adherent patients. Even after controlling for demographic factors, effective management of blood pressure was 45% better in highly adherent patients (Bramley, Gerbino, Nightengale, & Frech-Tamas, 2006). Poor blood pressure control can result in stroke or MI, among other life-threatening conditions; thus, serious, long-term negative outcomes can result from lower patient adherence.

Adherence to HIV medication can be particularly important; adherence is linked to various short-term and long-term disease outcomes, including viral load, CD4 cell count, and, ultimately, survival (Wainberg & Friedland, 1998). HIV medication management can involve significant challenges, of course, because of the complexity of the regimens, which often require taking multiple medications that have dosing schedules that challenge the conduct of daily life and that cause disturbing (and sometimes debilitating) side effects. Ideal outcomes in HIV include "undetectable" viral load, a high CD4 immune cell count, and prevention of drug resistance; these conditions may be achievable only with perfect, or near-perfect, adherence to treatment. HIV may be one of the conditions where the link between adherence and outcomes has been strongest and the level of adherence needed has been given the most research attention.

For HIV-positive patients taking protease inhibitors, one study showed that 21.7% of patients with adherence greater than 95% sustained virologic failure, whereas about 82% of patients who were less than 70% adherent did so (Paterson et al., 2000). In this study, higher CD4 counts and less frequent hospitalizations were also associated with better adherence. In other research that focused on behavior rather than medication, failure to achieve "undetectable" viral loads was associated with failure to keep appointments among HIV-positive patients following a protease inhibitor regimen (Lucas, Chaisson, & Moore, 1999). Recent treatment regimens for HIV/AIDS involving antiretroviral therapy have shown that less than 95% adherence was associated with greater likelihood of virologic failure (one definition of which was viral load at or greater than 200 HIV RNA copies/ml at week 24 of follow-up) (Collier et al., 2005). In a study that modeled both clinical and economic outcomes of HAART (highly active antiretroviral therapy), the authors differentiated between typical and ideal adherence, finding that 16.9 additional years of life were associated with typical adherence, whereas 19.2 additional years were associated with "ideal" adherence. Typical adherence also meant a loss of 12% in quality-adjusted life years (Munakata et al., 2006). Factors leading to better adherence may include positive provider-patient interactions and communication and greater confidence in one's ability to adhere. Although the effect on outcomes was not directly tested in this study, one could predict that effective and positive provider-patient communication is associated with better adherence and ultimately with improved treatment outcomes (Johnson et al., 2006).

Adherence to cancer treatment is associated with longer survival times and a reduced probability of cancer recurrence. Nonadherence can lead to the failure to contain localized disease. For example, irregular attendance at radiation therapy or chemotherapy appointments and premature discontinuation of treatment may increase the risk of metastasis and can increase the chances of metastasis and of disease recurrence (cf. Andersen, Kiecolt-Glaser, & Glaser, 1994). In one study, rural breast cancer patients of minority ethnicity who underwent breast conservation therapy and radiation had reduced rates of survival

when they did not adhere to their radiation protocols (Li et al., 2000). Conversely, in other work, individuals with colon cancer who completed adjuvant chemotherapy had a significantly higher rate of survival (Dobie et al., 2006).

Medication nonadherence among heart transplant patients has been found to predict adverse outcomes. This serious medical procedure requires complex follow-up care that can mean the difference between transplant success and failure. In one study of heart transplant patients taking immunosuppressive medication, nonadherent patients experienced significantly more transplant coronary artery disease over a 5-year follow-up period than did those who were adherent. Earlier and more frequent adverse clinical events were associated with poorer adherence (Dobbels, De Geest, Van Cleemput, Droogne, & Vanhaecke, 2004). In another study of adherence following heart transplant, failure to adhere to the prescribed medication regimen was significantly related to rejection of the transplant and development of coronary artery disease (Dew et al., 1999).

Adherence to diabetes regimens is also associated with more positive health outcomes, including better glycemic control. Diabetes is a chronic condition requiring multifaceted regimens involving medications, dietary restrictions, and insulin injections, among other therapeutic approaches. One study of glycemic control among 20 type 1 diabetes patients indicated that better control was associated with higher self-reported adherence to dietary restrictions (approaching traditional significance levels; $p < .10$) (Strychar et al., 1998). In an intervention in which "high-risk" diabetes patients received a blood glucose monitoring guide to self-management, a significantly greater number of patients in the intervention group experienced improved glycemic control (i.e., improved hemoglobin levels) (Moreland et al., 2006).

Recurrence or relapse of depression has been associated with discontinued antidepressant treatment. The probability of relapse or recurrence of depressive episodes increases when medication to control the symptoms of this mood disorder is not taken consistently. Early discontinuation of antidepressant treatment (defined as fewer than 4 prescriptions filled in a 6-month period) has been found to be associated with greater likelihood of recurring or relapsing (risk ratio = 1.77) (Melfi et al., 1998). An adherence intervention that involved greater involvement by health care providers in patients' care through visits, phone calls, and symptom monitoring resulted in greater improvement in the symptoms of depression, although not a significant reduction in the likelihood of relapse (Katon et al., 2001).

Among patients with hepatitis, adherence to medications is associated with better virologic response. In one study, patients who were more than 80% adherent had higher rates of virologic response (i.e., absence of HCV RNA) than did those who were less than 80% adherent to combination therapy with interferon (McHutchison et al., 2002).

Pharmacological treatments are not the only regimens for which adherence can affect patient outcomes. Considerable evidence indicates that adherence to behavioral treatments is associated with better outcomes. For example, better adherence by elderly hospitalized patients to a set of protocols, including orientation, mobility, and therapeutic activities, significantly reduced rates of patient delirium (Inouye, Bogardus, Williams, Leo-Summers, & Agostini, 2003).

There are some studies, of course, that have not shown a connection between adherence and better health outcomes. In the Medical Outcomes Study, for example, patients with hypertension, diabetes, MI, and congestive heart disease self-reported their levels of adherence, and the relationship between adherence and various health outcomes from the SF-36 was examined, and no consistent relationship of adherence to health outcomes was found (Hays et al., 1994). These results may be interpreted in a variety of ways, including the possibility that there were difficulties in adherence measurement, the fact that some medications and regimens may not have a strong effect on outcomes regardless of level of adherence, and the possibility that other factors, such as genetics, may play a greater role than adherence in determining disease progression.

Review Evidence Supporting the Relationship Between Adherence and Outcomes

Many quantitative reviews have been conducted to assess the relationship between adherence and health outcomes. One of the earliest reviews of this relationship included six studies and demonstrated that adherence was related to positive health outcomes in five out of the six investigations (Epstein, 1984). A meta-analysis of the relationship between adherence and outcomes across diseases indicated that the odds of a good health outcome are 2.88 times higher if a person is adherent and that there is a 26% greater risk of poor health outcomes in the context of nonadherence (DiMatteo, Giordani, Lepper, & Croghan, 2002). This effect is moderated by a number of factors; the relationship between adherence and outcomes was strongest in intestinal disease, hypertension, hypercholesterolemia, and sleep apnea (all p < .01). Analyses of moderators demonstrated a stronger relationship between adherence and outcomes for chronic illnesses than for acute illnesses and, among less severe illnesses, in nonmedication regimens and in pediatric populations. Further, studies that measured more subjective outcomes, such as pain, showed stronger effects than did those with more objective outcomes, such as blood pressure (DiMatteo et al., 2002). Additional quantitative review has shown a relationship between adherence and what may be considered the ultimate outcome, lower mortality risk. A meta-analysis of 21 studies of adherence to drug therapy showed significantly lower probability of death among "good" adherers than among those who were "poor" adherers (Simpson et al., 2006).

Research and Methodological Issues in the Adherence-Outcomes Relationship

Research studies of specific diseases and reviews of multiple disease conditions overwhelmingly demonstrate a positive, although not large, correlation between higher levels of adherence and better health outcomes. Several conceptual and methodological issues regarding this relationship are relevant to consider. First, the level of adherence necessary to achieve a positive health outcome may vary considerably from one disease to another. In HIV, for example, it has been

clinically proposed that 95% adherence to some medications is essential so that drug resistance does not occur. Some of the newer classes of medications may require only 80% adherence, although the efficacy of reduced levels of medication adherence and the implications for a variety of health outcomes are yet to be empirically determined (Johnson & Chesney, 2006).

Second, every medical condition may have a different definition of appropriate adherence, making comparison of the adherence-outcome relationship across conditions quite difficult. For example, studies suggest that for the treatment of sinusitis, similar outcomes resulted from 3 days and 10 days of antibiotic treatment (Kravitz & Melnikow, 2004). On the other hand, evidence is robust that a level of 80% adherence is essential for effective antihypertensive medication treatment, as well as for some orally administered cancer therapies (Paterson et al., 2000).

Third, the form of the relationship between adherence and outcomes may not be completely clear. Whereas most general linear model statistics test linear trends, it is possible that relationships between adherence and outcomes could be curvilinear or could follow a more complex trend, such as an initial reduction in effectiveness followed by a rapid and robust improvement in health outcomes. Or, a lower slope relating adherence to health outcomes may occur below a certain adherence threshold, whereas higher levels of adherence may produce a stronger correlation with health outcomes. Another possibility is that, above a certain threshold of adherence, there may be marginal improvements or even no added benefits to health outcomes (Kravitz & Melnikow, 2004).

Fourth, the relationship between adherence and treatment outcomes is likely to depend upon the circumstances surrounding care. Adherence achieved by closely monitored patients in clinical trials may be considerably higher than that exhibited by patients in the general population, influencing evidence for the effectiveness of treatment and for the relationship between adherence and efficacy (Horwitz & Horwitz, 1993). Further, the "intention to treat" and the actual receipt of treatment (as a result of adhering properly) may be quite different and may strongly influence evidence about outcomes. In clinical trials, there may be a wide range of adherence levels that "confound" the relationship between treatments and outcomes (Simpson et al., 2006).

Fifth, studies of the adherence-outcome relationship are correlational, and causal inferences must be made with caution. Certainly, if adherence is assessed well before health outcomes are determined, it may be possible to use temporal evidence for the likelihood that adherence causes outcomes, and not the reverse. It is always possible, however, that a "third variable" causes both adherence and outcomes, bringing about their correlation with each other. Examples might be patient poverty or ethnic minority status, which limits access to resources needed for adherence and also accounts for significant disparities in health outcomes (Betancourt, Carrillo, & Green, 1999).

Sixth, there is evidence that, in some cases, better patient adherence leads to worse health outcomes, most notably when treatment is the result of a medical error or is inappropriate for a particular patient. A meta-analysis of the relationship between adherence to drug therapy and patient mortality included two studies in which medication therapy was actually harmful to patients and those with better adherence had a greater mortality risk (Simpson et al., 2006).

It is also possible that patients may recognize the risk of inappropriate therapy and the possibility that adherence makes their health worse; in response, they may make a deliberate choice to be nonadherent.

The Relationship of Adherence to Placebo and Outcomes

Findings from numerous studies suggest that adherence to placebo may result in better outcomes than nonadherence to placebo. (See Czajkowski, Chesney, and Smith, 1990, for a more detailed discussion of the relationship between placebo and adherence.) The result of a meta-analytic study demonstrated that good adherence to a drug placebo was also associated with lower risk of mortality (Simpson et al., 2006). This finding, replicating the early work of Epstein (1984), suggests that there may be more to the positive outcome effects of adherence than simply the physiological and pharmacological aspects of treatment. Specifically, when the effect on health or disease outcomes does not depend on whether the treatment is an active drug or a placebo, a "main effect" of adherence occurs.

One of the first confirmations of this "main effect" was Epstein's finding that in five of six studies, adherence improved health outcomes regardless of the "active" nature of treatment (Epstein, 1984). This study suggested that the actions of a medication and the ensuing outcomes result not only from the specific, pharmacological properties of the medication but also from beneficial "nonspecific" therapeutic effects. A review conducted almost a decade later offered further evidence that patients who expect their treatment to be effective may, in turn, practice healthier lifestyle habits that facilitate achievement of the desired outcome (Horwitz & Horwitz, 1993).

Individual empirical studies have had similar findings. A study of cancer patients' adherence to oral antibiotics to reduce the chance of infection found that those patients with the highest levels of adherence were least likely to develop fever or infections, regardless of whether they received the active therapy or a placebo (Pizzo et al., 1983). Similarly, a study of patients undergoing alcohol withdrawal and taking beta-blockers to combat symptoms found a relationship between nonadherence and greater likelihood of alcohol relapse; the placebo condition findings mirrored those of the nonplacebo condition (Gottlieb, Horwitz, Kraus, Segal, & Viscoli, 1994).

A number of plausible explanations for these findings are possible. First, patients' expectations of the effectiveness of treatment could work to create a "self-fulfilling prophecy." Second, health habits such as eating a healthy diet, exercising, getting adequate sleep, and cutting back or eradicating harmful health habits (such as alcohol use or tobacco use) can complement medication in facilitating health outcomes (Horwitz & Horwitz, 1993). Third, the act of adherence may enhance adaptation and/or active coping behaviors that help to reduce or alleviate the stresses of serious illness (Horwitz & Horwitz, 1993). For example, a hypertensive patient who expects that medication will reduce the risk of stroke and heart attack may concurrently relax more, eat a healthier diet, begin walking for exercise, and even quit smoking.

Fourth, adherent patients may have stronger feelings of internal health-related locus of control and feel more positive about their health. Their optimistic thought processes and sense of well-being may have direct, and positive, physiological and immunological effects, although of course it is also possible that those who feel better are thus more optimistic (Epstein, 1984). Optimistic thought processes are also associated with changes in immune functioning, as has been demonstrated in studies of HIV-positive individuals (Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000). Specifically, optimism has been associated with greater numbers of helper T cells and greater natural killer cell activity (Segerstrom, Taylor, Kemeny, & Fahey, 1998). Optimism is also related to disease management in that patients who engage in positive thinking may cope better and subsequently experience more positive health outcomes (Fournier, De Ridder, & Bensing, 2002).

Not every study shows positive effects of adherence to placebos, however. A study of prevention of type 2 diabetes involved administration of metformin or a placebo; those who were adherent to metformin had a 24.8% reduction in risk over nonadherent patients. For placebo patients, however, adherers had a nonsignificant reduction in risk over nonadherers (Walker et al., 2006). It is possible that in this research, adherence may have been less important in the preventive regimens than in the regimens for a diagnosed condition. Findings that adherence to a placebo can have beneficial effects on health outcomes, however, leads us to further explore the nonbiological mechanisms through which adherence can be effective.

Mechanisms for the Relationship Between Adherence and Health Outcomes

Most medications have some pharmacological effects, and for many patients those effects are directly related to preventing or managing their disease or to achieving improvement in their symptoms. Evidence for the efficacy and safety of medication likely argue in favor of patients' adhering to all aspects of their prescribed regimen, including the dosage, timing of, and circumstances surrounding treatment. These circumstances may both affect and be affected by the medication regimen. For example, adherence may increase with and/or be increased by the availability of social support, which itself may affect and even be affected by the patients' health outcomes. Specifically, a more adherent patient might encourage family members to offer social support, and that social support might translate directly into more beneficial health outcomes (DiMatteo, 2004a).

There may be personal characteristics, such as conscientiousness, that provide advantage to the adherent patient (Gallagher et al., 1993). More conscientious people have been found to have better health behaviors than those who are less conscientious (Friedman et al., 1993).

Personality traits or psychological makeup might provide another explanation as to how adherence to placebo results in better outcomes. Adherent individuals may be more optimistic that their health will improve and their symptoms will abate, whereas pessimistic individuals may fail to adhere because they have little hope that their treatment will work. In addition, individuals

who are more adherent might have greater resilience to stress and/or more active coping strategies. Those who do not adhere may not cope well, on the other hand, or may use emotion-focused coping strategies, rather than the active strategy of choosing to be adherent. Furthermore, patient expectations and confidence that treatment is likely to work for them may affect both their likelihood of being adherent and their health outcomes (Horwitz & Horwitz, 1993). Patients are more likely to adhere if they believe treatment will work, and such patients are motivated and capable of following the regimen. A physician's confidence that treatment will help the patient to achieve the desired outcome may motivate patient adherence and contribute to more positive health outcomes for the patient (Czajkowski, Chesney, & Smith, 1990).

The lifestyle of individuals who are more adherent might provide another clue to better understanding the adherence-outcome relationship. Individuals who adhere might already have healthier habits, such as eating a low-fat diet, exercising more frequently, sleeping enough, following better hygiene practices, engaging in stress-reduction strategies, and exhibiting fewer risky or health-compromising behaviors than nonadherent individuals. Some researchers have described this as the "Healthy Adherer Effect" (Gallagher et al., 1993; Pizzo et al., 1983; Simpson et al., 2006). In addition, adherent patients may expect to have better health outcomes, making adherence to healthy lifestyle regimens easier for them because they are more motivated and confident about the expected end result of improved health (Andersen et al., 1994). On the other hand, nonadherent patients may not receive necessary information about how to improve their health habits because of limitations in communication and lack of rapport with their health care providers (Andersen et al., 1994).

Adherent patients might simply be initially healthier and have fewer complex regimens and treatments to which they must adhere (Gallagher et al., 1993; Pizzo et al., 1983). Patients who have difficulty with adherence may face more treatment challenges, more difficulties with medication side effects, and worse disease parameters than those for whom adherence is easier (Horwitz & Horwitz, 1993).

Some negative factors might mediate the relationship between adherence and outcomes, as well. Specifically, nonadherence may be a result of depression and mediate the relationship between depression and poor health outcomes (DiMatteo, Lepper, & Croghan, 2000). In one study of patients who were prescribed aspirin after Acute Coronary Syndrome, depressed, nondepressed, and intermittently depressed patients were compared over a 3-month period (Kronish et al., 2006). The persistently depressed patients took the least number of correct doses of aspirin across the entire measurement period, and, although mortality was not assessed, the findings indicated that nonadherence might represent the link to higher mortality risk in these patients. Findings also indicated that continuously depressed patients had poorer health behaviors; they were less likely to quit smoking, undergo cardiac rehabilitation, exercise, and modify their diet (Kronish et al., 2006).

Additional evidence demonstrating a link among depression, adherence, and outcomes can be found in the case of asthmatic patients. In a study of economically vulnerable patients who had recently been hospitalized for asthma-related emergencies and who were electronically monitored for adherence, patients with a greater number of depressive symptoms were

5.5 times more likely to be nonadherent to their prescribed regimen than those with fewer symptoms (Smith et al., 2006). Adherence, outcomes, and depression may be linked because pessimism, low energy, and poor motivation can create a situation in which adherence becomes difficult to achieve. Such research suggests the need for further studies of the adherence-outcome relationship to control for personal, psychological, and regimen factors that may affect this association.

Interventions, Adherence, and Outcomes

Addressing patient challenges to adherence has involved intervention research designed to alleviate some of the problems that stand in the way of patient adherence. Several studies suggest that health outcomes can be improved by enhancing patient adherence, and that barriers to adherence such as ineffective physician-patient communication, poor understanding of the treatment, the severity of the patient's condition, and emotional and mental health challenges can be improved to enhance adherence. Roter and colleagues (1998) conducted a meta-analysis of educational, behavioral, and affective intervention programs to improve patient adherence. These studies measured both subjective and objective health outcomes such as blood pressure, hospitalizations, survival, disability, pain, and gains in knowledge. Results indicated that interventions to improve patient adherence helped to lower the blood pressure levels of hypertensive patients. Cancer patients had improved survival times and lower recurrence rates as a result of interventions to improve their adherence. And adherence-enhancing interventions for patients on mental health regimens were associated with fewer hospitalizations (Roter et al., 1998).

In another meta-analysis of 95 independent samples of behavior-focused, educational, and combined interventions to improve adherence, 31 studies included a measure of health outcomes for a particular disease. The authors did not evaluate the relationship between adherence and outcomes (instead focusing on the effect of the interventions on adherence) but noted that there is an unknown relationship between adherence and health outcomes and that this relationship may depend on the disease and outcome in question (Peterson, Takiya, & Finley, 2003). Randomized controlled trials of interventions to improve adherence are extremely important because, with randomized experiments, it is possible to assess the causal effects of adherence on health outcomes. Further, studies of interventions to improve health and treatment outcomes that include an adherence or medication-taking intervention component would allow the assessment of both main effects and interactions of the adherence intervention on a variety of health and survival outcomes.

Conclusion and Implications

The role of patient adherence in determining patients' health outcomes is broad, particularly in light of the multiplicity of potential regimens for numerous conditions, as well as the myriad outcomes that are possible for any given

condition. There are both conceptual and methodological issues of importance in terms of what is known about the relationship between adherence and outcomes and what areas require further study.

Several conceptual questions remain important to consider. Convincing evidence exists for the adherence-outcome relationship in several chronic and severe illnesses, including heart disease, HIV/AIDS, and cancer. There are fewer studies of the adherence-outcomes relationship in pediatric conditions, however, than there are for adult conditions; meta-analytic evidence suggests, however, that the adherence-outcome relationship may be even stronger in pediatric than in adult populations (DiMatteo, 2004b). Next, low levels of adherence challenge health outcomes in important ways for many illness conditions, but the optimal level of adherence necessary for the treatment of many medical conditions has not yet been determined. In conditions where 80% adherence is acceptable, should patients be told what they will gain in striving for 90%? If for some conditions (e.g., sinusitis) taking antibiotics for 3 of 10 days is enough for a good outcome, should patients be told not to worry if they miss 7 days of medication? Or, better still, should they be prescribed only 3 days' supply? If the process of adhering itself does something good for patients, shouldn't they know what constitutes appropriate adherence for their condition so that they can reap the benefits of achieving it? Also, the mediators and moderators of the adherence-outcomes relationship are challenging to untangle. Such factors as patients' disease severity and physical and mental health status are issues that require further examination. An important next step for future research is to clearly elucidate these pathways.

It is important to compare adherent and nonadherent individuals to determine how they differ on psychosocial factors such as optimism or coping strategies and to assess the effect of these on outcomes (Horwitz & Horwitz, 1993). It is evident that being adherent can involve health behaviors well beyond simply taking medication. Systematic study is needed of the broader self-efficacy over health and lifestyle behaviors that may be an important link to a patient's achieved health outcomes to add to our understanding of this area (Gottlieb et al., 1994).

Several important methodological questions require study. First, it is clear that robust measurement of both adherence behavior and outcomes, as well as their potential mediating or moderating factors, is critical. Electronic assessments of adherence may be the most accurate, but they are also expensive and are not feasible in standard clinical practice. Good measurement may involve the use of multiple approaches to adherence assessment (DiMatteo, 2004b; Garber, Nau, Erickson, Aikens, & Lawrence, 2004). Next, there is a need for more research into aspects of the physician-patient relationship that may influence both adherence and outcomes. It is important to determine, for example, the extent to which physicians discuss the benefits of certain medications with their patients and options to deal with side effects or other barriers to adherence and thereby fully involve their patients in decision making. These areas of communication about adherence are crucial but remain relatively understudied (Ballard-Reisch, 1990; Kaplan, Gandek, Greenfield, Rogers, & Ware, 1995). Third, many of the studies described here involve medication adherence. It is important to explore nonmedication regimens, such as dietary changes or exercise programs. For example, how does adherence to a dietary or exercise regimen

affect outcomes for obese patients and for those with chronic diseases that require lifelong behavioral management?

There remain conceptual and methodological issues in understanding the adherence-outcomes relationship. Patient adherence may sometimes be critical, but it is also clear that positive health outcomes rely on more than the pharmacological effects of a drug. Patients' psychological mind-set, behaviors, and beliefs and expectations, as well as the communication they have with their doctor, play a significant role in adherence and the enhancement of health outcomes.

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Lessons Learned: What We Know Doesn't Work and What We Shouldn't Repeat

40

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The importance and central role of health behavior in improving human's health cannot be disputed. This book contains analyses and summaries of specific research questions on the study of health behavior. However, there are some issues or themes that cut across health behavior areas in the form of lessons learned, sometimes through painful experience. These lessons do not usually fit neatly into the standard format of a research report. Here we list several of these issues for consideration. They are in the form of "don'ts," or directions that we recommend you not repeat. We divide them into the "don'ts" that stem from a specific line of research and the "don'ts" that come from the process of doing research.

Research Don'ts

Don't Focus on Individual-Level Issues Without Considering the Environment

Any new strategy for disease control and prevention must recognize that human behavior is a major determinant of health outcomes (Hiatt & Rimer, 1999). A recent Institute of Medicine (IOM) report (Board on Population Health and Public Health Practice, 2005) estimates that lifestyle changes could prevent a significant number of deaths, and a recent position paper by the Centers for Disease Control and Prevention (CDC) (Gerberding, 2005) called for actions to reduce the burden of chronic disease through lifestyle changes. However, much of what we have considered to date rests with individual level variables—behaviors initiated and reported by participants in studies (Bowen et al., 2008). There is a growing interest and increasing research focus on the larger causes of human choices as a way to develop clearer and more lasting explanations for patterns of behavior. We must place more emphasis on the social, structural, and environmental causes of these lifestyle choices than has currently been done. Social and behavioral science research is critical to cancer prevention and control because translating knowledge into practice at the population level requires new methods for promoting social and behavioral change (including identifying cultural barriers to change), improved cancer communications, and continuous evaluation of the outcomes of cancer interventions. The recent focus on the social and structural causes of chronic disease also calls for increased research and training on societal interventions to reduce health disparities (Bowen et al., 2008).

One issue that illustrates this point is obesity reduction. The United States has spent a long time and billions of dollars figuring out that it is really impossible to lose weight and maintain the loss with traditional weight-loss programs. While we have been doing this, the epidemic of obesity in the United States and in western Europe has become a critical and frightening public health issue, arguably the most pressing health issue today. We virtually ignored the larger social and environmental foci that helped shape our obesity problem, separately and in conjunction with the focus on individual skills training. Given the lack of these behavioral and individual approaches to obesity reduction and prevention, the field is looking to the social, cultural, and environmental causes of this health issue. Does this mean that understanding the individual causes of human behavior is no longer necessary? Not at all. It simply means that humans are social creatures and that they are influenced by their social systems. Therefore, if we want to change behavioral patterns that lead to a negative health outcome, we need to consider the larger forces at play in shaping and influencing our individual choices and, ultimately, our health.

Don't Assume That the Cause of a Health Problem Is Solely Biological or Psychological/Social in Nature Until You Have Examined the Evidence

The assumption of a biological cause when social factors are also important is implicit in some of the new emphasis on genetic causes of health differences.

The National Institutes of Health's (NIH) definition of a disparity focuses on the difference between two subgroups. There is no inherent cause of disparity to be found in this definition, and no assumption is made about the role of biology in the definition. However, recent published definitions of disparity (Baquet & Carter-Pokras, 2002) focus on the social causes of disparities and on the social construction of conditions that lead to disparities, like racism. The word "disparities" is becoming increasingly associated with social or behavioral causes and less with biological differences. This shift in definition means that more emphasis should then be placed on research that identifies the social causes of disparities and the potential interventions that can reverse or eliminate them.

One current area of research that is drawing much attention from researchers, both positive and negative, is the area of genetic research as applied to health disparities. Whether a genetic difference can be considered a disparity hits at the heart of the controversy over the definition of a disparity. Do all biological differences fit into a disparity definition? Given that generally women are born with a uterus and men are not, are rates of uterine cancer to be classified as disparities? The field of health disparities would benefit from clarity of definition as we move forward in the identification of methods to reduce disparities in health.

Don't Assume That Lessons From One Group Automatically Fit Another

For years, while the biomedical model prevailed with little challenge, most research was conducted on men. The findings were later applied to women, with the implicit operating assumption that women are "little men" and that differences between men and women were not relevant (Haynes, 2000). For example, testing of drug treatments was historically conducted in men, but women later were prescribed these drugs. Pharmaceutical industries argued for the exclusion of women, citing safety concerns for women and their potential fetuses. Multiple examples indicate that this approach was incorrect and even shortsighted, since the drugs were prescribed to women as soon as they were approved by the U.S. Food and Drug Administration (FDA). Thus, the effectiveness and the safety of the medication for women were established only after the drugs were on the market and actively used by consumers. An FDA analysis of the labels of approved drugs indicated that 22% of labels report gender-related difference in the effects of medications (Evelyn et al., 2001). Some FDA-approved drugs had to be taken off the market when the dangers they posed for women became apparent (e.g., terfenadine [Seldane] in 1998) (U.S. Government Accountability Office, 2001).

This lesson does not apply only to drug safety and effectiveness. It applies just as much to behaviors. Safe-sex behaviors aimed at HIV prevention cannot be implemented by the promotion of similar interventions for women and men. An intervention that teaches safe-sex behaviors only to women without taking into account that some women's negotiation of safe-sex behaviors may be compromised by their unequal status in power is likely to be ineffective (Tinker, Finn, & Epp, 2000). Other research demonstrates that there are gender differences in the ability to change behaviors related to chronic diseases: smoking, physical inactivity, and high fat intake (O'Hea, Wood, & Brantley, 2003). Men and

women do not view these behaviors from the same perspectives, and therefore, changing some of these risk behaviors requires gender-specific interventions (O'Hea et al., 2003).

We must acknowledge an end to a "one size fits all" era and acknowledge the need for different tools for different groups. Sexually transmitted diseases (STDs) and HIV/AIDS provide good examples of the importance of this issue. Racial differences in STDs and HIV/AIDS rates have been documented, and research confirms that Blacks have higher rates of HIV infection and other STDs (Celentano et al., 2005; Hallfors, Iritani, Miller, & Bauer, 2007; Halpern et al., 2004). The prevailing assumption is that the best intervention for STDs is to reduce individuals' risk behaviors. The applicability of this premise to Blacks has been called into question by studies that demonstrate that STDs and HIV infection rates are higher in Blacks regardless of individual risk behaviors (Hallfors et al., 2007; Halpern et al., 2004). One likely explanation is same-race partner choice among Blacks and a greater tendency among Blacks than Whites to choose discordant coupling (the pairing of a high-risk individual with a low-risk-behavior partner). This discordance in risk behaviors in couples increases the likelihood of STD and HIV transmission among Blacks, regardless of individual risk behaviors (Hallfors et al., 2007). Different and targeted interventions targeted at Blacks are therefore necessary to reduce the documented differences.

Don't Make Assumptions About the Mechanism of Behavior Change Without Supporting Evidence

The field of youth smoking prevention in the United States is an excellent example of the need to be clear about what is behind behavior change. The original smoking prevention programs for youth were school based and focused on imparting knowledge about the harmful health effects of tobacco use. The idea was that youth did not fully understand or appreciate these long-term chronic disease effects, and therefore the best way to keep youth from smoking was to fully inform them of these harmful health effects. These early programs had no effect on the onset of smoking in young people (Thomas & Perera, 2006). Therefore, investigators focused on the social influences model of smoking prevention intervention, which is based on the finding that many youth who smoked also had friends who smoked. The "Just say no" programs, which taught youth skills to use in social interactions about tobacco use, were a result of this wave of research. These programs had no lasting effects on tobacco use, either (Peterson, Kealey, Mann, Marek, & Sarason, 2000). The current, perhaps more informed approach to reducing smoking among youth focuses on the mass media and reduction of exposure to tobacco in purchasing situations through advertising and via promotion of tobacco products by tobacco companies. These approaches carry promise for greater and longer-lasting effectiveness on use of tobacco among youth. Smoking cessation researchers spent approximately 40 years trying ineffective interventions because, in part, they did not stop to fully understand the mechanism of smoking behavior in youth. Identifying the mechanisms of behavioral choices—in this case, the influence of mass media advertising on youth smoking behavior—before trying various interventions is likely to promote more effective interventions.

Don't Assume That Maintenance of Initial Change Is Easy

Health behavior change is a critical and essential piece of behavioral approaches to disease prevention. However, the initial change in risk-related behaviors (e.g., a reduction in smoking) must be maintained over long periods of time to influence individual risk for developing disease. Countless studies have described short-term gains in behavior change but limited maintenance of the changed behavior. Sustained change needs to be studied separately, with interventions designed to *target* the maintenance of the newly achieved behavior. One example of this phenomenon was studied in research that focused on school-based youth behavioral change programs. Investigators identified significant initial changes in the targeted behaviors, including tobacco use, physical activity, and eating behaviors. However, only when individual classroom efforts were combined with community change was youth behavior change maintained over years (Ranney et al., 2006; Sowden, Arblaster, & Stead, 2003). The intervention that produced the initial change was not an efficacious means of maintaining behaviors, and it therefore had to be coupled with other types of intervention plans (e.g., changes in environmental cues and supports) if the changes were to be maintained.

Process Don'ts

Don't Settle for Second Place in Large Collaborative Disease Endpoint Studies

The shift over the past 30 years from a focus on the treatment of acute illnesses and chronic diseases to chronic disease prevention has led to a role for health behavior change that is central to improving disease rates. The data to support this shift come from large national or international studies in which the behaviors of interest are measured and disease outcomes are tracked. Most of these studies used a medical model approach to behavior change, where individuals were randomized to treatment or observed over time for specific disease outcomes. However, the focus on behavior change has provided opportunities to learn more about the role of behavior and its determinants in large populations samples. For example, the Women's Health Initiative (WHI) serves as a model for how to include social and behavioral scientists both as drivers of procedures for behavior change (e.g., diet change) and as experts in selecting the appropriate measures of a large-scale disease endpoint study, thereby allowing for several key behavioral hypotheses to be tested (Matthews et al., 1997). The WHI measures of interest included multiple psychosocial assessments, including quality of life, depression, sleep disturbance, sexual functioning, and anger and hostility, and the behavioral outcomes of the three major randomized trials were improved health behavior (dietary fat reduction, hormone therapy (HT) adherence, and calcium/vitamin D adherence). Access to these data was shared by behavioral and biomedical scientists, allowing for multiple papers and abstracts to be created through the Behavioral Committee and by psychosocial and behavioral colleagues across the country. Analyses of the WHI data are ongoing, and these data stand as the most integrated source of information on the behavioral and psychosocial aspects of women's health in the world. These

resources came about because of the determination of the initial group of social scientists to be included in the process of decision making about what to measure and because of the vision of the WHI Steering Committee members, who recognized that behavior was essentially a key aspect of the study in that all of the key interventions required expertise in behavior change and methods to enhance adherence.

Don't Assume That Policies Are Driven by Good Science

In 1983, the Drug Abuse Resistance Education curriculum (D.A.R.E.) was introduced nationally (U.S. Government Accountability Office, 2003), and it became the most widely used school-based substance abuse prevention program, operating in about 80% of all school districts in the United States (U.S. Government Accountability Office, 2003). There is no centralized accounting of the funds for D.A.R.E., which are provided by a variety of sources, including federal, state, local, and private sources (Shepard, 2001). Estimates of the total funds used for this program vary. D.A.R.E. itself estimates its costs at $215 million annually, which includes more than $41 million in federal funding, according to the Office of National Drug Control Policy (ONDCP) (Shepard, 2001). The main goal of D.A.R.E. is to provide children with information about drug abuse and to teach them the skills to live drug-free lives. In the 1990s, a number of studies were published that concluded that D.A.R.E. is not effective in preventing youth from using drugs and alcohol (U.S. Government Accountability Office, 2003). In 2003, the Government Accounting Office (GAO) published a report that concluded there were no significant differences in illicit drug use between students who had gone through the D.A.R.E. program in the fifth or sixth grade and students in a control group who had not attended D.A.R.E. (U.S. Government Accountability Office, 2003). Further, the D.A.R.E. program had no significant long-term impact on whether youth used illicit drugs, and those who had attended D.A.R.E. and those who had not did not differ significantly in their attitudes toward drug use and in their ability to resist peer pressure. Yet the D.A.R.E. programs continue to receive funding, perhaps because of the influence of law enforcement on funding and policy.

Abstinence-only education in sexual and reproductive health programs is another example of an education program designed to alter risky behaviors that was never tested for efficacy prior to implementation. The funding for abstinence-until-marriage programs comes from federal sources established through the 1996 Welfare Reform Act. The funding comes from the U.S. Department of Health and Human Services and increased steadily, from about $73 million in 2001 to about $158 million in 2005 (U.S. Government Accountability Office, 2006). The program's goal is to reduce the incidence of sexually transmitted diseases and unintended pregnancies. The intervention involves delivering to youth a curriculum that promotes abstaining from sexual intercourse until marriage. The Choosing the Best program (http://www.choosingthebest.org/), which focuses on abstinence, has eight defining characteristics: (1) it teaches the social, psychological, and health gains from abstinence, (2) it promotes abstinence from sexual activity as the standard for all school-age children, (3) it stresses that abstinence is the only certain way to avoid pregnancy, sexually transmitted diseases, and other health problems, (4) it holds out the premise

that a mutually faithful monogamous marriage is the standard of human sexual activity, (5) it asserts that sexual activity outside marriage is likely to have harmful effects, (6) it teaches that bearing children out of wedlock is likely to have harmful consequences for the child, the child's parents, and society, (7) it teaches young people how to reject sexual advances and how alcohol and drug use increases vulnerability to sexual advances; and (8) it stresses the importance of attaining self-sufficiency before engaging in sexual activity.

Recently, the GAO reported on the scientific accuracy of materials used in abstinence-until-marriage education programs and their effectiveness (U.S. Government Accountability Office, 2006). The review concluded that some of the materials included in the program were inaccurate about the effectiveness of contraception in preventing sexually transmitted diseases and HIV. The report did not directly address the effectiveness of abstinence programs and noted that the determination of effectiveness was hampered by the lack of scientifically valid evaluations. There is a lack of rigorously conducted research using experimental designs (e.g., intervention and control groups) and of follow-up assessments collected over a long enough time period to allow effects to be assessed reliably (U.S. Government Accountability Office, 2006). Data from a more recent and scientifically rigorous study concluded that abstinence programs are not effective (Trenholm et al., 2007). Young people who had gone through abstinence-only education did not differ in rates of abstinence from sex, number of sexual partners, age of initiation of sexual activities, and rates of unprotected sex from those who had not (Trenholm et al., 2007). Abstinence education program did not reduce the targeted behaviors, and it is unlikely that they reduced the incidence of sexually transmitted diseases and unwanted pregnancies, though these outcomes were not directly assessed as part of the study. Yet, the abstinence program remains the intervention of choice nationally for controlling these critical health issues for youth as expressed in the federal budget for fiscal year 2008, which allocated $204 million to abstinence-only education (White House, 2007).

Don't Assume That Companies Have Public Health Priorities

The phrase "follow the money" as advice for identifying the underlying rationale for an event indicates the power of money as a motivator. Financial motives are often key in explaining the actions of individuals or groups that seek to influence health-related policy. One recent example is the tobacco industry's opposition to the Occupation and Safety Administration Air Indoor Quality Rule (Bryan-Jones & Bero, 2003). This rule was implemented to provide protection through ventilation from secondhand smoke, yet it was withdrawn in 2001 after multiple hearings and efforts by the tobacco industry stalled or derailed the policy process. Using strategies such as continuing to debate and dispute the negative health effects of smoking (which have been publicly and scientifically proven for years) and promoting media coverage of the tobacco industry position, the industry group effectively blocked the rule from taking effect. States, rather than the federal government, now create rules to regulate indoor air policies, though these too have been actively opposed by tobacco industry-affiliated consultants and scientists (Bryan-Jones & Bero, 2003). Though progress on this issue at the state level is promising, ultimately the demise of a national-level

policy on this issue makes it more difficult to fight on a coherent and integrated level, thereby weakening the ability of antitobacco advocates to realize health-promoting policies.

This type of influence—for-profit corporations acting in their own best interests and against the best health interests of the public at large—occurs at a global level. For example, Germany's tobacco reduction advocacy system is tangled in a web of tobacco company advocacy groups, resulting in the highest prevalence of tobacco use in Europe (Gruning, Gilmore, & McKee, 2006). Documented relationships between national trade and humanitarian aid policies in developing countries by the tobacco companies effectively blocks tobacco control in developing countries where tobacco use rates are growing (Lawrence & Collin, 2004; Warner, 2005). These international issues highlight the clash between economic gain for some and efforts designed to protect and promote the health of the general population (see chapter 38 for further consideration of this point from an ethical perspective).

Even when the policy is a scientific recommendation for more policy, large corporate organizations may attempt to influence the outcome. For example, two internationally known scientists reported on the U.S. government's efforts, backed and influenced by the major food companies, to influence the United Nation's position on healthy eating and, specifically, to add sugar to both sweet and nonsweet foods (Brownell & Nestle, 2004). The UN report recommended straightforward changes to behavior—eat more fruit and vegetable foods, reduce sugar consumption—to prevent or slow the rising international epidemic of obesity. The U.S. Department of Health and Human Services issued a detailed critique of the UN's report, charging the UN with inaccurate science (Brownell & Nestle, 2004). These food company tactics did not ultimately work, and the policies were carried forward by the UN report and recommended for worldwide acceptance.

Conclusions

We have identified issues that come up in our work and that represent lessons learned from conducting research in health-behavior change and adherence. The research lessons are very different from the process lessons, with the primary distinguishing factor being the level of control individual researchers have over the issues. As researchers exert more control over the issues, we have the opportunity to use science to inform public policy and practice, which can be rewarding for scientists and have positive effects on health outcomes. If we ignore these research lessons, we run the risk of conducting scientific studies that do not take into account all of the evidence and that therefore are not of the highest quality possible. Ignoring environmental influences, for example, will lead us to only partially understand the causes of obesity or tobacco use. This partial understanding may delay our responses to the real and complex issues in public health.

The same level of control, however, is not always possible with regard to some of the process lessons. The last two examples provided suggest that public policies are outside the individual researcher's control. One process lesson deals with allowing special interest groups to set policies (e.g., the focus

on DARE and on abstinence). The second lesson deals with the influence of corporate interests on policies. Though individual researchers do not control these types of influences, they can share information and band together to advocate for the use of evidence in setting health policy, and they can conduct research in a way that is directly relevant and accessible to policy makers. These types of lessons are not often taught in scientific or graduate settings and must usually be learned through experience, though some professional societies provide technical assistance on how to link research to policy agendas. For example, learning to anticipate political opposition to specific scientific positions as the science is being published or considered for policy decisions might help scientists to create presentations that are more convincing. Understanding and anticipating the impact of corporations on the public health choices that we wish to influence through our own scientific findings will help us as scientists prepare to counter such opposition.

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