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Handbook of Clinical Behavioral Pediatrics

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Preface

Since 1978, the editors have collaborated on several research projects and spent many hours at conventions discussing research, graduate education, and patient care. The idea for this volume arose when we both concluded that the area of behavioral pediatrics needed a "how to" book. Several important scholarly reviews had recently appeared. They presented excellent summary information concerning the general assumptions and theories underlying the area of behavioral medicine with children. But these volumes devote very little attention to the application of clinical methods. What was needed, we thought, was a book that would allow graduate students and practicing clinicians the opportunity to peer into the minds of eminent practitioners and understand their thinking. Thus the book was conceived.

Editing books represents a special kind of challenge. One has to "sell" an idea to a group of distinguished colleagues. They have to believe enough in that idea to devote the considerable time and effort necessary to bring thought into reality. In this case, there were two ideas we tried to sell to our colleagues.

The first was that we wanted to produce a book in which readers could get a real feeling for the clinical nuances of behavioral pediatrics. The text contains four sections. Part One is devoted to discussions of the basic clinical issues of behavioral pediatrics. Parts Two and Three discuss various clinical disorders and describe the "how to" of treatment. The final part of the text contains chapters devoted to more general treatment issues. Each of the treatment chapters first presents a description of the disorder and how it is assessed, then briefly reviews the literature concerning the psychological problems associated with the disorder. This review concentrates on the material that the authors find most relevant to their clinical endeavors. We wanted to distinguish our book from others by having it focus clearly on the practical, applied issues that the authors find important in helping their patients. We wanted readers to go through the thought processes of outstanding clinician-researchers as they decide how to tackle their patients' difficult problems. This was accomplished by asking each author to provide a clinical case in which he could tell the reader how he solves the myriad of problems that patients present.

The second idea was that there are several newly emerging areas of behavioral pediatrics which, because of a paucity of published data, do not easily lend themselves to the standard chapter format. Nevertheless, we want readers to become familiar with these. Unlike other texts concerning clinical behavioral methods, this volume has two different sections devoted to disorders. One section focuses on problems that have been receiving attention from clinicians for many years. The other section is devoted to problems that have only recently begun to be attacked by behavioral clinicians. While an extensive literature concerning these topics has yet to be developed, these are problems that clinicians are regularly called upon to treat. To accomplish this, the book contains a series of mini-chapters, each of which details one of these emerging topics. The first few pages are devoted to a description of the medical problem and how it is assessed. The remaining pages provide a case illustration that will put the reader on the cutting edge of clinical behavioral pediatrics. We hope that readers will find this material interesting and informative; we also hope that it has great heuristic value. We want this text to be useful as a guide for health care providers, but we also would like it to serve the needs of educators training graduate students in health service professions.

While editing this book, we made several new friends and became better acquainted with some old ones. A decision that each editor has to make concerns how much editing to do of others' work. This translates to the intriguing and delicate question of when does an editor become an author? Our preference was to let readers become acquainted with the unique style of each author. As much as possible, each chapter is in the author's words. We have tried to edit only enough to keep the chapters consistent in format. Our respect for our contributors made this an easy task.

We would like to thank the contributors for their help in bringing this book from idea to fruition, for believing in these ideas and volunteering their time and effort, and for bearing with us during the sometimes tedious process of revision. Your support was invaluable. Even more important, we would like to thank our wives Jean and Marj, and our children Eli, Hanna, Ryan, and Ashley for their patience, encouragement, and enthusiasm during this project. About them, enough good things can never be said.

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Handbook of Clinical Behavioral Pediatrics

PART I

BASIC PRINCIPLES

CHAPTER 1

Clinical Behavioral Pediatrics

An Introduction

ALAN M. GROSS AND RONALD S. DRABMAN

INTRODUCTION

The involvement of psychologists in pediatric health care has risen dramatically during the past 20 years. Although psychology has long been viewed as a health science discipline, its health impact has been primarily defined as concerning clinical psychology, psychiatry, and mental illness (Schofield, 1969). The appointment of psychologists to departments of pediatrics in medical schools and general medical and surgical hospitals was once rare. Today it has become commonplace. This emphasis on the collaborative management of the health care needs of children is in part due to changes in the practice of pediatric medicine.

Richmond (1985) reported that following World War II and on into the 1950s, interest in child development and psychosocial aspects of children's health among pediatricians was minimal. Relatively speaking, morbidity and mortality rates were still high, and treatment of infectious disease was the pediatrician's major concern. However, during the 1960s, the biomedical revolution was well under way. The virtual elimination of diseases such as polio and smallpox had been achieved. Vaccines for the prevention of diphtheria, tetanus, measles, mumps, and rubella had been developed. These medical advances had a significant impact on morbidity and mortality rates. Pediatric care (e.g., immunization) now required a dramatic rise in well-child visits.

The 1960s also saw an impressive growth in medical technology. For example, more low-birthweight infants were surviving. These advances raised impor-

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tant child development questions. Moreover, the passage of the Civil Rights Act in 1964 led to the delivery of comprehensive health care services for poor children (Richmond, 1985). These programs contained a legislative mandate to define maximum developmental outcomes for youngsters born into poverty. This legislation resulted in the need for practitioners of pediatric medicine to have a better understanding of the role played by environmental and developmental variables in child health.

During the 1970s, pediatric medicine began to focus on issues surrounding chronic illness. Cures, declines in infectious disease rates, and further advances in medical technology reduced the need for pediatricians to concentrate primarily on the treatment of acute illness. These successes also raised questions concerning the impact of chronic illness on human growth and development. In addition, as morbidity and mortality rates associated with disease declined, it became apparent that accidents were a major child health problem. This set the stage for the expansion of the role of the pediatrician in health risk prevention (Richmond, 1985).

A major focus of medical care during the 1980s has been to encourage people to develop sound health habits. Nutrition and diet, exercise, smoking prevention, and alcohol education programs have become a routine component of health care. Health habit promotion is particularly relevant to pediatric medicine. The multiple visits associated with well-child care provide ample opportunity for pediatricians to work with patients in the early development of healthy lifestyles.

Treating children for acute disease and illness is still the major daily activity of pediatricians. However, current practice increasingly involves preventive care for ambulatory problems, as well as repeated care for chronic illnesses (Russo and Varni, 1982). These changes in medical practices have resulted in new demands on pediatricians. Unfortunately, traditional training in pediatrics may not prepare physicians adequately for these challenges.

A number of investigators have pointed out that the types of problems presented in a pediatric practice regularly involve developmental, behavioral, psychological, and educational issues (Task Force on Pediatric Education, 1978). McClelland, Staples, Weisberg, and Berger (1973) reported that requests for guidance concerning child-rearing and behavioral management issues occurred in 37% of well-child care visits. Academic problems were discussed on 19% of these visits. In another survey, practicing pediatricians judged psychological issues to be involved in 90% of their cases (Duff, Rowe, & Anderson 1972). Brazelton (1975) estimated that as much as 85% of his effort in a general pediatric practice is spent providing advice and counseling concerning behavioral and developmental problems. Finally, a study conducted by the Academy of Pediatrics (1978) found that in the preceding 5 years, the greatest area of change in pediatric practice was the volume of parental requests for help in problems related to school and child management.

Currently many pediatric appointments are for well-child care (Reisinger & Bires, 1980). These appointments often involve parents seeking assistance for behavioral, developmental, and/or psychological problems. This demonstrates the importance of psychological training for pediatricians. Unfortunately, this training encompasses a disproportionately small amount of study in pediatric medicine (Christophersen & Rapoff, 1980). Most pediatricians rate their training in behavioral, developmental, and/or psychological areas inadequate (Kempe, 1978).

One of the first to expound on the potential benefits of enhanced collaboration between psychology and pediatrics was Jerome Kagan (1965). He suggested that the collaboration of these health care specialties would yield a number of benefits. These benefits included a better understanding of the relationship of prenatal and perinatal factors to subsequent behavioral disturbance, early detection of psychosocial problems and severe childhood disturbances, and the development of therapeutic applications for children.

Wright (1967) suggested the term pediatric psychologist to describe psychologists working with children in a nonpsychiatric medical setting. Unlike psychiatrists, pediatricians do not have a primary interest in behavioral problems. Therefore, the pediatric psychologist must have a sound knowledge of child development, as well as excellent clinical skills. These attributes will make the psychologist useful in answering questions concerning childrearing and helping parents provide an optimum environment for the intellectual and interpersonal growth of their children. Wright (1967) also saw the role of the pediatric psychologist as involving the prevention of emotional problems.

Since the term pediatric psychology was first used, this area of health care has been referred to as pediatric psychology, behavioral pediatrics, pediatric behavioral medicine, and child health psychology (Kelley & Drabman, in press). Each term implies a different point of emphasis or orientation. For example, Roberts, Maddux, Wurtele, and Wright (1982) suggested that pediatric psychology involves clinical child psychologists with a strong appreciation of child development, working in health care settings. The pediatric psychologist responds to a medically based referral and serves primarily as a consultant to physicians and parents. At times, the pediatric psychologist will also provide direct treatment.

The term behavioral pediatrics, which has its roots in pediatric medicine, may be a more useful and accurate name for this area of health care. Unlike the term pediatric psychology, which focuses on the role of the psychologist in a pediatric setting, the label behavioral pediatrics may be used to describe an array of activities performed by individuals from many disciplines (Russo & Varni, 1982). Since pediatrics recognizes the importance of understanding the relationships among behavioral, environmental, and biological influences on child health and development, the label behavioral pediatrics may more clearly reflect the interdisciplinary nature of this area.

Russo and Varni (1982) suggested seven characteristics of behavioral pediatrics: (1) interdisciplinary in nature; (2) empirically based; (3) concerned with child management and the management of disease and its symptoms; (4) concerned with prevention, acute intervention, and long-term care; (5) data-based treatment involving collaborative decisions; (6) activities conducted in ambulatory and inpatient care settings; and (7) part of a field concerned with disease mechanisms and behavioral and biological interrelationships (p. 15). Reflecting these considerations, Varni and Dietrich (1981) have defined behavioral pediatrics as

> the interdisciplinary integration between biobehavioral science and pediatric medicine with emphasis on multidimensional and comprehensive diagnosis, prevention, treatment, and rehabilitation of physical disease and disabilities in children and adolescents. (p. 5)

It is our opinion that this interdisciplinary definition is most appropriate. It is broad enough to reflect interest in illness, child management, well child care, and prevention.

CHARACTERISTICS OF BEHAVIORAL PEDIATRICS

While practitioners may vary in how they define the field of behavioral pediatrics, agreement is unanimous concerning its essential component, that is, the emphasis on the integration of empirical knowledge resulting from interdisciplinary research. Roberts *et al.* (1982) reported that behavior-therapy methods are the most common procedures used in applied work in behavioral pediatrics. These investigators attributed this in part to the effectiveness and efficiency of these techniques. There is no doubt that behavioral methods have enjoyed great success as a technology of behavioral change. However, our belief is that the hallmark characteristic of behavior therapy—reliable and valid assessment of process and outcome variables—is the factor that accounts for the popularity of behavioral methods in behavioral pediatrics.

Russo and Varni (1982) suggested that interventions in behavioral pediatrics could be grouped into three general categories: (1) operant and social learning procedures (e.g., reinforcement and punishment procedures), (2) cognitive and self-regulation procedures (e.g., social skills training, desensitization), and (3) biofeedback and physiological self-regulation procedures, such as electromyographic [EMG] conditioning). These general categories by no means define the limits of intervention methods applicable to problems in behavioral pediatrics. In addition, we believe that further attempts to categorize the techniques would only serve to place arbitrary limits on a growing technology.

Rather than attempt to specify the various treatment techniques found in practice, it is more useful (and practical) to recognize that methodology is the basis of behavioral pediatrics (Russo, Bird, & Masek, 1980). That is, its procedures focus on behavior, they reflect the reciprocal relationship that exists between environment and behavior (both operant and respondent), and they require empirical validation for their acceptance.

CURRENT SCOPE OF CLINICAL BEHAVIORAL PEDIATRICS

Just as the practice of pediatric medicine has undergone significant changes over the past two decades, the field of behavioral pediatrics has seen rapid impressive expansion of its role in child health care. Christophersen and Rapoff (1980) discussed a number of pediatric problems for which effective behavioral treatments had been developed. These disorders included anorexia nervosa, asthma, child abuse, common behavioral problems (e.g., tantrums, mealtime disturbance), eating disorders, encopresis, enuresis, habit disorders, phobias, school problems, self-injurious behavior, toilet training, parent training, and prenatal counseling. Correspondingly, a study conducted by Schroeder (1979) showed that most behavioral problems seen in an ambulatory pediatric clinic involved negative behaviors (tantrums), developmental delays, school difficulties, sibling–peer problems, personality problems (dependency, impulse control), and family interaction difficulties (divorce, discipline).

These topics are consistent with early formulations of behavioral pediatrics in which the professional primarily addressed questions concerning behavior and development. There is no doubt that these problems are ones for which parents most commonly seek assistance. However, the field of behavioral pediatrics has greatly broadened over the past 15 years (Kelley & Drabman, in press). The trends have been toward assessment and treatment of illness and health-related behavior, the development of well-child care interventions, health risk reduction, and prevention. Moreover, the field has expanded to include attempts either to reduce the severity or duration of existing medical problems or to decrease long-term disability in order to lessen the likelihood that a patient will need a more drastic intervention, or both (Hobbs, Beck, & Wansley, 1984).

SCOPE OF THIS TEXT

The organization of this text reflects the current focus of clinical behavioral pediatrics. As an introduction to this volume, we point out that a number of topics have been purposely omitted from this volume (e.g., common behavioral problems, academic difficulties, child abuse, self-injurious behavior, anxieties, and phobias). Since these problems are generally discussed in child behavior therapy texts, it seemed more useful to focus on newer areas of intervention.

We have also chosen to emphasize the clinical aspects of each disorder. This volume is not intended to provide a comprehensive review of the research in clinical behavioral pediatrics. Rather, chapter format is designed to provide clinicians with a general working knowledge concerning behavioral interventions for various child health problems.

The chapters are arranged into four major sections. Part I discusses basic clinical principles of behavioral pediatrics. In Chapter 2, Roberts and Lyman present various models of consultation for psychologist working in a pediatric setting. These models provide behavioral guidelines for assisting psychologists in becoming successful treatment members of a pediatric treatment team. In Chapter 3, Ferrari discusses developmental issues in clinical behavioral pediatrics. The importance of considering a child's intellectual, social, and cognitive development during assessment and treatment is emphasized. Furthermore, the potential impact of illness on development is also discussed. In the final chapter of this section, Mash and Terdal explain basic assessment procedures in clinical behavioral pediatrics. In addition to detailing various assessment methods and devices, Chapter 4 examines the nature of assessment as it relates to diagnosis, treatment, and outcome evaluation.

Part II discusses eight major clinical problem areas in behavioral pediatrics. Each chapter presents a recognized expert's overview of the disorder and describes the ways in which the behavioral pediatrics specialist assesses and treats the problem. Moreover, each chapter includes a case illustration of the application of the procedures described. An attempt was made to maintain a similar format across chapters. However, each chapter offers valuable clinical insights of particular relevance to the specific disorder. For example, Varni and colleagues (Chapter 5) offer a persuasive argument for the importance of multidimensional assessment when working with the pediatric pain patient. Kelley and Heffer (Chapter 7) present a theoretical model that has guided their development of intervention strategies in pediatric eating disorders. In Chapter 9, Gross offers an explanation of the adherence difficulties to diabetes treatment in terms of immediate versus delayed contingencies. On the basis of this analysis, treatment suggestions are presented. Similarly, the chapters on asthma, self-catheterization and bladder-control problems, cancer, headaches, and sleeping disorders include an expert's discussion of practical problems they have encountered dealing with behavioral issues related to these disorders. The behavioral pediatrics specialists also provide suggestions for circumventing these hurdles.

Expert presentation of problem areas are also the focus of Part III. The chapter formats are similar to those in Part II. However, unlike Part II, the topics discussed have only been recently addressed by behavioral clinicians. Despite this, a number of significant successes in treatment have been accomplished. For example, Tarnowski and Rasnake (Chapter 13) discuss procedures that reduced treatment-related stress and noncompliance with pediatric burn patients. Similarly, the chapters on behavioral dentistry and cystic fibrosis include suggestions for enhancing medical treatment by reducing compliance problems particular to these disorders. The chapters discussing prematurity and low birthweight and children of short stature point out the beneficial impact that can be achieved by teaching parents specific clinical strategies. In Chapter 16, after explaining that few data exist to support the claim that sugar, sugar substitutes, and food additives adversely affect children's behavior, Rosen and Beyers provide a useful discussion of how to work with a family that remains convinced that food allergies are at the root of their child's difficulties. In Chapter 18, Feuerstein and Dobkin discuss the assessment and modification of various emotional and family characteristics that may play a role in etiology of recurrent abdominal pain. Issues of diet and behavior are addressed in the chapters devoted to elevated blood pressure and allergies. Ewart and Cunningham (Chapter 19) discuss diet restrictions and weight control as a method of controlling blood pressure.

Part IV includes some of the broader issues in the area of clinical behavioral pediatrics. Petersen and colleagues (Chapter 22) outline a number of useful techniques to prepare children for hospitalization and stressful medical procedures. The work is a result of data suggesting that reducing stress associated with medical and hospital treatments enhances recovery. Dunbar and Waszak (Chapter 23) report on general approaches to the problem of noncompliance with the medical regimen. This problem was also mentioned in some of the earlier chapters. However, given that rates of pediatric patient noncompliance have been estimated to range from 4 to 90% (Masek, 1980), it is clear that this is a pervasive difficulty that deserves attention. Effective strategies for coping with this problem will greatly enhance the role of the behavioral clinician in behavioral pediatrics.

A strong movement within pediatric medicine involves the prevention of injury. Reflecting this emphasis, Jones and colleagues (Chapter 24) discuss categories of unintentional childhood injuries and the factors commonly associated with these accidents. They present a model for accident prevention and provide an illustrative example of how to teach emergency fire evacuation skills to children.

Our final chapter is entitled "Psychology and Pediatrics: The Future of the Relationship." After discussing various models for the collaborative relationship between these two disciplines, Routh offers ideas concerning the future of clinical behavioral pediatrics and the demands that will be placed on behavioral clinicians and pediatricians.

SUMMARY

Over the past 30 years, changes in pediatric medicine have resulted in great opportunities for the development of a collaborative relationship between behavioral science and medicine. Early involvement in pediatric medicine by behavioral psychologists was largely devoted to common child clinical issues, such as general behavioral problems, toilet training, emotional difficulties, academic issues, and family relationship problems. However, the role of behavioral psychology in pediatric medicine has been greatly expanded. Recognition of the impact of behavior on health has provided opportunities for practitioners to demonstrate the effectiveness of behavioral methods in altering response patterns that adversely affect health. The chapters included in this volume represent recognized expert's opinions regarding the current and future practice of clinical behavioral pediatrics.

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CHAPTER 2

The Psychologist as a Pediatric Consultant

Inpatient and Outpatient

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INTRODUCTION

There has been a proliferation of terms describing the generic field of practice and research in psychological applications to pediatric problems and children's health. Roberts (1986a) discusses the various terms and what they convey. This chapter uses the term *pediatric psychology* to describe the roles and functions of psychologists in consultation with pediatricians because this term has been extant longer than any other and properly denotes the psychologist aspects of behavioral pediatrics. Roberts, Maddux, and Wright (1984) state that "pediatric psychology as a field of research and practice has been concerned with a wide variety of topics in the relationship between the psychological and physical well-being of children including behavioral and emotional concomitants of disease and illness, the role of psychology in pediatric medicine, and the promotion of health and the prevention of illness among healthy children" (pp. 56–57).

Pediatric psychologists research, practice, and consult in a variety of medical and primary health care settings. These may include hospitals, clinics, private pediatric practices, developmental centers, and health maintenance organizations, although the pediatric psychological intervention may actually take place outside of these settings. The consultation issues facing the psychologist are quite similar whether in inpatient or outpatient settings (cf. Drotar, Benjamin,

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Chwast, Litt, & Vajner, 1982; Roberts & Wright, 1982). Most of the pediatric patients in the United States are seen in pediatric outpatient office practices, with the smaller proportion of patients seen in inpatient medical center settings typified by chronic illness and acute, severe medical problems (Roberts, 1986a). Pediatric psychologists tend to be affiliated with medical centers (e.g., Drotar, 1983; Koocher, Sourkes, & Keane, 1979), although office practice is increasing (e.g., Schroeder, 1979). Therefore, many of the problems and disorders considered part of the domain of pediatric psychology, such as those discussed in this volume, are the chronic or severe acute medical problems.

Roberts (1986a) compared referring problems in three different pediatric psychology settings, using data from Kanoy and Schroeder (1985), Ottinger and Roberts (1980), and Walker (1979). Children's negative behaviors and school-related problems constituted a high percentage of referral problems followed by personality problems, divorce, and family problems. These might be seen as more traditional clinical child psychology problems, but they were initially seen by a pediatrician and referred to a psychological practice. In all three practice settings, however, there were frequent referrals for developmental delays, physical complaints, and a variety of other problems such as infant management and adjustment to disease and handicap. These types of cases typify the problems usually thought to characterize pediatric psychology. These problems of development and physical health comprise the focus of the chapter topics in the present book on clinical behavioral pediatrics.

In dealing with all these problems and working in the various medical settings, the pediatric psychologist will need to work with medical professionals, primarily pediatricians and pediatric nurses. This "working with" constitutes the consulting role. There are several conceptual models of pediatric consultation (Burns & Cromer, 1978; Drotar, 1978; Roberts & Wright, 1982; Stabler, 1979). These conceptualizations are applicable to different medical settings, whether inpatient or outpatient.

Because of the types of problems typically presented and the usual pattern of referrals from pediatricians, pediatric psychologists have typically developed more consultative relationships than traditional clinical-child psychologists. The pediatric psychologist consults not only to pediatricians but also to parents, nursing staff, teachers and school personnel, welfare agencies, juvenile courts, and other health and social service agencies. Psychologists and pediatricians collaborate to respond to a variety of psychiatric, psychosomatic, developmental, learning and other problems that are encountered in children's health care settings. The psychologist–pediatrician relationship is growing stronger, although a number of barriers still stand in the way of effective collaboration.

It is important for psychologists to realize that pediatricians offer the most immediate and effective resource available to parents for the diagnosis and treatment of a wide range of problems in childhood. Lee Salk (1969), an early pediatric psychologist, stated that a "pediatrician sees more human beings than any other professional during the most crucial stages of early development. . . . He is the first to be brought face to face with more developmental, learning, and emotional problems and has the greatest potential influence on child care practices" (p. 2). It is this front-line aspect of pediatric practice that allows for maximally effective interventions in childhood problems. Pediatricians often have long-term relationships with children and families that enable them to intervene with minimal resistance. In addition, little stigma is attached to pediatric services, while the process of obtaining services from a psychologist may be viewed with suspicion and apprehension.

Although there are distinct advantages to the provision of psychological services through the pediatrician, there are significant disadvantages as well. Most pediatricians lack specific training (and interest) in psychological assessment and intervention and find it difficult to stay current with new developments in the psychosocial field. In addition, pediatricians are usually hard pressed to meet even the medical demands of their practices and seldom have time to conduct psychological assessments or implement such interventions (Drotar, 1983; Roberts & Wright, 1982).

Collaborative efforts by psychologists and pediatricians offer a way to use the advantages of the pediatric context, while reducing the disadvantages of limited pediatrician time, training, and interest. Pediatricians are more often calling on pediatric psychologists much as they might request consultation from another medical specialist, such as a dermatologist or cardiologist. Such consultation requests may vary from referrals for formal testing or psychotherapy to a request that the psychologist "take a look" at a hospitalized child or merely discuss the case with the pediatrician without ever seeing the patient directly. In some cases, specific questions are posed; in other instances, only vague concerns are expressed. On occasion, the psychologist may work with the pediatrician's office staff or hospital personnel rather than directly with the pediatrician. In almost all cases, however, the pediatrician maintains a continuing treatment relationship with the patient and views him or herself as responsible for coordinating the efforts of all consultants, including the pediatric psychologist.

BASIC ISSUES

Roberts and Wright (1982) delineated three models of consultation in pediatric psychology that are expanded by Roberts (1986a). These three models can be used singly or in combination in any consultative relationships. No model is inherently better than the others. Many pediatric psychologists change from one model to another depending on the characteristics of the case or the preferences of the referring pediatrician. An underlying principle of all three models is that the psychologist should provide services geared to the needs of the patient and pediatrician regardless of the specific problem or consultation setting (inpatient or outpatient). This may require considerable individual modification of the consultation model. Psychologist–pediatrician consultation is a two-way function requiring input and agreement from both parties as to what each needs and expects from the other. Whatever model of consultation is undertaken, clarification of expectations in advance insures greater satisfaction on both parts. Once entered into, a model of consultation can be modified, but knowing *a priori* what is expected and accepting it enhances consultative functioning. Roberts and Wright's (1982) three models include independent functions of psychologist and pediatrician, indirect psychological consultation, and a collaborative team of interdisciplinary professionals.

Independent Functions Model

According to this model, the pediatric psychologist acts as a specialist who independently undertakes diagnosis and/or treatment of a patient referred by the pediatrician. Except for exchanges of information before and after the referral, the pediatrician and psychologist work non collaboratively. This model follows the usual pattern used by most medical specialists. The independent functions model has been described by Drotar (1978) as the "noncollaborative" approach and by Stabler (1979) as the "coordination of multi-services." Often referrals made to psychologists according to this model are for purely diagnostic services, since many pediatricians hold the view that assessment is all that psychologists do. Collaborative information sharing that might correct such a perception is limited by the independent functions model because each professional does his or her activity separately. If asked only for psychological testing, sometimes the psychologist can use the report back to the pediatrician to indicate useful interventions that the psychologist could implement. It is a serious breech of protocol, however, to implement a course of treatment without the referring physician's approval, if the referral has been made solely for diagnostic purposes. At the very best, this practice will result in a termination of referrals from the pediatrician and at worst can lead to ethics charges being filed against the psychologist.

The psychologist should also determine how the referring pediatrician wishes to handle such matters as reporting test results and making prognostic statement to children and their families. Many pediatricians expect to communicate all such data to patients themselves and would be offended by the usurpation of this role by a consultant. The advantage to having the pediatrician communicate to parents is that there may be a longer-term, more trusting relationship between the parties that may allow the parents to respond without defensiveness. The disadvantages to having the pediatrician communicate to parents is that he or she may be unfamiliar with the assessment procedures and results and may, therefore, misinterpret the results or be unable to answer parents' questions. It is beneficial for the psychologist to attempt to clarify this issue with the pediatrician as early as possible in a referral and, optimally, suggest willingness to communicate assessment results and recommendations to parents. In all cases, test reports or other assessment summaries sent to pediatricians should be written plainly and concisely, without psychological jargon and speculation regarding intrapsychic dynamics. These reports should be understandable by a pediatrician without specialized mental health training.

Often, the independent functions model permits the psychologist to go ahead with interventions after evaluation because the pediatrician has little time or interest in providing further services to the patient or family. This is especially true if the problem is primarily psychological. In this case, the psychologist can proceed with his or her regular treatment procedures involving patient, parents, schools, or other systems. Generally, a treatment summary is then provided the pediatrician to follow-up on the referral. This independent functions consultation is probably the most prevalent form of consultation because it follows the more traditional medical procedure of referring to another independent professional. Many clinical child-psychology problems can be handled in this way such as behavioral noncompliance and learning problems but, additionally, pediatric psychological problems can be managed by each profession taking separate treatment roles with a patient (e.g., for diabetes regimen compliance or encopresis treatment).

The independent functions model can be an effective and comfortable one if both parties maintain appropriate communication and mutual respect for each other's expertise. The model may be restrictive if the psychologist permits it to be and does not communicate the full range of his or her professional capabilities to the pediatrician. The psychologist also is limited to the degree communication with the family is permitted or arranged by the pediatrician. The time availability and expertise of the pediatrician can also limit the effectiveness of the psychologist consultant. The pediatric psychologist who is unwilling to operate within these limitations should clarify expectations at the beginning of a referral and not accept those in which the psychologist cannot communicate results and recommendations directly. An unfortunate aspect of the independent functions model is that it offers little opportunity for pediatricians to become more educated about the number of things psychologists can do (and how well they can do them).

Indirect Psychological Consultation Model

A second approach to a consultation arrangement is one in which the pediatrician retains the major responsibility for patient management. The psychologist works with the pediatrician, who in turn provides psychological services to the patient and family. The psychologist has limited or no contact with the actual client and usually only has access to information gathered by the pediatrician, hence the label *Indirect Psychological Consultation Model.* This pediatrician–psychologist relationship is more collaborative than the Independent Functions Model outlined in the previous section, but it provides even less opportunity than that model for the psychologist to provide diagnostic and treatment services independently. This form of consultation is often found in academic hospital settings because the consultee–consultant relationship frequently assumes the form of a teacher–learner interaction rather than a collaboration between equal peers. Thus, a faculty psychologist may be consulting with a pediatric resident who is actually seeing the patient about a psychological–behavioral problem. This consultation model appears to be increasing in usage because of the new emphasis being given to the provision of mental health services by primary care physicians (Wright, 1978). It may be that the next generation of pediatricians, familiar with this model from their training, will more frequently turn to pediatric psychologists to provide such indirect psychological services.

This consultation can take several forms. The pediatrician may request brief contact (e.g., by telephone call) to obtain specific information. This information may involve (1) the appropriateness of a child behavior and possible interventions (e.g., bedwetting at 6 years of age), (2) the interpretation of test data (e.g., IQ or school achievement test scores), (3) community sources of assistance (e.g., special education classes or parent training courses), and (4) the appropriateness of a referral (e.g., what a psychologist can do for an emotionally disturbed, retarded child). The psychologist may be able to answer these questions briefly or may suggest that the pediatrician gather more data or make a full referral to the psychologist.

A second form of indirect consultation to pediatricians can occur through the presentation of information in seminars, conferences, or continuing education programs for pediatricians, nurses and pediatric staff. Many psychologists setting up new practices in pediatric settings have found these activities helpful for advertising their availability and expertise and for instructing others in basic psychosocial approaches (Drotar, 1982). This form of consultation is often not oriented to specific cases but rather to more general psychological approaches. A psychologist who is effective with this approach can have a positive impact on far more patients than he or she could ever see directly.

A third approach to providing indirect patient care involves the development of standardized treatment protocols by the psychologist for use by pediatrician and nursing staff, in given situations. This practice requires a high degree of trust in the pediatrician's ability to assess the clinical situation accurately and implement the treatment procedure. Edward Christophersen, a pediatric psychologist, has designed a number of protocols that pediatricians or nursing staff might use for a variety of problems. He prepared guidelines for clinicians and for parents on (1) how to handle temper tantrums and bedtime crying or resistance (Christophersen & Rainey, 1976), (2) how to treat enuresis and encopresis (Christophersen & Rapoff, 1983), and (3) how to encourage use of child safety seats (Christophersen & Gyulay, 1981).

All three of these forms of indirect consultation may be present in a pediatric psychology practice. One limitation of this approach is that it is completely dependent on the ability and interest of the pediatrician to assess and treat the clinical problem properly. Consequently, the psychologist may need to teach the pediatrician basic assessment skills and principles behind psychological interventions. This instruction may include such areas as interviewing skills, reinforcement paradigms, and relaxation techniques. The educative process requires considerable diplomacy in how it is presented. Rather than lecturing a busy, often inattentive, pediatrician, it may work better to prepare one- or two-page summaries of research literature, diagnostic considerations, and brief treatment recommendations for different clinical situations. This material would be available for the pediatrician to review as needed, as well as to share with nursing and office staff and parents. One- or two-page summaries are much more likely to be read than a lengthy list of references in a given area.

A major concern with the indirect consultation model is the prevention of resentment on the part of the pediatrician because he or she perceives a power imbalance, with the physician occupying a subservient role to the psychologist. Conversely, the psychologist may resent relinquishing the primary responsibility for psychological diagnosis and treatment. Indeed, ethical psychological practice may require caution in this regard. Careful structuring of the consultation relationship and frequent clear communication are necessary to prevent these concerns from interfering with effective patient care. A final problem that prevents the indirect consultation model from being more widely used in private practice settings is the difficulty in billing patients for psychologist's indirect services and the unwillingness of pediatricians to personally reimburse the psychologist for his or her time. Perhaps as this consultation model becomes more widely used, alternate reimbursement mechanisms will be established.

Collaborative Team Model

The third model of psychologist–pediatrician consultation is one of true collaboration. In this approach, pediatrician and psychologist work together with shared responsibility, joint decision-making and mutual involvement in direct patient care. Case management is conducted conjointly, with each professional contributing unique skills and perspectives. In this approach, roles often are not clearly demarcated in the provision of any particular service. Close cooperation and mutual respect are therefore critical to the success of this model. This model is similar to the models of process consultation (Stabler, 1979) and collaboration (Burns & Cromer, 1978).

This model represents the optimal consultation paradigm. It is most likely to exist in specialized hospital units or outpatient clinics, such as those in oncology, renal dialysis, burn treatment, surgery, and prenatal intensive care. In such settings, teams of social workers, physicians, psychologists, speech and hearing specialists, educators, nurses, and others can collaborate with the common goal of using all available resources to benefit the patient. These teams are less likely in private pediatric practice, although more psychologists and other nonphysician specialists are affiliating with large private pediatric clinics.

A number of clinical problems are exemplified by chapter topics in this book that have both psychological and medical components, making them ideally suited to assessment and treatment by the collaborative approach. These include eating disorders, drug abuse, mental retardation, hyperactivity, physical handicaps, and chronic diseases. In the case of food refusal, the extensive weight loss and accompanying problems (e.g., gastric hypoacidity, carotenemia, hypoproteinimia) are medical concerns. The pediatrician would monitor these problems as well as prescribe an appropriate diet and dietary supplements. The psychologist might be employed in establishing behavioral contingencies for eating and weight gain, improving family communications, and working with the patient in psychotherapy to increase self-perceptions of competence and control. The need for closely coordinated efforts in both areas of intervention precludes the effective use of an independent functions model of consultation in this case.

It may become the psychologist's or pediatrician's responsibility to create a collaborative team in the community for cases which require this model of intervention. In child-abuse cases, for instance, the pediatrician who first encounters the problem may have to locate and coordinate resources to deal with the child's psychological response to the abuse, the pathological family environment, and the child's need for an alternative home environment. Such teams may be constructed on an ad hoc basis or may assume more permanent status.

Another major area for collaborative team efforts is community prevention programming (Roberts, 1986b; Roberts & Peterson, 1984a,b). Pediatric psychologists have only recently become involved in such community health efforts as immunization programs, projects to increase children's use of seatbelts, programs to encourage proper nutrition for pregnant women and/or breastfeeding for newborns, and screening efforts for children entering school for the first time for mental and physical health problems. Psychologists have particular expertise to offer to these and similar programs, however, they are often unaware of such efforts or unwilling to work collaboratively with a team of other health professionals. These collaborations are likely to increase as the salience of community problems and psychologists' potential contributions become more recognized.

The major advantage of the collaborative approach is that it permits the specific competencies of the pediatrician and psychologist to be used with maximum effectiveness and flexibility. Among the disadvantages are the reality that such an approach is often time intensive and therefore expensive. There are also problems of diffusion of responsibility and contradictory communication with patients that are more likely to occur when multiple practitioners are involved.

PEDIATRIC PSYCHOLOGICAL CONSULTATION

The psychologist functioning as a pediatric consultant should not feel obligated to follow only one consultation model. Selection of a consultation model depends on a variety of factors, some of which are not under the psychologist's control. It may even be that the consultation model followed will change over the course of working on a single case (e.g., from the independent functions model to the collaborative team model). More important than the model of consultation is the psychologist's commitment to providing quality services while increasing the effectiveness of the pediatrician with whom he or she is consulting. When psychologists help solve pediatricians' problems, they enhance the physician's reputation as well as their own. This result is likely to open many more opportunities for service and research and increase acceptance of the collaborative relationship between psychology and pediatrics.

Screening for Psychological Problems

One of the most useful activities for a psychologist to engage in while consulting with a pediatrician is establishment of procedures for screening children for mental health and developmental problems. Since the pediatrician sees many children at critical periods of development, it is logical that the pediatric practice offers the best opportunity for initial identification of children with problems. Screening is a concept already familiar to pediatricians, that is, the separation of patients on the basis of key indicators of medical problems, such as routine blood tests of newborns for phenylketonuria (PKU). Data gathered by screening procedures are considered suggestive of problems, not totally diagnostic; in-depth follow-up examination is usually required to establish or rule out a diagnosis.

Most pediatricians have already been exposed to some psychosocial screening procedures. For example, many are familiar with the Denver Developmental Screening (DDST) (Frankenburg, Fandal, Sciarillo, & Burgess, 1981), which offers an early, rough assessment of an infant's developmental status. Unfortunately, many pediatricians do not realize that more comprehensive infant-assessment instruments, such as the Bayley Scales of Infant Development (Bayley, 1969) are available and should be used when the DDST suggests developmental problems. Many pediatricians also do not realize that psychosocial interventions are available for developmentally delayed children that reduce the probability of impaired later functioning. Because of this ignorance regarding effective interventions, they hesitate to point out a developmental problem to parents, relying instead on such homilies as "he'll do it when he's ready" and "all children are different."

The pediatrician may benefit from information regarding other psychological screening instruments relevant to problems commonly encountered in pediatric practice. For example, a general psychological portion has been developed for the Pediatric Multi-phasic Examination (Allen & Shinefield, 1974; Metz, Allen, Barr, & Shinefield, 1976). The various sections of this examination for children ages 4–16 years are used to screen for various psychological problems with referral for more intensive diagnostic testing and treatment. The Personality Inventory for Children (PIC) is a true–false questionnaire that can be completed by parents of children as young as 3 years of age without involvement of the pediatrician or his or her staff. The PIC can be scored by computer or by clerical staff and simple criteria established by the consulting psychologist determine which cases require further diagnosis and possibly treatment. There are numerous other screening instruments under development or in use which can be useful in identifying infants and children at risk. The pediatric psychologist can help the pediatrician by periodically reviewing the tests available and recommending adoption of some as standard screening instruments or for use in specifically defined instances. The psychologist can also be useful by training pediatric staff in administration, scoring, and gross interpretation of test results. The pediatrician should also be familiarized with the purpose and value of psychological assessment instruments which are beyond his or her capabilities to administer. A clear set of guidelines for the referral of children to the psychologist for in-depth assessment can be invaluable in the early identification of children with problems.

Another area in which the psychologist may be useful to the pediatrician is in the establishment of accurate developmental and behavioral norms. Many pediatricians have inaccurate ideas regarding the developmental sequence of such behaviors as bedwetting, speech development, fears, and separation problems. Although they may have seen many children, their contacts have been brief in duration and in the artificial environment of the examination room. The psychologist can often correct the pediatrician's misconceptions about developmental sequences quickly and tactfully through the preparation of written summaries of development in such areas as motor behavior, social behavior, toileting, speech, and cognition.

Protocols for Psychological Problems

Written protocols can also be used in the implementation of standardized treatment procedures. The pediatrician and staff can conduct many psychological interventions by following a previously designed course of action with the consultation of the pediatric psychologist. The use of established procedures permit the controlled treatment by staff or parents for presenting problems that recur frequently. The procedure can include branching decision-making trees that permit the treatment to be individualized or changed when problems arise. Christophersen and Rapoff (1983) suggest condensing treatment procedures for behavioral problems into protocols of one or two pages. The advantage of having prepared standardized treatment protocols is that they are immediately available and can be implemented during the initial clinic visit. Logan Wright (1980) described the use of such protocols as a means of providing standardized compliance procedures. A protocol provides (1) a rationale and procedure for the intervention and any necessary compliance, (2) a standardized mechanism for delineating and recording interactions of the patient or the parent and the practitioner, (3) a means for evaluating and improving the degree of compliance, and (4) requiring the structured involvement of the practitioner.

When working on toilet training, for example, the psychologist or pediatrician can provide parents with a copy of *Toilet Training in Less Than a Day* (Azrin & Foxx, 1974), and checklists can be drawn from the book for pediatric staff to monitor parental actions and child progress (e.g., Christophersen & Rapoff, 1983; Walker, 1978). The consulting psychologist may wish to develop and use treatment protocols for such pediatric problems as headaches, encopresis, eating disorders, pain management, abdominal pain, juvenile diabetes, asthma, and many other frequent referral problems, such as those described in this book.

These protocols may be of benefit in the implementation and monitoring of treatment procedures by the pediatrician and his or her staff. Brief intervention protocols or brochures for parents are also available that deal with simple problems. Roberts (1986a) presents a number of problems for which protocols have been developed and published.

The type of standardized psychological intervention suggested here should be primarily employed for fairly simple and circumscribed problems. The psychologist should maintain some control to ensure appropriateness of application. In addition, the psychologist must emphasize that problems can occur with the use of these treatment procedures and that he or she is available for consultation or initiation of more extensive treatment in these cases.

Bibliotherapy

Another way in which the psychologist can assist the pediatrician is through consultation regarding bibliographic materials. Many books and articles are available for parents to read for their own education or which can be read to children in order to enhance adjustment and understanding of a particular problem or situation. Often the materials designed for parents are more general or more extensive than the information contained in the pediatrician's prepared protocols. The materials for children may provide pictorial or simple verbal information to reduce misunderstandings and may present fictional or biographical accounts of individuals with a particular disorder, handicap, or life crisis to lessen a child's feelings of aloneness and persecution. Roberts (1986a) presents selected titles for use with parents and children, and the *Journal of Clinical Child Psychology* regularly reviews books for bibliotherapeutic uses.

The psychologist can further influence pediatric services by providing the pediatrician and his or her staff with selected readings for professionals on particular problems. Lewis (1978) provides a list of references for professionals on terminal illness, grief, developmental changes in perceptions of illness, reactions by parents, and reactions by professionals to children's terminal illness. The psychologist needs to screen recommended readings to ensure that they are accurate, practical, and understandable by the pediatrician and staff.

Psychological Interventions

Two specific areas of pediatric practice in which psychologists have developed intervention procedures can greatly enhance the pediatrician's effectiveness. The first of these concerns the amelioration of medical fears. Many children express considerable fear of medical procedures and personnel. This fear can interfere with diagnosis and treatment or can prevent a child from reporting pain or disability. The remediation of children's medical anxiety makes the pediatrician's treatment more effective, safer, and easier to implement. There are several techniques that the psychologist consultant can use to reduce this anxiety. Presentation of written, pictorial, or audiovisual information that corrects misconceptions or portrays other children successfully undergoing medical procedures can be effective. Giving emotional support and teaching coping strategies prior to the anxiety provoking event can also help (Elkins & Roberts, 1983). Hypnosis and relaxation training have also been cited in the research literature as effective interventions for medical anxiety (Hilgard & LeBaron, 1982).

The second area of pediatric practice in which psychologists have demonstrated effective interventions is in increasing compliance with medical regimens. In order for any pediatric treatment to be effective, it must be implemented according to instructions. Some estimates place the percentage of pediatric patients who do not comply with physician instructions as high as 90%. These cases range from not taking cough medicine to failure to administer insulin or seizure medication correctly. In some cases, extended noncompliance can have fatal consequences.

Noncompliance is clearly a behavioral problem for which psychological interventions can be helpful. Based on research and experience, practitioners have found that medical compliance can be enhanced by (1) clearly informing the parents and child about the rationale for treatment, (2) fitting the treatment regimen to the patient's daily schedule, (3) getting a commitment from parents and child that the treatment regimen is understood and will be followed, (4) having the pediatrician and nurses express interest and concern regarding completion of the treatment regimen, (5) using step-by-step protocols and checklists to monitor compliance, and (6) establishing reward procedures to get children initially invested in compliance and identifying natural reinforcers to maintain compliance once established. In these ways, the pediatric psychologist can help make pediatric treatment more effective (Varni & Wallander, 1984).

Practical Problems for Pediatric Psychology Consultation

Although the potential for effective collaboration between psychologists and pediatricians is great, a number of potential problems could arise and undermine the collaborative relationship, especially when one moves outside one's own discipline (Drotar, 1982, 1983).

One significant potential problem can be described as a "turf issue." Who is in charge of treatment and who is involved in what elements of patient care? Physicians are clear regarding their status *vis-à-vis* most other health care professionals, but there may be uncertainty concerning psychologists. Many pediatricians have little information about the training and licensure of psychologists and are unsure whether to treat them as equals or subordinates. The use of psychosocial interventions with traditionally pediatric problems only increases pediatricians' confusion and concern. Effective pediatric psychologists will present themselves as equal but noncompetitive professionals who recognize the pediatrician's position in the health care delivery system and whose goal is to enhance the effectiveness of the pediatrician's diagnostic and treatment efforts.

Several procedural differences between pediatric training and practice and traditional mental health training and practice often interfere with the pediatric psychologists' effectiveness. Gaining knowledge about pediatricians background and current thinking enhances a psychologist's ability to consult (Drotar, 1983; Roberts, 1986a). One of these differences involves the different paces of medical and mental health practice. When a pediatrician requests a hospital consult from a pediatric psychologist (or any other specialist), he or she usually expects that the child will be seen that day or the next and that a preliminary note will be written in the chart immediately. In traditional mental health practice, there may be a delay of a week or longer between the request for services and the initial appointment. Assessment reports can frequently be mulled over for days or weeks prior to a final writing. These differences in time expectations can cause a pediatric psychologist to be viewed as hesitant, unresponsive, or incompetent by medical practitioners.

Another potential problem for the pediatric psychologist is the medical jargon used by pediatricians and medical staff. Psychologists may not understand what is expected of them because of a lack of familiarity with this jargon, and they may be unable to communicate assessment findings and/or recommendations in the language that medical practitioners expect and are comfortable with. While asking questions may provide some clarification, it further marks the psychologist as an outsider in the medical arena. As part of the basic preparation for pediatric psychology practice, all psychologists should familiarize themselves with basic medical terms and abbreviations. Some of these are defined by Roberts (1986a).

There are also conceptual differences in the approach of psychologists and pediatricians to clinical problems. Physicians tend to use a process of differential diagnosis that rules out competing hypotheses, while psychologists use assessment procedures to rule in an explanation. Psychologists tend to discuss causal explanations that have little relevance for treatment, while pediatricians are often content with an effective treatment even if they do not understand the cause of the disorder. It is necessary for both psychologists and pediatricians to understand the other profession's approach in order to work effectively.

A final potential problem which may interfere with a pediatric psychologist's effectiveness is the ignorance of many psychologists regarding medical etiquette and protocol. Examples of actions that are viewed as improper in medical circles include failure to acknowledge a referral with return information; exceeding the limits of a referral request; telling a patient that his or her doctor is wrong, incompetent, or outdated; contradicting a doctor in front of patients or nursing staff; and encouraging a patient to switch doctors or discontinue seeing one. Clearly, the psychologist is in an uncomfortable position if the referring physician is incompetent or wrong in a particular case. Disputes between physicians can be resolved through the local medical society, the intervention of colleagues or in the privacy of the hospital doctor's lounge. The psychologist may not have access to these avenues of reconciliation, however, and may be viewed as automatically wrong in any dispute with a physician. Although no magic solution exists, a history of competence and positive professional relationships with a number of physicians may help in the resolution of psychologist–pediatrician disputes.

Roberts (1986a) elaborates on the process of consultation and collaboration and discusses how to enhance the role of the pediatric psychologist and minimize the conflicts and disadvantages. The best consultants will always be those who know what they are doing. Familiarity with disorders and treatments such as discussed in this book and elsewhere (Routh, 1988; Wright, Schaefer, & Solomons, 1979; Magrab, 1978; Millon, Green, & Meagher, 1982; Roberts, 1986a; Tuma, 1982; Walker & Roberts, 1983) will help considerably.

CASE ILLUSTRATIONS

The following are presented as illustrations of the conceptual models, procedures and results in actual pediatric psychology cases encountered by the authors.

Case 1

Thomas was an 11-year-old boy with frequent severe asthma attacks. The attacks occurred most often at school, when Thomas was called on to make class presentations or otherwise speak before a group. He had been hospitalized once the previous year for asthma. Thomas's pediatrician requested (in a phone call from his secretary) "personality testing" from a pediatric psychologist at a nearby University clinic. The testing indicated the existence of severe performance anxiety and poor self-esteem. The psychologist, in her report to the pediatrician, noted that relaxation training had been shown to be effective in such cases. She included a reprint from a child psychology journal reporting on the successful treatment of a similar case and indicated her willingness to attempt such an intervention. One week after sending her report to the pediatrician, the psychologist received a telephone call from Thomas's mother, who stated that the pediatrician had told her to call the psychologist and "see what she could do" about Thomas's problem. The psychologist began weekly sessions with Thomas that consisted of relaxation training and *in vivo* desensitization to public speaking. The frequency of Thomas's asthma attacks dropped noticeably, and his school grades improved. After 3 months of treatment, the psychologist reduced Thomas's sessions to one per month and, upon receipt of a written release from the mother, wrote a letter to the pediatrician describing the interventions that had been implemented and Thomas' progress. In the 6 months following this letter, she received two referrals for testing and one for family therapy from the pediatrician whom she had yet to meet in person.

Case 2

Allison was a 3-year-old girl who had endured 24 separate middle ear infections in her lifetime. It appeared that for substantial periods of time her hearing had been severely impaired. Since having tubes put in her ears 6 months ago, Allison's ear infections had virtually disappeared and her hearing had apparently returned to normal. However, her speech was substantially delayed. She spoke approximately 15 words, most of these having appeared in the last few months. She exhibited a number of autistic and self-stimulatory behaviors. Allison's pediatrician heard a presentation on intellectual assessment of deaf children given by a pediatric psychologist employed by the medical school's family practice residency program and asked whether the psychologist would test this child to see if she was "retarded." After discussing the case with the pediatrician for several minutes, the psychologist stated that the child was almost certainly developmentally delayed, at least in the language area. He told the pediatrician that he would research the area further and let him know if formal testing would be useful. Approximately 1 week later, the psychologist sent a two-page letter to the pediatrician summarizing the findings of several articles in pediatric and psychology journals that had found significant language delays in children with chronic otitis media. The articles suggested that much of the deficit was remediable although some degree of impairment might be permanent. The psychologist indicated that he saw little need for formal testing at this time and recommended a speech therapist who specialized in preschool children and a daycare program for economically deprived children that contained strong verbal enrichment component. Two years later, the psychologist received a call from Allison's parents requesting a developmental evaluation. The psychologist conducted the evaluation and was gratified to discover that Allison demonstrated only a mild deficit in language skills and that the autistic-like behaviors had largely disappeared. Upon receipt of a written release, the psychologist sent a written report of the test results to the pediatrician. The psychologist had no further contact with Allison or her parents.

Case 3

John was a seven-year-old boy who was soiling his underpants everyday. He had begun hiding the soiled underwear in his bedroom. His classmates were remarking on the smell and he had become rejected and isolated at school. This problem had been going on for approximately 1 year. John's initial toilet training was uneventful. He was a moderately obese child whose favorite pastime was watching television alone. His diet consisted mostly of junk food. He was poorly supervised by his mother, a single parent. John's mother had taken him to see his pediatrician to see whether there was a "physical" cause for his encopresis. The pediatrician, in turn, called a local pediatric psychologist in private practice for consultation. The child was admitted to the hospital where gastrointestinal radiographs showed the presence of megacolon. The pediatrician and psychologist jointly interviewed the mother and determined that the child's diet and level of exercise had deteriorated during the past year and that he had developed a pattern of retaining feces at school because of the embarrassment of asking to go to the bathroom. The pediatrician ordered a program of suppositories, laxatives, and a high-fiber diet while the child was in the hospital. The psychologist counseled the mother on reinforcement techniques to reward daily bowel movements and the importance of increased exercise and proper diet, after the child left the hospital. The pediatrician also advised the mother to give the child 3 teaspoons of mineral oil per day. The pediatrician and psychologist met jointly with the child and mother every week for 6 weeks after hospital discharge. At that time, soiling had virtually disappeared, and radiographs revealed that the child's colon was of normal size. Joint weekly meetings were discontinued, although the psychologist continued to see the child for weekly psychotherapy sessions focusing on poor self-esteem and deficient social skills. The mother was seen periodically by the psychologist in order to monitor the home program and provide reinforcement for her increased involvement with her son.

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CHAPTER 3

Developmental Issues in Behavioral Pediatrics

MICHAEL FERRARI

INTRODUCTION

Ideally, behavioral pediatrics should derive a substantial portion of its data base from studies of developmental issues as they present in children and adolescents, if for no other reason, by virtue of the very nature of whom the field serves. Yet this has not always been the case. Instead, the clinical assessment and treatment considerations applied to children have often been developmentally insensitive downward extensions of adult models (Ferrari, 1986; Harris & Ferrari, 1983). In recent years, however, this state of affairs seems to be changing. Indeed, as we look at the development of the disciplines of pediatric medicine and child psychology, we see that, increasingly, developmental factors have been emphasized (Richmond, 1985; Richmond & Janis, 1983; Roberts, 1986). Of course, there are many reasons for this changing emphasis (Green, 1985). Varni (1983) suggested that the practice of pediatrics itself has changed from a focus on acute infectious diseases to chronic diseases and problems in which "somatic factors represent only one component of comprehensive care" (p. 3). Pediatricians now practice in an era characterized by lower morbidity in children with decreased risk of infections and nutritional problems, increased prevalence of chronic conditions, and higher percentages of ambulatory care and partial hospital services (Friedman, Phillips, & Parrish, 1983; Green, 1985).

In child and adolescent psychology, the changes have also been evident. With the emergence of the field of pediatric psychology, developmental issues are now readily being considered crucial in decisions about the types of services

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most likely to be effective (Roberts, Erickson, & Tuma, 1985), as well as their role in developmental disorders (Ferrari, 1982) and chronic illnesses (Morgan & Jackson, 1986). Also of importance, models of education emphasizing developmental and psychosocial factors are now being taught in medical schools (Rosenblum & Frankel, 1984); conceptual frameworks for the collaboration of pediatric psychologists and pediatricians are demonstrating their efficacy (LeBaron & Zelter, 1985; Roberts & Wright, 1982). Since pediatricians are often the first to hear about child and family health problems, even those primarily concerned with mental health (cf. Kempe, 1978), working relationships with pediatric psychologists are crucial.

THE DEVELOPMENTAL APPROACH

What is the developmental approach to behavioral pediatrics? How do we go about applying developmental considerations? What is the value of data derived from research in developmental psychology? How significant a role can developmental theories play in day-to-day clinical practice? How often are developmental considerations really employed?

Each of these questions strikes at the core issues of operationalizing developmental concerns in pediatric work. And yet, while they seem quite basic questions, answering even the most fundamental of them requires that we come to understand the implications of the developmental approach and, quite frankly, what can happen when developmental issues are ignored.

We are beginning to learn how often developmental concerns are actually employed in clinical work. In a study of pediatricians, Whitt and Dykstra (1981, cited in Whitt, 1982) illustrated just how infrequently they may be employing certain developmental considerations in their communication practices with their child patients and families. Based on a sample of 500 pediatricians who commented on their communication techniques with pediatric patients with chronic illnesses such as diabetes, cystic fibrosis, epilepsy, and asthma, Whitt and Dykstra found that only 15.9% of pediatricians ever met with children ages 8–11 years alone to explain their illness to them. Although they were more likely to meet with older children alone, this would seem to be a disproportionately small number of children who were communicating directly with their physicians. Developmentally, we know that such communicating relationships are quite important, even to children. Studies such as that reported by Raskis (1965) strongly suggest that children in the 8 to 11-year range are in great need of open communication with their physicians. In fact, in the Raskis report, children in the concrete operational stage of cognitive development (approximately ages 7 to 11) often were found to perceive of their pediatrician as the person who was their primary health protector.

Developmental Applications

How one learns to apply a developmental approach in work with children translates into more than merely recognizing children as different from adults.

It requires an overall approach that is sensitive to the sequential nature of human maturational growth, despite variations that may exist in the rate of development, as well as the complex interactions with multiple environments in which children live. In addition, the developmental approach also requires an appreciation of the deeper meaning levels of a child's behavior and how these meaning levels may be qualitatively distinct across different developmental periods, even though one behavioral form may have given rise to another that is quite discontinuous in appearance.

There are many ways in which developmental applications can be made in behavioral pediatrics, but we must recognize from the outset that they may be as important in the initial conceptualizations of a child or adolescent problem as they are in choosing techniques to employ in assessment and treatment. For example, a practitioner of behavioral pediatrics may be interested in whether it is appropriate to consider the use of cognitive self-instructions in the control of presurgical anxiety or postsurgical pain in a 6-year-old child. A steadfast move toward the application of procedures that may have proved efficacious in other situations may not result in a useful outcome. Moreover, we might wish to know what type of instructions would be most useful and whether they should be generated by the child, a family member, or even the therapist. Appropriate developmental responses to these questions may make the difference between a successful intervention and one that is less likely to yield good results or perhaps even maximize a child's frustrations or undermine a therapeutic relationship.

How each clinician comes to apply developmental considerations in daily practice will depend in large part on their familiarity with developmental research. Unfortunately, good developmental data that are readily translatable into clinical practice are not always easy to find. One reason may be that many of the traditional sources of developmental data were not generated for the purposes of clinical application (Harris & Ferrari, 1983). Fortunately, this appears to be changing, perhaps best exemplified by the publication of more applied journals that emphasize developmental issues. Yet for the practicing clinician of today, the absence of clear developmental data in an area may signal difficulty in appropriate decision-making and underscore the need for other resources. One alternative in this situation is the applied use of specific developmentally based theories. Whether the practitioner of behavioral pediatrics employs the developmental conceptualizations of Erikson (1964), Piaget (Piaget & Inhelder, 1969), Gesell (1928), or Werner (1957), particularly when used in conjunction with empirically derived developmental data, theoretical systems can provide firm groundwork with which to test clinical hypotheses and guide meaningful intervention plans.

ASSESSMENT ISSUES

Each time we do an assessment of a child in the field, we consider simultaneously a broad range of factors. We are concerned quite often about the situational specificity of behavior, the social responses that it may get, the presence of associated behaviors or symptoms, and the role of preceding conditions.

Other factors that concern us should include a clear attention to the developing systems of the child (e.g., cognitive, motor, psychoemotional) as well as the developmental and demographic dimensions of the family (cf. McGolderick & Carter, 1982).

Normal Behavior for Age

Common practice suggests that most clinicians have a sense of the typical behavior for a child at a certain developmental level. Being observers of children and adolescents, we develop our own set of internalized norms for behavior. Personal experiences such as raising children of our own greatly influence our developmental judgments of how children change longitudinally. Although each of us is usually aware that we must not generalize from small samples, the real risk is that we will become victims of our own biases.

In clinical training we learn that such variables as a child's age are extremely useful markers of development that can help us make rough estimates for appropriate assessment of behavior and in planning treatment (Maddux, Roberts, Sledden, & Wright, 1986; Mash & Terdal, 1981), but we must be fully aware that age does not explain development, lest we be led to believe that "Jason believes as he does because he is 2." Nonetheless, understanding the relationships that do exist between age and development help us structure our assessments and effectively narrow potential hypotheses. For example, in preventative health work, it is useful to know that health risks to children change quite dramatically as a function of the child's increasing sophistication in motor developmental tasks. Infants and young children are most likely to have increased morbidity and mortality rates as a function of falls and accidental poisonings (Achenbach, 1982; Maddux *et al.*, 1986). Older children are more at risk of pedestrial and recreational accidents and of athletic injuries of certain types. It is clear that age does not explain the differences evident, but affixing an age to the information makes it quite handy for the clinician to use in anticipatory guidance. We must, nevertheless, be cautious in our application of age-related data. Spinetta, Deasy-Spinetta, McLaren, Kung, Schwartz, and Hartman (1982) discussed the potential for misapplication of age-related cognitive concepts to adolescents with cancer. These investigators warn of situations in which incorrect decisions about communicating with adolescents with cancer are made on the basis of the application of a myth that just because a child is beyond 11 or 12 years of age (and supposedly at a point of functioning when their mental operations are like that of an adult), that communications to them should be the same as if they were adults. This is often a colossal mistake. Just because an adolescent of 14 understands the universality of death and its biological necessity does not mean that he or she has personalized it in the same way that an adult might.

Mental Age and Maturation

Other aspects of the variable age are also of use in developmental assessment in behavioral pediatrics. Assessing a child's mental age might be useful to the degree that it provides a more appropriate structure for understanding the child's behavior. This is probably most useful in cases in which developmental disabilities are likely to be involved. Meaningful assessments and intervention plans for children with mental retardation or cerebral palsy are likely to be much more validly geared to normative estimates of behavior based upon mental age rather than chronological age. Likewise, biophysiologic markers of age are also sometimes important. Assessments of a child's bone age or dental age can be useful when the clinician wishes to obtain predictions of a child's eventual size or height. For children with serious illnesses and for those who require complex and physically taxing treatments, such as radiation and chemotherapy, such information might be very important, particularly for its psychosocial implications. In addition, obtaining the age of illness onset or initial diagnosis sometimes permits the formulation of hypotheses about the types of developmental areas that may have been affected (Achenbach, 1978; Ferrari, 1984).

Maturational and biodevelopmental markers are also very useful to assess. Knowing that a child is an early or late maturer is likely to affect the views that you construct of a child, the types of intervention strategies that you plan, and the degree to which you may alter the environmental expectations placed on that particular child.

Attributional Age

How old a child or adolescent may look developmentally suggests yet other important developmentally related considerations. As clinicians, we might be privy to chronological, biomaturational, and mental ages of our patients, but members of the surrounding social network may not. We know from research that children who are likely to look older or younger than their actual age are more likely to be treated by the social world according to the age that others attribute to them (e.g., Fry & Willis, 1971). It is also the case that the same behavior demonstrated by children of different ages is likely to be met with very different feedback. For illustration purposes, suppose that you observe two children in a supermarket. One looks 2 years old and the other looks 10. Each child is observed to be crying loudly, which leads to a temper tantrum. As a member of the social world, you are likely to respond to the younger child with supportive glances to ward the parent who has to deal with this behavior, while sending less positive nonverbal messages to the parent of the older child. As clinicians, we need to make reasonable estimates of how the social world views our patients, since this will be a strong indicator of the types of expectations that will be placed on their behavior. In the pediatric inpatient setting, in which regressive behavior is quite likely to occur (Brown, 1979), this must be even more of a concern.

THE SOCIOEMOTIONAL DOMAIN

Research studies suggest that for many children who are forced to cope with illness, hospitalization, frequent doctor visits, and medical treatments, there is considerable risk of the development of emotional and psychosocial adjustment problems (Ferrari, 1987; Ferrari, Matthews, & Barabas, 1983; Harris, 1987; Lindemann, 1981). Although there is much debate about the possibilities of long-term emotional effects of many illness-related phenomena, such as the process of hospitalization (cf. Klinzing & Klinzing, 1987; Thompson, 1985), studies of the immediate effects of the inhospital experiences show some clear consistencies. Of importance for our purposes, one of the areas of greatest consistency involves age-related developmental differences in children and adolescents.

Preschoolers

For children in the preschool years and early childhood, the major emotional impact of medical procedures that require hospitalization concern the child's adaptation to separation from their primary caregiver (cf. Mahler, Pine, & Bergman, 1975; Whitt, 1982). Generally speaking, hospitalized children under the age of 4 or 5 years seems to have the most difficulty in this area. It is not unusual, however, to find a 9- or 10-year-old youngster in serious despair over the absence of a parent. The practitioner of behavioral pediatrics would do well to be aware of the more common problems exhibited in their developmental context. One broad area in which difficulties are likely involves the presentation of developmental regressions in emotional and behavioral organization. For example, young children are likely to express increasing fears relating to their families at home when they are hospitalized (Astin, 1977; Klinzing & Klinzing, 1985). Long after behavioral mastery, problems for a child may arise in getting to sleep or in spending time on their own. The research suggests the likely return of other less developmentally advanced behaviors for young children in hospitals, such as enuresis, fecal soiling, thumb sucking, the use of transitional objects, and a less organized approach for dealing with pain (Klinzing & Klinzing, 1987; Tesler, Wegner, Savedra, Gibbons, & Ward, 1981).

Prugh and Eckhardt (1980) suggested a sequential progression of adjustment responses of children to hospital experiences. These workers contend that a young child's emotional responses progress from a type of protest over the loss of attachment figures and the trauma associated with the hospital experience often to an experience of emotional despair, and finally detachment. As might be expected, protest and despair are emotional responses that are perceived by hospital staff with considerable concern. Emotional detachment, when unrecognized as such, is often misunderstood and indirectly welcomed by staff as a signal of good patient adjustment or favorable compliance (LaGreca & Stone, 1985). These are important signals of emotional distress worthy of careful clinical investigation. Developmentally, we must be aware that serious disruptions in the caregiver–child attachment relationship are often functional antecedents for failure to thrive and other serious physical and emotional complications (Gordon & Vazquez, 1986; Roberts & Maddux, 1983).

Middle Childhood

During middle childhood, a child's socioemotional world is greatly influenced by peer contacts as regularized friendship patterns are emerging (Lewis & Rosenblum, 1975). Although the school-age child is still vulnerable to problems that stem from parental separation associated with their illness experiences, we do not yet fully know how their emotional indicators of distress may be qualitatively distinct from younger children. We do know whether frequent interruptions of a child's life due to illness and hospitalization in the middle childhood period often leads to social suffering by the child (Kleinberg, 1982). Children are frequently removed from the social development world of school and thus may be deprived of opportunities to develop greater social skills and have time for meaningful peer contacts.

Willis, Elliott, and Jay (1982) made use of Erikson's (1964) model of psychosocial development for an understanding of the psychological concomitants of physical illnesses in children. In their application, the psychosocial challenges associated with different developmental periods are integrated with the clinical presentations of disability and disease. Other workers (e.g., Siegel & Kornfield, 1980) have attempted to isolate specific developing socioemotional functions, such as interference that may be present in a child's emotional identification with a parent, that may occur during the middle childhood years. These papers make particularly instructive reading, as the application of specific theory-dependent developmental concepts provides a good model for practitioners.

Adolescence

In adolescence, the focus of emotional development is on issues relating to the development of a meaningful personal identity. This identity and associated sense of self (cf. Lewis & Brooks-Gunn, 1979) must originate in separation from, but at the same time connection to, the family (cf. Bowen, 1978; McGolderick & Carter, 1982). Adolescents are very peer oriented and responsive to imitating the persons in their peer group whom they value. For example, the diabetic youngster who develops control problems in adolescence and repeatedly enters ketoacidosis may have nonetheless have a strong need to feel and act the same as others in the reference group.

The emotional concerns of adolescence are very important items for our clinical attention to developmental factors. Many adolescents are likely to express great concern over their developing bodies. They are often deeply concerned over whether their bodies look normal, sexually developed, and appropriately proportioned. Adolescent social exchanges repeatedly remind them of their social attractiveness and physical appeal. In a recent study by Morgan and Jackson (1986) of adolescents with sickle cell anemia, adjustment difficulties in the developmental tasks of adolescence were most associated with decreased time in social activities, school problems, limited physical capacity, and delayed puberty. The assessment of functioning in these developmental areas is likely to yield important considerations for treatment.

THE COGNITIVE DOMAIN

In recent years, the vast majority of studies that have focused on developmental issues in behavioral pediatrics have concentrated almost exclusively on cognitive developmental domains. One of the fundamental assumptions of the cognitive developmental approaches suggests that how a child comes to an understanding of his or her illness, its causes and what implications it may have for life are major determinants of that child's adjustment (Kister & Patterson, 1980; Varni, 1983). The planning of interventions with children is also an area in which considerable attention has been drawn to cognitive developmental mechanisms and how "matches" between a child's cognitive level and specific interventions may be the most logical approaches (Harris & Ferrari, 1983; Maddux *et al.*, 1986).

Theoretical Perspectives

To date, it would appear that the Piagetian developmental model (Flavell, 1977; Piaget, 1970) has been the most frequently employed in research. As will be seen, there appears to be considerable value in this model. Nonetheless, the reader should note that other cognitive developmental models (e.g., Ausubel, Novak, & Hanesian, 1978; Bruner, Olver, & Greenfield, 1966) may also be useful to the clinician working with children and adolescents. In fact, some investigators recently reported limitations in the applied use of the Piagetian approach in clinical settings. In a study of adolescent's understanding of their illness, Fletcher and Johnson (1982) argued that the concept of formal operational thinking has little or no explanatory power in the clinical setting. Gochman, as well, has expressed concerns. In a recent report of family determinants of children's health and illness concepts, Gochman (1985) contended that the Lewinian developmental perspectives (Lewin, 1935) may be just as useful in explaining the developmental trends in children's understanding as the Piagetian approaches. The practicing clinician would do well to avoid strict allegiance to any one developmental conceptual framework without convergent support from empirical data.

Developing Concepts of Health and Illness

Some clear general developmental trends in the data concerning children's cognition appear to be of considerable importance to the practitioner of behavioral pediatrics. One of these regards children's changing conceptions of health. Some of the earliest work in this area was done by Nagy (1951, 1953). In a study of healthy children aged 6 to 12, Nagy (1951) reported that children's concepts of getting ill changed as a function of age; 6- to 7-year-olds in this study were found to think that illnesses were caused by infection but to have little understanding of what types of mechanisms were involved. The 8- to 10-year-old children were more likely to conceive of illness causation as a function of micro-organisms, but it was not until age 11 or 12 that children consistently made a link between different illnesses and different micro-organisms. More recently, studies by Bibace and Walsh (1980) and Natapoff (1982) have replicated the general findings of Nagy. Most importantly, these studies strongly suggest that children's health concepts are closely connected to preoperational, concrete, and formal operational Piagetian stages. Other studies have also supported the general trends of increasing sophistication of health and illness concepts with cognitive developmental stages through the specific application of Piagetian tasks, such as those of conservation and causality, as predictive variables (Redpath & Rogers, 1984).

With regard to the development of illness concepts, clinicians should be aware that young children are particularly susceptible to types of magical thinking and to the overextension of certain illness concepts, such as contagious to noncontagious illnesses and injuries. In a study by Kister and Patterson (1980) of healthy children's illness concepts, two thirds of preschoolers and one third of the kindergarten-age children overapplied the contagion concept of exemplars such as toothaches, scraped knees, and headaches. Young children are also very likely to accept imminent justice explanations for illness and to believe that misbehavior and illness are causally linked. It is noteworthy that the concepts of imminent justice and specific punishments as causes of illness are largely consistent with numerous theories of moral development (e.g., Kohlberg, 1984).

Studies suggest that other aspects of a child's knowledge about health and illness also undergo developmental change. Parcel and Meyer (1978) showed that children's health locus of control gradually becomes more internalized with age. General cognitive developmental changes and locus of control factors have also been shown to relate to children's concepts of healing (Neuhauser, Amsterdam, Hines, & Stewart, 1978). Moreover, children's awareness of their own illnesses undergoes change with development, moving from a highly specific focus on each health problem to a recognition of multiple clusters of symptoms in illness that, while distinct, may be related to one another. Finally, children advance to a point at which they recognize that abstract internal processes of their bodies (Whitt, 1982). In a study designed to evaluate children's understanding of the internal processes of body function, Whitt, Dykstra, Johnson, and Taylor (1979) asked groups of children and adolescents to draw the insides of their bodies and to label all its parts. Their findings were clearly developmental. The adolescents (ages 12–16) not only drew a greater number of internal organs than did the younger groups of children, but they were clearly in recognition of the internal organizational complexity, which was not recognized by the younger children (ages 5–7).

Gochman (1975, 1985) suggested one other area of health and illness that has been very poorly studied but should receive more attention. That area involves the motivations that children develop to be healthy and how they translate these into health habits. Gochman showed that there is, in fact, a developmental decrease in children's motivation to be healthy after the age of 9. This drop in health motivation is most obvious when contrasted with an increasing motivational concern at this age, i.e., appearance motivation.

Safety

Closely related to children's motivations to be healthy are knowledge and practical decision-making concerning personal safety issues (Marotz, Rush, & Cross, 1985). Again, cognitive developmental factors have been shown to be important. In a study of children's causal reasoning ability and cognitive style as predictors of understanding about safety and prevention, Coppens (1986) showed that a child's causal reasoning ability was the most important predictor. The study also demonstrated an important point for clinicians, i.e., that developmentally, children must first learn how to differentiate between safe and unsafe conditions before efforts to learn prevention techniques can be successful. As such, a developmentally geared intervention for child safety should first include an assessment of a child's skills at making the safe–unsafe distinction, followed by training in this discrimination, if necessary, before teaching prevention skills.

Death

Since so many children involved in pediatric care settings are exposed to experiences associated with death, it would appear quite clear that pediatric workers should have an understanding of the developmental framework in which children and adolescents conceive it. Much of the foundation for our understanding of children's views of death again comes from Maria Nagy (1948, 1959). Based on a study of children's viewpoints of death, Nagy suggested that children go through a three-stage developmental sequence. Before age 5, death is seen as sometimes reversible, lacking in aspects of finality and irrevocability. Between 5 and 9 years, Nagy concluded that death is often personified in a child's view, usually as a particular entity that takes children away (e.g., the devil, the bogey monster). During this age period, death is also likely to be linked to children's appreciation of rules. Bad or disobedient boys or girls are those likely to be taken away by death. By age 9, children were observed by Nagy to represent death as a process governed by certain laws and to see death as more or less universal and inevitable.

Other developmental researchers also have proposed stage models of the death concept. Although many propose stages that are different from those advocated by Nagy (cf. Plank & Plank, 1978), most researchers have stage-based systems that closely ally developmental changes in the child's concepts of death to broader cognitive-developmental transitions. Koocher (1973, 1974) presented a very well-known model that uses the Piagetian approach to explain children's changing views of death. He suggests that preoperational children (ages 2–7) are most likely to think magically about death. For example, children in this cognitive-developmental period are apt to think that wishing someone dead may lead to their death or that physical death is the direct consequence of bad behavior. Koocher suggests that concrete operational children (ages 7–11), on the other hand, use more logical thought processes when they deal with the death concept. These children also tend to focus their thinking about death on the physical means in which it occurs. An interesting study by White, Elsom, and

Prawat (1978) supported this type of shift in children's understanding. Based on a sample of 170 children in kindergarten to fourth grade, White and colleagues showed that certain aspects of the death concept (e.g., universality) are tied to structural transformational shifts in the child's mental development. For example, between first and second grade, the percentage of children that understand the universality of death increases from 38 to 67%. This large jump roughly corresponds to the shift to the concrete operational stage, which in the study was measured by a child's skills at conservation tasks, the hallmark of concrete operational thinking.

Clinicians should be aware that not all researchers in this area have found a strong tie between children's death concepts and developmental changes. Orbach, Gross, Glaubman, and Berman (1986) and Yalom (1980), among others, argue that individual experiential factors are more important in formation of the death concept. Some examples include acquired anxieties concerning past separations and specific experiences with the deaths of other persons. In support of their views, Kane (1979) found that children who had experienced the death of someone close to them showed a better comprehension of all aspects of death (e.g., finality, universality) and often a different sequence in the acquisition of specific death concepts.

How children conceive of death will greatly modify the types of clinical interventions we recommend for use. For example, it would be unwise for parents to explain the mechanisms of death to a preoperational children using metaphoric terms like "God reached down and took Daddy to heaven while he was sleeping" (Salliday & Royal, 1981, p. 209), since this type of message may support the young child's magical thinking and may invoke severe fears of normal activities (e.g., sleeping). Obviously, evaluating where a child is developmentally is a necessary prerequisite to intervention. Beyond this, it is often useful for the clinician to determine how the child's family has instructed the child about death. We know very little about the relationships among developmental age, family and personality dimensions, and the spiritual and emotional components of the death concept. However, the practicing clinician must be certain to approach this situation with great care and with a genuine demonstration of respect.

DEVELOPMENTAL ISSUES IN PEDIATRIC TREATMENT

Given all that we have learned about the developing child and adolescent, the practitioner of behavioral pediatrics is no doubt faced with an enormous task if he or she wishes to carefully employ developmental perspectives. This section reviews many of the more commonly used clinical treatment strategies and techniques in terms of their demonstrated application to pediatric clinical practice. In covering these treatment procedures with the pediatric population, I have chosen to integrate many of the developmental issues as they are often encountered in cases frequently seen in a typical practice of behavioral pediatrics.

Developmental Stages and Clinical Communications

Our review of socioemotional and cognitive development has demonstrated broadly the differing capacities of children and adolescents from adults. These differences have tremendous importance for how we communicate with children. Clinicians must be alert to how messages are sent and the meaning levels of the sender. Depending on the child and the developmental sensitivity of the clinician communicating a message, children are likely to receive the message as intended or perhaps construe a very different meaning.

We know from research that children can hear the same exact words as those of the adult but come to a different understanding. For example, Bordzinsky, Pappas, Singer, and Braff (1981) reported that a common mistake adopting parents often make with their child is to explain to them the meaning of adoption at an early age (e.g., 5 years) and then assume that the child is forever aware of the concept's meaning. In the clinical context, it is often useful to evaluate a child's concept of their disease or illness periodically as you should expect it to change, and in fact, facilitate its change with development.

Case 1

In a case of an 11-year-old named Terry with Tourette's syndrome, I was quite surprised to learn, upon my evaluation, that this normally intelligent boy still held to etiological concepts of his disease that had been told to him when he had been originally diagnosed at the age of 4 years, 8 months. He believed that his complex tic disorder was caused by various things that he had eaten, largely foods with sugar. He elaborated upon questioning, his thoughts about the causal mechanisms involved. Terry believed that the sugars he ate during the day were stored in his body. At night, when he was asleep, these sugars rose up to his brain. Since there was too much sugar in his diet, and consequently in his body, this collection of sugar in his brain led to the increased activity of motor and vocal tics the next day.

Cases like Terry illustrate to us how important it is to carefully evaluate the messages children are sent and the developmental framework in which they receive them. Clinicians would do well to question children about their current understandings and during times in which they are given information, to patiently request that the child tell us back what they have comprehended. Too often, we assume that just because a child has seen what we have and says they understand, we can be assured that they truly do. More often than not, this is a mistake.

Case 2

Sarah, a 6-year-old with a mixed seizure disorder, was brought to my office because her parents had become very concerned that Sarah felt that she was going to die from her epilepsy. After a comprehensive evaluation of psychological functioning, which showed that Sarah was mildly developmentally delayed, it was learned in the third session with this child and family that the way the parents had explained epilepsy to Sarah was quite significant. Apparently, the parents had followed directly from what their physician had recommended. Their doctor had originally told them that "having seizures was like a machine that didn't really always do what you wanted" but instead "like a lawn mower that won't shut off, seizures were very similar to the mower that would just start by itself as well." Not knowing some of the implications connected to this analogy for Sarah, her parents proceeded to explain the occurrence of her seizures to her using the lawnmower metaphor. With a normal susceptibility to magical thinking, Sarah linked these communications, and an overprotective attitude of her parents with fears that she had of ghosts and things that were conceptually for her, all signals of death. She, like many children her developmental age, also saw her illness as a deserved punishment for her misbehavior and thus firmly believed she was going to die from her seizures and that she indeed deserved to.

It behooves us as child clinicians to be sensitive to the developmental needs of children with whom we communicate. Before the age of 7 or 8 and the achievement of logical reasoning and concrete operational thought, children's language–communication networks are characteristic of their centration and basic difficulties in recognizing the multiple meanings of words. They are much more likely to profit from global nonspecific information about their illnesses than from elaborate explanations designed for adults (Potter & Roberts, 1984). After the attainment of concrete operational thinking, children are more likely to understand and benefit from information that includes concrete exemplars, and illness specific explanations, although they are still not prepared for abstract hypothetical messages.

Clinical Procedures

Increasingly, the practitioner of behavioral pediatrics is able to rely upon a wider base of clinical tools and procedures that work with children. In recent years, there have been numerous demonstrations of the efficacy of cognitive self-instruction (CSI) procedures (Copeland, 1981; Mostofsky & Piedmont, 1985), relaxation and mental imagery (Kohen, Olness, Colwell, & Heimel, 1984), modeling (Ross, 1981), and efforts to teach specific coping procedures (Kendall & Braswell, 1986; McCaul & Mallot, 1984).

The application of developmental considerations is again important in the preselection of clinical procedures and their modification. One example involves CSI techniques. Specifically, CSI techniques have shown differential effectiveness, depending on a child's age (cf. Hobbs, Moguin, Tyroler, & Lahey, 1980). Developmentally, the child of 5 or 6 years of age is not likely to actively employ effective covert speech in the control of their behavior (Flavell, Beach, & Chinsky, 1986; Miller, Weinstein, & Karniol, 1978). As such, overt cognitive instructions are necessary for young children to succeed using CSI approaches. Other differences in the effectiveness of self-instruction with children relate to the degree of abstraction of the instructions (Copeland, 1981). Older children may do well with less concrete, more generalized instruction, but young children clearly do not do well when given abstract instructions alone.

The use of mental imagery is another area in which treatment programs must be developmentally based. In a recent study by Kohen *et al.* (1984), they reported very good success in the use of relaxation–mental imagery in the management of 505 pediatric patients aged 3–20. However, a close look at their data shows that the poorest success rates involved imagery induction with 3- to 5-year-olds. Although Kohen and co-workers suggest that young children can use imagery and self-hypnotic techniques successfully (e.g., Gardner & Olness, 1981), the developmental data would suggest the use of considerable caution. Kendall and Braswell (1986) report that the consideration of imagery procedures with children is useful, first starting at about age 9. Purkel and Bornstein (1980) showed that not until age 7 or 8 years can children make effective use of images and, as such, imagery is developmentally not the best choice of clinical technique in early childhood.

Case 3

An 11½-year-old named Andy who was being treated for kidney failure was to start renal dialysis. Upon the introduction to the procedure through his physician and nursing staff, Andy had reacted violently saying that the medical staff had already taken out his kidneys and now they were going to take all of his blood. Like many children his age, Andy had few direct-action coping mechanisms at his disposal to help him with his illness or to control his anxiety. The initial plan of the physician included a discussion with Andy's parents about ways they could convince him to believe that the medical team was acting in his best interests, and an individual conference with Andy and the physician to explain to him the mechanics of his illness and the need for dialysis. After these attempts failed to reduce Andy's anxieties or get him to go to dialysis willingly, a second plan was initiated. Although Andy was near the age that formal operational thinking is first evidenced, Andy demonstrated difficulties with abstraction and appeared clearly concrete operational in his cognitive processing. Andy was first taught to use a type of cue-controlled muscle relaxation and slow-breathing procedure paired with a verbal cue. When it was determined that Andy was able to imagine many things, a list of mental images that included pleasant peaceful details was gradually paired with the verbal cue from the relaxation procedures. Andy was then shown a videotape of the dialysis machine followed by a tour of the hemodialysis facility with a dialysis patient. Although Andy first used many of the imagery and relaxation procedures as distractions from his anxiety, he gradually began to generate a type of comforting self-instruction each time he had to go to dialysis.

In this case, it can be seen that Andy gradually moved from a catastrophizing approach (cf. Brown, O'Keefe, Sanders, & Baker, 1986) in dealing with his illness, to an approach characterized by multiple intrapsychic and direct action coping strategies. The effective techniques employed included relaxation, controlled breathing, paired cue verbalization, the use of incompatible images, desensitization, and modeling. The initial interventions likely proved inadequate, since they were intended to change his belief system about the motives of the medical staff through parental pressure and abstract explanations of his illness. Developmentally, they were poor choices since these types of techniques require a patient who has the capability to readily modify their judgments of the intentions of others' behavior (independently of the behavioral consequences) and also require a substantial degree of abstract hypothetical reasoning.

Clinicians should be aware of many other treatment considerations that may not fit conveniently into the above structure, yet nonetheless have clear developmental bases in childhood and adolescence. For example, I have not discussed parents or the significant roles they play in the treatment of problems in behavioral pediatrics. In additions to assessing family development variables, clinicians may need to teach parents about developmental issues (Varni, 1983) and developmentally appropriate ways to communicate with their children. Parents often need to be told that it is alright to be honest with their children when discussing their illness or a medical procedure. A parental separation from a young hospitalized child can many times be eased by simple instructions to the parent to reassure the child based upon their honesty.

Other developmental concerns revolve around the needs of children and adolescents to have their own "turf," wear their own clothes in the hospital when possible, and have their privacy and confidentiality respected (Denholm & Ferguson, 1987). Children more at risk of an externalized health locus of control (as are many in the practice of behavioral pediatrics), need to have some choices in their lives (Erlen, 1987). Even if they are simple, such as physical therapy now or after lunch, or which arm would you like to use for the I.V., having choices can greatly affect the child's sense of mastery of their surroundings and minimize learned helplessness.

CLOSING NOTES

Selecting and modifying the right clinical techniques to fit the child and the specific situation is surely no simple task. I have argued in this chapter that the basic principles upon which meaningful behavioral pediatric interventions are based must include careful attention to biomaturational, cognitive, and socioemotional developmental factors. While there is no substitution for a firm grounding in developmental research and theory, some clinicians have begun to recommend ways to organize clinical procedures into developmentally meaningful sequences (Kendall & Braswell, 1986). These organizational frameworks will no doubt provide useful guidelines for the clinician. However, we must be cautioned not to adhere to them too rigidly. A meticulous and multifocused developmental assessment is still necessary as an initial step since many of the markers we assume to be valid indicators upon which to base normative judgments (e.g., chronological age), are likely to be less valid in the environments in which the practitioner of behavioral pediatrics operates.

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CHAPTER 4

Assessment Strategies in Clinical Behavioral Pediatrics

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INTRODUCTION

Assessment strategies in behavioral pediatrics are characterized by tremendous diversity. These strategies constitute a hybrid, the result of a necessary, often imperfect, but frequently rich amalgamation of assessment concepts and practices drawn from at least three related areas:

1. *General psychological assessment techniques* that include clinical interviews with children (Greenspan, 1981) and parents (Gross, 1984; Haynes & Jensen, 1979), behavioral checklists and questionnaires (Barkley, 1988), adaptive behavior scales (Nihara, Foster, Shellhaas, & Leland, 1974), neuropsychological evaluations (Fletcher, 1988), tests of personality (Knoff, 1987), academic achievement (Taylor, 1988), and intelligence (Kaufman & Reynolds, 1984), and projective techniques (Krahn, 1985). Several discussions of the use of such general clinical assessments in the context of child health psychology have appeared (e.g., Magrab, 1984).
2. *Illness and health-oriented assessments* aimed at describing and understanding: (a) particular medical conditions, (b) the complex network of interacting systems that influence the child's and family's adaptation to illness (Turk & Kerns, 1985), and (c) factors associated with effective illness management (Russo & Tarbell, 1984). Dietary monitoring forms for diabetic children (e.g., Johnson, 1984), ratings of pain associated with

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procedures such as bone marrow transplant (e.g., Dolgin & Jay, 1989) or dental care (e.g., Lindsay & Roberts, 1980), questionnaires for assessing knowledge of disorders such as AIDS or diabetes (e.g., Johnson, 1988), schedules for monitoring the effects and/or side effects of medication (e.g., Barkley, 1981), and measures for assessing therapeutic adherence (e.g., Jay, Litt, & Durant, 1984; Litt, 1985), illustrate the wide range of illness and health-oriented assessments that have been used in behavioral pediatrics.

3. *Assessments reflecting the conceptual and methodological tenets of behavioral analysis and behavioral assessment* (Mash & Terdal, 1981, 1988a; Ollendick & Hersen, 1984). Conceptually, behavioral approaches have emphasized an empirical orientation to treatment, a focus on the individual case, functional analysis of behavior, the moderating influences of situational determinants on behavioral adaptations, and the importance of conducting assessments that have direct relevance for treatment and prevention. Procedurally, behavioral assessments have been characterized by the use of multiple informants and methods (Mash, 1987; Mash & Terdal, 1988b), direct observations of behavior (Foster & Cone, 1986), and the inclusion of single-subject designs for the evaluation of treatment outcomes (Barlow & Hersen, 1984).

In light of the number and variety of assessment emphases and methods encompassed by the above three areas, one of the greatest needs at the present time in behavioral pediatrics is for the development of decision rules and criteria for selecting , implementing, and evaluating cost-efficient and relevant assessments.

ASSESSMENT IN BEHAVIORAL PEDIATRICS

The significance of assessment in behavioral pediatrics has been noted in a number of important general references in the field (e.g., Krasnegor, Aresteh, & Cataldo, 1986; Russo & Varni, 1982a; Tuma, 1982; Varni, 1983). Karoly (1985a), for example, states: "In considering what the discipline of psychology has to offer medicine, our most valuable asset involves the theory and technology of measurement. . . ." (p. xi).

In spite of such comments, attention to assessment issues in clinical behavioral pediatrics has lagged considerably behind that given to treatment. Although information about assessment strategies is emerging, with the exception of a handful of journal articles (e.g., Eyberg, 1985; Russo, Bird, & Masek, 1980), book chapters (e.g., Dolgin & Jay, 1989; Johnson, 1988; Magrab & Lehr, 1982; Melamed & Johnson, 1981; Robinson & Eyberg, 1984) and books examining assessment issues and procedures in health psychology (e.g., Karoly, 1985a; Karoly & Jensen, 1987) and behavioral medicine (e.g., Keefe & Blumenthal, 1982), it has more typically been the case that discussions of assessment have been embedded within, and often secondary to, discussions concerning the treatment of specific health problems.

Nevertheless, three points evident in most discussions to date are that assessment strategies in behavioral pediatrics must be (1) both flexible and sensitive to the unique clusters of concerns associated with differing childhood illnesses; (2) sensitive to those features common to differing diagnostic conditions, and (3) geared to the needs of individual children and their families, recognizing the variability known to characterize different children within similar diagnostic categories. This chapter begins by outlining a number of general assessment themes that cut across both individual-specific and disorder-specific parameters. It then identifies frequent assessment targets in clinical behavioral pediatrics and selectively describes the methods used to assess them. Some of the practical issues associated with the use of these methods and strategies in behavioral pediatrics are shown through the use of a case illustration.

GENERAL THEMES IN BEHAVIORAL PEDIATRICS

A number of general themes characterize work in behavioral pediatrics, each having direct implications for the types of assessments to be carried out.

Medical Context for Assessment

The fact that assessments in behavioral pediatrics are usually initiated by a medically based referral, are carried out in health care settings, and involve interdisciplinary involvement and collaboration, all contribute to the content and structure of the assessment process. In fact, some investigators suggest that the acceptance of behavioral methods in health care will, in large measure, be based on the compatibility of behavioral assessment with traditional medical assessment techniques (Russo, Bird, & Masek, 1980).

Practical Orientation

This reflects a commitment in behavioral pediatrics to the development and implementation of assessment and treatment techniques that are demonstrably effective, time efficient, and economical. Furthermore, in the case of both acutely and chronically ill children, clinical exigencies will often demand that assessment information contribute directly and immediately to treatment.

Systems Orientation

Increasingly, assessment strategies in behavioral pediatrics have recognized the complex interrelationships between health-related behaviors, social system variables, and illness management and prevention. Such recognition has led to a multidimensional assessment focus on parent–child interactions, clinician–parent–child interactions, social influences on therapeutic adherence, the marital relationship, social supports, peer and sibling relationships, and school adjustment. It has also become apparent that the controlling mechanisms for many health conditions are often at a level higher than that of immediately present environmental contingencies, and that any narrow approach to assessment that fails to take into account more distal controlling events may result in an incomplete or inaccurate analysis of the problem (Russo & Budd, 1987).

The systems orientation in child health care is perhaps most evident in a growing interest in understanding the relationship between family coping and child coping (Drotar, Crawford, & Bush, 1984). In the case of chronically ill children, the impact on family functioning may include role strains and shifts, changes in both extrafamilial and intrafamilial communication patterns, altered family and extended family alliances, readjustments in the parent–child relationship, loss of confidence in parenting skills, and the differential use of disciplinary practices for ill versus well children in the family (Johnson, 1985; Tritt & Esses, 1986).

Acute illnesses requiring medical attention (e.g., elective surgery, pediatric, or dental visits) create stress for both the child and family, particularly when hospitalization is required. In addition, recovery from acute illness may involve social isolation and the interruption of daily routines at school and home. Often parents in such circumstances must cope with uncertainties about outcome and at the same time provide comfort for their child as well as maintain their ongoing family, work, marital and personal roles and responsibilities (Melamed and Bush, 1985).

Health Orientation

Assessments in behavioral pediatrics emphasize the relationships between health-directed behaviors and health status and how such relationships influence child and family adaptations to disability, chronic illness, or acute health care procedures. The focus in assessment and treatment is not solely on the reduction of symptomatic distress, but also on the promotion of health enhancing lifestyles.

Developmental Perspective

Many investigators have emphasized the importance of incorporating developmental information and concepts into the practice of behavioral pediatrics (e.g., Roberts, Maddux, & Wright, 1984). In relationship to assessment, two developmental questions are of central concern:

1. To what extent does the child's illness interfere with adaptations to developmentally salient tasks, such as the formation of secure attachments during infancy, development of autonomy during the preschool years, establishment of reciprocal peer relationships during childhood, and separation from the family during adolescence and young adulthood?

2. What is the nature and extent to which the child's developmental level and characteristics interact with various health-related needs, including those associated with illness management and prevention? The child's understanding of illness, of the relationship between health and behavior, of the ability to assume control over one's own health care, and the acceptability of differing treatments are all likely to be affected by salient developmental processes (Maddux, Roberts, Sledden, & Wright, 1986).

Ongoing Assessment

Karoly (1985b) identifies a number of important features needed in establishing a viable model of developmental health competence. Among these are a focus on (1) the *continuous* multidirectional transactions among children, their social and inanimate environments, and salient disease characteristics; and (2) *ongoing* processes of adaptation as opposed to single or discrete outcomes. Such a dynamic model, particularly in the case of children with chronic illness, dictates that assessments must of necessity be ongoing, iterative, and sensitive to the changes associated with both developmental and disease progressions.

Idiographic

Although recognizing commonalities in behavior and context often associated with particular disease or health conditions, assessment strategies in behavioral pediatrics must be directed at the individual child and the family. Both medical and psychological research indicate that the expression and modifiability of disease and health processes are often idiosyncratic to the individual case. Individual-specific environmental precipitants for asthma attacks, headache onset, the occurrence of seizures, and responses and possible side effects to medication, all reinforce the notion that individual case analysis should be a prepotent assessment theme.

Multiple Informants

Concepts of health and illness are typically defined for children by people within their social environment and by exposure to media. Consequently, in addition to identifying the types of health information available to children, and their disorder-related cognitions, it is important to describe patterns of family communication about health and illness and the types of criteria and standards employed by significant others in establishing norms for health and illness.

The use of multiple informants in clinical behavioral pediatrics presents some of the same measurement difficulties that have arisen in others areas, notably those related to interpreting a lack of concordance between informants (Peterson, 1984). Discrepancies in reports from different informants are likely a function of the unique individual and role perspectives held by different people in the child's environment and, importantly, are also related to characteristic variations in children's behavior across situations.

FRAMEWORK FOR ASSESSMENT

Several frameworks have been suggested for organizing health assessment information. For example, Thompson (1982) presents an assessment model for integrating information concerning developmental disabilities, which encompasses the interactions between (1) *etiological factors* (genetic–chromosomal, metabolic, unknown, hormonal, or environmental–infectious, psychosocial, nutrition, hypoxia, trauma); (2) *developmental period* (prenatal, perinatal, postnatal); (3) the *system implicated* (cognitive/intellectual, language, neuromotor, physical, affective, sensory/perceptual, learning). Karoly (1985c) describes an assessment model based on the interactions among targets of assessment, sources of assessment, and purposes of assessment.

The complexity implicit in these frameworks dictates that the most appropriate model for assessment within clinical behavioral pediatrics is one that emphasizes an ongoing decision-making framework. Such a decision-making framework specifies that in the case of any individual child, a wide range of factors must be taken into account when developing an appropriate assessment strategy and in answering such questions as: What elements of child and family functioning are to be assessed? Of the many assessment procedures that are available, which ones are to be used? How are assessment results to be integrated and interpreted? How are assessment results to be communicated to professionals with differing backgrounds, interests, and priorities? And, perhaps most importantly, how are assessment findings to be used in the design, implementation and evaluation of a comprehensive treatment plan?

PURPOSES OF ASSESSMENT

Assessment purposes can be roughly organized into four groupings: prevention and early detection, diagnosis, design for treatment/rehabilitation, and evaluation of treatment outcomes.

Prevention and Early Detection

Infants with very low birthweights (e.g., less than 1500) are at risk of impairments in later functioning and illustrate one type of assessment strategy that has been used for early detection and prevention. Assessment and followalong strategies now take into account that medical factors at the time of birth and infant intelligence tests may not be highly predictive of outcomes when compared with a combination of early family factors (Corter & Minde, in press). The current practice is to implement an ongoing multicomponent assessment that includes medical, motor development, sensory-vision, hearing, and developmental assessments, as well as an examination of family variables such as maternal education, marital status, and family coping and support systems.

Very often, assessments focusing on early detection and prevention involve seeing a child at predetermined age intervals using a *multiple gating* assessment strategy. Initial assessments at each age may be quite broad and cost efficient: however, when problems are suggested, more detailed and usually more costly assessments designed to provide entry into treatment programs may be required.

Diagnosis

Early diagnostic assessments address questions related to general screening and administrative decision-making, such as: Can the child be appropriately served by a particular agency or educational program? Is the child eligible for certain services? Is there a problem? What is the nature and extent of the problem? Diagnosis in the narrow sense of formally assigning children to specific categories drawn from either a system of disease classification, or from empirically derived behavioral taxonomies, is a commonly associated feature of assessments in clinical behavioral pediatrics.

In a broader sense, diagnosis refers to an analytic information gathering process in which efforts are directed at understanding the nature of the problem, possible causes, treatment options, and projected outcomes. Behavior-analytic formulations of the problem in relationship to possible antecedent and consequent controlling events are an integral feature of diagnostic assessments in behavioral pediatrics.

Design for Treatment/Rehabilitation

The treatment contexts within which behavioral pediatrics assessments are carried out include (1) the direct treatment of medical problems using procedures, such as biofeedback; (2) supportive or ancillary care related to fear reduction or producing increased compliance with treatment procedures; and (3) health care systems and education as would be the case with the development of preventive strategies (Lutzker & Lamazor, 1985).

A common reason for assessment referral and consultation in behavioral pediatrics is that a child and family are not coping with the management requirements associated with a chronic illness. A diabetic child may not be taking insulin on a regular basis or may veer sufficiently from dietary restrictions so as to seriously jeopardize health. Consistent with a decision-making framework, a variety of factors that may account for problems in adherence must be considered. The form that treatment takes will often be based on the factors found to be most relevant in promoting therapeutic compliance.

Evaluation of Treatment Outcomes

The application of single-subject designs (see Barlow & Hersen, 1984) involving the collection of baseline information, the introduction of intervention(s), and the evaluation of treatment effects (where possible using such controls as reversals or multiple baselines), seems especially well suited to the medical context. There have been numerous case reports in behavioral pediatrics of such applications (see Varni, 1983). Single-subject evaluations have had an enormous impact on child health care practices, promoting a general sensitivity to the importance of ongoing monitoring and data collection, accountability in service delivery, and objectivity in problem definition. The impetus for an empirical orientation to child health intervention stems in large measure from the many interesting case reports that have used some variation on a single subject design.

Nevertheless, there has also been some discontent concerning the extent to which the evaluative model implicit in single-subject designs (e.g., treatment as an experiment) is able to capture the dynamic system complexity that characterizes many pediatric health care concerns. It is also not clear that the practical and financial exigencies of most clinical service settings will permit the routine and systematic use of intensive and ongoing data-collection procedures. One of the current challenges in the field is to develop evaluation models that adequately represent complex clinical concerns and that translate the empirical rigor of the behavioral approach into clinical practice in a cost-efficient manner. In this regard, the increasing use of microprocessors for data collection and integration in health settings may facilitate such a translation (Rachman, 1983; Romancyzk, 1986).

POTENTIAL TARGETS OF ASSESSMENT

The range of potential areas of assessment typically reflect the following categories and their interactions: (1) characteristics of the illness, (2) characteristics of medical/social interventions, (3) characteristics of the child, and (4) characteristics of the environment. Assessments in each of these areas will be required in order to develop a comprehensive treatment plan (Russo & Varni, 1982b).

Characteristics of the Illness

An understanding of disease characteristics is essential to formulating effective assessment strategies. Such strategies should lead to an optimal match between client/patient characteristics and choice of treatment. The biological and genetic factors associated with some conditions *may* place limitations on the extent and rate of behavioral change that is possible and on the types of interventions that are likely to be most effective in producing change. Such limitations may occur, for example, in attempting to teach social skills to individuals with Fragile X syndrome, in teaching self-control of eating to children with Prader–Willi syndrome, or in using aversive controls to decrease the self-destructive behavior of individuals with Lesch-Nyhan's disease (Russo & Budd, 1987).

Various illness dimensions that are important to assess include the type of disease (e.g., acute versus chronic), typical age of onset (e.g., congenital versus adventitious), etiology (e.g., hereditary versus nonhereditary), disease course (e.g., stable versus progressive; cyclical versus episodic), type of impairment, illness severity (e.g., Hurtig & Koepke, 1987), visibility of the disorder, and illness impact. Karoly (1985b, p. 10) describes many possible negative outcomes associated with chronic illness in children, all of which constitute potentially important areas for assessment. These include (1) painful, disfiguring, incapacitating, functionally limiting, or life-threatening symptoms; (2) psychological reactions to symptoms, such as fear, embarrassment, disgust, depression, withdrawal, or self-hate; (3) short-term treatment effects, such as pain, discomfort, and fear; (4) long-term treatment effects, such as medical compliance and school absenteeism; (5) the effects of hospitalization, such as fear, loneliness, or helplessness; (6) the impact of illness on peer relationships and friendship formation; (7) the impact of illness of family life; and (8) the impact of illness on emergent concepts of self and other normative developmental adaptations.

Characteristics of Medical/Social Interventions

Several characteristics are associated with interventions for specific illnesses that also have implications for assessment.

Side Effects of Medical Treatment

Numerous side effects are associated with many medical treatments. Pain caused by invasive diagnostic procedures or treatment (e.g., postsurgical pain, postradiation pain, postchemotherapy pain) is a frequent assessment focus (Jay, Elliot, & Varni, 1986). Nausea, vomiting and loss of hair may be associated with chemotherapy (Redd, Jacobsen, Die-Trill, Dermatis, McEvoy, & Holland, 1987). A tragic side effect for many individuals with hemophilia has been possible exposure to the AIDS virus through blood transfusions.

Demands on Patient for Monitoring and Adherence

Many chronic illnesses require lifelong management. Insulin-dependent diabetes, for example, requires particularly complicated efforts to adhere to a multicomponent treatment consisting of diet management, exercise, the monitoring of blood sugar levels and daily insulin injections. Assessment tasks include understanding these requirements and determining how they may affect relationships in order to help the child and family keep a perspective on normal emotional and social growth. It is important that disease management not become the sole focus of family functioning.

Assessment of Compliance

Deaton (1985) notes that compliance is often viewed as forgetfulness, irresponsibility, or carelessness on the part of the parent, rather than as an active decision or choice. However, under certain circumstances, noncompliance may be adaptive and related to accurate parental perceptions. Witness one parent, who states: "a doctor sometimes is right but they better listen to a mother sometimes too because she's with these kids 24 hours a day" (Deaton, 1985, p. 11).

Other investigators have presented the view that rigid compliance may at times be indicative of a patient's "disinclination to experiment and test the limits of their illness," a view consistent with an attitude of resignation (Reiss, Gonzalez, & Kramer, 1986). In such circumstances, compliance may be associated with poorer outcomes. These points suggest that the assessment of compliance should be directed at understanding a "process in context," rather than at tabulating the occurrence or nonoccurrence of a checklist of conforming behaviors.

Characteristics of the Patient

The assessment of a range of individual child characteristics is of great importance in determining the child's adjustment to illness and his or her reactions to differing types of treatment. A good prescriptive match between child characteristics and proposed interventions seems especially important to treatment outcome. Perhaps the most fundamental child characteristic is developmental level. Other child characteristics reported to be significant contributors to health adjustment, health management, and reactions to medical procedures include cognitive styles, levels of fear and anxiety, locus of control, intelligence, coping strategies, daily health habits, arousal levels, and personality characteristics such as defensiveness (Melamed & Bush, 1985).

Characteristics of the Environment

Characteristics of the environment include factors at the family, community, and societal levels. For example, such influences as the attitudes and responses of the child's social network toward the illness, the impact of the illness on the family's finances, impact on siblings (Cimini & Silverman, 1986), social support, stress (O'Grady & Metz, 1987), peer relationships, educational and health care environments, cultural attitudes toward health promotion, socioeconomic conditions, nutritional factors, and ecological hazards to health all need to be examined.

ASSESSMENT METHODS

Within the decisional framework advocated here, the choice of methods appropriate to the individual case should be determined by specific assessment needs. We believe it is not only difficult, but also inappropriate, to attempt to evaluate the quality of any assessment method independently of its intended clinical purpose.

INTERVIEWS

Unstructured interviews are probably the most important medium for health care providers in establishing rapport and in forming an ongoing relationship with clients. Interviews serve many functions including obtaining information, providing information, understanding the child's and family's level of adaptation, and assessing the impact of the illness on the family. Clinically, the interview should follow an interactive format so that family members feel free to express their concerns and to ask for clarification on issues that are unclear. It is not uncommon for parent(s) of a chronically ill child to come to an appointment with a prepared set of questions that they wish to raise. In such situations, it can create considerable anxiety for the parent if he/she feels hurried, perceives the interviewer as overly controlling, or does not have an opportunity to raise these questions.

General Guidelines

As much as possible, the following general interview guidelines should be in place, particularly around the stressful time surrounding the initial diagnosis:

1. Both parents should be present. In the case of separated or divorced parents, it is critical that both parents be involved. It is particularly important in divorced families to inquire about visitations between a child with a chronic illness and the noncustodial parent.
2. The communication between clinician and parents must be interactive, with give and take and ample opportunity for questions.
3. Time should be taken to discuss and deal with the feelings of all family members, including siblings.
4. Specific instrumental help should be provided in assisting the family in formulating plans for the next action(s) to be taken.
5. A follow-along plan should be initiated to provide support and feedback to the family.

Interviews with Parents

As a basis for designing an effective treatment program, the following seven areas are important to assess:

1. *Coping with the diagnosis:* Drotar, Baskiewicz, Irvin, Kennel, and Klaus (1975) provide a useful framework for considering the stages of adjustment (e.g., shock, denial, sadness, anger, adaptation, and reorganization) of parents to the massive crises initiated by the information that their child has a significant disorder of indefinite duration. Though partly sequential, these stages are intended to be dynamic and fluid. Parents may move in and out of a particular stage, but this process normally takes place over a substantial period of time.

2. *Problems associated with implementing specific management issues:* What are the necessary behavioral requirements for treating or managing the particular illness? For example, do the parents understand the disorder and all aspects of the management requirements? Do they have beliefs or attitudes that may conflict with adherence to a prescribed plan? In what specific ways has adherence to the treatment plan broken down? Do parents have difficulty communicating

with hospital staff, school personnel, or friends and relatives concerning the disorder?

3. *Parent–child relationships:* A number of questions concerning parent-child relationships are important. How do the parent(s) and child relate with respect to the requirements of the management program? How do the parent(s) and child relate in everyday relationships? Is there overprotection or scapegoating of the ill child? Is inadequate attention being given to the needs of healthy offspring? Are siblings of the ill child being burdened with additional responsibilities?

4. *Marital functioning and support systems:* Are family members able to communicate openly about the child's illness and treatment plans? Is there overinvolvement of one parent to the exclusion of the other? In divorced families, are the custodial and noncustodial parents able to communicate about the child, the illness, and the treatment? This latter point is especially critical to assess, because breakdowns in communication may place the child at risk with respect to changes in medication or diet routines when one parent is unaware of these changes.

5. *Significant stressors:* Apart from the stress associated with the child's illness, are there other stressors (e.g., economic strain, family violence) that distract the family from the day-to-day management of the child's needs, and in other ways disrupt the family's ability to adapt and cope?

6. *Problems with adherence to a program:* The specifics of adherence will be determined by the particular illness and its management requirements. For example, Johnson (1988) observed that for diabetic children, knowledge about one area of diabetes does not correlate with knowledge about other areas. Similarly, adherence to one phase of treatment may not be correlated with adherence to other phases (see also Delamater, in press). Each phase of management will need to be reviewed. It is important to create an atmosphere in which the parents and the child are comfortable in discussing problems with adherence. For some individuals, there may be a strong tendency to "look good" and to report that diet or another aspect of treatment is going well, when in fact it is not. Adherence problems may occur as a child matures and begins to assume more and more aspects of the treatment. It is important to provide consultation to the child and family so that the child's participation is appropriate from a developmental point of view and that the child's efforts are monitored. For some families it is helpful to reframe the adherence issue in ways that promote mutual or shared responsibility.

7. *Feedback from parents:* Getting feedback from parents concerning their clinic visit(s) is also important. The following questions may be raised in either an unstructured interview or through the use of a brief standardized evaluation form. Were your questions and concerns about your child and the disorder adequately addressed? Were your questions about management of the illness adequately answered? Have we provided you with the specific help you need for behavioral management of your child's condition? Have you received help in coping with the stresses associated with your child's illness?

In the unstructured interview, it is also important to inquire about the parents' perceptions of how their child gets along with siblings, peers, classmates, and teachers, and how the child meets academic demands. There is considerable variability in the way families cope with chronic illness, and a review of how the child functions in a variety of settings is crucial. For example, one family with a child with hemophilia thought it was necessary to have their child totally avoid peer contacts for fear that the child would be bumped or hit and would suffer bleeds. Children with asthma, heart disorders, hemophilia, diabetes, and other conditions are likely to miss many days of school due to illness, and it is important to review how the family makes the decision to keep a child home. Some families err consistently on the side of caution, and this may prove costly in terms of missed opportunities for the child. Other families miss or downplay important symptoms that a condition, such as asthma, is worsening and requires active intervention. By inquiring about a child's activities and interests in age-appropriate areas, it is possible to determine the functional implications of the disorder and to review guidelines and possible choices.

Interviews with Children

Concerns regarding the reliability and validity of interview procedures with children have led to their limited use, especially with younger children. However, it has become increasingly apparent that interviews provide essential information concerning the child's perceptions, cognitions, and feelings. Perceptions of self and family, reactions to and understanding of the illness and proposed treatment procedures (e.g., feelings about doctors), and expectations regarding outcome are a few of the many areas that will need to be addressed (Eyberg, 1985). Assessment of such perceptions provides the clinician with an opportunity to correct misperceptions, provide reassurance when necessary, and design treatment regimens that are sensitive to the feelings and expectations of the child.

Most interviews with children are carried out in an unstructured and often unsystematic fashion and there is a need to develop and standardize brief structured interview formats that systematically assess the symptoms, cognitions, and behaviors associated with specific medical conditions (Eyberg, 1985). For example, Ross and Ross (1985) describe a 23-item Pain Test, administered in an interview format, which takes about 15 min to complete. This measure has been used in conjunction with preventive educational programs dealing with children's understanding of such topics as the early warning function of pain, the value of pain both as a diagnostic aid and in evaluating treatment, pain descriptors, and coping strategies such as self-distraction and thought stopping. The child responds to such interview questions as:

> "Steve is going in to the hospital on Wednesday to have an operation on his knee. This will be the first time Steve has been in the hospital. He's really scared. What could he do to stop feeling so scared?" (p. 58)

and

> "If you had a *very bad* pain and you went to the doctor about it, what things would your doctor want to know about your pain?" (p. 58)

Any interview format must, of course, be adapted to the developmental level of the child, and useful guidelines for doing this in the clinical context have been presented (Bierman, 1983; Bierman & Schwartz, 1986). With very young children, the use of puppets and other toy materials is common. For example, Linn, Beardslee, & Patenaude (1986) describe the use of puppets as a vehicle for working through concerns related to confinement, regression, abandonment, medical procedures, and body image in a 4-year-old boy who was confined in a laminar airflow room for two months while undergoing bone marrow transplantation for Wiskott–Aldrich syndrome.

While interviews are an integral part of any behavioral pediatrics assessment strategy, it is also the case that such subjective reports require elaboration through the systematic use of more structured questionnaire and observational procedures. A selective review of such procedures follows.

CHILD-COMPLETED QUESTIONNAIRES

The use of child-completed questionnaires in behavioral pediatrics has been extensive. The questionnaires that have been used fall into two related categories: (1) questionnaires directed specifically at the child's medical condition and its management, including measures of somatic complaints, concepts of health and illness, health beliefs, knowledge of particular disorders, and behaviors related to successful adaptation to illness; and (2) questionnaires that do not tap illness or health dimensions directly but are related to the more general cognitive, behavioral, social, and affective processes that moderate the child's adjustment to illness and treatment. These include measures that assess the child's fears and anxieties, depression, body image, self-concept, locus of control, and peer relations.

Illness-Related Questionnaires

Children's Conceptualization of Illness

Several investigations (e.g., Bibace & Walsh, 1980; Perrin & Gerrity, 1981) have examined children's conceptualizations of illness in relationship to stages of cognitive development. These studies (many of which are reviewed by Varni, 1983, pp. 16–28) have shown that children's understanding of illness and medical procedures varies across cognitive stages. From a clinical standpoint, explanations of illness dimensions and treatment procedures must be presented in ways that are most relevant to the child's current and changing views of the world.

Health Beliefs Questionnaires

Several questionnaires have been developed to assess children's general health beliefs. One such measure, developed by Dielman, Leech, Becker, Rosenstock, and Horvath (1980) for children of ages 6–17, describes six dimensions of health beliefs: (1) general health concerns (e.g., how much do you worry about getting sick?); (2) specific health concerns (e.g., how worried would you be if you had a fever?); (3) perceived general susceptibility to illness (e.g., how often do you get sick compared with others your age?); (4) perceived susceptibility to specific conditions (e.g., how much of a chance is there that you might throw up in the next few months?); (5) perceived seriousness of and susceptibility to illness (e.g., when you are sick, how bad do you usually feel?); and (6) perceived parental control (e.g., when you are sick, how much do your mother and father seem to worry about you?).

Knowledge of Disorder Measures

These measures focus on such issues as the patient's knowledge of the disease and management requirements, pain and discomfort associated with the disease or treatment, and adherence behaviors. Johnson (1988) provides an excellent overview of these issues and a review of disease specific measures. Harkavey *et al.* (1983) developed the "Test of Diabetes Knowledge," a measure which samples information about diabetes as well as problem-solving in hypothetical situations involving choices about care and management. Lindemann and Haynes (1986) have developed a similar type of measure for assessing hemophilia patients' and their families' understanding of AIDS and its transmission.

Management and Prevention: Disease-Related Behaviors

An exemplary measurement program for the identification of behaviors that are important to teach in the management of pediatric asthma, the most common chronic disorder of childhood, has been described by McNabb, Wilson-Pessano, and Jacobs (1986). Initially, a critical incidents technique was used in which respondents (children, parents, physicians, nurses, school nurses, teachers, and others) were asked to think of a recent situation in which the child was especially effective or ineffective in dealing with some aspect of his or her asthma. Effective responding was defined as leading to improvement in the child's asthma; ineffective responding was defined as a behavior that hindered self-management or that was detrimental to the asthma. All responses were recorded on an index card. Once the situation was identified (e.g., she was spending the night at a friend's house when she was 7 years old), the respondent was asked (1) what the child did that was effective/ineffective (e.g., she brought her alarm clock and medicine with her because she had to take her medicine on time at 6 AM; (2) why the behavior was effective (e.g., she took her medicine on time and so didn't wheeze badly); (3) whether the child was assisted by anyone and, if so, what that person did (e.g., her friend made sure the child got up at 6 AM and had a glass of water ready for her to take her medicine); and (4) whether the assistance was helpful or detrimental.

Using these procedures, four areas of behavior were inductively derived, consisting of behaviors related to prevention, intervention, compensatory behaviors, and external controlling strategies. Multiple categories and subcategories (e.g., critical self-management competencies) within each of these areas were also described. For example, included under the area of prevention are such incidents as avoids allergens (e.g., foods, pollens), avoids irritants and other precipitants (e.g., humidity, extremes in air temperature), controls or avoids emotions that trigger attacks (e.g., fears, anxieties, anger), takes preventive medicine, and ensures that medications for relief of symptoms are accessible.

This assessment model is particularly useful in that it identifies behaviors that lead directly to treatment recommendations. Using a validational model, it is then possible to assess whether changes in these behaviors alter the child's condition (McNabb, Wilson-Passano, Hughes, & Scamagas, 1985). These procedures are also useful in identifying, from the child's and parents' perspective, what aspects of behavior are important in the management of the illness and by doing so may indicate areas of inaccuracy and/or inconsistency between parents or between parents and children.

Management and Prevention: Skills for Self-Regulation of Health

Karoly (1985b) notes that many chronic illnesses involve "*recurrent* and *predictable* stressors taking their toll on children's *subjective reactions* and usually at times and places that *preclude thorough adult surveillance*" (p. 11). It follows that the need to assess the child's self-regulatory competencies becomes especially critical. In rejecting simplistic notions of self-regulation as equivalent with self-care, or the use of simple skills such as self-observation, self-recording, or self-directed verbalizations, Karoly (1985b) defines health self-regulation, in terms of developmentally appropriate self-regulatory operations, as:

> "the ongoing process by which individuals gather, represent, organize, and act upon data relevant to their physical well-being (with minimal external guidance) and formulate long- and short-term "standards" or "goals" that impact on their health status." (p. 12)

Specific skills that need to be assessed include the child's knowledge of the characteristics and challenges of their specific illness in relationship to their emergent developmental capacities for coping; the ability to formulate action–outcome goals that affect on health status; the ability to modulate affect through cognitive and/or behavioral strategies; the capacity to self-monitor bodily functions, sensations, or appearances and to recognize important normative deviations; the ability to make use of environmental feedback in the modification and/or reordering of goal priorities; a conception of self as willing and able to carry out extended behavioral projects relevant to disease control and health maintenance; and recognition of the "continuum of control" possible in any situation, rather than the adoption of an "all-or-none" philosophy that may undermine persistent efforts at mastery (Karoly, 1985b, pp. 13–14).

The richness evident in this conceptualization must be tempered by the fact that only in a few cases are there available standardized, reliable, or valid instruments with which these dynamic skills can be assessed. While some of the measures being discussed here tap these dimensions, it is more often the case that clinical constructions via interview and integration of test information lead to more general formulations of the child's self-regulatory skills. A current challenge for health assessors is the translation of this type of conceptual model into specific assessment operations, which in turn will lead to the generation of specific treatment recommendations.

General Process Questionnaires

Fears and Anxieties

Measures of fear have included both general measures (reviewed by Barrios & Hartmann, 1988), such as the Fear Survey Schedule for Children—Revised (Ollendick, 1983), and specific measures for assessing the fears of children undergoing hospital (e.g., Katz, Kellerman, & Siegel, 1980) or dental procedures (e.g., Dental Fear Survey; McGlynn, McNeil, Gallagher, & Vrana, 1987). Some of the more commonly used measures for the assessment of anxiety (Achenbach, 1985) include the Children's Manifest Anxiety Scale (Reynolds & Richmond, 1978) and the State Trait Anxiety Inventory for Children (Spielberger, 1973).

Depression

The study of depression in infants and young children is a relatively recent phenomenon. However, current work has shown that depression is both identifiable and measurable during childhood (e.g., Costello, 1986; Kazdin, 1988). The Children's Depression Inventory (Kovacs, 1981) is perhaps the most frequently used measure of children's depression.

In addition to the above areas, many questionnaires have been used to assess such areas as locus of control (e.g., Parcel & Meyer, 1978), Type A and Type B behaviors (e.g., Matthews & Angulo, 1980), self-concept (Harter, 1982), and peer relationships (Hops & Greenwood, 1988).

PARENT-COMPLETED CHECKLISTS

Parent completed checklists are frequently an integral component of the assessment process in behavioral pediatrics. These checklists include those in which parents provide information about their children and/or information about themselves.

General Child Behavior Checklists

The Child Behavior Checklist (Achenbach & Edelbrock, 1983) has become the most frequently used parent-report measure of children's behavior problems and competencies. There have been numerous applications of this measure within the context of behavioral pediatrics with populations of children with Reye's syndrome (Benjamin, Levinsohn, Drotar, & Hanson, 1982), suicidal tendencies (Cohen-Sandler, Berman, & King, 1982), cancer (Cimini & Silverman, 1986), constitutionally short stature (Gordon, Crouthamel, Post, & Richman, 1982), epilepsy (Herman, 1982), diabetes (Lavigne, Traisman, Marr, & Chasnoff, 1982), obesity (Israel & Shapiro, 1985), and sexually abused children (Friedrich, Urquiza, & Beilke, 1986).

Questionnaires about Parents

A variety of questionnaires concerning parental functioning have also been employed. The most commonly used have focused on depression (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), the marital relationship (Spanier, 1976), stress (Loyd & Abidin, 1985), and social support (Dunst & Trivette, 1985).

Questionnaires about Family Needs

Bailey and Simeonsson (1985) developed a 35-item *Survey of Family Needs* to be used as a clinical tool in identifying important goals in interventions with families of young handicapped children. This measure also provides a useful prototype for the preliminary identification of family needs in populations of children with chronic or acute illness. Family needs are organized into six areas.

1. *Needs for information:* e.g., "I need more information about my child's condition or disability," "I need more information about the services my child might receive in the future."
2. *Needs for support:* e.g., "I need to have more friends that I can talk to," "I need to have more opportunities to meet and talk with other parents of handicapped children."
3. *Explaining to others:* e.g., "I need more help in how to explain my child's condition to his/her siblings."
4. *Community services:* e.g., "I need help locating a dentist who will see my child."
5. *Financial needs:* e.g., "I need more help in getting special equipment for my child's needs."
6. *Family functioning:* e.g., Our family needs help in discussing problems and reaching solutions.

Items are rated on a three point categorical scale: 1 = I definitely do not need help with this area, 2 = Not sure, and 3 = I definitely need help with this area. This measure could easily be revised for establishing family needs in a variety of illness populations and provides a useful entry point in setting objectives and providing services. Furthermore, the identification of treatment needs by the parents themselves is likely to enhance compliance with treatment procedures. However, in instances in which families may be unable or unwilling to report their needs, such direct measures may be insufficient.

SELF-MONITORING

Shapiro (1984) describes the use of a range of self-monitoring procedures for use with children. Varni (1983) describes a multidimensional procedure to assist patients with hemophilia or arthritis self-monitor pain. Several investigators (e.g., Joffe, Bakal, & Kagonov, 1982; Masek, Russo, & Varni, 1984) have described self-monitoring procedures for headache patients. Generally, these procedures involve recording the time and place of headache occurence, headache intensity and related physical symptoms (e.g., nausea or vomiting), medication use, and antecedents and consequences for the headache. Similar procedures have been devised for the self-monitoring of eating behaviors in bulimic individuals (Schlundt, Johnson, & Jarrell, 1986).

MONITORING BY PARENTS AND OTHERS

Ratings of Pain

The pervasiveness, intrusiveness, and discomfort associated with pain-related features of illness and treatment have resulted in considerable attention to procedures for the assessment and management of pain (e.g., Karoly & Jensen, 1987; Keefe, 1982; Masek *et al.*, 1984). Typically, pain assessment in behavioral pediatrics is ongoing, employs multiple measures, and makes few assumptions concerning psychological versus organic origins or whether the child's reports are real or imagined (Masek *et al.*, 1984).

Varni, Katz, and Dash (1982) present a four-category framework for pediatric pain problems involving pain associated with (1) physical injury or trauma (e.g., burns, lacerations, fractures); (2) disease state (e.g., arthritis, sickle cell disease, hemophilia); (3) medical/dental procedures (e.g., injections, lumbar punctures, bone marrow aspirations); and (4) pain not associated with a well-defined cause or stressor (e.g., migraine, recurrent abdominal pain).

In one of the more clinically sensitive discussions of pain assessment, Masek *et al.* (1984, pp. 1114–1115) outline three essential goals in pain behavior assessment with chronically ill children: (1) describing the behaviors of the child when in pain (e.g., How do others know when the child is in pain? How is medication administered and used?); (2) determining possible functional limitations that the pain has imposed on the child's relationships with peers and siblings, participation in organizations or sports, personal and family activities and school performance (e.g., days missed from school); and (3) the identification of possible maintaining events for pain behavior (e.g., contingent attention, medication use only when pain occurs).

In addition to the assessment of pain behavior, the child's subjective perceptions of pain, its perceived causes, and styles for coping with pain are also potentially important to evaluate in designing treatment programs. Similarly, environmental events known to affect reports of pain, such as the presence of certain people, varying situations, or changes in environmental stimuli, must also be evaluated. However, the necessity of relying on the child's subjective reports in assessing pain perceptions often leads to data lacking in reliability or validity; therefore, the implications of pain assessment data for treatment are often less than direct.

Standardized observational procedures for assessing pain related to specific illnesses have also been developed. For example, Anderson, Bradley, McDaniel, Young, Turner, Agudelo, Keefe, Pisko, Snyder, and Semble, (1986) describe a standardized procedure for assessing pain in rheumatoid arthritis. Initially, patients were asked to identify the joints and body areas in which they were presently experiencing pain. They were then videotaped for a 10-min interval while performing a standardized sequence of sitting, walking, standing, and reclining maneuvers. Videotapes were coded by trained observers using operational definitions of seven behaviors thought to be indicative of rheumatoid arthritis pain (e.g., guarding, bracing, grimacing, sighing, rigidity, passive rubbing, active rubbing). These observational measures were validated against a number of clinical and laboratory measures.

Ratings by Parents

Parent recordings provide a convenient method of assessment for infrequently occurring events, as well as events that take place primarily in the home with very young children. Deaton (1985) describes the use of a "Breathing Self-Report" postcard on which parents of children with asthma record breathing difficulties, attacks, and medication regimens on a daily basis. Within the clinical context, we have found the use of telephone answering machines to be quite cost efficient in having parents report the information they have collected on a daily basis.

Ratings by Professionals

A number of measures are available to assist dentists or physicians rate pain and to evaluate patient behavior in response to invasive medical procedures. Lindsay and Roberts (1980) describe a behavior checklist of children's behaviors during dental procedures. Venham, Gaulin-Kremer, Munster, Bengston-Audia, and Cohan (1980) have developed a six-point anxiety and uncooperative behavior scale: 0 (relaxed, smiling, willing, and able to converse) to 5 (e.g., child out of contact with reality of the threat, general loud crying, no effort to cope). Several studies have also employed nurses for rating children's behavior in medical settings. For example, Spiga (1986) employed nurses ratings of hostility, impatience, and gross motor agitation in order to study type A behavior in fourth- and fifth-grade students.

MEASURES OF FAMILY FUNCTIONING

In spite of the increasing role being given to parents in the management of their ill children (e.g., Drotar *et al.,* 1984), relatively little attention has been given to the development of measures for the direct assessment of parent–child interactions, especially in the case of children with acute illness (Melamed and Bush, 1985). While direct observations have been used relatively more frequently with families of chronically ill children, it has been noted that the primary factor limiting our knowledge concerning the family and the child with chronic illness is the general lack of reliable and valid methods for measuring families (Johnson, 1985). It is often the case that such measures in chronic populations are designed to identify general patterns of interaction characteristic of particular diagnostic categories rather than to evaluate family functioning and communication on health and health management issues. In this regard, it has been suggested that health-related evaluations are likely to offer more than measures of general family functioning (Johnson, 1988). Following are two examples of measures designed to assess family functioning, one with an acute condition and the other with a chronic disorder.

Melamed and Bush (1985) observed mothers and their children interacting while awaiting clinic examinations. A multicategory observational coding system consisting of four classes of child behavior and six classes of parent behavior was developed for this purpose. The child categories included attachment behaviors (e.g., touching parents), distress (e.g., crying or fear-related verbalizations), exploration (e.g., locomotion and handling objects), and social-affiliative responses (e.g., verbal interaction, play). Parent behavioral categories included ignoring (e.g., reading, no eye contact), reassurance (e.g., verbally indicating understanding or praising the child for being brave), distraction (e.g., conversation or play that was unrelated to medical context), restraint (e.g., verbally chastising the child or holding child in place), agitation (e.g., pacing, finger tapping, expressions of anger), and informing (e.g., answering questions, exploration).

A number of maternal behaviors were additively and interactively related to child behaviors. For example, children were responsive to maternal anxiety; when mothers were agitated, children evidenced high distress. This was true for maternal manifestations of anxious behavior in the waiting room and not for anxiety as assessed by questionnaires. Furthermore, the effectiveness of various maternal coping strategies was related to the interactive context. The use of distraction or reassurance by mothers who were agitated was associated with higher distress in children. While these types of observational assessments have not received widespread use in clinical practice, in part because of their costs, they do have direct implications for treatment. If mothers can be identified in terms of their skills in helping their acutely ill children cope with stressful medical procedure, then parents who show low levels of such skills can be taught to use more effective strategies.

Bobrow, AuRuskin, and Siller (1985) described a procedure to evaluate mother–daughter interactions during discussions of issues associated with diabetes and treatment management requirements and problems. Mother–daughter interactions that were confrontive or negative were associated with poorer adherence. Mothers and daughters who raised questions and discussed tentative solutions in a nonconfrontive manner demonstrated better adherence to treatment management procedures.

Other studies have also used standardized laboratory assessments to identify the more general problem-solving styles of families in which a member is chronically ill. In one of the more ambitious efforts in this area, Reiss *et al.* (1986) view general problem-solving styles as an important resource for assisting families in dealing with the enduring stress and uncertainty associated with chronic illness. Such dimensions as *configuration* (i.e., pattern or coherence families can recognize in dealing with complex and ambiguous situations), *coordination* (i.e., the family's belief that they must, necessarily, face ambiguous situations as a unified group rather than as individuals), and *delayed closure* (i.e., the family's openness to new information) are assessed. These dimensions are empirically derived from behavioral indices taken from family interaction tasks involving pattern recognition and card sorting. Although the tasks used in this work seem rather abstract, a series of studies have shown these measures to be related to illness adjustment and outcome in a population of end-stage renal disease patients (Reiss *et al.*, 1986).

Other frequently used measures of family functioning in illness populations have been the *Family Functioning Index* (Pless & Satterwhite, 1973) and the *Family Environment Scale* (Moos & Moos, 1986).

PARENTAL COPING

Measures have also been developed for looking at broader family variables such as parental coping strategies. For example, McCubbin, McCubbin, Patterson, Cauble, Wilson, and Warwick (1983) examined coping in parents of children with cystic fibrosis, including such patterns as (1) increasing the integration and stability of the family, (2) getting support from friends and co-workers outside the family or by solitary accomplishment, and (3) getting medical knowledge and support. Relationships between coping strategies and outcome depended on which parent was responding and the type of outcome being assessed (e.g., height and weight versus pulmonary functioning).

Another measure of parental coping styles, the *Ways of Coping Checklist—Revised* (Vitaliano, Russo, Carr, Maiuro, & Becker, 1985) contains five subscales examining preferential response style to stress, including (1) problem-focused coping, (2) avoidant strategies, (3) seeking social support, (4) wishful thinking, and (5) self-blame. The use of avoidant, wishful and self-blaming coping styles has been shown to be associated with higher levels of distress in mothers of premature infants in a neonatal intensive care unit (Williams & Mabe, 1986).

ASSESSMENT OF MEDICAL PARAMETERS

Varni (1983) describes a number of specific medical parameters assessed within the context of behavioral pediatrics. These include such factors as the number of analgesics required for pain relief, units of factor-replacement products for the treatment of bleeding episodes of hemophilia, articular index scores for joint tenderness in arthritic disorders, number of excoriations in exfoliative dermatitis, weight in obesity programs, and prescribed medications for hypertensive patients.

A number of physiological parameters are also assessed, which include biochemical (e.g., metabolic by-products of a drug or diet regimen, identification of a physiological marker placed in medication, direct identification of a therapeutic agent in blood or urine), electrodiagnostic (e.g., EEG, EMG, ECG, GSR), thermography (e.g., temperature via thermistor on skin surface or infrared imaging photography, blood flow by plethysmography), and musculoskeletal measures (e.g., muscle strength/power, endurance parameters as measured by isokinetic and isometric instruments).

CASE ILLUSTRATION

Given that there is no "typical" case in behavioral pediatrics, any single example will undoubtedly be unrepresentative. In the following case, the referral question concerned a child whose primary medical condition was out of control, thus exposing the child to very severe health risks. The following broad issues were addressed:

1. The parents' understanding of the child's medical condition and their emotional adjustment to it
2. Parent and child adaptations to management of the disorder, through the collection of information concerning beliefs, attitudes, and behavior in specific problem areas
3. Parent–child behavior around specific issues associated with management of the disorder
4. The overall quality of parent–child interactions
5. Marital adjustment and social supports

The evaluation used multiple measures including interviews, parent ratings of child behavior, and direct observations of parent–child interaction. It was carried out over four sessions involving 9 hrs of direct patient contact time, with the findings integrated into a single report. The following material represents sections of the report that highlight the contributions of family factors thought to relate to poor adherence.

Case Study: PKU Clinic

Psychological Consultation

Cindy, aged 6 years, was seen for a psychological consultation in the PKU clinic. Concerns centered about consistently high phenylalanine (PA) levels. This report addresses issues concerning the parents' adaptation to the demands of PKU, particularly with respect to dietary restriction and management.

Interview

Parent Perception of Diet Management. Mr. and Mrs. Jones were interviewed about their daughter's PKU and issues of diet management. Both reported that during the first 20 months of Cindy's life, dietary management was easy. The father reported that since about 2½ years of age, Cindy would ask questions during mealtime like, "How come I can't eat that?" and "What does it taste like?" The father reported that his standard response has been, "If you want to try this, I will give you a taste." The father continued, "I'd say it tastes good to me, so I'll give you a taste. You may like it or you may not, but you can't be eating it." The father commented, "If you hide it from her she'll want more." Then he added, "I'm not going to stop her from a taste—that is a learning thing—maybe her curiosity will be settled." The father indicated that Cindy has had meat, cheese, fish, eggs, peanut butter, and a variety of foods as "tastes." He also reported that on special occasions, such as a birthday, Cindy might be told that she can eat anything she wants and has had whole hamburgers. Her father also reported that he believes most of the high PA levels have come from foods that may be okay in strict moderation but that Cindy has not stayed within those strict moderations. These foods include mainly starches such as breads, crackers, potatoes, and potato chips. The father stated that Cindy knows what she can eat and is her own worst enemy.

The parents were interviewed regarding their perceptions of the age at which a child should assume primary responsibility for their diet management. The parents indicated that they were not certain, but the father estimated that a child should be able to manage their diet associated with PKU at about five years of age.

Regarding examples of self-control behavior, the parents report that Cindy has learned that if she is at a neighbor's house and is offered a food that is unfamiliar to her that she will call her mother or father on the telephone and ask about it. While this is a positive step, the parents indicated that if she is offered a preferred food that she knows is not on her diet, she will eat it without a phone call.

Behavior Rating Scales

The mother and father independently completed the *Eyberg Child Behavior Inventory* (Eyberg, 1980). Their perceptions of Cindy were quite similar. The mother's intensity rating of Cindy's behavior resulted in a score of 125, which is within 1 standard deviation (SD) of the normative mean. She indicated that out of a list of 36 problems, 10 were significant. Again, this is within 1 SD of the normative mean. The results are consistent with the reported perceptions of both parents that Cindy is not a child with major behavioral problems. They describe her as being largely compliant, as not having temper tantrums. However, they do see her as having a short attention span and as being restless and distractible.

Parent–Child Observations

Cindy was observed in a standardized free play and task situation, while interacting individually with her mother and with her father. She was also observed on two occasions during mealtime with the family.

Clinic Observations. These interactions were coded using the Response-Class Matrix (Mash, Terdal, & Anderson, 1973; Mash & Barkley, 1986), and retained as a baseline sample of interaction. In the parent–child interaction between mother and child, Cindy was highly interactive and social, engaged appropriately in play behavior, and was responsive to cues from her mother. The mother was nondirective and provided ample opportunity for Cindy to make choices in the play situation.

In a task session, the mother asked Cindy to put toys away, to complete two pages of pre-academic paper and pencil test materials, copy figures, and to solve a puzzle. Cindy showed a high compliance rate, and the mother was effective in having the child stay on task. She used praise appropriately.

Similarly, the interaction between the father and child was quite positive. The father indicated that he spent a lot of time playing with Cindy, and describes their relationship as very good. The free play was active, and father and child were quite responsive to one another. In the task situation, Cindy initially refused, but the father was able to get her to complete the tasks, which included looking at a puzzle, putting toys away, and having a focused discussion on diet and diet management.

Observations at Mealtime. Cindy was observed at the family's apartment on two occasions at mealtime. On each occasion, Cindy was served food that was well within the range of her dietary restrictions. Cindy showed good appetite and was cheerful during mealtime. While the rest of the family ate a very different diet, including hamburgers, Cindy did not ask for samples of what they were eating. The parents were instructed that during the week they were being evaluated to be very strict with the diet and to let us know at any time whether Cindy showed any adverse behavioral reactions to a very strict regimen. No such reports were made by the parents.

Marital Adjustment and Supports

The parents were interviewed individually with respect to the degree to which they view one other as supportive or intrusive. By interview, and also by observation, these parents presented themselves as being supportive of one other, and as not being intrusive. They indicate that they talk over problems, that each encourages the other to pursue their own interests, and that they comfort each other when things go wrong. Mrs. Jones reported that a second major support for her are her parents who live nearby. She reported that she finds them to be very supportive, but mildly intrusive, in the sense that they may give unsolicited advice or suggestions.

Recommendations

Cindy shows many behaviors consistent with a youngster who would be able to tolerate a strict dietary regimen. Unlike many children who have gone out of control on diet, she is still compliant and socially responsive and appears relatively easy to manage, both by observation and by parental report. The major focus with this family will be to help them reframe their attitudes and beliefs about dietary restrictions.

The following is a list of problem areas that reflect attitudes and behaviors that seem to relate to poor adherence in this case:

1. Offering food "to taste" has probably served to extend, rather than to satisfy curiosity
2. The opportunity to taste foods that are off the diet may have served to minimize the necessity of strict control, both for Cindy and for her parents
3. Offering meat as an occasional treat may heighten the contrast for Cindy between the PKU diet foods and regular diet
4. The parents' apparent misreading of the child's ability to self-manage and to underestimate the need for strict supervision on their part

5. The parents' (particularly the father) feeling that withholding certain foods deprives the child

The father indicated at one point that it would tear his heart out to simply say that she can't even try a particular food.

It is recommended that Cindy be monitored weekly as to her blood levels and that the parents reinstate the procedures that they have used in the past for recording her diet. A major focus should be to review with both parents their views about food and the meaning of diet restriction. The parents will need to be provided with step-by-step rules for handling diet management, including the need for them to be much more assertive and communicative with neighbors and relatives so that no food is offered that is problematic. The school Cindy attends will also follow the dietary plan in a very strict and matter of fact manner.

SUMMARY

The field of behavioral pediatrics provides both interesting and significant assessment challenges to psychologists to participate within an interdisciplinary framework in assisting children and their families cope with illness and handicapping conditions. The diversity of issues is brought on in part by the seemingly infinite number of disorders that can effect functioning in so many different ways. This chapter focuses on both disorder-specific variables and adjustment issues that appear to be common across disorders. The contributions of psychology in behavioral pediatrics will be greatly strengthened by an increased effort to apply standardized, cost-effective, sensitive measurements covering such issues as prevention, early detection, diagnosis, and treatment evaluation. It is believed that such measurements are best applied within a decision-making framework in which assessments are ongoing and flexible in relationship to meeting expected treatment goals.

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PART II

CLINICAL DISORDERS

CHAPTER 5

Cognitive–Biobehavioral Assessment and Treatment of Pediatric Pain

JAMES W. VARNI, GARY A. WALCO, AND
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INTRODUCTION

Pain in children represents a complex cognitive–developmental phenomenon, involving a number of biobehavioral components that synergistically interact to produce differential levels of pain perception and verbal and nonverbal manifestation (Varni, 1983). In marked contrast to the rather extensive clinical research literature on adult chronic pain assessment and management, the systematic investigation of pediatric pain from a cognitive–biobehavioral perspective represents a relatively recent area of scientific inquiry (Varni, Katz, & Dash, 1982). Given children's various cognitive–developmental stages, their conceptualizations of pain and discomfort must be taken into consideration (Thompson & Varni, 1986). Thus, an accurate understanding of pain in children cannot be gleaned from simply applying downward the knowledge of pain in adults; rather, research and clinical practice in pediatric pain assessment and treatment must develop a separate, if not parallel, data base from the adult pain field that is sensitive to the unique characteristics of children. During the past several years, a growing number of investigators have begun generating a substantial data base

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from which the clinical potential of cognitive–biobehavioral techniques in managing pediatric pain has become clear.

Varni has identified four primary categories of pediatric pain: (1) pain associated with a disease state (e.g., hemophilia, arthritis, sickle cell anemia); (2) pain associated with an observable physical injury or trauma (e.g., burns, lacerations, fractures); (3) pain not associated with a well-defined or specific disease state or identifiable physical injury (e.g., migraine and tension headaches, recurrent abdominal pain); and (4) pain associated with medical and dental procedures (e.g., lumbar punctures, bone marrow aspirations, surgery, injections, extractions) (Varni, 1983; Varni *et al.*, 1982).

This chapter presents case studies representing chronic and recurrent pain associated with the pediatric chronic diseases hemophilia, juvenile rheumatoid arthritis (JRA), and sickle cell anemia. The other three categories of pediatric pain are addressed elsewhere in this volume on headaches, recurrent abdominal pain, burns, and preparation for hospitalization. Reviews on procedural pain associated with bone marrow aspirations and lumbar punctures in childhood cancer have also recently been published (Jay, Elliott, & Varni, 1986; Varni & Katz, 1987). Before describing the cognitive–biobehavioral assessment and treatment of pain associated with pediatric chronic diseases, an overview on pediatric chronic and recurrent pain is provided.

PEDIATRIC CHRONIC AND RECURRENT PAIN

In the cognitive–biobehavioral assessment and treatment of pediatric pain, it is essential to distinguish between acute and chronic pain. Acute pain serves an adaptive biological warning signal, directing attention toward an injured part or disease condition, functioning within an avoidance paradigm to encourage escape or avoidance of harmful stimuli, and indicating the need for rest or treatment of an injured area. While neurophysiological processes may distinguish acute from chronic pain (Bonica, 1977), it is often the severe intensity of acute pain and its associated anxiety reaction that most parsimoniously differentiates acute and chronic pain expression (Varni, 1983). Particularly during painful medical procedures, the anxiety component must be taken into consideration (Jay *et al.*, 1986).

Pediatric chronic pain, on the other hand, is typically characterized by the absence of an anxious component, with a constellation of reactive features such as compensatory posturing, lack of developmentally appropriate behaviors, depressed mood, and inactivity or restriction in the normal activities of daily living. These chronic pain behaviors may eventually be maintained independently of the original nociceptive impulses and tissue damage, being reinforced by socioenvironmental influences (Varni, Bessman, Russo, & Cataldo, 1980). By contrast, acute pain typically occurs in temporal proximity with a pathogenic agent or noxious stimulus. In pediatric chronic diseases, the chronic musculoskeletal pain associated with JRA and hemophilic arthropathy correspond to the chronic pain model described above. In the recurrent episodical pain of acute bleeding episodes in hemophilia and sickle cell crises, the clear distinction between acute and chronic pain is not evident. The case studies that follow in this chapter will elucidate this clinically essential differential approach to pediatric chronic and recurrent pain.

PEDIATRIC CHRONIC AND RECURRENT PAIN ASSESSMENT

For adult chronic pain patients, the most widely used and respected assessment instrument has been Melzack's McGill Pain Questionnaire (MPQ) (Melzack, 1975). Subsequent to its publication, other investigators have further developed the reliability and validity of the MPQ across a diversity of adult pain syndromes. Varni and Thompson (1985) developed a pediatric pain questionnaire modeled after the MPQ but designed to be sensitive to the cognitive–developmental conceptualizations of children. The Varni/Thompson Pediatric Pain Questionnaire (PPQ) is a comprehensive multidimensional assessment instrument specifically designed for the study of acute and chronic pain in children, with child, adolescent, and parent forms. The PPQ—Child Form addresses the intensity of pain on a visual analogue scale and body outline, and the sensory, affective, and evaluative qualities of pain perception. The PPQ-Adolescent Form additionally addresses potential socioenvironmental influences on pain perception. The PPQ—Parent Form consists of similar components to the PPQ—Child and PPQ—Adolescent forms to allow for cross-validation. A comprehensive family history section addresses the child's pain history and the family's pain history with questions pertaining to symptomatology, past and present treatments for pain, and socioenvironmental situations that may influence pain perception. Thus far, the published reliability and validity of components of the PPQ are available for chronic musculoskeletal pain in JRA (Varni, Thompson, & Hanson, 1987), with ongoing studies in progress with other pediatric chronic and recurrent pain syndromes. A case study is presented later in this chapter that illustrates the utilization of the PPQ.

COGNITIVE–DEVELOPMENTAL ASPECTS OF PAIN PERCEPTION IN CHILDREN

Increasing attention is being paid to the cognitive-developmental level of the child when approaching the task of pediatric pain assessment. A child's cognitive–developmental level may have a significant effect on his or her perception and report of pain. Lack of communicative ability may prevent a child from adequately expressing the pain that he or she is feeling, and lack of knowledge of the hospital environment may inhibit a child from asking for pain relief (Thompson & Varni, 1986). Few studies have related pain perception to cognitive development. However, the findings of the available studies indicate developmental changes in certain aspects of pain perception.

The determination of whether developmental aspects of pain tolerance and pain threshold exists is hampered by a small number of studies and contradictory findings. Haslam (1969) found pain threshold to increase with age, while Beales, Keen, and Lennox Holt (1983) found adolescents with JRA to experience more severe pain than children with JRA. Conceptual and methodological differences noted between these studies may help account for the different findings (Lavigne, Schulein, & Hahn, 1986). Haslam's report was concerned with pain threshold, while Beales and co-workers' study reflected pain threshold and pain tolerance. Also, Haslam was measuring laboratory pain, and Beales and co-workers measuring clinical pain. Personality and cognitive factors may have contributed more to clinical pain than to laboratory-induced pain.

An interesting hypothesis derived from the work of Beales *et al.* (1983) is that age differences in reports of pain severity may be related to differences in cognitive level, and particularly to differences in the sophistication of the child's conception of illness. Certain types of conceptualizations about illness may facilitate the processes of "catastrophizing" about pain, resulting in experiencing pain of greater severity (Lavigne *et al.,* 1986).

Bibace and Walsh (1980) identified six stages of cognitive development in the content area of physical illness, formulated from Piaget's stages of general cognitive development. This is the most detailed and well-defined system outlined thus far in the literature (Burbach & Peterson, 1986). Each stage is briefly described below (the ages provided are approximate ages generally found during the transition between stages).

The prelogical stages (2–6 years of age)

1. *Phenomenism:* This is the most developmentally immature explanation of illness. During this stage, children conceptualize the cause of illness as a concrete phenomenon that may co-occur with the illness but that is spatially and/or temporally remote (e.g., people get colds from "the sun").
2. *Contagion:* This explanation is offered by the more mature prelogical children. In this stage, the cause of illness is located in objects or people who are proximate to, but not touching, the child. The link between cause and illness is conceptualized in "magical" terms (e.g., people get colds "when someone else gets near them").

The concrete–logical stages (7–10 years of age)

1. *Contamination:* At this stage of development, children can distinguish between the cause of illness and how the cause of illness becomes effective. The cause is often viewed as a person, object, or action external to the child that has an aspect of quality that is "bad" or "harmful" for the body (e.g., people get colds "when outside without a hat").
2. *Internalization:* Children at this stage of development still consider the cause of illness to be external but now link the external cause of illness to some internal effect on the body. An example of internalization would be swallowing or inhaling (e.g., people get colds by breathing in bacteria).

The formal–logical stages (11 years and older)

1. *Physiologic:* Although children believe that the cause of illness may be triggered by external events, the source and nature of illness are thought to lie in specific internal physiologic structures and functions. Children are able to conceptualize the breakdown of internal processes and structures as a step-by-step internal sequence (e.g., people get colds from viruses).
2. *Psychophysiologic:* Children at this stage of development conceptualize illness in terms of internal physiologic processes while also considering the psychological cause of illness (e.g., "people get heart attacks from heart malfunctioning, which is brought about by tension and stress).

With changes occurring in the way that children conceptualize disease processes, it is likely that similar changes will occur in how they understand pain, and particularly in how they conceptualize the relationship between pain and disease (Lavigne *et al.,* 1986). Gaffney and Dunne (1986) addressed this critical point in a large scale research project aimed at investigating how children think about several aspects of pain. Their conclusions support the hypothesis of a developmental model of pain conceptions in children. A group of 680 Irish schoolchildren, aged 5–14 years, were asked to complete the sentence, "Pain is. . . . " The responses to this question were then examined to ascertain whether children's definitions of pain change with increasing age. Piaget's theory of cognitive development and studies documenting levels of understanding of illness were used as the models of how responses might vary with developmental level. The results of Gaffney and Dunne's study indicated significant differences between age groups in the use of concrete definitions, semiabstract definitions, and abstract definitions. There was a developmental pattern toward increasing abstraction of definitions of pain with increasing age. Gaffney and Dunne (1986) suggest that the relationship between cognitive stage and conceptualization of pain may prove useful as a guide in communicating about pain with children of various ages.

PAIN ASSESSMENT IN CHILDREN

The ideal assessment of pediatric pain requires an interdisciplinary, multidimensional, and comprehensive approach. A combination of self-report, behavioral, cognitive, socioenvironmental, medical, and biological parameters is called for (Thompson & Varni, 1986; Varni, 1983). Generally, research in pediatric pain assessment has not addressed all these parameters; therefore, conclusions about the reliability and validity of the existing measures must be drawn cautiously (Varni, Thompson, & Hanson, 1987).

Selection of colors to communicate pain intensity has received some attention in the literature. Red has been reported to be the color most frequently chosen by children to represent pain (Savedra, Gibbons, Tesler, Ward, &

Wegner, 1982; Scott, 1978). In studies examining recurrent migraine headaches and chronic musculoskeletal pain (Unruh, McGrath, Cunningham, & Humphreys, 1983) and chronic musculoskeletal pain in JRA (Varni *et al.,* 1987), red was the most frequently selected color to represent pain. However, other colors such as black and green were also selected by children to represent pain, illustrating the importance of allowing children to make their own color/pain intensity match (Varni, *et al.,* 1987). In a study examining pain related to intramuscular injections, prekindergartners used a self-selected color spectrum to assess pain (Eland, 1981). The children selected colors from among eight color squares to represent four levels of pain (from no hurt to most painful). This four-point scale was then successfully used to assess the child's pain report following injections, showing that even very young children seem able to use colors to represent levels of pain intensity.

Pain intensity has also been measured in children using the visual analogue scale (VAS). A VAS is a 10-cm horizontal line with no numbers, marks, or descriptive vocabulary words alongside. Descriptive words, such as "no pain" and "severe pain" may be placed outside the actual length of the line. The child responding is free to mark at any place along the line to approximate the level of pain being experienced. The VAS has been reported as a valid and reliable measure of the intensity of pain in adults (Price, McGrath, Rafii, & Buckingham, 1983; Huskisson, 1974) and has recently been used to examine children's perceptions of pain. For example, Varni *et al.* (1987) found that a developmentally appropriate VAS provided highly reliable measures of the children's perception of present pain when compared with parental ($r = .72, p < .001$) and physician ($r = .65, p < .001$) estimates of present pain on a similar VAS. The children were able to distinguish reliably between present pain ($M = 1.63$) and worst pain for the previous week ($M = 4.74$). Cross-validation was provided by the parent's estimation of present pain ($M = 2.93$) and worst pain ($M = 4.27$). Worst-pain estimates were also found to be reliable between the child and the parent ($r = .54, p < .013$). Pain report increased with increased JRA disease activity, providing support for the construct validity of the PPQ's developmentally oriented VAS as a measure of pain perception.

Ongoing research into how children describe their pain has also focused on the generation of lists of pain descriptors by children, indicating that children can verbally describe their pain experiences (Gaffney & Dunne, 1986; Ross & Ross, 1984; Savedra *et al.,* 1982). The erroneous beliefs that children lack the verbal ability to describe whatever pain they do feel, or lack the memory span to remember past pain experiences have been discounted by these and other empirical studies. Young children do feel pain, can give graphic descriptions of it, and have excellent recall of their pain experiences (Ross & Ross, 1984).

For example, Varni *et al.* (1987) found that children and their parents selected similar sensory, affective, and evaluative pain descriptor terms for chronic musculoskeletal pain, such as sore, aching, uncomfortable, miserable, and tiring. Children as young as 5 years of age were able to use the PPQ pain descriptor word list to communicate the sensory, affective, and evaluative qualities of their pain experience. While considerably more work needs to be conducted in the field of pediatric assessment, it is now apparent that children can reliably communicate their pain experiences if developmentally appropriate assessment measures are used.

TREATMENT

The primary cognitive–biobehavioral treatment techniques used in the management of pediatric pain may be categorized into (1) pain perception regulation modalities through such self-regulatory techniques as progressive muscle relaxation, meditation, and guided imagery; and (2) pain behavior regulation, which identifies and modifies socioenvironmental factors that influence pain expression and rehabilitation (Varni, 1983). The mechanisms of these techniques and the theoretical principles involved in their utilization are beyond the scope of this chapter and are not discussed.

PRACTICAL PROBLEMS

Within the literature on adult pain patients, a chronic intractable benign pain syndrome (the prototype of which is chronic low back pain) is discussed in which nociceptive input is minimal, while patterns of social isolation, depression, and in many cases drug abuse, persist (Crue, 1985). In these cases, the pain is considered central in nature, requiring a very different treatment approach. Fordyce (1976) asserted that a great deal of chronic pain behavior is learned and that as long as secondary gains for such behavioral patterns are available, they will remain intact.

Although no syndrome of chronic benign intractable pain has been described in children, patterns of social isolation, depressed mood, and a propensity toward drug abuse are not uncommon in children with medical syndromes that predispose them to recurrent pain (Walco & Dampier, 1987). In these cases, steadfast reliance on interventions appropriate for acute pain, such as administration of analgesic medication and the encouragement of bed rest or immobilization, continue to reinforce the maladaptive pattern. Thus, an integration of both self-regulatory techniques and behavior-modification strategies aimed at promoting rehabilitative behaviors is often indicated in pediatric chronic and recurrent pain.

CASE ILLUSTRATIONS

Thompson, Varni, and Hanson (1987) developed an empirical model using multiple regression analysis for statistical prediction of pain perception in 23 children with JRA. The criterion variable (dependent measure) was the PPQ's VAS, and the predictor variables included child psychological adjustment, family psychosocial environment, and disease parameters. This empirical model was able to predict statistically 72% of the variance in child pain perception and report. The following case study illustrates this comprehensive approach.

Following the model of biobehavioral assessment formulated by Varni (1983) and Thompson and Varni (1986), a multidimensional assessment was used to evaluate the child's level of pain, psychological adjustment, family psychosocial environment, and level of daily functioning. The Varni/Thompson Pediatric Pain Questionnaire (Parent and Child forms), Child Behavior Checklist (Achenbach & Edelbrook, 1983), Family Environment Scale (Moos & Moos, 1981), and Disease Activity Scale (Varni *et al.,* 1987) formed the assessment battery.

Case 1: Juvenile Rheumatoid Arthritis

The child was an 11-year-old girl with polyarticular JRA. At the time of the assessment, she had morning stiffness for approximately 4 hr each morning. Sixteen joints exhibited active disease. A pediatric rheumatologist rated the child's overall disease activity as moderate (4) on a 5-point scale. Naprosyn was reported as being used to control pain episodes.

The child's mother completed the Varni/Thompson PPQ-Parent Form. The PPQ documented the child's pain as adversely affecting her mobility, appetite, sleep, and social activities. School attendance was, at times, interfered with. On the 10-cm VAS, the child's mother estimated her present pain intensity at 9 cm (quite severe pain). The words "burning," "aching," "tiring," "sharp," and "spasms" were chosen by the mother to describe her child's pain. On a body diagram, the mother localized the child's pain in the shoulders, elbows, wrists, knees, ankles, toes, and fingers.

The Varni/Thompson PPQ—Child Form was administered to the child. A word list, similar to the list the mother completed, was presented to the child. She chose the words "sharp," "pinching," and "squeezing." On the 10-cm VAS, which is anchored by happy and sad faces with the words "no pain" and "severe pain" and related developmentally appropriate words to measure child self-report of pain intensity, the child estimated her pain at 5 cm. She estimated her worst pain of the previous week at 9.5 cm (a rating very close to her mother's rating of present pain intensity). The attending rheumatologist estimated the child's present intensity at 7 cm. When localizing pain on the body diagram provided for the children, the child localized pain in her shoulders, elbows, wrists, knees, ankles, toes, and fingers—the very same locations chosen independently by her mother.

This child chose red to represent no hurt, yellow to represent a little hurt, blue to represent more hurt, and green to represent a lot of hurt (no pain, mild pain, moderate pain, severe pain, respectively), illustrating the importance of allowing the child to select the color–intensity match, since most children chose red most frequently to represent severe pain (Varni *et al.,* 1987). Consistent with a diagnosis of polyarticular arthritis, she colored in with green (severe pain) both knees and her left temporomandicular joint. Both hands, wrists, and shoulders, and the right temporomandibular joint were colored in blue (moderate pain). Both elbows, feet, and ankles were colored with yellow (mild pain). The rest of her body was colored in red (no pain).

The child's scores on the Child Behavior Checklist (CBCL) (completed by the mother), used to give a rating of child psychological adjustment, were within normal limits on all subscale scores, with the exception of somatic complaints. The elevation in the somatic complaints scale was most likely secondary to having JRA. There was also a large elevation in the depressed scale for this child. While the score was not in the CBCL range for mental health clinic-referred children, it was elevated to the extent that it suggested this child may be at-risk for some psychological adjustment problems.

The Family Environment Scale (FES), completed by the mother, was used to develop a profile of family psychosocial functioning. The FES describes the socioenvironmental characteristics of all types of families. This family's scores were within normal limits on all subscales, with the exception of increases in the moral–religious and active–recreational subscales. From this it can be inferred that a heavy emphasis is placed on religious and family social activities. Thompson, Varni, and Hanson (1987) examined the family environment profiles of 23 families who had a child with JRA. This study found that increases in family cohesion were associated with decreases in pain intensity reported by the child. This particular child did not show the increases in cohesion that typified most JRA families studied.

The assessment provided through use of this battery (see Thompson *et al.*, 1987, for a complete review of instruments used) provides a comprehensive basis for developing pediatric pain management programs. By using a developmentally appropriate instrument such as the PPQ, pain intensity, pain location, and the qualitative aspects of the pain experience can be obtained from the child, as well as potentially modifiable psychosocial and socioenvironmental factors from the parent.

Case 2: Hemophilia

Whereas recurrent acute pain in the hemophiliac is associated with a specific bleeding episode, chronic musculoskeletal pain as a result of hemophilic arthropathy (similar to osteoarthritis and caused by repeated hemorrhages in the joint areas) represents a sustained condition over an extended period of time. Thus, pain perception in the hemophiliac truly represents a complex psychophysiological event, complicated by the existence of both recurrent bleeding pain and chronic arthritis pain, requiring differential treatment strategies (Varni, 1981a, 1981b). More specifically, acute pain of hemorrhage provides a functional signal, indicating the necessity of intravenous (IV) infusion of factor replacement, which temporarily replaces the missing clotting factor, converts the clotting status to normal, and allows a functional blood clot to form. By contrast, arthritic pain represents a potentially debilitating chronic condition that may result in impaired life functioning and analgesic dependence (Varni & Gilbert, 1982). Consequently, the development of an effective alternative to analgesic abuse and dependency in the reduction of perceived chronic arthritic pain that does not interfere with the essential functional signal of acute bleeding pain has been the goal of the behavioral medicine approach to hemophilia pain management (Varni, 1981a, 1981b; Varni & Gilbert, 1982).

Unfortunately, approximately 10% of hemophilic children develop an inhibitor to factor replacement, presenting a serious problem in the management of bleeding episodes. Although the bleeding frequency is not different, the neutralization of factor replacement by an inhibitor (antibody) makes the control of bleeding ineffective. The pain associated with uncontrolled hemorrhage can be extremely severe, with narcotic analgesics traditionally prescribed. Thus, although the acute pain of hemorrhage provides a functional signal indicating the necessity of factor replacement therapy, in the hemophilic child with factor replacement inhibitor, the intensity of the pain supersedes its functional intent, and analgesic dependence is of constant concern. Consequently, an effective alternative to analgesic dependence in the reduction of perceived pain in the patient with an inhibitor has been greatly needed.

The child was a 9-year-old hemophilic child with factor replacement inhibitor reported by Varni, Gilbert, and Dietrich (1981). At 4 years of age, when the inhibitor developed and subsequent factor replacement therapy became impossible, the child began to require narcotics in order to tolerate the pain of each hemorrhage. Progressively, the need for pain medication increased both for bleeding pain and for arthritic pain in his left knee secondary to degenerative arthropathy. Since the arthritic pain eventually occurred almost daily, the requests for analgesics further increased. Thus, the acute pain of hemorrhage required increasing doses for pain relief, even though home medication and joint immobilization continued for the management of bleeding episodes. As a consequence of bleeding and arthritic pain in the lower extremities, the child was wheelchair bound nearly 50% of the time, hospitalized 16 times in the 4½-year period prior to the study for a total of 80 days after the development of the inhibitor, and kept analgesic medication at his school for pain control. The final precipitating event in this steadily worsening cycle occurred during an evening visit to the emergency room because of a very painful and severe left knee hemorrhage that had not responded to home therapy; the administration of an adult dose of meperidine and IV diazepam provided no pain relief.

Training in the cognitive–behavioral self-regulation of pain perception consisted of three sequential phases. The child was first taught a 25-step progressive muscle relaxation sequence involving the alternative tensing and relaxing of major muscle groups (Varni, 1983). He was then taught meditative breathing exercises, consisting of medium deep breaths inhaled through the nose and slowly exhaled through the mouth. While exhaling, the child was instructed to say the word "relax" silently to himself and initially to describe aloud and subsequently visualize the word in warm colors, as if written in color chalk on a blackboard. Finally, the child was instructed on the use of guided imagery techniques, consisting of pleasant distracting scenes selected by the child. Initially, the child was instructed to imagine himself actually in the scene, not simply to observe himself there. The scene was evoked by a detailed multisensory description by the therapist and subsequently described out loud by the child. Once the scene was clearly visualized by the child, the therapist instructed the child to experiment with other different scenes to maintain interest and variety.

The child recorded the severity of his pain on a 10-point scale for a 1½-week baseline prior to self-regulation training. The average score for both arthritic and bleeding pain during this period was 7, indicating rather intense pain. At a 1-year follow-up after the initiation of the self-regulation training, the child reported that both arthritic and bleeding pain were reduced to 2 on the scale when he engaged in self-regulation techniques. In addition to this measure of pain perception, the child's evaluation at the 1-year follow-up session on a comparative assessment inventory (Varni, 1983) indicated substantial positive changes in arthritic and bleeding pain, mobility, sleep, and general overall functioning.

As can be seen in Table 1, once the child began using the self-regulation techniques for pain management, there were no further requests for meperidine during the 1-year post-treatment assessment, with substantially decreased amounts of acetaminophen with codeine elixir required. Table 1 also shows significant improvements in other areas of functioning, including improved mobility, as evidenced by the physical therapy measures,

TABLE 1. Parameters Associated with Pain Intensity[a]

Parameters	One year before self-regulation training	One year after self-regulation training
Pain intensity (1 = mild; 10 = severe)	7[a]	2[b]
Meperidine	74 tablets (50 mg/ea.)	0 tablets
Acetaminophen/codeine elixir	438 doses (24 mg codeine/dose)	78 doses (24 mg codeine/dose)
Physical therapy measures		
Range of motion	Normal R knee 0–150° Arthritic L knee 15–105°	R knee 0–150° L knee 0–140°
Quadricep strength (0–5 scale)	Normal R knee 4– Arthritic L knee 3+	R knee 4+ L knee 4
Girth (knee-joint circumference)	Not available	R knee 26 cm L knee 25.8 cm
Ambulation on stairs	2–3 maximum	No limitation
School days missed	33	6
Hospitalizations		
Total days	11	0
Number of admissions	3	0

[a] From Varni *et al.* (1981).
[b] A 2.5-week preassessment during pain episodes just prior to self-regulaton training.
[c] A 1-year average rating during pain episodes when using self-regulation techniques.

in his arthritic left knee compared with his normal right knee on the dimensions of range of motion (0–150 = normal) and quadricep strength (1 = no joint motion, 5 = complete range of motion against gravity with full resistance). Normalization of psychosocial activities is suggested by increased school attendance and decreased hospitalizations and by parental report, which noted a distinct elevation of the child's overall mood, with considerably less depression during pain episodes because he had the skills to reduce his pain perception actively without depending on pain medication.

Analysis of the various parameters assessed in this study suggests a significant improvement across a number of areas. As envisioned by Varni *et al.* (1981), a deteriorating cycle was evident before the intervention, schematically represented as hemorrhage → pain → analgesics/joint immobilization → atrophy of muscles adjacent to the joints/joint deterioration → hemorrhage. Thus, as was previously suggested (Dietrich, 1976), pain-induced immobilization results in muscle weakness surrounding the joints and sets the occasion for future hemorrhaging. By breaking this deteriorating cycle at the point of pain severity, the child was offered the opportunity to decrease immobilization and increase therapeutic activities such as swimming, subsequently improving the strength and range of motion in his left knee. With this improved ambulatory status, school attendance and his general activity level were consequently increased. The possibility that this early intervention may have prevented or reduced the likelihood of later drug abuse must also be considered (Varni & Gilbert, 1982). Finally, it is important to reiterate that these procedures were used for a child with an inhibitor. For the hemophiliac without an inhibitor, bleeding pain serves as a functional signal and is best managed with factor replacement therapy. In the present case, however, no effective medical procedure was available to control severe bleeding pain other than powerful narcotic analgesics, clearly an undesirable therapy modality for recurrent pain.

Case 3: Sickle Cell Disease

In sickle cell disease, vaso-occlusion in the small blood vessels leads to bone or joint pain that may last hours to several days and may vary in intensity. Analgesic treatments range from aspirin or acetaminophen for less severe episodes to parenteral narcotic administration on a fixed dosing schedule for severe pain (Scott, 1982). In addition, self-regulatory techniques have been shown to be of benefit to patients experiencing a painful episode (Zeltzer, Dash, & Holland, 1979).

Walco and Dampier (1987) reported on a population of 260 pediatric and adolescent to young adult patients (aged 0–25 years) with sickle cell disease. It was found that during a 12-month period, 194 (74.6%) of the patients had no admissions for pain, while 66 (25.4%) required hospitalization. Of the latter group, 54 (20.8%) were hospitalized only once for an average stay of 7 days. The remaining 12 patients were admitted much more frequently (3–15 times per year) and had longer lengths of stay (10–12 days). Of note is that this small group of patients (less than 5% of the population) accounted for one half the total hospital days for treatment of pain.

Demographic data on the 12 patients showed that there were 7 males and 5 females between the ages of 14 and 23 years (comprising 12.1% of patients between 14 and 25 years of age). Ten of the patients had hemoglobin SS disease and two had hemoglobin SC (HbSC) disease. Eight of the patients were funded through medical aid, while four were funded by private insurance companies.

No consistent hematologic parameters have been found that differentiate the overutilizing group from others. Clinical practice indicated, however, that these patients had adopted maladaptive coping patterns, including social isolation and school absenteeism and failure.

A 17-year-old boy with HbSC exemplifies the clinical presentation for this disease. Except for episodes of sinusitis and *Mycoplasma* pneumonia, the course of this adolescent's sickle cell disease had been complicated only by recurrent painful episodes. Before the age of 14, he had been hospitalized five times for pain, with an average length of stay of 3.7 days. In the succeeding 36 months, he required hospitalization 16 times for a total of 87 days (5.4 days average length of stay). Onset of frequent painful episodes coincided with his failing the eighth grade. During hospitalizations, variations in narcotic dosages had no differential analgesic effect. He was clinically depressed, with melancholia, excessive sleep, social withdrawal (including refusal to attend school), and periodic suicidal ideation. In addition to pain, he reported a host of vague somatic complaints (headaches, nausea, vomiting, fainting), none of which had ever been substantiated medically. His family offered little support or consistency and neither his mother nor grandmother, with whom he alternatively resided, was able to cope with his complaints. His mother had a long history of psychiatric disorders, including psychotic episodes and suicide attempts. Efforts at psychological interventions for his affective disorder and self-regulation of pain met with active resistance. He was most content when hospitalized and resisted discharge.

The behavioral pattern exhibited by this patient demonstrates the danger of adhering to an acute pain model of intervention without examining the larger psychosocial context of the patient's pain experience. Certainly for most patients, the acute model is appropriate. That is, a vaso-occlusive crisis is a temporary interruption in an otherwise generally adaptive life-style. Thus, rest and immobilization are encouraged and analgesics prescribed to help the patient cope with this finite episode, as it is assumed that the patient is motivated to reduce pain and return to a normal level of functioning.

Clearly, that assumption is invalid for a patient who lacks the skills needed to cope with a chronic illness and recurrent pain. In these cases, acute pain interventions promote further social isolation (e.g., bed rest, immobilization, and hospitalization preclude school attendance) and potential misuse of narcotics. Unfortunately, in the present case, the maladaptive pattern was recognized only after it was firmly intact.

The situation became more difficult as the patient developed an adversarial relationship with the medical staff. Given the complex psychological and socioenvironmental issues, it was impossible to determine the extent to which specific pain episodes were related to acute vaso-occlusion or chronic psychological factors. Consequently, the patient's self-report and asystematic behavioral observations were the data on which treatment decisions were based. Thus, at each hospital presentation, the patient was put in the position of trying to convince a sometimes doubting physician that his pain was severe enough to warrant hospitalization. As a result, pain behaviors were emphasized and typically positively reinforced. Nonpain behaviors, such as ambulation, were either ignored or punished (e.g., through reduction of analgesic doses), as they were automatically interpreted as indicators of improvement.

Recognizing some of the operant factors contributing to this pattern, an effort was made to alter the contingencies. Our first attempt to do so involved the blind dosing of narcotics while the patient was hospitalized. Constant attention to narcotic dosages and the threat of reduction was seen as a factor maintaining or exacerbating pain behavior. As a solution, the patient was given an intramuscular (IM) injection of 1 ml liquid in a standard-size syringe every 3 hr; he was not told which drug he was receiving or its quantity. Instead, the patient was merely to keep us informed of the analgesic effect of the drug.

While the rationale for this plan was based on reducing manipulative and malingering behavior related to analgesic dosages, the strategy had the opposite effect. The patient knew that as his hospitalization progressed, the dosage of narcotic would be tapered; and therefore, after the first day or two of hospitalization, he continuously complained that the dose was inadequate. Furthermore, when an attempt was made to introduce oral medication, pain behavior and verbal complaints also increased dramatically, as that was an indication of impending discharge. Consequently, the plan was abandoned.

It became clear that any effort aimed at breaking the pain–depression–pain cycle that required intrinsic motivation or active participation by the patient (e.g., psychotherapy or pain self-regulation) had a low probability of success. The passive and relatively helpless stance that had been adopted was firmly entrenched. Therefore, the next strategy invoked was aimed at breaking the cycle by making the "pain patient" role less available.

A behavioral contract was instituted in which the frequency and duration of hospitalizations (for uncomplicated painful episodes), narcotic dosing schedules, frequency of emergency room visits, and availability of narcotics for outpatient use were specified in great detail. In the initial contract, these variables approximated the patient's utilization at that point in time. Over the subsequent months, each of the parameters was modified with the target of approximating the norms for patients of similar age and hemoglobinopathy. All medical personnel were provided with the protocol so that there responses were standardized, and no decisions were based on subjective viewpoints.

This strategy was indeed successful for curbing utilization and the frequency and intensity of manipulative or malingering behavior decreased. Quality of life outside the hospital, however, did not improve dramatically. It was not until the patient was hospitalized in a psychiatric unit after a suicide attempt that the depression aspect of the cycle was addressed. During that admission, while receiving antidepressant medications, there were no reported significant painful episodes. Furthermore, during the 10-month period following that admission, there were only three admissions for painful episodes. As a final note, the patient reinitiated contact with the psychologist, seeking to learn more about self-regulation techniques for pain control.

This case demonstrates the need for a flexible approach to pediatric pain management. Rigid adherence to an acute pain model without consideration of the larger psychosocial context is not only ineffective, but it may actually facilitate the development or maintenance of an extremely maladaptive behavior pattern. In this case, only after the pain–depression–pain cycle was comprehensively addressed did the patient really make progress. Unless there is a degree of cooperation from the patient, self-regulatory techniques are doomed to failure. Psychological and psychiatric interventions focusing on affective problems are inadequate as long as pain behaviors remain unchecked. Likewise, operant strategies aimed at modifying pain responses alone are insufficient. It was only after these multiple paradigms were invoked simultaneously that the patient's comprehensive needs were addressed.

These cases reinforce the need for further systematic research into the relationships between psychosocial and medical factors as they affect pain experience in children (cf. Thompson, Varni, & Hanson, 1987). As long as the focus is on one set of these variables at the expense of others, assessment and intervention strategies will remain relatively primitive and insufficient.

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CHAPTER 6

Headache

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MIGRAINE IN CHILDHOOD

Increasing numbers of children with headache problems are being referred to pediatric psychologists for evaluation and treatment. The impetus for this trend was provided by the rapid expansion of research literature supportive of biobehavioral treatment for headache and other pain syndromes in children (Masek, Russo, & Varni, 1984; Varni, Jay, Masek, & Thompson, 1986).

The biobehavioral approach to pediatric migraine is the focus of this chapter. A review of pertinent medical information about the disorder is provided for purposes of orientation. An overview of biobehavioral treatment procedures currently in use is followed by a discussion of clinical biobehavioral intervention in children with chronic headache. Finally, case material illustrative of the biobehavioral treatment process is presented.

Epidemiology

Migraine by far is the most common cause of headache in children (Barlow, 1984). Epidemiological studies indicate that approximately 5% of children between the ages of 7 and 15 years suffer from some form of migraine disorder (Bille, 1962; Sillanpaa, 1976). The incidence of migraine is slightly higher in boys before age 10, but between 10 and 15 years of age, girls outnumber boys by a 3 : 2 margin (Bille, 1962; Congdon & Forsythe, 1979). This trend continues into adulthood, with the female incidence approximately 70% (Lance & Anthony, 1966; Prensky, 1976).

Longitudinal investigations of migraine patients provide some idea as to the

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prognosis of childhood-onset migraine. Bille (1981) reassessed the 73 patients originally studied as children (Bille, 1962) 23 years later and found that 60% were still suffering from migraine. Sillanpaa (1983) reported that 78% of his school-age sample were still experiencing migraine 7 years later. Hockaday (1978) found that 73% of her original sample of 102 children and adolescents reported continuation of migraine into adulthood. An interesting finding of all three studies was that migraine symptoms were less disabling in adulthood.

Very little is known about the morbidity experienced by children with migraine. Migraine can be a relatively inconsequential symptom when it occurs infrequently, particularly when there are few associated symptoms. The infrequent migraine rarely imposes serious hardship for the child and usually can be managed with rest and nonprescription analgesics. By contrast, chronic severe migraine poses a challenge for the child's coping ability and has been associated with a greater number of somatic complaints, depression, and behavioral problems (Prensky & Sommer, 1979; Andrasik, Burke, Attanasio, & Rosenblum, 1985). These personality and behavioral characteristics have also been observed in chronic musculoskeletal pain (Cunningham, McGrath, Ferguson, Humphreys, D'Astous, Latter, Goodman, & Firestone, 1989); chronic benign intractable pain (Dunn-Geier, McGrath, Rourke, Latter, & D'Astous, 1986) and recurrent abdominal pain (McGrath & Feldman, 1986). It stands to reason that poor adaptive functioning is a potential consequence of chronic severe headache in children, but many questions remain unanswered: What percentage of children with migraine are vulnerable? What psychological and physical factors determine vulnerability? Is poor adaptive functioning a reversible consequence? Research in this area has barely begun to scratch the surface.

Clinical Characteristics

Migraine headaches are recurrent paroxysmal attacks of throbbing head pain. In childhood, the pain is typically bilateral, accompanied by nausea, vomiting, or abdominal pain and relieved after sleep (Prensky, 1976). Family history for migraine is a factor in approximately 90% of pediatric cases (Barlow, 1984). Symptoms that occur with lesser incidence include (1) visual aura preceding the headache, (2) vertigo or light-headedness, (3) paresthesia of the extremeties, and (4) unilateral head pain (Barlow, 1984).

Pathophysiology of Migraine

There is general agreement that migraine is an inherited disorder characterized by vasomotor instability of cranial arteries leading to excessive vasoreactivity (Barlow, 1984). However, the pathophysiologic mechanisms that lead to a migraine attack are speculative. Both extracranial and intracranial arteries are involved in a process of dilation and pulsation, but vasodilation does not fully explain the throbbing quality of the pain (Edmeads, 1979). Current thinking favors the release of a vasoactive neurohumoral substance that triggers the painful vascular phenomenon; the most recently proposed candidate is substance P (Moskowitz, 1984). The mechanisms involved in the visual aura and other symptoms that precede the headache, prolonged attacks of several days duration, and the unilateral pain phenomenon are not well understood.

Precipitating Factors

Environmental or biological events may precipitate migraine episodes. Commonly reported events include psychological stress, fatigue, exposure to sun, physical exertion, hypoglycemia, hormonal factors, and food sensitivity (Barlow, 1984; Werder & Sargent, 1984). Although the role played by psychological factors in aggravating the frequency and severity of pediatric migraine is unquestioned (Leviton, Slack, Masek, Bana, & Graham, 1984), there is little evidence to support the often held assumption that emotional factors are of etiological significance (Barlow, 1984). The concept of a "migraine personality" in children lacks empirical support and is seldom referred to anymore in the clinical literature.

Pharmacologic Treatment

Prescription and nonprescription analgesics, such as Fiorinal (aspirin–butalbital), acetominophen, and aspirin, are mainstays of medical therapy for pediatric migraine. These medications in combination with rest often provide enough symptomatic relief for the severe but infrequent and less severe forms of migraine (Barlow, 1984).

Prophylactic medications are considered for children who have not responded to symptomatic medication or whose attacks are frequent and incapacitating. The antidepressant, amitriptyline, and the β-blocker, propranolol, are the two most widely prescribed prophylactics that must be taken daily to be effective. However, surprisingly few clinical trials have been published investigating the efficacy of these medications for pediatric migraine. Ludvigson (1974) studied the effectiveness of propranolol using a double-blind crossover design with 28 children between the ages of 7 and 16 years. He reported that 20 children experienced a complete remission of headache while taking propranolol, while only three children experienced complete remission during the 3-month placebo trial. Forsythe, Gillies, and Sills (1984) conducted a similarly designed study with 53 children aged 9 to 15. However, these investigators did not find a positive effect for propranolol or placebo with regard to frequency, severity, or duration of migraine. Lack of supportive evidence on the efficacy of pharmacological treatment for migraine, the side effects of the medications, and parental concerns about the long-term implications of drug treatment has deterred many physicians from aggressive pharmacological management of migraine in children.

BIOBEHAVIORAL INTERVENTION

A review of 18 studies of the efficacy of biobehavioral treatment of pediatric migraine indicate reductions in headache activity following treatment ranging from 60% to 100%. (For a comprehensive review and critique of this literature, the reader is referred to Hoelscher and Lichstein, 1984.) Biobehavioral treatment procedures for pediatric migraine and other chronic pain disorders in children fall into three general categories: contingency management of pain behavior, cognitive behavior therapy, and self-regulation training, such as biofeedback and relaxation.

Treatment Procedures

Contingency management of pain behavior is based on Fordyce's (1976) conceptualization that pain behaviors (e.g., grimaces, immobilization, verbal complaints, analgesic ingestion) are learned responses that are maintained by social attention or avoidance of unpleasant circumstances. Contingency management treatment instructs parents and other authority figures to minimize their attention to the child's pain behaviors and to provide positive reinforcement for the child's efforts to engage in normal activity patterns and positive coping behaviors. Single case studies of the use of contingency management treatment of children with recurrent headaches associated with high rates of school absenteeism were reported by Lake (1981) and Ramsden, Friedman, and Williamson (1983). In both cases, teachers and parents were instructed to ignore the child's pain reports consistently and to reinforce the child positively on headache-free days. Lake (1981) reported that the subject's school attendance significantly increased during and after treatment. These results were maintained at 1-year follow-up. Using a multiple baseline across settings design, Ramsden *et al.* (1983) demonstrated that positive reinforcement of headache-free days at school and later at home resulted in a significant decrease in the child's headache reports. These treatment gains were maintained at a 10-month follow-up. It is important to note that neither investigation attempted to assess whether the children's headache activity was actually diminished. Instead, the primary goal of both was to demonstrate that altering the contingencies associated with headache reports can significantly alter the child's level of dysfunction with a headache.

The focus of cognitive behavior therapy is the modification of negative arousal-inducing cognitions associated with headache activity that can trigger attacks or cause intensification of headache symptoms. The basic therapeutic strategy involves helping the patient identify these negative cognitions and then rehearsing the patient to substitute problem-solving reassuring self-statements. For example, a child's initial negative thought, when reminded of headache, might be: "I hate when I get a headache because it makes me so sick and takes so long to go away." This statement can be replaced with the more positive statement: "I do not have to be afraid of a headache. I always feel better after I sleep." Children are also taught an imagery or autogenic relaxation technique to use when they are feeling anxious about the prospect of having a headache.

The efficacy of cognitive behavior therapy in the treatment of pediatric migraine lacks, for the most part, empirical support, although many clinicians acknowledge the usefulness of the approach. To our knowledge, the study by Richter, McGrath, Humphreys, Goodman, Firestone, and Keene (1986) provided the only experimental data relevant to this discussion. A control group outcome design was used to test the efficacy of a cognitive coping intervention versus relaxation therapy versus an attention–placebo-control condition. Results indicated that the cognitive behavioral intervention was as effective as relaxation therapy in reducing migraine attacks in children. Both treatments were superior to the attention–placebo intervention.

Training in self-regulation is by far the most frequently employed intervention for pediatric headache disorders. Typically, the treatment combines some form of biofeedback training with relaxation instruction. The goal of this intervention is to teach children to monitor their physiological state and to effect a relaxation response when needed. In so doing, it is hypothesized that the patient learns to attenuate sympathetic outflow and "short circuit" cerebral vasomotor hyperactivity that is capable of triggering a migraine attack.

Biofeedback training involves the presentation of information in the form of an analogue signal about some physiological function—heart rate or skin temperature, for example. The analogue signal is usually depicted as a polygraphic tracing or line-graph output to a television screen. A variable pitched tone or a light bar display is also used on occasion. The feedback is paired with the instruction to try to cause an increase or decrease in physiological activity through mental activity. Change in the desired direction is presumed to be reinforcing and the basis for establishment of control of the physiological function. Children generally have no difficulty learning an appropriate strategy to produce the desired response (Werder & Sargent, 1984).

Relaxation techniques take several forms, including meditative breathing (Benson, 1975), progressive muscle relaxation (Jacobson, 1938), and autogenic training (Schultz & Luthe, 1969). All these procedures specify four basic elements: (1) a mental device similar to a mantra to aid concentration, (2) a passive attitude, (3) decreased muscle tension and awareness of other sensations (e.g., warmth or numbness), and (4) a comfortable resting position in a quiet environment.

Thermal biofeedback combined with autogenic phrases and electromyographic (EMG) biofeedback combined with progressive muscle relaxation have been employed to treat pediatric migraine. The first approach teaches the patient to concentrate on repeated phrases that describe a heaviness in the limbs, a sense of warmth on the limbs and abdomen, control of heart rate, and cooling of the forehead (Schultz & Luthe, 1969). We have found that children often respond more readily when concrete visual images are employed, such as warming their hands before a fire or feeling a cool breeze across their forehead. Simultaneously, the patient is provided with analogue feedback of the finger temperature and is instructed to try to increase it gradually. At first, it was thought that learning to increase surface skin temperature corresponded to a shunting of cerebral blood flow to the periphery, creating the potential to abort a migraine attack before it is established. However, this hypothesis has given way to one that supposes a general sympatholytic effect of the relaxation response that reduces the risk of a migraine attack (Hoffman, Benson, Arns, Stainbrook, Landsberg, Young, & Gill, 1982).

The second approach combines instructions to the patient to reduce muscle tension systematically in various body regions while being provided with analogue feedback of EMG activity typically recorded from a forehead site. Originally, it was presumed that this approach would be most beneficial for patients suffering from muscle-contraction headache. However, recent studies indicate that EMG biofeedback plus relaxation training is highly effective for pediatric migraine (Mehegan, Masek, Harrison, Russo, & Leviton, 1987; Fentress, Masek, Mehegan, & Benson, 1986). Moreover, it has been argued that facial muscle hyperactivity is a prominent symptom both before and during a migraine attack (Pickoff, 1984).

Substantial evidence for the efficacy of biofeedback and relaxation training for the treatment of pediatric migraine comes from four recent controlled investigations (Labbe & Williamson, 1984; Fentress, Masck, Mehegan, & Benson 1986; Larsson & Melin, 1986; Richter *et al.*, 1986). Labbe and Williamson (1984) found that adolescents receiving thermal feedback and autogenic relaxation training reported significantly fewer headaches than did a waiting-list control group. Similarly, Fentress *et al.* (1986) reported that elementary school age children provided relaxation training alone or in combination with EMG biofeedback were significantly improved at the end of treatment, while the waiting-list control subjects were unchanged. The other two studies employed attention placebo-control groups and found that nonspecific or placebo factors did not result in significant headache improvement, while the active treatments of cognitive restructuring or progressive muscle relaxation resulted in significant improvement in children aged 9–18 years (Larsson & Melin, 1986; Richter *et al.*, 1986).

In summary, the pediatric treatment literature of the past decade has documented the efficacy of the biobehavioral approach to the treatment of childhood headache disorders. These positive findings parallel the treatment results reported in the adult headache literature. Collectively, this research suggests that children can benefit from treatment (1) as young as 6 years of age, (2) whether or not they are taking prophylactic medication for migraine, and (3) in the normal range of intelligence. Still unanswered are questions about the relative effectiveness of biobehavioral procedures for the various subtypes of pediatric migraine, and about the effectiveness of biobehavioral intervention for severe forms of these diagnostic subtypes.

Clinical Issues

Consideration of a child for biobehavioral treatment proceeds only after the headache problem has been investigated by qualified medical personnel, preferably a pediatric neurologist. Migraine must be distinguished from several other categories of headache, including nonmigrainous vascular headache caused by fever, convulsive states, or hypoxia; traction headache caused by brain tumor, subdural hematoma, or arteriovenous malformation; headache related to a sinus condition, visual refractive error, or temporomandibular joint dysfunction; and headache as a manifestation of primary psychopathology (e.g., childhood depression). The headache history and neurological examination provide the central diagnostic information in this regard. Additional diagnostic workup may include a computed tomography (CT) scan, electroencephalogram (EEG), or lumbar puncture, but these tests are neither routinely indicated nor necessary to confirm the diagnosis of migraine (Barlow, 1984).

Assuming that a referral has been made from a qualified medical specialist, the next step is to interview the patient with a parent present. It is important to hear first hand a description of the character of the headache, its frequency and severity, a description of the pain and its location, the temporal aspects of the headache such as time of onset and duration, and other associated symptoms. When reviewing possible associated physical manifestations, an inquiry should be made about autonomic symptoms, such as pallor, nausea, vomiting, and abdominal pain, and about neurologic deficits, such as photophobia, sonophobia, muscle weakness, or speech difficulty (Shinnar & D'Souza, 1981). Suspected precipitants of migraine attacks should be investigated. Common precipitants in children are sleep deprivation, a long interval between meals, anticipation of an event, fear of failure (usually about schoolwork), and anxiety about social situations. Past efforts to treat the headache problem should be described.

Finally, there should be some questioning about the consequences of headache for the child and family, particularly whether social reinforcement or avoidance of unpleasant circumstances are factors serving to maintain headaches. To evaluate the possible role of avoidance or attention, information should be obtained on school attendance patterns, parental response to pain behavior, and whether participation in valued activities is affected by headache activity.

Assessment of the headache problem should be ongoing. It is important that the child keep a headache diary from the time of the initial interview. Parents should be as minimally involved in this process as possible. In the Behavioral Medicine Clinic at the Children's Hospital, we have been using a simple one-page form for the past 8 years on which the children record severity, duration, medication, antecedent events (if any), and consequences of their headache. One week's worth of information can be recorded. The diaries are typically discussed at the beginning of each treatment session. Noncompliance with the diary request is usually best handled as a matter between the therapist and the child. Parents are called upon most often to validate diary information. Sometimes it is not critical to the success of treatment for the child to keep a diary because the headaches occur either infrequently or very predictably. In other instances, a simplified version will suffice. In cases in which diary information is critical to the treatment effort, it is sometimes suggested that treatment be delayed until the child is in a better position to cooperate. The benefits to the use of a headache diary are that it yields more objective and reliable information than a global self-report, it documents variations and patterns in headache activity, and it is sensitive to treatment effects.

The average length of treatment in our clinic is seven sessions (not including the initial evaluation), extending over a period of 10–12 weeks. The first four or five appointments are weekly, and the remaining appointments are 2–4 weeks apart, depending on how much improvement is shown. A follow-up session 2–3 months after treatment has ended is very important to reinforce maintenance of the effective elements of the intervention. Written feedback is provided to the referring physician after the initial evaluation and after the last treatment session or follow-up appointment. If questions arise about medical management of the headache problem during the course of treatment, patients are instructed to consult their physician. A situation that occurs frequently in this regard is whether the patient should continue taking a medication that does not help or that no longer appears to be necessary because the biobehavioral treatment is working. The answer may seem obvious to the therapist, but it is not within his or her purview to make a recommendation directly to the patient.

In the first few sessions, children are exposed to several relaxation techniques (e.g., meditative breathing, progressive muscle relaxation, and imagery). A cassette tape recording of the relaxation procedure with which the child is most comfortable is made by the therapist as the child is rehearsing the procedure. The tape is usually 7–10 min in length, addresses the child by name, and includes personal material about the child's headache problem. A daily practice time for rehearsal of the relaxation procedure is established with the child and parents in an effort to facilitate compliance. Occasionally, it is helpful to have the parents provide social reinforcement to the child for relaxation practice. In subsequent treatment sessions, the goal is to encourage the child to use a briefer simplified relaxation strategy at various times during the day. The child is also taught how to identify psychosocial stressors and to use the relaxation response to moderate arousal.

Children are also exposed to biofeedback training in the first session. Sensors are taped to the index and middle fingers of one hand to record skin temperature and heart rate. A disposable surface electrode is placed on the forehead to record EMG activity from facial muscles. Parents are usually present for the first session to help the child feel more comfortable with the equipment. Most children receive 15–20 min of biofeedback training per session. Frontal EMG is the parameter most commonly used because of the ease with which children can learn to produce the desired response (i.e., a decrease in EMG activity). We view biofeedback training as a useful clinical tool in the treatment of headache to facilitate learning of the relaxation response and to provide a mastery experience for the child.

Our treatment experience with pediatric headache disorders involves more than 500 children between 6 and 16 years of age. The vast majority have had some form of migraine. Controlled investigations of smaller samples drawn from this patient population suggest that the clinical approach outlined above results in clinically significant improvement in 80% of cases.

CASE ILLUSTRATIONS

Case 1

C. was 6½ years old when he was referred by his pediatrician for treatment. His first migraine attack occurred when he was 3 years old. The headache was described as a throbbing pain located above both eyes, usually accompanied by nausea and vomiting. Before a headache began, his cheeks became flushed and his eyes filled with water. There was positive history of migraine in a maternal grandmother and aunt. He rarely missed school because of migraine. The only pattern identified was that headaches occurred when there was a lot to do at home in preparation for a family activity. Headaches were managed with aspirin and rest. Phenobarbital was tried for 6 months but was discontinued just before treatment because it made him "hyper," according to his mother, and the effect on his headaches was minimal.

Four weeks of headache diaries collected prior to the start of treatment indicated that C. averaged two headaches per week; they were characterized as "severe," lasted 1–2 hr, and started at the end of the school day, before dinner or late Saturday morning. C. was seen for a total of 10 treatment sessions. Frontal EMG activity was initially quite high, but after six sessions he was unable to decrease EMG activity during biofeedback training or when he was practicing his relaxation techniques. He chose for his relaxation technique a combination of meditational relaxation and guided imagery, and he elected not to practice listening to a tape recording of the procedure. Not surprisingly, he often forgot to practice.

After five treatment sessions, there was no improvement in C's headache pattern. On the sixth session, he was taught progressive muscle relaxation, and the procedure was tape-recorded. He agreed to practice with the tape once a day in exchange for 10 min of computer game time at the end of the session. Biofeedback training was shifted to finger-temperature feedback, in which the task is to increase skin temperature. These changes in treatment resulted in a significant decrease in headache activity over the next four sessions. He practiced the relaxation technique regularly and demonstrated the ability to increase finger temperature reliably in the biofeedback laboratory. His headache diary for the last 4 weeks of treatment indicted only three headaches rated "mild" that averaged 30 min. Follow-up sessions 3 and 6 months after treatment ended indicated that he had maintained the improvement by listening to the relaxation tape three or four times per week. Furthermore, his mother reported that he began to practice relaxation without the tape when he noticed he was getting overly excited or when he felt flush and his eyes were watery. She felt that he had avoided a migraine on several occasions in this way.

Case 2

J. was referred at age 11 years for treatment of recurrent headaches. His family history was positive for migraine. A neurological examination, including an EEG and CT scan, was normal. He first began experiencing headaches at 7 years of age. He described the headache as a sharp, pinching pain located in the left temple. He reported no symptoms associated with the pain. The typical headache lasted about 2 hours and occurred at least twice a week. J. was seldom allowed to miss school because of a headache. Resting and aspirin were reported to bring moderate relief. Other medical concerns included recurrent ear infections, asthma, and attention-deficit disorder. At the time of the referral, J. was taking Ritalin for his attentional problems.

J.'s parents were separated when he was 7 years old and divorced when he was 9 years old. J. lives with his mother and older sister. He visits his father on the weekends. J.'s mother reported that her son's headaches began shortly before the separation and occurred more frequently during times of overt marital conflict.

Treatment of J.'s headaches followed the standard protocol of self-monitoring of headache symptoms, patterns, and precipitants via the headache diary, as well as frontal EMG biofeedback training, and instruction in progressive muscle and meditational relaxation techniques. Over the course of seven sessions in a span of 11 weeks, J. reported fewer headaches. For the last 4 weeks of treatment, he reported no headache symptoms, which pleased both parents tremendously. Follow-up at 6 months indicated one headache in 4 weeks.

Toward the end of treatment, J.'s mood became increasingly dysphoric, his behavior at school was more agitated and disruptive, and some suicidal ideation was expressed. Simultaneous with this was an increase in family strife, and J. began to speak more openly about his anger and confusion regarding his parents' marital problems. As his headaches lessened in frequency, communicating to his parents via pain behavior to stop arguing became less operational. A referral was made for J. and his family to become involved in individual and family counseling. J. was treated pharmacologically for depression.

Following 6 months of family therapy, J. was able to express his concerns in a healthy adaptive manner. J.'s parents learned to abide by ground rules when the three of them were together, to avoid conflict. J.'s school performance was described as much improved. At the conclusion of family therapy, J.'s headaches were still in remission.

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CHAPTER 7

Eating Disorders

Food Refusal and Failure to Thrive

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INTRODUCTION

Eating disorders in children and adolescents are commonly encountered in pediatric inpatient and outpatient settings and are sources of frequent parental concern. This chapter discusses two such problems: food refusal and failure to thrive. Both problems generally involve deficits in appropriate eating or weight gain and can lead to numerous medical complications. Failure to thrive and food refusal have been distinguished from one another in the literature and do in fact often differ with regard to topography and factors contributing to the maintenance of problem behavior. This chapter, however, highlights the similarities of the two disorders and suggests that a behavior analytic model of assessment is applicable to both. The practical advantages of such a model are discussed and illustrated through case examples.

FOOD REFUSAL

Description

Food refusal in children is characterized by insistance on eating only a small number of foods, only foods with a given texture, or an amount of food insufficient to maintain appropriate weight gain (Kreiger, 1982; Williamson, Kelley, Cavell, & Prather, 1987a). The problem often begins with the introduction of a

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new food texture, such as when the child is switched from pureed to solid foods or following intervals of restricted eating due to illness or surgery (Siegel, 1983). Children's restricted eating frequently is accompanied by other behavioral problems, such as mealtime dawdling, throwing a tantrum, spitting, gagging, or protracted periods of chewing (Williamson *et al.*, 1987).

Eating problems are a common concern of parents with as many as 45% of all preschool children exhibiting some degree of eating or mealtime behavior problems (Bentovim, 1970; Hertzler, 1983a, 1983b). Serious disturbances in eating are more common in developmentally and physically disabled children than in the general population (Riordan, Iwata, Finney, Wohl, & Stanley, 1984).

The consequences of food refusal generally vary with the severity of the problem. Relatively mild instances of food refusal may be accompanied by aversive parent and child interactions during mealtime and parental distress over the problem (Hertzler, 1983a,b). Severe cases of food refusal may produce social isolation, significant family conflict, and numerous medical complications associated with malnourishment (Williamson, Prather, Heffer, & Kelley, 1988). Pediatricians frequently offer as consolation to parents the fact that many children apparently outgrow restricted eating patterns. Such spontaneous remitting of problem eating cannot be assumed, however. For example, in two adolescent males with whom we are familiar, very restricted eating patterns that developed in childhood continued to persist in a manner that produced numerous psychological and medical complications.

Assessment

Numerous studies have been conducted in which children's food refusal was conceptualized and treated from a behavior analytic perspective (e.g., Bernal, 1972; Riordan, Iwata, Finney, Wohl, & Stanley, 1984). However, typical applications of behavioral assessment have not emphasized the complex interplay between biological, behavioral, and environmental variables that often are operating in the development and maintenance of eating disorders (Palmer, Thompson, & Linscheid, 1981). For example, numerous medical problems may contribute to the development of feeding disorders. The behavior analytic model shown in Fig. 1 is proposed, therefore, as a heuristic for guiding the multidisciplinary assessment and treatment of children's eating disorders. (This model was first presented by Kelley & Drabman, [in press].) As shown in Fig. 1, behavioral, environmental, and biological variables can contribute to the maintenance of inappropriate eating. In addition, the model emphasizes the influence of setting events on subsequent stimulus–response interactions. In many instances, disease or medical conditions that influence feeding interactions might be conceptualized as setting events. Other setting events that may prove relevant to children's inappropriate eating and ineffectual family interactions during mealtime include maternal depression or isolation (Wahler, 1980). Models similar to the one shown in Fig. 1 have been proprosed elsewhere (Bijou & Baer, 1978; Redd & Rusch, 1985).

The biological–behavioral model proprosed in Fig. 1 suggests an idi-

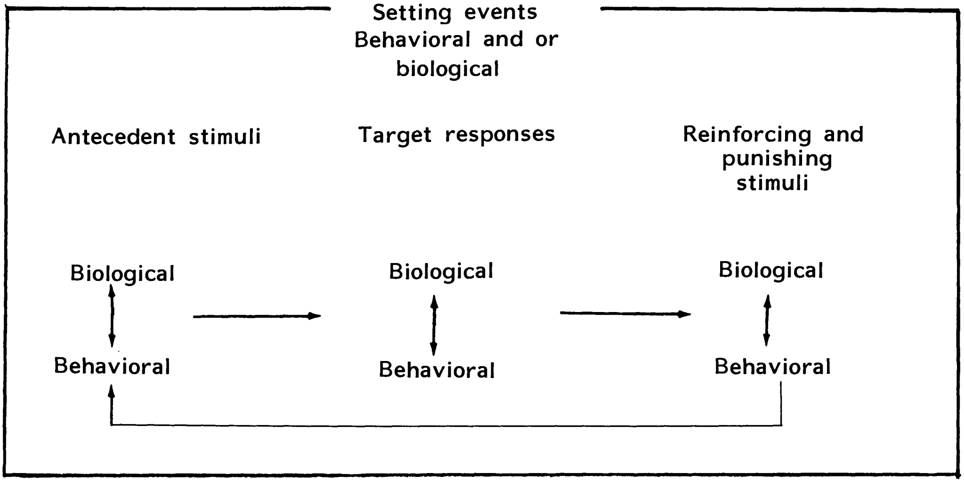

FIGURE 1. Behavioral analytic model.

ographic, multidisciplinary approach to the assessment of food refusal. Although minor problems of food refusal often are maintained primarily by environmental variables, initial assessment efforts should be multidisciplinary. The comprehensiveness of the assessment will depend on the severity of the child's eating problems. However, a medical evaluation typically is obtained prior to treatment as numerous physical problems can contribute to children's restricted eating. The child's developmental, medical, and dietary history should be ascertained through interviewing parents and other important caretakers. The interviewer should obtain very detailed and specific information on the topography of the child's eating and factors associated with the onset of restricted eating. It also is helpful to assess what specific attempts have been made to increase appropriate eating. Krieger (1982) developed an eating questionnaire that can be a useful interview aid. The questionnaire is used to gather information on types of foods eaten by the child, eating skills, and parents' reactions to the child's mealtime behavior.

Observational assessment of parent–child interactions during mealtime is important to generating an accurate functional analysis of the contingencies maintaining inappropriate eating (Williamson *et al.*, 1987). Although observational assessment may be impractical or unnecessary in assessing minor mealtime problems such as picky eating or dawdling during meals, it is essential with children whose eating patterns significantly deviate from the norm. Videotaping rather than directly observing mealtime behavior is preferred in that the former is less intrusive, allows for the intensive study of interaction patterns, and can be reviewed by parents during treatment. Ideally, several observational sessions should be conducted in order to vary mealtime, types of foods offered to the child, and caretakers.

It is important to obtain accurate information on the amount and types of foods eaten by the child each day as well as to document relevant situational variables (e.g., who fed the child, time of meal). This can be accomplished in a number of ways but may include monitoring of the number of bites eaten by the child, type of food, the child's response to bite presentation, and parental consequences (Riordan *et al.,* 1984).

The assessment of family demographics, family and marital conflict, and maternal and child psychopathology also may yield information important to the selection of effective treatments (Williamson *et al.,* 1988). For example, if significant levels of child noncompliance or family distress are present, a narrow focus on the child's eating behavior may prove ineffective. Maternal depression or isolation also may impede satisfactory treatment progress. Information regarding family psychopathology or distress must be obtained in a sensitive manner as many parents may be offended by the implication that their child's eating disorder is influenced by such factors.

Treatment

Treatment of food refusal should be individualized and tailored to the specific behavioral, biological, and environmental excesses and deficits maintaining inappropriate eating (Palmer, Thompson, & Linscheid, 1981). Treatment decisions should be guided by the physical status of the child, the degree to which the child's eating deviates from the norm, family resources for remediating the problem, and parental expectations for treatment. Severe cases of food refusal or cases in which parents are judged to be unable or unwilling to initiate treatment often are best treated in the hospital. Hospitalized children often are initially treated by trained staff members, with control over treatment transferred to parents only after improvements in eating have been obtained (Linscheid, Oliver, Blyler, & Palmer, 1978)

Severe cases of food refusal can be quite difficult to treat and require a carefully executed intervention. More minor problems, however, that are common to many preschoolers, often can be remediated through parent education and simple modification of the mealtime routine (Christophersen & Hall, 1978). As such, parent education strategies for modifying minor mealtime problems are discussed next, followed by procedures commonly employed for remediating severe cases of food refusal.

Prevention and Treatment of Minor Mealtime Problems

Christophersen and colleagues (Christophersen, 1982; Christophersen & Hall, 1978) provided detailed guidelines and parent handouts for modifying mealtime problems, such as dawdling, picky eating, and noncompliance. For example, Christophersen and Hall (1978) emphasize the importance of introducing new food textures at the appropriate age and to avoid backtracking once a new food substance has been introduced. It is also important to provide parents with developmental and nutritional information to ensure that they have age-appropriate expectations of their children.

Christophersen and Hall (1978) also recommend that parents structure the mealtime routine and their children's opportunities to eat. Meals should be distinguished from play time and be used as an opportunity to shape appropriate mealtime behavior. Children should be offered a variety of foods but should not be expected to eat all foods offered. Parents should maintain some flexibility with regard to their children's food preferences because children's likes and dislikes frequently vary from day to day. Children should not be allowed to eat only a small number of preferred foods, nor should they be allowed to snack between meals if their intake during the previous meal was insufficient. (A more detailed list of guidelines are presented in Christophersen & Hall, 1978.)

Mealtimes often are one of the first situations in which parents encounter a good deal of inappropriate behavior and child resistance to their attempts to establish mealtime rules. Given these considerations and the importance parents often place on establishing appropriate eating, teaching parents procedures for modifying minor mealtime problems can be an excellent opportunity to introduce parenting skills in a pediatric setting. By focusing on mealtime behavior, parents can be quickly taught to use contingency management procedures with young children. Teaching can be expedited through the use of handouts that address specific mealtime problems (Christophersen & Hall, 1978; Kelley & Drabman, in press). Given that the situation is time limited, yet offers many opportunities to shape appropriate behavior, parents can practice an array of skills applied to a very discreet situation. For example, we have taught parents to effectively increase tasting new foods through their use of differential attention and star charts. Inappropriate behavior such as throwing a tantrum, crying, or playing with food often is easily corrected through the contingent, brief removal of the child's plate or placement of the child in timeout. In addition, these basic parenting skills applied to mealtime routines can be easily taught to pediatricians who routinely encounter parent questions about eating and other mealtime problems (Kelley & Drabman, in press).

Operant Conditioning Procedures

Severe cases of food refusal generally are modified through the highly structured use of differential attention and shaping procedures. Use of these procedures have been effective in increasing the amount and type of foods eaten in both developmentally disabled and normal children (e.g., Bernal, 1972; Linscheid *et al.*, 1978; Riordan *et al.*, 1984; Riordan, Iwata, Wohl, & Finney, 1980; Thompson, Palmer, & Linscheid, 1977).

Intervention planning should be conducted in a multidisciplinary fashion (Williamson *et al.*, 1988). In doing so, information concerning the child's physical and developmental status, eating skills, and nutritional needs can be considered and thus, increase the likelihood that an appropriate intervention with the fewest negative side effects is initiated. For example, we have found the input of physical therapists skilled in evaluating children's eating capabilities to be an invaluable source of information. Nutritionists and dieticians can suggest methods for increasing caloric intake without increasing amount of intake.

Treatment for children whose eating behavior deviates significantly from the norm often begins by severely restricting their opportunities to eat preferred foods (Linscheid *et al.,* 1978; Riordan *et al.,* 1984). Often this is most easily accomplished in a hospital setting where medical personnel can monitor the child's physical status and provide medical care when deemed appropriate. Treatment aimed at increasing the intake of nonpreferred foods generally has involved the use of shaping procedures in which the child is offered a specific number of bites of foods during a single meal (Riordan *et al.,* 1984). With young children, prompts to eat may involve the presentation of a food substance on the end of a spoon and a verbal cue to eat. With older children, food presentation may be less formal and allow for self-feeding. Typically, the child is offered foods judged to be the least aversive of the nonpreferred foods, such as those the child may occasionally taste. Often foods that are bland, such as cereals are more likely to be eaten than foods with strong tastes (Hertzler, 1983a). With children who do not eat solid foods, it may be important to avoid introducing new textures and new tastes simultaneously. Instead, eating foods with new textures can be shaped through incremental changes in the consistency of a given food (Palmer *et al.,* 1981).

Reinforcement of appropriate eating often occurs after each bite during initial treatment phases. Reinforcement often involves providing enthusiastic verbal acknowledgment of the behavior and offering the child a bite or drink of a preferred food. This also may function to decrease the likelihood that the child will spit out the nonpreferred food (Riordan *et al.,* 1984). In addition, brief periods of toy play accompanied by praise also has been used effectively. Reinforcement occurs less frequently after appropriate eating has been established.

Consequences for refusal to eat a nonpreferred food or for engaging in inappropriate behavior, such as spitting or crying, usually have involved briefly ignoring the child (Bernal, 1972; Thompson, 1977). Some investigators have placed the child in time out for throwing a tantrum or for refusing to eat a sufficient amount during the meal (Linscheid *et al.,* 1978). Physical restraint is sometimes used to interrupt a response sequence shown to lead to gagging or spitting.

Because children often behave in a highly disruptive fashion in order to terminate the meal, it may be necessary to initiate treatment without the parent's assistance as they may find the procedure too difficult to administer. When parents are introduced to the feeding situation they should be carefully coached in the use of the procedures.

Classical and Operant Conditioning Procedures

Siegel (1982) successfully treated a 6-year-old boy's food refusal through the combined use of classical and operant conditioning procedures. In this study, respondent procedures were employed after a contingency management program failed to produce changes in the boy's eating. The child frequently gagged whenever he attempted to taste a new food. Because the behavior was considered respondent in nature the child was instructed to first smell aversive foods and then instructed to chew, taste, and swallow the foods in a gradual, incremental fashion. In order to decrease physiological responding to the aversive foods, the child was allowed to watch TV while engaging in the target responses. The program was effective in increasing the child's eating of nonpreferred foods.

Practical Considerations

Often, numerous practical problems must be considered in order to treat children effectively when eating behavior is life-threatening and/or significantly deviates from the norm. One of the most important obstacles to successful treatment can be the coordination of a multidisciplinary team in a busy pediatric setting. Treating these children often is very labor intensive. Medical personnel unfamiliar with the logistics of behavioral interventions often are perplexed by the amount of time and effort required to establish significant treatment gains. The team members should be made aware of the intensity and length of the treatment prior to initiating an intervention.

Another obstacle is the host of family and maternal problems (i.e., setting events) that sometimes accompanies children's food refusal. As we serve primarily low-income families, the stress of poverty appears to produce numerous obstacles to the effective administration of treatment techniques once the child leaves the hospital. The problems must be carefully and sensitively addressed in order to ensure treatment maintenance. For example, we have sometimes found it necessary to assist parents in obtaining social services in order to increase the availability of food in the home. In families of varying income levels, mothers are sometimes excessively preoccupied with their children's eating in ways that appear to reduce their enjoyment of their children. Problems of depression or isolation sometimes interfere with the mother's ability to carry out the intervention.

The use of contingency management procedures may sometimes prove ineffective (Siegel, 1982). Likewise, the procedures may be judged to be unacceptable to parents irrespective of their potential effectiveness. For example, we encountered a situation where prompts to eat appeared to serve as a discriminative stimulus for disruptive behavior (Heffer, Cavell, Kelley, Fishbein, & Drumm, 1985). In addition, the mother, who for practical considerations was responsible for implementing the treatment, found the use of operant conditioning procedures to be too aversive to implement. Consequently, we modified the treatment by increasing our focus on antecedent conditions that functioned to increase eating. Prompts to eat and discussion about eating were replaced with alternative mealtime conversation. The treatment was associated with increased eating and minimal disruptiveness.

Case Illustration

Bill was a 2-year-old boy hospitalized for his lack of eating an amount of food sufficient to produce appropriate weight gain. He lived with his unemployed parents and an older and younger sibling. Bill's cognitive and motor development were within normal limits. Reportedly, he had a history of frequent vomiting after meals and of being difficult to feed. According to the parents, the vomiting subsided 4 months before admission when the mother discontinued feeding Bill foods that assumedly occassioned vomiting and feeding difficulties.

Observational data indicated high rates of aversive parent and child interactions during mealtime. The parents appeared to hurry meals with little regard for their son's chewing and swallowing. For example, they frequently held their son's chin in order to insert bites into his mouth without noticing whether or not he had finished a previous bite. This behavior often resulted in the child screaming, placing his hands in front of his mouth, and turning away from the fork. His mother reported that feeding her child was highly aversive. In addition, his mother reported experiencing a good deal of stress due to the family's financial situation. She also had few sources of social support.

Treatment involved increasing positive mealtime interactions between parent and child. Initial treatment efforts involved our staff feeding the child with the parents observing. Thoughout treatment, the parents' active involvement in generating solutions to problem behavior, such as ways to reduce messiness and allow the child to feed himself, were encouraged. Based on these discussions and the parents' observation of positive therapist–child interactions, the parents were instructed in methods for allowing the child to feed himself and to differentially attend to his behavior during the meal. For example, they were encouraged to present him with small bites on his tray and to present only a small amount of food. Because the child's messiness was highly aversive to the mother, she was instructed in various strategies for preventing spills and informed about age appropriate mealtime behavior. Through the use of instruction, modeling, and feedback, the parents were taught to reinforce appropriate mealtime behavior in a variety of ways and to engage in child-oriented mealtime conversation. In addition, the parents were encouraged to discuss other sources of stress. During later outpatient sessions, methods of increasing social support and alleviating financial and other sources of stress were generated with the parents by means of a problem-solving therapeutic approach. Treatment resulted in the child's increased intake and weight gain as well as a reduction in family distress.

FAILURE TO THRIVE

Description

Failure to thrive (FTT) is a potentially life-threatening pediatric problem that affects approximately 1% of hospitalized children (Schor, 1984). According to English (1978), FTT is a descriptive term, rather than a diagnostic category, used to identify children whose weight for age is persistently below the 3rd to 5th percentile (Hamill, Drizd, Johnson, Reed, & Roche, 1976). FTT also is indicated when an established pattern of weight gain is not maintained, such as when a child's weight drops two or more major percentiles (e.g., 50th, 25th, 10th, 5th) on a standardized growth curve. Considerable confusion with regard to the definition and conceptualization of FTT has plagued empirical efforts for quite some time (Smith & Berenberg, 1970; Casey, 1987). Simply stated, however, FTT may be referred to as failure to gain weight (Gotlin, 1984; Stickler, 1984).

In approximately 80% of cases, FTT presents in infants and toddlers younger than 18 months of age (Bithoney & Rathbun, 1983). Although almost all serious pediatric illnesses may result in FTT (Bacon, Spencer, Hopwood, & Kelch, 1982), suboptimal weight gain also may be attributed to psychosocial variables, such as parental abuse, neglect, or emotional deprivation; conditions of impoverishment; an irritable or passive infant; parental psychopathology; and/or feeding problems (Roberts & Maddux, 1982). FTT has traditionally been subgrouped into two mutually exclusive categories: (1) organic FTT (OFTT), and (2) nonorganic FTT (NOFTT). In OFTT, a physical disorder is identified as a contributor to poor weight gain; in NOFTT, organic causes are ruled out.

Many investigators have found a dichotomous categorization of FTT to be insufficient to explain the plethora of possibilities for inadequate weight gain in young children (Accardo, 1982). Indeed, physical, behavioral, and environmental variables often interact to produce a given level of weight gain or loss in children (Bithoney & Dubowitz, 1985; Frank, 1985). In addition to OFTT and NOFTT categories, Homer and Lugwig (1981) offered a mixed category for FTT, in which both organic and nonorganic deficits contribute to poor weight gain. Whether an organic, nonorganic, or mixed/interactional etiology for inappropriate weight gain is identified, FTT is a health-threatening problem of undernutrition in young children (Bithoney & Dubowitz, 1985).

Like Linscheid and Rasnake (1985), we find it useful to conceptualize FTT, especially NOFTT, as a specialized problem of food refusal. In contrast to the general problem of food refusal, however, NOFTT typically presents in infants and toddlers aged three years and younger (Bacon, Spencer, Hopwood, & Kelch, 1982) and is clearly linked to increased health problems and to developmental delays (Galler, Ramsey, & Solimano, 1985; Singer & Fagan, 1984).

Assessment

Chronic undernutrition in FTT may result from a multitude of medical difficulties, such as neurological, gastrointestinal, endocrine, pulmonary, renal, or metabolic disorders (Bacon *et al.*, 1982), as well as psychosocial (i.e., nonorganic) problems. Nonorganic variables, such as situational variables (e.g., poverty, stress, isolation), behavioral deficits of child or parent, and dysfunctional parent–child interactions, particularly feeding interactions, often are identified contributors to FTT (Heffer & Kelley, in press). The biological–behavioral model discussed previously in this chapter, therefore, is an effective guide for the assessment of FTT.

The application of the model presented in Table 1 to the assessment of FTT represents a clear departure from traditional approaches. The idiographic assessment approach emphasized in behavior analysis suggests that categorization of these infants (e.g., OFTT, NOFTT) is unnecessary. Instead, the model views behavior analysis as a theoretical perspective that can incorporate both medical and psychological variables. Traditional approaches to FTT have viewed the assessment of psychological variables as a separate diagnostic tool that accompanies medical approaches.

The advantages of a behavior analytic approach to the assessment of FTT might be best illustrated through an example. In many instances, an infant's lack of appropriate weight gain may be caused to a large extent by medical problems. These medical problems could be conceptualized as setting events that influence subsequent feeding interactions. Assuming that the effect of these biological variables is to increase the likelihood of coercive interactions between parent and child during meals, remediation of these problems may or may not be sufficient to produce effective mealtime interactions.

Given that behavioral, environmental, and biological variables often interact to produce inappropriate weight gain (Singer, 1987), assessment of FTT should be multidisciplinary (Peterson, Washington, & Rathbun, 1984). When an initial diagnosis of FTT is made, physicians typically assess an infant's health status by means of a physical examination, laboratory tests, family growth patterns, medical history of the infant (e.g., course of pregnancy, perinatal events, history of development, illnesses, and weight gain), and current anthropometrics (i.e., weight, height, and head circumference). Nutritionists and dieticians are especially qualified to obtain a nutritional history for the infant, to assess current nutritional requirements, and to monitor food intake during hospitalization. Information with regard to family size, income, living conditions, and resources is crucial to an assessment of FTT (Drotar, Nowak, Malone, Eckerle, & Negray, 1985; Frank, Allen, & Brown, 1985). An evaluation of structural or movement deficits that contribute to inadequate food intake may be obtained from occupational or physical therapists. Psychologists frequently are consulted to obtain data regarding the infant's developmental status, temperament, family psychopathology, and parent–infant interactions during feeding and nonfeeding situations.

Much of the information provided previously in this chapter with regard to evaluating food refusal in young children is directly applicable to assessing behavioral and environmental components of FTT in infants and toddlers. For example, we have used the eating questionnaire developed by Krieger (1982) as a guide for interviews with parents of FTT infants.

Information regarding the infant's prenatal history may be obtained from the medical chart and from an interview with the mother. In addition, a history of medical complications experienced by the infant after birth should also be gathered. The Obstetric Complications Scale and the Postnatal Complications Scale may be used to quantify information about perinatal events (Littman & Parmalee, 1978). Perinatal and medical information obtained via an interview should be verified through medical records when possible because parents may be unreliable historians (Simons, Ritchie, Mullett, & Liechty, 1986).

A FTT infant's developmental status may be determined by the use of standardized screening instruments, such as the Minnesota Child Development Inventory (Ireton & Thwing, 1974) or the Denver Developmental Screening Test (Frankenburg, Dodds, Fandl, Kazuk, & Cohrs, 1975). One drawback to the use of screening tests, however, is that many rely solely on parental report. In contrast, a more objective and thorough developmental assessment may be obtained through administration of the Bayley Scales of Infant Development (Bayley, 1969).

Family psychopathology or distress also may contribute to problems associated with FTT and, therefore, should be assessed thoroughly. Parents may be asked to complete the SCL-90-R (Payne, 1985), a 90-item self-report inventory of adult adjustment and psychopathology, or other instruments specifically designed to screen for depression or anxiety. In addition, parents' knowledge of normal child development, special medical conditions, and nutritional requirements should be evaluated with regard to the appropriateness of expectations and caretaking behavior. Finally, parental perceptions of infant behavior and temperament are especially relevant to an assessment of FTT and may be obtained by means of the Infant Temperament Questionnaire (ITQ; Carey & McDevitt, 1978) or the Toddler Temperament Scale (TTS; Fullard, McDevitt, & Carey, 1984). The ITQ and the TTS provide the caretaker's perceptions of infant behavior across several situations, such as sleeping, feeding, bathing, and reactions to new people.

Behavioral observations of parent–infant feeding interactions are vital to a comprehensive assessment of FTT because they can provide specific targets for treatment (Heffer & Kelley, in press). Behavioral observations yield data important to the functional analysis of feeding problems. Without obtaining these data, feeding interaction problems, such as episodes of forced feeding or an exceptionally passive infant, may go undetected.

Observations of infants and caretakers in nonfeeding situations (e.g., play) also may yield valuable data regarding the general interactional patterns of both members of the dyad (Alfasi, 1982; Gordon & Jameson, 1979). Adult behavior, such as responsivity to infant cues; ability to elicit alertness from, and to comfort, the infant; and the extent to which the infant is provided with a variety of sensory experiences may be evaluated in this fashion. Passivity or fussiness on the part of the infant may be noted through observations of nonfeeding interactions. Follow-up interviews with the caretaker may reveal information of the frequency and perceived quality of general parent–infant interactions at home.

Treatment

When an organic problem is identified as a primary cause of FTT, treatment follows the medical protocol appropriate for the disorder(s) diagnosed. Although some professionals may consider medical management of OFTT sufficient, Bithoney and Dubowitz (1985) noted that behavioral and environmental components of weight loss exist even in cases of FTT in which an organic etiology is identified. Likewise, NOFTT infants ultimately become vulnerable to physical disorders due to inadequate nutrition (Frank, 1985). Treatment of FTT should therefore be multimodal and idiographic. For example, physicians and specialized consultants should work collaboratively beginning within hours of a FTT infant's hospital admission to formulate an individualized treatment plan (Berkowitz, 1985).

Feeding Problems

Because we conceptualize FTT as a specialized case of food refusal, the operant and respondent treatment approaches described previously are pertinent to treatment. Special care may need to be given, however, in the implementation of such procedures in cases in which physical disorders are the central feature of FTT. For example, because of severe malnutrition or complications of a disease process, nonoral feeding methods (e.g., NG tube) may be necessary. Thus, observation of feeding interactions and the use of specific strategies to alter maladaptive feeding and eating must be postponed. Treatment planning should continue, nonetheless, in other areas (e.g., family ecology, caretaker education) associated with the poor weight gain.

When the infant is medically able to be assessed developmentally and behaviorally, intervention should proceed by focusing on specific parent and infant behavior excesses and deficits, for example, a parent's sensitivity to behavioral cues from the infant during feeding interactions (Satter, 1986) or an infant's gagging or expelling food may be targets in treatment. We have found that by developing treatment plans directly from a thorough biobehavioral assessment and by allowing ongoing data collection to guide the process of treatment, inappropriate or ineffective behavioral treatments of feeding disturbances can be avoided.

Poverty and Lack of Education

In addition to treating feeding problems in FTT, other variables associated with poor weight gain should be addressed. If parents lack parenting skills or have inadequate resources to care properly for their FTT infant, education, financial assistance, and access to nutritious foods should be arranged (Gordon & Vazquez, 1985).

The association of poor caretaking information and poverty with poor infant weight gain was exemplified by a 19-year-old mother with whom we worked. She was a single parent of a 6-month-old boy whose weight had dropped from the 15th to the 5th percentile over a few months. His weight steadily improved during hospitalization for FTT. Interviews with the mother revealed that she had a history of diluting her baby's formula in order to save money. Her cost-cutting measures had provided her baby with less than adequate nutrition. Arrangements were made for the mother to receive a low-cost formula and to attend nutrition classes for new parents. At follow-up, her infant continued to make appropriate developmental progress and his weight increased to, and remained at, acceptable levels.

The importance of nutrition to the maintenance of FTT was emphasized in a study by Whitten, Pettit, & Fischhoff (1969). These workers concluded NOFTT was caused by undereating (i.e., food not offered to or not accepted by infants) based on their study of 16 infants referred for growth failure without organic cause. Thirteen hospitalized infants were offered adequate calorie intake while experiencing low-level stimulation (i.e., only handled for basic physical care) for 2 weeks. In spite of the understimulation, which was designed to simulate these infants' home environment, 10 of the 13 infants showed significant weight gain when offered appropriate caloric intake. One of the three remaining infants demonstrated weight gain the following week (during which the understimulation condition continued), and two of these infants had inadequate food intake, presumably due to food refusal.

Inadequate Infant Stimulation

Inadequate infant stimulation, particularly in the form of nurturing interactions (e.g., bathing, playing, dressing) may contribute to FTT. Linscheid and Rasnake (1985), for example, reported that a subtype of NOFTT may exist in infants younger than 8 months due to a lack of infant and caretaker interactions that allow the infant to learn that his or her behavior influences the environment. Through such contingency experiences, parent and infant develop a communication system in which the behavior of both dyad members becomes mutually contingent (e.g., behavioral cues from the infant come to elicit proper caretaking from the parent). Dysfunctional parent–infant interactions, including feeding interactions, in turn, may result from a lack of contingency experiences (Ramey, Hieger, & Klisz, 1972).

Infant stimulation interventions should be implemented when general deficits in parent–infant interactions are identified through observational and interview data. Field (1978) suggested that dysfunctional interactions between adults and infants may be enhanced by increasing the adult's ability to elicit infant alertness and provide a variety of sensory experiences. Through experiencing contingent interactions with the child, the parent also learns to "read" the infant's behavior effectively. Sensory experiences for the FTT infant should include a variety of situations and sensory modalities (i.e., visual, auditory, olfactory, tactile, and gustatory) in order to provide ample contingency experiences for the infant (Linscheid & Rasnake, 1985).

Professionals may be used initially to model nurturing behaviors in the hospital or during home visits. Often, trained nurses are available in medical facilities to educate parents about infant stimulation, special medical care, and general caretaking. Parents should be faded in as participants in the adult–infant interactions and medical care of the infant. Feedback and behavioral rehearsal should be used to improve parental performance. Addressing deficits in caretaker stimulation may not lead to significant weight gain but may improve the infant's overall functioning. Combining stimulation programs with nutrition and feeding interventions often results in weight gain and improved developmental status.

Treatment should also address conflicts between family members that may contribute to an infant's failure to gain weight (Drotar, Malone, & Negray, 1980). Although mothers of FTT infants apparently do not display psychological disorders at a greater than expected level (Pollitt, Eichler, & Chan, 1975), if parental psychopathology impedes opportunities for contingency experiences, treatment of the adult should precede, or be conducted concurrently with, behavioral treatment of FTT.

Practical Problems

The logistical difficulties in successfully assessing and treating food refusal (as discussed previously in this chapter) are equally germane to interventions with FTT infants. Communicating with multidisciplinary services, addressing the special needs of low-income families, and making recommendations in a socially valid manner are frequently cumbersome yet essential tasks when one is consulted on a FTT case.

Perhaps owing to continued thinking of FTT in all-or-none organic versus nonorganic terms, psychologists may not be consulted until extensive medical workups fail to identify a clear organic etiology for poor weight gain. Frequently, when an infant is admitted with a diagnosis of FTT, he or she is submitted to a "cascade of esoteric diagnostic procedures" (Rosenn, Loeb, & Jura, 1980, p. 704) and fed by the nursing staff. If laboratory and physical findings are negative for a physical disorder and the infant gains weight under the care of nurses, NOFTT is assumed to be the culprit for poor weight gain. This approach, however, does not typically provide specific targets for change. One important goal of psychologists interested in working with FTT infants and their families, therefore, should be to raise awareness with medical personnel as to the interaction of biological, behavioral, and environmental variables (to a greater or lesser degree in a given case) in FTT. Likewise, psychologists should be aware of, or willing to learn about, medical problems associated with FTT.

Case Illustration

Tom was a 26-month-old boy with numerous physical problems, including Hirschprung's disease (i.e., congenital megacolon). Children with Hirschprung's disease are especially susceptible to bowel problems, vomiting, and failure to thrive. Because of anorexia, which is also associated with Hirschprung's disease, all of Tom's feedings occurred through a G-tube while he was in the hospital.

Tom had a history of multiple hospital admissions for treatment of urinary tract infections, ottis media, and dehydration. A typical pattern for Tom was the development of an infection, increased vomiting and bowel problems, and dehydration leading to hospitalization. Typically, when Tom was hydrated and treated with antibiotics in the hospital, he stopped vomiting.

When we were consulted by Tom's pediatrician, Tom had been hospitalized for 5 weeks. His admitting diagnosis was dehydration secondary to a urinary tract infection. Although Tom's infection resolved with treatment and his vomiting decreased initially, he had begun to vomit almost all his intake after every G-tube feeding of blenderized formula and baby food. Tom's weight had been below the 5th percentile for his age since birth but had "tracked" the growth curve. Over the past 2 months, however, Tom's weight for age fell below the 3rd percentile. Tom became lethargic, dehydrated, and unresponsive to adult contact.

An interview with the parents confirmed Tom's hospital diet was identical to his diet at home, which he generally tolerated well. Observations of Tom and his mother during G-tube feeding revealed that Tom's mother held him during the meal and would shift her weight or speak to Tom when he coughed, gagged, or made tongue-thrusting movements that often preceded vomiting. Tom's mother reported that at home, feedings usually took 10 min and did not involve vomiting unless Tom was ill. If Tom was especially fussy and emitted numerous prevomit responses, however, she took as much time as was necessary (e.g., up to 1 hr), to ensure a successful feeding.

Observations of Tom by the nursing staff showed that they did not hold Tom during nor remain at his crib after feeding him. When a nurse approached Tom's crib including during meals, Tom engaged in prevomit behaviors. Shortly after meals, Tom vomited almost all his intake.

On the basis of an interview and observational data, we recommended that Tom's meals be reduced to at least half-strength formula and delivered over three intervals separated by at least 10 min. Gradually, the formula strength was increased, but only when Tom was able to tolerate full-strength blenderized food were the feeding intervals lenghtened. A student nurse assigned to Tom was instructed to provide him with tactile and auditory stimulation during meals. When Tom engaged in prevomit responses, the nurse terminated all stimulation and withdrew from his visual field. Immediately after the inappropriate behavior stopped, she resumed interacting with him. If Tom vomited, the nurse stopped stimulation, cleaned him, and resumed feeding. At least once between feedings, the student nurse also provided 10 min of stimulation, governed by the same rules in place during meals.

Monitoring data showed that food intake increased and vomiting decreased dramatically during this intervention. Tom began to gain weight and became more interactive with caretakers. When Tom's discharge appeared imminent, special arrangements were made for his parents to stay with Tom for 2 days. During this time, the parents were instructed to employ the treatment via modeling, behavioral rehearsal, and feedback and were observed during feeding and nonfeeding interactions. After discharge, Tom was followed as an outpatient. His weight for age again began to "track" the growth curve at around the 5th percentile.

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CHAPTER 8

Cancer in Children and Adolescents

ERNEST R. KATZ, MICHAEL J. DOLGIN, AND
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INTRODUCTION

Advances in biomedical science and technology have resulted in dramatic changes in the prognosis of children and adolescents diagnosed with cancer. While in the past survival was measured in terms of months, today many children are surviving 5 years and longer, with an ever-increasing number who are completely cured (Sposto & Hammond, 1985). Childhood cancer has gradually evolved from an inevitably fatal illness to a life-threatening chronic condition. With the increased probability of long-term survival, psychological factors have assumed a more salient role in overall child and family coping (Katz & Jay, 1984; Varni & Katz, 1987).

The annual incidence of childhood cancer in the United States is approximately 12 per 100,000 children, with 6000 to 7000 new cases diagnosed annually. Leukemia, central nervous system (CNS) tumors, lymphomas, sympathetic nervous system tumors, kidney tumors, and bone tumors are the most frequent childhood cancers (Pratt, 1985). Childhood cancers tend to occur in developing tissues and organ systems and are therefore qualitatively different from the most common adult cancers, which tend to occur in the breast, lung,

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and colorectal areas (Sutow, Fernbach, & Vietti, 1981). Although relatively rare, cancer accounts for more childhood deaths than any other disease and is second only to accidents as the leading cause of death in the pediatric age range. However, with the recent continued decline in childhood cancer mortality, it has been estimated that by the year 2000, one in each 1000 individuals under the age of 20 will be a survivor of childhood cancer (Pratt, 1985).

Increased survival has become possible in large measure because of the adoption of progressively more potent and aggressive methods of treatment. The multimodal approach to cancer treatment now incorporates surgery, chemotherapy, and radiation therapy, alone or in combination, to ensure the best therapeutic outcome. Unfortunately, these treatments may be painful, frightening, and disfiguring and often have aversive short- and long-term side effects that can alter one's physical and emotional well-being (Katz, 1980; Kellerman & Varni, 1982).

In order to understand the psychological needs of children and adolescents with cancer, it is essential to have an understanding of the different phases through which the illness may progress, as well as some of the major coping and adjustment issues associated with each. Similar to other diseases, cancer is a dynamic process that may progress rapidly or slowly or be completely arrested when treatment is optimally effective. Table 1 lists the major phases encountered in the cancer experience, although not every phase is encountered by every patient, nor are these phases always independent as outlined (Katz & Jay, 1984). The following brief review of these illness phases and major psychosocial concerns associated with each will serve as a background for a review of major behavioral issues and pediatric interventions that follow.

TABLE 1. Phases of Cancer Illness

Phase	Description
I. Prediagnostic and diagnostic period	Encompasses diagnostic workup and conformation of malignant disease
II. Initiation of treatment	Presentation, acceptance, and initiation of treatment plan
III. Remission or illness stabilization	No evidence of disease or further disease advancement evident
IV. Completion of medical therapy	Discontinuation of medical therapy due to completion of regimen with positive outcome
V. Long-term survival and cure	
VI. Relapse or deterioration	Recurrence of disease or further progression of disease
VII. Terminal illness and death	
VIII. Postdeath adjustment of family members	Immediate and long-term

Prediagnostic and Diagnostic Phase

The initial phase of illness is often reported as being among the most stressful experiences encountered (Koocher & O'Malley, 1981). Children may have been evaluated by numerous professionals before a definitive diagnosis is established. For parents and children, learning that benign physical symptoms may actually be cancer represents a major crisis situation. How children and families react to this experience may be influenced by pre-illness emotional strengths and weaknesses developed as individuals and a family unit (Katz, 1980; Spinetta & Deasy-Spinetta, 1981). Prior experiences with serious illness, cancer, or death may sensitize families in helpful and unhelpful ways, emphasizing the need for clear information about similarities and differences of this and other illnesses (Christ & Adams, 1984).

The child's developmental level of understanding will influence their ability to comprehend what is taking place and their need for medical intervention (Jay & Elliott, 1983; Varni, 1983). Tolerating separation from family and friends and the pain and anxiety of invasive medical tests are major issues for the patient. Parents and children (depending on their age) will experience a variety of emotional reactions to a confirmed diagnosis of cancer, including shock, denial, grief, anger, and depression. One must learn to respect individual patterns of response without labeling them as pathological or inappropriate (Kellerman, 1980).

Patterns of communication between family members and medical staff can enhance or hinder effective adaption (Spinetta & Maloney, 1978). Providing clear age-appropriate information to patients and their parents can help demystify the illness and encourage communication. Since numerous health care professionals may be involved at this stage, the information provided should be consistent, to avoid confusion. Individuals under stress may need several presentations of illness information before they understand it (Spinetta, 1980). Children and families can benefit from knowing that their reactions are not bizarre, but are rather understandable and generally transient manifestations of adjustment (Kellerman, 1980).

Initiation of Treatment

Once treatment has been initiated, the child and family can focus on concrete tasks that need to be done (e.g., medications, treatments, schedules), enabling them to distance themselves somewhat from the possible implications of the disease. Children and families must adjust to complex treatment schedules and frequent medical visits and procedures; they must also learn to tolerate drugs and treatments that are toxic and that make them feel and look poorly (Katz, 1980). Because of their normal developmental needs, adolescents with cancer may have major concerns about their appearance, vitality, and enforced dependency, placing them particularly at risk of noncompliance with their treatment regimen (Katz, 1980; Kellerman & Katz, 1977; Dolgin, Katz, Doctors, &

Siegel, 1986). Adolescents need information about sterility and sexuality that may be affected by their disease and treatment (Zeltzer, 1980).

Returning to normal pre-illness activities, such as school, is important for overall adjustment. Discipline and family routines are vital to the patient's and family's well-being but may be complicated by concerns for making things "easier" for the patient. Parents may need help understanding that inordinate attention and privileges heaped on a sick child can paradoxically increase poor adjustment and behavioral problems (Katz, 1980).

Remission or Illness Stabilization

Most children and adolescents with cancer will experience either a remission of their disease or a favorable response to treatment, resulting in a plateau when the disease is arrested. Such periods may last for days, weeks, months, and even years. Depending on the length of relative calm and the treatment needs for maintenance chemotherapy, the illness and related issues may retreat into the background and no longer be the primary focus of attention. Parents generally report continued doubts and fears about potential problems recurring, and support may be needed to help the family move ahead in its adjustment.

Completion of Medical Therapy

Successful cessation of treatment because of no further disease is a phase encountered by more and more children (Siegel, 1980). After months of treatment, perhaps even years, chemotherapy can acquire an emotional as well as medical role, with patients and families feeling reassured by its efficacy in warding off further disease (Nitschke, Humphrey, Sexauer, Catron, Wunder, & Jay, 1982). Cessation of treatment may be met by ambivalent feelings: joy at not having to tolerate the discomfort and routines any longer and fear that its protection is no longer present. Weaning families from frequent medical appointments is important in helping increase their self-reliance and independence from medical personnel (Varni, 1983).

Long-Term Survival and Cure

Long-term survivors of cancer are increasingly being studied, with evidence that many may be at risk of developing learning problems secondary to chemotherapy and/or radiation therapy administered to the CNS (Moss & Nannis, 1980; Rubinstein, 1984). Endocrine dysfunction may also result from treatment affecting growth, development of secondary sexual characteristics, and possible sterility (Li, 1977; Shalet, 1985). Survivors of childhood cancer are at higher risk of developing another cancer later in life and may have emotional sequelae to their prolonged experiences with life-threatening illness and fears about its recurrence (Koocher & O'Malley, 1981). Continued medical follow-up for life is generally recommended for all survivors (Pratt, 1985).

Relapses, Recurrence, or Deterioration

Most children with cancer experience a relapse or disease complications requiring more intensive treatment. Depending on the length of remission, a relapse may be experienced as starting all over, with the same emotional reactions experienced at diagnosis. Many parents report that a relapse is even harder than the initial diagnosis, as their hopes for survival may have grown to a point where they no longer considered the possibilities of further problems (Koocher & O'Malley, 1981).

The patient diagnosed at an early age who later relapses may need to relearn basic information about the disease as the child may not accurately recall details of the illness and treatment. Many children will experience more than one cycle of relapse–remission, with the family having to adjust to the emotional roller coaster of ups and downs.

If conventional drugs and treatments are no longer effective, parents and patients may want to consider experimental treatments and nontraditional alternatives. Physicians may vary widely on their own recommendations for pursuing experimental drugs, and parents are often required to make decisions for their children about whether to continue with experimental treatments or accept supportive care with no hope for cure. Such decisions can be highly stressful and anxiety provoking, requiring sensitivity and discretion on the part of medical support staff. Deciding to stop all treatment may be a reasonable, albeit difficult, decision to make when no hope for further benefits is clear.

Terminal Illness and Death

Terminal illness and death are no longer a necessary outcome of childhood cancer but are still the reality for many children. Much has been written about helping children and families cope with this final phase of life (Armstrong & Martinson, 1980; Spinetta & Deasy-Spinetta, 1981). Depending on the child's developmental level, their comprehension will vary along with their needs for information and support. Even preschool-age children have been shown to be sensitive to the cues from their families that signify the approach of death. They require support for parents in helping them through this most difficult of life events (Spinetta, 1974). Concrete strategies such as hypnosis and relaxation to enhance comfort and reduce anxiety during terminal illness have been reported as useful and appealing to children and their parents (Olness, 1981; Katz, 1985b).

Children and adolescents will generally choose when and with whom to discuss their impending death, and this may not be the psychologist or social worker who assisted them throughout their illness. The involved clinician will need to take the cues from the child and family, rather than attempt to impose personal values on how best to cope with this period. Professional input can be extremely valuable in helping parents prepare other family members for the child's death, as well as in providing consultation and support to the medical staff, who may be feeling frustration and failure at not curing the child's disease (Spinetta, 1974).

Home care hospice programs now attempt to support patients in their home environments rather than at the hospital during the final stage of their illness. Although very appropriate and desirable for many patients with emotional, familial, and community resources, home care may not be the appropriate modality for every family (Armstrong & Martinson, 1980). Families need to know their options and be assisted in making decisions that they will be most comfortable with, now and in the future. Some parents and children need the security of a hospital during this time, and hospitalization should always be available even when a patient is cared for at home. Pain and anxiety management of the patient requires constant professional attention to ensure comfort (Armstrong & Martinson, 1980). Family members may benefit greatly from active involvement with the patient at home or in hospital to help them later feel they did everything they could to help during the illness.

Coping with the Child's Death

The period following death has not been well studied because regular contact with hospitals and staff generally ceases after the child's death. The bereavement process can be highly individualized, requiring sensitivity to individual family variables and philosophies. Spinetta, Swarner, and Sheposh (1981) found that those families that integrated their loss into a meaningful belief system (i.e., religion) were able to adjust more easily than were other families. Families may need assistance in finding resources to help them with their grief, and this need for help may only arise after a considerable amount of time has actually elapsed after the child's death.

MAJOR CLINICAL ISSUES AND INTERVENTIONS

This section presents the major clinical issues and interventions, along with illustrative case examples.

Coping with Acute and Chronic Pain

Most pain problems encountered by children with cancer are acute in nature and are related to medical procedures such as bone marrow aspirations, spinal taps, chemotherapy infusions, and injections (Katz, 1982b; Katz, Varni, & Jay, 1984). In acute pain experiences, anticipatory anxiety and fear have been identified as major factors that modulate behavioral response, with a second major component focusing on the actual noxious stimulation introduced.

Major assessment strategies for acute pain in childhood cancer have used behavioral observations (Katz, Kellerman, & Siegel, 1980; Jay, Ozolins, Elliot, & Caldwell, 1983), self-report (Eland & Anderson, 1977; Jay *et al.*, 1983; Katz, Kellerman, & Siegel, 1982), and psychophysiological measures (Jay, Elliot, Katz,

& Siegel, 1987; Katz, Sharp, Kellerman, Marston, & Hershman, 1982). Generally speaking, younger children exhibit greater degrees of behavioral distress in response to medical procedures. Qualitative differences between younger and older children indicate that younger children are more likely to express their pain with gross motor movements, while older children exhibit increased levels of control and verbal reactivity.

Unlike adults, chronic pain in pediatric oncology is less pervasive than acute experiences but may present more complex treatment challenges. The most common chronic pain experiences are related to cancer infiltration of the bones, joints, and soft tissues, metastases to organs, and postamputation chronic pain (Miser, Dothage, Wesley, & Miser, 1987). In contrast to acute pain, few empirical assessment studies have been performed (Miser *et al.*, 1987). Aggressive pharmacologic approaches are generally indicated in chronic pain situations, along with behavioral interventions that consider medication schedules and consequences of pain behavior (Varni, 1983).

Major behavioral interventions for cancer-related pain are as follows:

Patient and Parent Education

Children require age-appropriate information about their disease, treatment, and the pain they are experiencing. It is unrealistic to expect children to tolerate repeatedly aversive medical procedures without a clear understanding as to why the procedure is necessary or what is making them feel pain. In the absence of factual information, children will rely on their perceptions, which may be a scramble of fact and fantasy (e.g., "I get bone marrows to suck out the cancer bugs," or "my back hurts because the cancer is too heavy").

Even when a child has previously received direct information about the disease and its treatment, one cannot assume that the information has been retained correctly or is now appropriate, given a new developmental level. Particularly for a child diagnosed at an early age, periodic developmentally appropriate information updates are essential.

Assessing parental understanding of the pain experience is equally crucial to working directly with the child. The verbal and nonverbal communication between children and parents are demonstrated factors in how children cope with medical procedures and must be taken into account (Rubinstein & Katz, 1983). Basic educational approaches include developmentally appropriate printed materials, didactic discourse with providers, video modeling, and so forth (Melamed, Robbins, & Graves, 1982).

Procedural Preparation and Desensitization

Preparing children and teens for aversive medical procedures is an important strategy in reducing distress. Direct presentations using dolls, medical equipment, and appropriate modeling can effectively desensitize children and help promote coping and adjustment (to stress inoculation Jay *et al.*, 1987). Play therapy that integrates medical information and materials in a nonthreatening manner can be an effective approach to desensitizing a fearful child and help increase their coping. Care must be exerted to recognize the individual child's coping style, so as not to arouse anxiety inappropriately by preparing too far in advance or providing unnecessary detail (McCue, 1980).

Hypnosis and Self-Hypnosis

Recent conceptualizations of clinical hypnosis have focused on the cognitive–behavioral components of the experience, using focused attention, deep relaxation, imagery, and suggestions to help young patients cope more effectively with traumatic and painful experiences (Clarke & Jackson, 1983). As a cue-controlled conditioned response, the hypnotic state can be a highly potent coping alternative to anxiety, fear, and noxious stimulation associated with cancer and its treatment (Gardner & Olness, 1981; Hilgard & Hilgard, 1975; Katz, Kellerman, & Ellenberg, 1987).

Several studies have demonstrated the efficacy of hypnosis in acute pain associated with pediatric cancer (Kellerman, Zeltzer, Ellenberg, & Dash, 1983; Hilgard & LeBaron, 1982; Zeltzer & LeBaron, 1982; Katz, Kellerman, & Ellenberg, 1987). Training in hypnosis is generally most effective when undertaken first in a very safe, nonthreatening environment. Once a child has developed basic hypnotic skill, shifting to the actual treatment setting for practice before treatment onset will ensure a better response during the actual procedures. Although the presence of a therapist to help the child use hypnosis during procedures may be necessary at first, with practice and the development of confidence in their techniques, children can develop self-hypnotic skills without therapist presence. No controlled studies exist to evaluate the efficacy of hypnosis in chronic pain experiences. The anecdotal literature supports the notion that chronic pain and anxiety of terminal illness can be effectively reduced through hypnosis (Ellenberg, Kellerman, Dash, Higgins, & Zeltzer, 1980).

Case 1

Michael was 4 years old when he was first diagnosed with acute lymphoblastic leukemia (ALL). He achieved a rapid remission on chemotherapy but had great difficulty tolerating bone marrow aspirations (BMA) and spinal taps. On days on which procedures were scheduled, he would become beligerent at home and school, with progressively more agitation and anxiety upon arrival at the clinic. He needed to be physically restrained for the procedures and would be completely out of control during the entire process. Once the procedures were completed (approximately 10 min), he would gradually regain his composure but would strike out at those around him.

At this time, Michael was referred for intensive psychological assistance, which began with the development of rapport and nonspecific play therapy. At subsequent sessions, medical materials were added to the play, and discussions of medical experiences and his illness were incorporated. Michael received clarification of the mistaken notion that his leukemia was a punishment for being bad and that his procedures were part of the punishment. Michael was taught to use hypnosis through a process of active imagination and traveling to a favorite place (Disneyland), where he could choose the rides he wished to go on and control the speed with which they would travel. Through role playing and simulation in the office, Michael was taught to use hypnosis whenever he felt himself beginning to get upset and during medical procedures.

Practice with his coping techniques then shifted to the actual clinic setting at a time when he was not scheduled for any aversive experience. He was seen immediately before his next three BMA for hypnosis and was accompanied for the procedures by the psychologist who had assisted him during the tests by helping him focus on his imagery and use his "special" talents. Michael became progressively less aggressive and anxious about his procedures and no longer required active restraint. His mother was taught to reinforce his new skills and demonstration of self-control, and concrete reinforcers were used whenever he practiced (i.e., "happy face" stickers). Michael was finally able to help the nurses prepare him for his BMA and was calm throughout and following the actual test.

School and Social Reintegration

It has been noted that school for children is analogous to work for adults. Children remaining out of school for extended periods run the risk of developing adverse psychological reactions similar to those observed in unemployed adults (Katz, 1980). In order to promote optimal adjustment and rehabilitation, several investigators have advised that the child with cancer return to normal pre-illness environments and activities as soon as medically feasible (Kagan-Goodheart, 1977; Katz, Kellerman, Rigler, Williams, & Siegel, 1977; Spinetta & Deasy-Spinetta, 1981). As the primary social and educational environment of childhood, regular school participation has been demonstrated to be necessary for psychosocial well-being (Katz, 1980).

Cancer and its treatment can make regular school participation very difficult, and at times impossible. The diagnosis of a life-threatening illness in a child may cause parents to be very protective and to keep their child safely at home rather than at school (Lansky, Lowman, Vats, & Gyulay, 1975). Some children may use their illness as an opportunity to avoid situations that may not have been gratifying before their illness. For this reason, it is essential to have a good pre-illness school history.

Treatment-induced side effects such as hair loss, weight gain or loss, or disfigurement can make children very self-conscious about their appearance and reluctant to be with peers, particularly during adolescence (Kellerman & Katz, 1977). Chemotherapy may induce nausea, vomiting, and general discomfort, as well as lowering resistance to normal childhood infections that may now be life-threatening, resulting in further isolation (Katz, 1980).

Teachers and school personnel may be uninformed about the modern management of childhood cancer and frightened of having children with these diseases in their classrooms. Medical personnel may lack information concerning the essential nature of school experience to the ill child, unwittingly encouraging the child to attend alternate school programs when he or she could be in a regular situation. Absences due to repeated medical visits and treatments can be an additional burden to the teacher. This can cause the child to be continually behind peers in academic work, leading to feelings of inadequacy and despair (Cairns, Klopovich, Hearne, & Lansky, 1982).

In order to maximize the child's ability to participate meaningfully in school, Katz *et al.* (1977, 1980, 1985) identified several intervention strategies to consider as follows:

1. Provision of education soon after diagnosis to parents, children, and school personnel about the realities of cancer and its treatment, and the importance of continued school participation, along with planning for its accomplishment
2. Short-term counseling to help reluctant parents and children make the transition back to school and normalcy as soon as medically feasible
3. Establishing a working liaison between the hospital/medical practice and the teacher to ensure that the school is informed of changing medical realities that could enhance or hinder participation
4. Informing classmates in a sensitive manner about why the sick child looks differently and is often absent, clarifying stereotypes and misconceptions they may have about "catching" cancer if they interact
5. Assisting in the accurate assessment and placement of children with learning disabilities due to illness and treatment (schools vary dramatically in their ability to assist children with such special needs that may not fit into a pre-existing educational category)
6. Providing ongoing follow-up with the child, parents, and school to ensure that school participation continues and that problems are dealt with preventatively

Even for the child facing death, participating in school can be extremely meaningful and can offer a continued focus for living (Katz, 1980; Katz & Ingle, 1989). As a child's medical condition deteriorates, teachers and peers may need additional information and support. After a child dies, many teachers have benefited from professional advice as to how they might help classmates understand what happened and minimize distress.

Direct treatment of the CNS (i.e., brain and spinal cord) with chemotherapy and radiation therapy is now advocated for many children with acute leukemia. These treatments are undertaken to prevent the spread of leukemia cells into the brain and/or eradicate any cells that are already present (Moss & Nannis, 1980). Long-term follow-up of many children who have received these treatments indicates an increased incidence of learning disabilities associated with treatment (Meadows, Gordon, Massari, Littman, Ferguson, & Moss, 1981; Rubinstein, 1984).

Because treatment-related deficits in learning may not be immediately apparent, but only after months and even years have elapsed, careful longitudinal monitoring of patients using psychoeducational and neuropsychological tests is warranted (Copeland, Fletcher, Pfefferbaum-Levine, Jaffe, Reid, & Maor, 1985). School systems are generally not prepared to provide this type of assessment and may need guidance in understanding the needs of the child with treatment-related problems. Recent research has indicated that short-term memory is most clearly impaired, but significant individual differences may be present (Meadows *et al.*, 1981). Mathematical skills may decline noticeably, as well as general learning, which requires following verbal directions and good attentional abilities.

Remediation should be obtained for any child exhibiting learning disabilities. Unfortunately, because of their generally intact intelligence, children with such deficits may not readily qualify for public school assistance. Assertive advocacy on behalf of such children may be needed to secure necessary services. In general, they will benefit most from continuing in their regular school placement, along with tutoring or assistance in a resource room setting (Katz, 1985a). Parents and teachers need to understand that the child has an actual problem and is not just being lazy or uncooperative (Kleinberg, 1982).

Case 2

Valerie was a 16-year-old girl diagnosed with Hodgkin's lymphoma at age 12, while in junior high school. By the time she began high school 3 years later, the family had moved to a new school district, and Valerie showed no physical signs of her past medical problems. Valerie's parents were primarily Spanish speaking, and they did not inform the school about her illness. Although she had relapsed once on her original treatment program, she had since remained in remission and was off all therapy.

During a routine medical examination, Valerie's doctor noted an enlarged cervical node. She was immediately admitted to the hospital, and a biopsy confirmed that her disease was in relapse. Valerie's parents did not inform the school as to why she was absent because they had forgotten to do so and were overwhelmed. A truancy officer was sent to the child's home after 3 days of unexplained absence. At this time, a member of the medical team called the school to communicate the child's current status. Since the school nurse was only on campus 1 day a week, the school's primary communicator was Valerie's counselor. Until this time, she had never met Valerie because "her grades were good, and she stayed out of trouble." Hospital personnel encouraged concerned teachers and friends to visit Valerie while she was hospitalized.

The school district was notified that Valerie would be needing a home teacher because of the severity of her upcoming chemotherapy schedule. Between chemotherapy appointments, hospitalizations, and a low white blood cell (WBC) count, there were very few times when she could attend a full day of school. Valerie wanted to attend regular classes, but when she did attend, teachers felt uncomfortable grading her on the same continuum as her healthy peers. An intermittent home teacher was established, enabling Valerie to attend school when she was physically able, shifting the responsibility of the grading procedures to a hometeacher.

The week that Valerie returned to school, she, her mother, and the hospital representative met with all her teachers, nurse, counselor, and principal. It was understood that while Valerie was so seriously involved with her medical treatment, her school time should emphasize social and emotional fulfillment.

Valerie typically attended her two favorite class periods when she was physically able. Because she was somewhat shy, she was not well known throughout the school. Rather, she was very close with the students in two particular classes. A classroom presentation was arranged that combined the classes. Because her friends had been previously told of the physical side effects of her disease and treatment, they were supportive and empathetic as her fragility increased.

After a week-long absence from school, Valerie ultimately died. Her school was called by the hospital that day, so that staff and friends could attend the funeral if they wished. Many of her classmates attended the funeral and were invited to the family's home afterward.

The following week, the hospital-based liaison addressed the two classes that she had previously met. She was able to share with them some of the more memorable positive experiences that had taken place in Valerie's last days. She also shared with them how important they had been in Valerie's life and the many times Valerie had spoken highly of them. Ultimately, the school decided to dedicate their yearbook to her.

Chemotherapy-Related Nausea and Behavioral Distress

Chemotherapy-related side effects are among the most distressing experiences that cancer patients mut encounter in battling their disease. In addition to gastrointestinal upset, anorexia, and nutritional debilitation, chemotherapy has been associated with symptoms of behavioral distress, including anxiety, depression, sleep disturbances, and noncompliance (Frytak & Moertel, 1981; Katz & Jay, 1984; Dolgin, Katz, Doctors, & Siegel, 1986).

Although the physiology of chemotherapy-induced nausea and vomiting is not fully understood, various CNS and peripheral sites have been proposed as the sites of the emetic action of chemotherapeutic agents (Siegel & Longo, 1981). However, physiological explanations do not account for the occurrence of anticipatory (i.e., pretreatment) nausea and vomiting (ANV). ANV has been conceptualized as the result of a conditioning process in which sensory, spatial, temporal, and cognitive cues become associated with emetogenic chemotherapy and acquire similar nausea/emesis eliciting properties (Redd & Andersen, 1981; Katz, 1982a). Thus, sights, odors, places, people, and cognitions associated with treatment may trigger nausea and vomiting without actual toxic effects of the chemotherapy.

Only recently have studies begun to focus on these questions in pediatric populations (Dolgin, Katz, McGinty, & Siegel, 1985; Spirito, Masek, Hewett, & Katz, 1987). The major intervention strategies that have been used include hypnosis and distraction techniques.

Hypnosis

Hypnosis has proved useful in reducing both the frequency and intensity of nausea and vomiting associated with chemotherapy (Zeltzer, Kellerman, Ellenberg, & Dash, 1983; LeBaron & Zeltzer, 1984). Both anticipatory and post-chemotherapy nausea and vomiting are amenable to hypnotic intervention.

The general approaches to hypnosis for nausea and vomiting are similar to those described earlier in the section on pain. Practice and training should begin in a neutral nonthreatening environment and gradually move into the actual treatment setting. During the actual administration of chemotherapy, beginning the hypnosis experiences before insertion of the needle (or IV) and continuing throughout the infusion is most effective. Patients should be given post-hypnotic suggestions to continue experiencing a sensory shift in focus toward pleasant images and activities, away from somatic sensations, during the postchemotherapy period. It is during this time that patients receiving toxic drugs are likely to feel gastric upset. Suggestions to practice self-hypnosis when it would be beneficial, along with a rapid return of feeling well and balanced are also helpful.

Case 3

Billie was a 10-year-old boy diagnosed with non-Hodgkin's lymphoma, for which he was being treated with a combination of oral and IV chemotherapy. Billie was referred for evaluation when, after several months of receiving chemotherapy, he began to experience anticipatory nausea and vomiting. His nausea would begin several hours before a scheduled clinic visit and was triggered in particular by the clinic "odor." He also began experiencing anxiety and nausea when having blood drawn or when having his central venous catheter flushed; he was unable to take oral chemotherapy or antiemetic medication at home without regurgitation.

Billie presented as a timid and fearful boy who appeared somewhat depressed, yet motivated for treatment. In introducing self-hypnosis, it was necessary to address Billie's preconceptions about hypnosis and in particular, his fear of being put "under a spell." Hypnotic induction began with controlled breathing and sensory focusing via eye fixation on a point across the room. Billie deepened his relaxation by visualizing himself descending a staircase, at the bottom of which was a large wooden door that led to a favorite place or activity. Billie's favorite images revolved around summers spent on his grandfather's farm and around fantasies of soaring through the skies as a jet pilot. Sessions were initially held in the therapist's office and were later transferred to the clinic area and eventually to the infusion room, allowing desensitization to the treatment setting. Billie's anticipatory symptoms decreased during these therapist-attended sessions and continued to improve during subsequent clinic visits. A shaping procedure using tokens that could be redeemed for small toys was successful in treating Billie's aversion to oral medication. These behavioral strategies, along with reinstitution of oral antiemetic medication, improved Billie's tolerance of chemotherapy, as well as his overall pre- and post-chemotherapy distress levels.

Distraction Techniques

Patients who are not motivated for, or susceptible to, hypnotic intervention often benefit from other supportive distraction techniques (Zeltzer, LeBaron, & Zeltzer, 1984). These patients may be told that they can learn to keep their minds busy by playing games, noticing objects in the treatment room, and practicing other techniques to help during infusions and to use these methods later at home. Simple relaxation techniques may be useful, such as deep breathing or counting, as well as facilitating supportive measures such as the child's squeezing a parent's hand during needle insertion.

More recently, active cognitive distraction techniques have been used in the management of chemotherapy-related distress in pediatric patients. Kolko & Rickard-Figueroa (1985) tested the effects of video games made available to patients during chemotherapy administration and found a reduction in self-reported and observed anticipatory symptoms and post-chemotherapy side effects. Video games may be a particularly potent distraction technique because they involve numerous sensory modalities at the same time (visual, auditory, and kinesthetic).

Compliance with Therapeutic Regimens

Although cancer is a life-threatening illness, several factors may promote noncompliance with treatment in some patients. Cancer is frequently considered an incurable disease, and patients and their families may weigh their chances for survival against the ordeal of aggressive therapy. Alternatively, noncompliance may represent denial of the illness and its implications (Zeltzer, 1980). For the adolescent patient in particular, the diagnosis of cancer interferes with fundamental developmental tasks, including the attainment of a positive self-concept and body image, autonomy, and future orientation. The compliance research also indicates that treatment regimens that are protracted and complex in nature tend to result in reduced compliance. Aversive medical procedures and chemotherapy side effects may also hinder compliance, especially since these continue while the disease is in remission and the patient is asymptomatic and otherwise feeling well.

Clinical observation indicates diverse patient–family–treatment dynamic patterns that may result in noncompliance. Grossly, these patterns can be categorized as parent- or patient-initiated noncompliance. Parental overinvolvement and protectiveness may impair doctor–patient communication and trust and may sabotage the therapeutic alliance. In one case, the mother of an 18-year-old girl insisted on concealing her daughter's diagnosis from her; when the patient later learned of her diagnosis, the irate mother focused her anger on the attending physician. From that point on, the mother refused medical procedures, canceled clinic appointments, and resisted medical recommendations.

Conversely, parental underinvolvement and neglect can result in failure to comply. A 13-year-old boy's parent dropped him off outside the hospital and returned to pick him up later in the afternoon. The responsibility of scheduling, interacting with caregivers, and negotiating a complex medical system was too great a demand for this patient to meet without parental support and supervision. Finally, parental ambivalence regarding treatment can result in poor compliance, particularly when the patient is only marginally motivated to comply.

Patient-initiated noncompliance most often reflects the patient's inability to tolerate the distressing side effects of therapy or represents denial of the illness and its severity. This may apply to adolescent patients in particular. Compliance problems may be superimposed on a pre-existing child–parent struggle for autonomy and control; the child's illness and treatment provides an area in which the struggle unfolds. In other cases, noncompliance with treatment may be a single manifestation of a broader pattern of delinquent or antisocial behavior, in which the physician and health care team represent adversarial authority figures.

Intervention approaches to increasing compliance must begin with detailed interviews with the patient and parents to determine the extent of the problem.

Intensive psychotherapy with a child or teenager may be indicated, along with the development of a behavioral contract with appropriate reinforcement for compliance (Varni & Katz, 1987). The therapist assisting with such a case must maintain extremely close contact and communication with the primary health care providers to ensure that they understand the dynamics of the problem behavior and will actively support the treatment plan. It is not unusual for noncompliant children and teenagers to generate anger among caregivers who do not fully comprehend the complexities of a given situation (Dolgin *et al.*, 1986).

CONCLUSION

The major psychological issues confronting a child with cancer and the family are numerous and are only highlighted in this chapter. It is important to note that multiple emotional pressures are also exerted on caregivers involved in the treatment of children and adolescents with cancer and other life-threatening conditions. Although intensive psychological interventions with seriously ill children may create personal stress among clinicians, the opportunity to effect a noticeable enhancement of quality of life can be particularly gratifying to those who persevere.

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CHAPTER 9

Behavioral Management of the Child with Diabetes

ALAN M. GROSS

INTRODUCTION

Insulin-dependent diabetes mellitus (IDDM) is the most common endocrine disorder of childhood. Pancreatic failure produces a disturbance in the normal insulin mechanism. This results in an inability of the body to oxidize and use carbohydrates. Onset symptoms include fatigue, excessive thirst, increased urination, and weight loss despite increased eating. Although the child's food consumption supplies adequate blood glucose, the body is unable to utilize this sugar because of the absence of insulin and because blood glucose levels become abnormally high. The body reacts as if it is in a state of starvation and begins to break down fats. Increased urination is exhibited as the Kidneys attempt to eliminate the high levels of fatty acids. The child feels tired, weak, hungry, and thirsty (Johnson, 1984).

Following the diagnosis of diabetes, treatment shifts from dealing with the acute manifestations of the diabetic state to long-term management. To achieve the goal of a normal life, diabetic children and their families are educated about diabetes. Patient education includes a number of components. The child is taught to self-administer insulin and is also informed about its importance and function. The impact of diet on diabetic control is explained. The patient is taught a system whereby meals are planned in accordance with both the insulin regimen and nutritional requirements. In addition, the patient is instructed to compensate for changes in activity level by altering either daily diet or insulin levels, or both. Finally, patient education includes teaching the child or parents

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how to test blood glucose and urine ketone levels. These procedures provide the necessary feedback to ensure maintenance of the optimum balance of diet, activity, and insulin.

Because failure to comply with the medical regimen can result in serious diabetic symptoms, this medical regimen should become a way of life for the child with diabetes. Diabetic ketoacidosis can occur if insulin is omitted or deficient. Manifestations of ketoacidosis can include nausea, vomiting, dehydration, and weakness and can lead to coma. Hyperglycemia is characteristic of patients who allow their blood sugar levels to become greatly elevated. This condition often occurs when dietary restrictions and insulin requirements are ignored. Hyperglycemia can result in hyperglycemic hyperosmolar coma and ketoacidosis (Sussman, 1971). If the blood sugar is allowed to become too low because of skipped or delayed meals or extraordinary exercise, hypoglycemia can result. Left untreated, hypoglycemia can lead to cerebral damage, myocardial infarction, severe central nervous system (CNS) damage, and death.

Insulin-dependent diabetes mellitus is also associated with a number of long-term complications. These include blindness, renal failure, and cardiovascular disease. Complications usually appear 15–20 years after diagnosis. These additional difficulties arise during young adulthood, placing further burdens on the patient (Johnson, 1984).

The influence of psychological variables in IDDM has received a great deal of attention. Until recently, most of this work focused on identifying general personality characteristics that differentiated between children with and without diabetes. Reviews of this research indicate that youngsters with diabetes do not display higher levels of emotional problems than their nondiabetic peers (Dunn and Turtle, 1981). In instances in which adjustment difficulties exist, they most commonly involve peer relations (Delbridge, 1975; Kaplan, Chadwick, & Schimmel, 1985; Tavormina, Kastner, Slater, & Watt, 1976). Moreover, interpersonal relationship problems seem to be related to diabetes control (Simonds, 1977). It is not clear, however, whether the adjustment problem is a cause or result of poor metabolic control.

The chronic nature of diabetes requires a number of life-style changes. The onset of these behavioral demands frequently occurs at a time when peer group acceptance is of paramount importance. Moreover, the youngster with diabetes most often must learn to cope with these social stresses without the benefit of good diabetic peer models (Gross, Heimann, Shapiro, & Schultz, 1983). As such, it is not surprising that some children with diabetes experience social difficulties.

The current trend in psychosocial research is toward the analysis of specific variables that may affect health status in direct and specified ways. In particular, there is growing interest in problems of adherence to the medical regimen, the role of family and peer relations in diabetes control, and identification of how knowledge of diabetes may affect metabolic control and medical regimen compliance.

An alarming consistent finding is that children with diabetes demonstrate inadequate knowledge about their disease. These youngsters frequently do poorly on general diabetes knowledge tests. Observational data also indicate that

40–80% make errors in blood glucose testing and insulin administration (Gross, 1987). When adequate knowledge and skill concerning one particular aspect of management is demonstrated (e.g., insulin administration or urine glucose assessment), that skill is not predictive of skill in other diabetes-related health care behavior. In addition, Johnson (1984) demonstrated that when children possess facts about diabetes, they frequently are unable to apply them in different situations. The failure of the youngster to use knowledge and skills regarding diabetes is particularly alarming, given recent data linking good control to a decrease in long-term diabetic complications (Cahill, Etzwiler, & Freinkel, 1976; Pirart, 1978).

A number of findings suggest that family environment is an important factor in diabetes control. Anderson, Miller, Auslander, and Santiago (1981) reported that families of children in good diabetes control exhibited greater family cohesion, less conflict, and more encouragement of independence than did families of youngsters in poor metabolic control. Bobrow AuRuskin, and Siller (1985) examined the communication patterns of mothers and their insulin-dependent diabetic daughters. These workers reported significantly higher levels of conflict and negativistic statements in the families in which the daughter displayed difficulties in metabolic control. Hanson and Henggeler (1984) and LaGreca (1982) also reported that family environment is related to diabetes control in children.

Compliance with the health care requirements of the diabetes treatment program is also a critical factor in attempting to achieve good metabolic control. At the onset of the disease, the child is generally cooperative. Interest is displayed concerning learning about urine ketone and blood glucose testing, insulin administration, and following the diet. However, as the novelty wears off, the diabetic program becomes boring, and the child becomes more uncooperative (Gross, 1987).

Estimates of noncompliance in the general medical literature range from 20 to 90% (Masek, 1982). Patient noncompliance with the diabetes regimen is common. Noncompliance to dietary restrictions is often reported, as is failure to conduct urine and blood glucose testing as prescribed (e.g., Khurana & White, 1971; Simonds, 1979). It has also been reported that in some instances children will perform the necessary tests but will deliberately inaccurately report (underestimate) the amount of sugar in their blood or urine (Belmonte, Gunn, & Gonthier, 1981).

Johnson (1984) also suggested that inadvertent noncompliance is a problem in this patient population. Inadvertent noncompliance occurs when patients believe they are following recommended procedures but through errors in knowledge or skills fail to follow treatment instructions. In a study reported by Johnson, Pollak, Silverstein, Rosenbloom, Spillar, McCallum, and Harkavy (1982), it was noted that 40–80% of youths made errors in insulin administration and urine glucose testing. Similar results were reported by Epstein, Coburn, Becker, Drash, and Siminero (1980).

The failure of diabetic children to follow treatment instructions is the most commonly reported reason for parents to seek psychological treatment. Prompting from parents to get the youngster to adhere to the medical regimen often leads to parent–child conflict. Noncompliance can also be associated with a child's concerns about peer acceptance. As such, behavioral interventions designed to eliminate this problem frequently result in improvement in parent–child relations and peer group difficulties (e.g., Gross, Magalnick, & Richardson, 1985).

ASSESSMENT

Since an understanding of the medical regimen is integral to the patient's ability to follow a treatment program, assessment of the diabetic child's knowledge of the health care regimen should be a routine component of any intervention. Parental sophistication concerning treatment behaviors may also need to be examined. When the patient with diabetes is a young child, parents frequently carry out or supervise many of the diabetes management tasks.

Most often, general knowledge is assessed using written tests. These paper-and-pencil measures vary from clinic to clinic. The questions are created by physicians and diabetes nurse educators and reflect current treatment knowledge and the treatment philosophy of health care professionals. Test items ask very specific questions about diabetes (What causes diabetes? When should you routinely test blood sugars?). Recently, Johnson and colleagues (1982) developed standardized multiple-choice tests to assess general diabetes knowledge (When does lente insulin have its peak effectiveness?) and knowledge concerning coping with more complicated health care situations (You are at a football game and begin to feel shaky and dizzy—What should you do?). They report that these instruments have good reliability and validity.

The assessment of knowledge concerning the diabetes treatment regimen using locally developed knowledge tests is an adequate means of determining whether patients understand the requirements for controlling their illness. However, employing standardized measures would result in a number of potentially important long-range benefits. For example, normative data concerning the relationship of age to knowledge acquisition could be obtained. Harkavy, Johnson, Silverstein, Spillar, McCallum, and Rosenbloom (1983) suggested that age was related to diabetes knowledge acquisition in a population of diabetic children in a summer camp setting. As such, it is recommended that greater effort be directed toward employing standardized measures of diabetes knowledge.

Direct observation is the most appropriate method of assessing a youngster's knowledge and ability to perform appropriately specific diabetes management behaviors (e.g., insulin administration, blood glucose testing). These observations can be conducted in the youth's natural environment or an analogue setting. It is extremely important to have the child demonstrate the procedures. Many youngsters can adequately describe how the procedure is to be performed but subsequently make errors in the performance of these behaviors. For example, a child may be able to describe the appropriate manner in which precise amounts of urine and water should be mixed in a urine glucose test and then display errors in technique using the dropper to obtain these proportions (Epstein, Figueroa, Farkas, and Beck (1981).

When assessing the ability of children to monitor their urine glucose, it may be most effective to provide a child with a solution containing a specific glucose concentration. This technique will provide a precise standard against which accuracy can reliably be determined (Epstein *et al.,* 1980). A similar procedure for the evaluation of accuracy of blood glucose monitoring involves obtaining a drop of blood on a second reagent strip when the child provides the specimen for the test strip.

Insulin administration skills should also be assessed by direct observation. Gilbert, Johnson, Spillar, McCallum, Silverstein, and Rosenbloom (1982) developed a behavioral skills test in which 27 response components of insulin administration are delineated. While going through the process of self-administering insulin, the child is given a pass/fail rating for each of these behaviors. This procedure results in the identification of very specifically defined problems that may occur at various points of insulin administration.

Gross and Johnson (1981) developed a measure of diabetes-related social skills for use with children and adolescents. The Diabetes Assertiveness Test (DAT) is a role-play test in which youngsters are asked to respond to eight socially stressful situations particular to children with diabetes (e.g., peer pressure to violate diet; teasing and embarrassing questions from peers concerning the diabetes regimen). The youth's responses to the scenes can be scored for verbal content as well as for nonverbal behaviors considered important components of effective interpersonal behavior. Gross and Johnson suggested that this measure was particularly useful with children who were ashamed, embarrassed, or uncomfortable regarding admitting to peers that they have diabetes.

The measures and procedures described above will be useful in determining whether the child with diabetes is experiencing certain diabetes-related social difficulties or has knowledge deficits concerning the medical treatment regimen. However, most children are referred for treatment because of behavioral and compliance problems. As such, the identification of behavioral difficulties will most often be achieved using a behavioral interview.

In this procedure, the therapist generally begins by meeting alone with the child's parents and asking open-ended questions about the nature of the presenting complaint. After parents describe, in global terms, the issue that has prompted them to seek treatment, the therapist asks questions designed to help parents describe the youth's behavior in as precise a manner as possible (e.g., Describe in detail what she did when you told her it was time to test her urine).

Once the behavior has been defined, the therapist attempts to identify the conditions under which the response is likely to occur (e.g., What is going on when she reports that she has completed her blood test when in fact she has not?). In addition to questions concerning antecedent events, questions must be directed toward discovering typical consequences of the problematic responding (e.g., What happens when you discover she has violated her diet?).

Following the survey of problem behaviors and possible controlling variables, the therapist should encourage the parent to delineate acceptable behavioral alternatives. In some cases, the preferred behavior may not be in the child's repertoire. For these children, the response must be shaped. In many instances, however, the child may exhibit the appropriate behavior in some settings, but it has gone unnoticed by the parents. Frequently, this type of inquiry may help ameliorate the parents negative perceptions of their child.

Another important interview function is to identify potentially reinforcing stimuli for the child. Direct questioning concerning the youngster's preferred activities generally uncovers this information.

Haynes (1978) suggested reserving a portion of the initial interview for surveying areas other than those already described by the parents. This is particularly important for families with a child with diabetes. Family functioning has been shown to be related to metabolic control in diabetic children. The interviewer may simply ask whether any problems in the family have not been discussed. This information will help the therapist determine whether factors other than the child's behavior (e.g., marital difficulties) need to be assessed further.

After meeting with the parents, a brief interview with the youngster alone should be conducted. This interview can be initiated by asking the youngster why the family has come to the clinic. Following the youth's response, the therapist shares his or her opinion about the issue with the child. The clinician's reply should attempt to convey to the child that the entire family would like to work to make things more pleasant at home. The therapist should also use this opportunity to inquire about social and peer relationships, as well as to observe the youth's behavior in order to roughly estimate the child's social skills and deficits before treatment.

Following the meeting with the child, the initial assessment interview should be concluded with the clinician conducting a brief summary discussion with the youngster's parents. During this time, the therapist should present the conceptualization of the problem areas. Suggestions as to which problem area should be immediately targeted are also discussed. As the summary is presented, the clinician attempts to provide a behavioral framework within which parents can view their difficulties. An overview of the therapist's approach to treatment is also appropriate at this point in the session. Finally, homework assignments (e.g., writing down what occurs when you ask Amos to do a blood glucose test before dinner) are often requested at the conclusion of the interview. These assignments are useful in gathering further information concerning the frequency of the problem and additional detail regarding possible antecedents and consequences of the behavior. Asking parents to collect data also provides an indication of how compliant to treatment procedures parents are likely to be. Moreover, having parents monitor target responses often results in their developing a more realistic appraisal of the severity of their difficulty.

TREATMENT

Children must possess a thorough knowledge of health care behaviors if they are to be expected to control their illness adequately. If management skill deficits are demonstrated during the assessment, an instructional intervention involving modeling and feedback is recommended. In this procedure, the target behavior is explained to the child, who is then asked to demonstrate the response. Immediate feedback concerning the accuracy of the behavior is provided. For example, Epstein, Beck, Figuera, Kazdin, Daneman, and Becker (1981) provided children with test tubes containing various concentrations of glucose. The children performed urine glucose tests and were then informed of the correct glucose concentration for each tube tested. Subjects exposed to the feedback procedure went from accuracy on 36% of trials to accuracy on 72% of trials. Subjects who simply practiced the procedure did not exhibit any improvement in performance. Similar feedback approaches have been used effectively to ameliorate problems in administering insulin and blood glucose testing (e.g., Gross, Magalnick, Richardson, & Davidson, 1985; Gilbert *et al.*, 1982).

Although knowledge deficits in diabetes health care are a serious problem, these difficulties are most frequently tackled by diabetes nurse specialists. Behavioral clinicians are generally consulted for compliance problems. Compliance problems commonly include refusal to adhere to dietary restrictions, failure to perform urine and blood tests, and unwillingness to self-administer insulin and/or rotate injection sites. In addition, parents often seek help for what they consider their child's uncooperative attitude concerning diabetes. Parents define this attitude problem as their child's, assuming no responsibility for diabetes management. That is, the parents must remind the child to conduct almost all aspects of treatment. Parents maintain that if they did not prompt the youth, the task would not be completed.

Gross (1987) suggested that environmental contingencies support noncompliance rather than compliance with the diabetes treatment regimen. He suggests health care behaviors are associated with both immediate and long-term consequences. For example, the immediate consequences for performing blood glucose tests are minor and slightly aversive (e.g., inconvenience, slight discomfort from finger prick). The immediate consequences for noncompliance are also minor, but pleasant (e.g., no interruption in activities, avoidance of discomfort, attention). The delayed consequences for these two behaviors are major. Adherence to treatment requirements increases the likelihood of good health, while noncompliance greatly increases the probability of occurrence of major health problems. Children with diabetes are asked to exhibit a variety of behaviors that produce some slight immediate aversive consequence in return for a larger future reward. It is important to note that these future large rewards are potential, while the immediate consequences of compliance versus noncompliance are quite real for the child. If this temporal variable did not exist, there would be no problem in compliance; the stronger consequence would control responding. Instead, noncompliance frequently results in no immediate aversive consequence, while good patient behavior does. Difficulty discriminating the long-term rewards increases the likelihood that behavior will be controlled by its immediate consequences (Gross & Wojnilower, 1984).

The implications of this model are clear. On the immediate level, the naturally contingencies occurring favor noncompliance with the diabetes health care regimen. In instances in which children exhibit appropriate behavior, additional immediate reinforcement contingencies supporting compliance exist. This analysis suggests that a remedial approach to compliance problems would be to create additional reinforcement contingencies that make performance of health care regimens more reinforcing than aversive.

A recommended method of changing the reinforcement value of diabetes health care behaviors is to use parents as behavioral change agents. In addition to the benefits of enhancing Mom and Dad's parenting skills, this approach is useful because of the positive impact it will have on parent–child interactions. In most cases, a number of coercive behavior patterns (Patterson, Reid, Jones, & Conger, 1975) developed as parents have attempted to prompt their children to perform the diabetes treatment behaviors. Moreover, this method can serve as the basis from which the family can learn negotiation and contracting skills. These skills will be increasingly useful as children approach adolescence.

Once specific target behaviors have been defined and baseline data obtained, parent training begins by educating parents about behavior–environment relationships. Discussing parental reactions to their child's noncompliant behavior is a useful starting point. For example, reinforcement is illustrated by parental nagging designed to prompt blood glucose testing, extinction is illustrated by occasions in which a child's successful completion of a health care behavior (insulin administration, urine test) goes unnoticed, punishment is illustrated by parents who take away privileges after a child has honestly reported a high blood sugar, and negative reinforcement can be seen in the behavior of a parent who becomes impatient with a child and takes over the duties of insulin administration. In addition to facilitating an understanding of the basic principles of behavior analysis, these examples also help parents see how their behavior negatively influences their child's conduct. This understanding is particularly useful, since few parents appreciate how their behavior may be encouraging their child's irresponsible attitude toward health care.

Following the discussion of the relationship between behavior and its consequences, the therapist should begin instruction in specific parenting skills. These include teaching parents to issue direct commands, to state response–reinforcer relationships clearly, and to deliver rewards for appropriate responding.

Teaching the Premack principle can facilitate the development of these skills. For example, inconsistent performance of blood glucose testing is a problem for families with diabetic children. While diabetic children are asked to monitor their blood glucose three to four times daily (before breakfast, before lunch, before supper, and before going to sleep), few do so. Moreover, a very common complaint from parents centers around the conflict that results from their attempts to prompt their child to perform these assessments. Instructing parents to tell their child that access to desired activities is contingent on conducting blood glucose tests often results in dramatic improvement in the youngster's behavior. More importantly, it provides a framework for the parent to practice stating precisely the relationship between the child's behavior and the consequences it will produce. Since this procedure is very effective, it also gives parents an opportunity to begin to attend (reinforce) to their son or daughter's appropriate behavior (e.g., "You are doing a great job giving your insulin injections").

When parents can reliably issue commands in terms of very specific response–reinforcer relationships they should be taught how to develop additional contingencies to support diabetes health care behavior. This skill is particularly useful in instances in which children are being asked to perform new behaviors. For example, there are a number of places on the body where the diabetic individual can receive insulin injections (e.g., biceps, thighs, stomach, buttocks). When taking insulin, it is recommended that the site of injection be rotated across three different areas. Often when children learn to self-inject insulin they have great difficulty learning to use more than one of these places. While parents could use the Premack principle to prompt this behavior, having the ability to establish additional reinforcement contingencies to shape this response would be useful. Moreover, this strategy may seem less aversive to the youngster (e.g., "If you give your shot in the arm, you can play with your friends after school. But if you give your shot in your leg today instead of your arm, I will take you and your friends to the park after school").

Parent management skills are useful in controlling diabetic noncompliance and the family conflict associated with this behavioral problem. However, because some diabetic children have social difficulties that appear to result from their discomfort and embarrassment with their disease, social skills training particular to the social stresses associated with diabetes is a useful treatment for these youngsters.

Social skills training consists of modeling and role-play exercises. Gross and Johnson (1981) identified a number of socially stressful diabetes-related situations involving children. Using scenes that the youngster has identified as stressful, the child and therapist take turns role-playing the different characters in the specific situation. For example, a child who is uncomfortable answering questions from classmates concerning having to have a morning snack in class practices by role-playing, asking and answering these questions. The therapist models the appropriate response and coaches the child in his or her performance of the demonstrated behaviors. The child receives praise and feedback for performance. In addition to verbal content, appropriate nonverbal social behaviors such as posture, eye contact, and voice tone are coached.

While only a few systematic social skills programs for children with diabetes have been conducted and evaluated, they seem to result in a dramatic improvement in children's comfort concerning their illness (e.g., Gross *et al.*, 1981, 1983; Kaplan *et al.*, 1985). The social skills literature provides an empirical basis for determining a number of social skill behaviors that should be included in training (e.g., loudness of voice, response latency, eye contact, facial and body expressions). A consensus regarding the appropriate verbal responses to be exhibited by children when they are required to address a diabetes-related social stress have not been well delineated. Gross, Johnson, Wildman, and Mullett (1981) reported that children could be provided with an effective set of verbal responses to a variety of difficult social situations by being taught how to explain simply to their peers what diabetes is, that the illness is not contagious, and that a diabetic can do anything anyone else does as long as treatment instructions are followed.

PRACTICAL PROBLEMS

Approaches to eliminating behavioral noncompliance with the health care regimen, developing better parenting skills to enhance family relationships, and increasing social coping skills in children with diabetes differ little from the application of behavioral technology to these problems in other populations. However, a number of factors particular to the complexity of diabetes management present serious problems for clinicians working with these families.

Diabetes treatment involves an attempt to balance diet, insulin, and activity such that normoglycemia can be achieved and maintained. Unlike many illnesses, the nature of diabetes requires that patients and their families make daily clinical decisions concerning adjustments in treatment. These treatment decisions must be made across various times of the day. Moreover, because of the interactive nature of the relationships between the various components of the health care regimen, more then one treatment adjustment can be used to solve management problems. For example, if an afternoon blood glucose test shows high blood sugar levels, the youngster can adjust the afternoon insulin dose, reduce caloric intake at supper, or engage in a brief bout of exercise before dinner.

Since diabetes management is an ongoing daily process, a large number of treatment behaviors occur at times when direct observation of the youngster's performance will not be possible. This problem results in the necessity of relying on the child's self-report concerning the performance of these tasks. This is particularly problematic when attempting to improve the child's compliance with diet restrictions. Since most school cafeterias offer a wide variety of foods that the diabetic child is supposed to avoid, the child is presented daily with discriminative stimuli for inappropriate behavior. More importantly, there are few immediate aversive consequences for displaying these inappropriate responses, and the likelihood of getting caught by parents is not very great.

Some parents attempt to control school diet by sending the child to school with a meal that was prepared at home. They also attempt to monitor the amount of money the child takes to school. However, children overcome these inconveniences by trading food with peers and spending their milk money on sweets.

At first glance it may seem reasonable to monitor children's blood glucose levels to determine whether they have been adhering to their diet. That is, if a child comes home from school with an unusually high blood sugar level, this might be attributed to dietary noncompliance. However, the complex relationship of the factors involved in diabetes metabolic control makes this strategy inappropriate. These high blood sugar levels could just as well be the result of stress, lower-than-usual physical activity, or the onset of a cold or influenza virus (Fisher, Delameter, Bertelson, & Kirkley, 1982).

In addition to difficulties monitoring children's performance of the various aspects of their health care regimen, the multiple determinants of unusual blood glucose levels set the stage for parent–child conflict. Parental concern about the importance of diabetes control often prompts them to react strongly to hyperglycemia. Since most families have a history of dietary violations, it is not unusual for the parents to suspect that this is what is accounting for the child's high blood sugar level. On many occasions, this assumption may be accurate. When this is not the case and the child's denials are not accepted, such children tend to conclude that their parents will not believe them if they tell the truth. Arguments about the cause of high blood glucose levels are common. This situation results in aversive consequences for honest reporting. When children report normal blood sugars, parent response is positive. This pattern of parental response inadvertently encourages children to lie about the results of their blood glucose tests.

Parents should be encouraged to avoid falling into a pattern in which they reinforce their child to lie. Such a goal can be achieved by explaining to parents the effect of their adverse reaction to high blood sugar values on their child's behavior. Parents should be encouraged to reward their child for performing the blood glucose test. Questions concerning what may have influenced the results may be useful in educating the youngster about the disease, but accusations are unwarranted. Appropriate treatment adjustments to compensate for the high sugar level should also be taken ("Your sugar level is high. Lets go for a quick walk around the block and bring it down."). Punishment should be avoided. Praise for normal blood sugar levels should be provided. Offering social rewards for some aspect of the blood glucose testing procedure regardless of blood glucose levels should eliminate some of the motivation for lying.

While not all children falsely report the results of their blood glucose tests, some do. The magnitude of this problem can be reduced by informing youngsters that at times they will be required to perform a second blood glucose test immediately following the one they have conducted on their own. This policy can be explained as a way to help them avoid making careless errors. Random surveillance has been shown to enhance the reliability of self-report.

Parents cannot possibly monitor all aspects of their child's compliance with the diabetes treatment program. (This is particularly the case concerning dietary restrictions.) The all-encompassing nature of treatment requires the use of child self-report data. Moreover, even if parents could more closely scrutinize their child's behavior, such scrutiny would come into conflict with the goal of encouraging the child to be a responsible manager of the illness. To promote responsibility, parents should set up reward programs for treatment components that they can accurately monitor (e.g., insulin injection, home blood glucose tests). Once these behaviors are occurring at a consistent level, the rate and magnitude of reinforcement for these responses should be varied. Rewards and praise for all instances of observed appropriate behavior should also be delivered. Intermittent surveillance can be employed to promote accurate self-report. Consistent attention to appropriate behavior, followed by the gradual thinning of reinforcement schedules, in conjunction with avoiding delivering aversive consequences when a youth displays an occasional high blood sugar level, should help encourage the development of responsible health care behavior.

A final caution also needs to be discussed. It has been suggested that to promote accurate self-report, parents should occasionally observe their child perform various aspects of their diabetes regimen. Most frequently, this involves checking the results of a blood glucose test. Blood glucose testing involves placing a drop of blood on a plastic reagent strip. Following a specific development time, the drop of blood is blotted from the strip. The strip is then either compared with a color chart or inserted into a reflectance photometer, which presents a digital readout of the blood sugar value. Instead of watching the child conduct the entire procedure, parents often simply ask the child to show them the strip so they can compare it with the color chart, or they ask to see the reflectance meter so that they can read the test result.

Although this type of checking is useful, it still allows children to cheat on their test results. In particular, children can artificially obtain lower blood glucose values by not waiting the entire development time before blotting the drop of blood from the reagent strip. Similarly, if they rub the blood from the strip rather than gently blotting, it will produce lower blood glucose values than in fact exist. Urine glucose testing can also be influenced by adjusting the urine-to-water concentration. Asking children to perform a second test immediately following the one they performed on their own, as well as watching the entire procedure, will demonstrate these potential irregularities. It is also useful to inform children that parents may randomly check their testing. It is hoped that a child's awareness of these contingencies will reduce the likelihood of cheating and prevent a parent–child confrontation concerning false reporting.

CASE ILLUSTRATION

Amos was a 9-year-old boy who was brought to the outpatient clinic on the recommendation of his pediatric endocrinologist. At the initial visit, Amos remained in the waiting room while his parents explained to the therapist that they were experiencing great difficulty getting Amos to follow his doctor's treatment recommendations. They reported that he frequently failed to perform his blood glucose tests and that when he did conduct them, it was not uncommon for him to lie about the result. A recent hospitalization for diabetic ketoacidosis was attributed to this behavior. His parents indicated that Amos was good about administering his insulin. While dietary restriction violations occurred, they were not considered a major problem. Amos's mother prepared all his meals, and he brought his lunch from home to school. Mr. and Mrs. A also indicated that Amos's uncooperative behavior resulted in a great deal of diabetes-related family conflict. Yelling, threats, and their attempts to use punishment to control his behavior had not proved successful.

After Amos's parents explained what had prompted them to seek help, the therapist informed them that their child wanted to ask them some very specific questions about their interactions with Amos. Mrs. A was then asked to describe a recent difficulty with Amos:

MRS. A: Well, we had quite a fight about doing a blood test this morning.

THERAPIST (T): What happened?

MRS. A: I was making breakfast when he came downstairs. He started getting his insulin ready, and I asked him if he had done his blood test. He said he had and that his blood glucose was 137. Since I had just emptied the trash, I went upstairs while he was eating and checked to see if he had used his test equipment. I found a discarded lancet, test strip, and alcohol swab. However, he simply had opened these up and thrown them into the trash can.

T: What did you do then?

MRS. A: I confronted him about lying to me and told him that he had better get himself upstairs right then and do the test.

T: Did he obey?

MR. A: He started complaining about how much he hated the test, that it hurt. I lost my temper and started yelling at him.

T: What happened next?

MR. A: I told him that if he didn't get moving, he couldn't watch TV for the rest of the week.

T: Did that get him going?

MRS. A: He went upstairs but didn't do the test. It was getting late, and we needed to leave to arrive here on time. So we just skipped the test and came here.

T: Is it common that his oppositional behavior results in the avoidance of blood testing?

MRS. A: Not all the time. Sometimes I simply perform the test on him.

T: Will you stick to your promise of no TV?

MR. A: Probably not for the entire week.

After obtaining a fairly clear description of parent–child behavior in these problem situations, the therapist met alone with Amos. The therapist attempted to assess the youth's knowledge of why he was in the clinic as well as to determine potential rewarding stimuli.

T: Do you know why you are here?

AMOS: No. Maybe 'cause of my diabetes.

T: Your Mom and Dad tell me that you don't like doing some of the things that you have to do to control your diabetes. They said that all of you sometimes fight about it and that they want to learn how to get along without yelling and spankings. Would you like that?

AMOS: Yeah.

T: Your Dad tells me that you are quite a basketball player. Do you have a favorite team?

AMOS: I like Larry Bird and the Boston Celtics.

T: Do you ever watch them on TV?

AMOS: Sometimes. Dad says he might take me to see Ole Miss play.

T: Would you like that?

AMOS: Sure.

At the conclusion of his interview with Amos, the therapist met with Mr. and Mrs. A and presented a brief summary of his assessment observations and an overview of what therapy would entail.

T: There are a number of things that you can do to help alleviate the problems you are having with Amos.

MRS. A: That would be great.

T: It is very trying when you ask your child to perform a task and he ignores you, or lies about doing it. Frequently, parents scold, threaten, or punish the child for such behavior. If repeated attempts to coerce the child to do what has been requested don't work, parents may give up and perform the behavior themselves. This is seen frequently with noncompliance to requests such as, "Please pick up your toys." Often giving up is simply less aversive for Mom than fighting. Unfortunately, in relieving her own stress, Mom teaches her son that if he ignores her request he can avoid doing it, or that she will do it for him. From what you have described this sometimes occurs when you try to prompt Amos to do his blood tests.

MRS. A: That's true.

T: Another result of the scolding and hollering is that noncompliance results in a large amount of parental attention. While you may see this type of attention as aversive, it is attention. In many families, the only attention children receive from parents involves scolding. You can see how this develops. It is easy not to comment on good behavior, such as the way Amos does his own insulin injections. However, it is hard to overlook disruptive responding. When children do something wrong, parents comment on it. As such, bad behavior receives all the attention and appropriate behavior is largely ignored.

MRS. A: I understand what you are saying. It is not easy to ignore his refusal to do his blood tests.

T: I am not arguing that you ignore noncompliance. However, we will discuss a number of strategies that you can use that will help you alter these old interaction patterns. Between now and next week, please keep a record of the frequency of Amos's noncompliant behavior regarding blood glucose administration. Also note your responses to it.

The results of the assessment interview indicated that Amos's behavior was most likely being maintained by parental attention and avoidance of unpleasant tasks. As such, it was decided that therapy would involve parent training. Amos' parents were taught to use direct commands, state response reinforcer relationships clearly, and to deliver rewards for appropriate responding. Mr. and Mrs. A were also given instruction in how to develop reinforcement contingencies.

T: You have done a great job collecting information on your interactions with Amos. Last week, we discussed how Amos' noncompliance with requests to perform his blood glucose tests often result in him not having to do the test, or that he gets a lot of attention for being uncooperative. I want to talk about a different way to handle this situation. When you issue a command, it is important that Amos has a chance to do what you ask. It is also imperative that you convey to him the consequences for compliance, and the consequences for noncompliance with your request. When you tell him to conduct his blood test and he doesn't respond, don't yell at him. Rather, repeat the request and add a description of what will occur if he obeys or does not do what you ask. For example, if he is watching TV and you ask him to measure his blood glucose and he responds by complaining and saying he doesn't want to do his test, you should say, "Do your test now and you can continue watching TV before supper. If you don't do the test, I am going to shut off the TV and you will have to go to time out for 5 minutes. After the 5 minutes are up, you will come back and be asked to do your test." More importantly, when he does what you ask, give him lots of praise and attention.

MRS. A: What is time out?

T: I will explain that shortly. First let me add that by stating your commands in this manner you are teaching Amos the relationship between his behavior and the consequences it produces. This command style also gives him the opportunity to make the appropriate response after an initial failure. This provides the chance to be successful and earn a reward for good behavior rather than simply being punished for bad behavior. Time out is a punishment procedure. It involves having Amos sit by himself in an isolated place in the house. I recommend a chair in the dining room in which he is asked to sit facing the wall. When in time out, he is not to have any contact with anyone. Use the timer on the stove to measure the time spent in time out. Remember, after completing his assigned period in time out, you repeat the command and reward him for task completion. If he fails to comply, he goes back into time out, and the procedure is repeated.

Mr. and Mrs. A complained that Amos lied about the results of his blood glucose testing. This problem required that Mr. and Mrs. A also develop a reinforcement program to reward accurate testing.

T: It is important that you not only get Amos to conduct his blood glucose tests, but that he do them accurately. Remember, behavior is a function of its consequences. In order to get him to do the tests and reduce the likelihood that he will falsely report blood glucose values, you need to make the immediate consequences for these behaviors greater than those that exist for noncompliance. The use of the time out procedure we discussed will achieve this, but it is preferable to add reinforcers for good behavior rather than solely to add aversive consequences for bad behavior. You stated that staying up beyond his bed time would be a treat for him, particularly if he can use this time to play games. I want you to explain to him that everyday you are going to watch him conduct three of his blood tests. If he performs them accurately and without a fuss, he can stay up an additional half-hour and, during this time, if he desires, you will play table games with him. Make it clear to him that you are interested in his performing the test correctly and that his rewards are not dependent on having perfect blood glucose levels. At this point, we are working to get him to perform the tests accurately. You are watching him to have the opportunity to praise his good behavior and to eliminate any possibility that he can cheat. If he has a high sugar level, you should ask him about it and deal with it appropriately. However, please do it in a nonthreatening manner. For example, questions about why it is high and what he should do about it will help him develop a better understanding of his illness. Suggesting that he do a little exercise before dinner to lower the sugar will be more productive than scolding him for a possible earlier diet violation at school.

At the conclusion of the session, Mr. and Mrs. A were told to try these procedures at home. They were also asked to collect data on Amos's performance and their own throughout treatment. These data allowed the therapist to monitor their progress and the effectiveness of the intervention. Moreover, this information helped identify problems associated with the application of the procedures, as well as new problems that developed. When a problem occurred, time was spent in the session helping Mr. and Mrs. A learn to use their new child management skills in that situation.

Within 4 weeks, Mr. and Mrs. A reported that Amos was reliably performing his blood glucose tests without a fuss. They also indicated that he seemed to be much more accepting of his treatment requirements. A dramatic improvement in family interactions was also reported. At this point in therapy, treatment focused on teaching Mr. and Mrs. A to reduce the frequency of observing Amos perform his tests. They were told to inform Amos that because he was doing so well he could conduct some of his tests on his own. However, they would occasionally ask him to conduct a second test in their presence so they could check to make sure he hadn't made a mistake.

After 10 sessions, Mr. and Mrs. A felt that they had successfully solved their difficulties controlling Amos's noncompliant behavior. The therapist suggested that they spend the remainder of their final session discussing potential diabetes-related health care problems common to families with a diabetic child. These included teaching insulin injection site rotation, diet violations, and peer social difficulties. Therapy was concluded with the therapist encouraging Mr. and Mrs. A to call him if further difficulties developed.

The case described is a relatively straightforward and simple treatment program. Parents brought their son to the clinic because he was especially noncompliant concerning one aspect of his diabetes treatment program. Attempts to obtain cooperative behavior from him had failed, and a great deal of family conflict occurred as a result of their unsuccessful efforts. An assessment consisting of interviews was performed, target behaviors selected, and a parent training program initiated. Data collection by the child's parents demonstrated that the intervention was successful.

Many families with a diabetic child may present with difficulties more involved than those seen in the present example. In those cases, assessment may need to be expanded (e.g., teacher interview, social skills evaluation). Additional problem behaviors may require attention. However, the treatment format described provides a framework on which to structure an approach to treatment.

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CHAPTER 10

Bladder-Control Problems and Self-Catheterization

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INTRODUCTION

Bladder-control problems are, for the most part, defined by societal norms and attitudes. Starfield (1972) noted that the age at which children's bed-wetting normally stops varies across cultures and social class. In countries of the Western hemisphere, Starfield reports that 20% of children were still wetting the bed at a high frequency by age 4–5 years. Bed-wetting was reported at a rate of 13% for children 6–7 years and 2–3% in children 14 years old. These data are consistent with those reported by Vogt (1975) taken from the U.S. National Health Survey. The U.S. data showed that bed-wetting was reported by parents at the rate of 15% in the age range of 6–11 years and 5% in ages 12–17 years.

Starfield (1972) found that bed-wetting was reported at a ratio of approximately 2 : 1 in boys as compared with girls and that the rate was higher in lower-class families. A familial component was also noted, as was an association of bed-wetting with decreased bladder size. This latter finding of decreased bladder size is likely related to the findings of Paschalis, Kimmel, and Kimmel (1972) who noted differences in the frequency of urination rate of enuretic and nonenuretic children. Nonenuretic children urinated on an average of 3.5 times per day (ranging from 3 to 5), while enuretic children urinated on an average of 5.8 times per day (ranging from 4 to 12).

The definition of enuresis in the Diagnostic and Statistical Manual III—R of the American Psychiatric Association (1987) indicates it to be the involuntary or

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intentional discharge of urine into bed or clothes in the absence of organic pathology after an age at which continence would be expected (at least twice per month between 5 to 6 years of age and at least once per month for older children).

Two types of enuresis are described. The incontinence is referred to as secondary if it was preceded by a period of at least 1 year of urinary continence; otherwise, it is referred to as primary. Both types of incontinence may be referred to as diurnal or nocturnal, or both. Diurnal enuresis refers to wetting that occurs during waking hours, and nocturnal enuresis refers to wetting that occurs while sleeping (most common). The manual also specifies a criterion of the child having a mental age of at least 4 years. However, parental concerns regarding bladder control will obviously be presented in a clinic on the basis of parental attitudes and expectations. A survey of 1435 parents of children ages 4 and over in a pediatric clinic setting indicated that parents typically become concerned over bladder-control problems much before the age of 6 (Hague, Ellerstein, Gundy, Shelov, Weiss, McIntire, Olness, Jones, Heargarty, & Starfield, 1981). In this survey, they contrasted parents of bed wetters with those of non-bed-wetting children. The findings indicated that the parents of bed-wetting children expected dryness on the average at 3.18 years, while parents of non-bed-wetting children expected dryness at 2.61 years. There was no difference in the expectancy on the basis of the child's sex. Both groups of parents viewed bed-wetting as a significant problem, while those with less education indicated greater worry over the issue. Parents of bed wetting children most often saw the primary cause to be "heavy sleeping," while one third of both groups of parents thought the cause of bed-wetting was typically emotional in nature. Again, a familial component was noted in that one third of the parents of bed-wetting children stated they had had the same problem when they were children, compared with only one tenth of the parents of non-bed-wetting children. It was also noted in the survey that parents of lower education were more likely to use punishment as a management procedure for bed-wetting than were parents of higher education. This latter point is important in that severe and punitive toilet training has generally been considered to be associated with negative side effects, while reward-based positive training has been repeatedly demonstrated to be successful and to have positive side effects in some cases (O'Leary & Wilson, 1987).

Overall, the majority of clinical cases referred for bladder-control problems are nocturnal enuresis type. Night bladder control usually follows day control automatically, as the child learns continence, while occasional lapses should be expected particularly under novel and stressful conditions, even in older children (O'Leary & Wilson, 1987). When incontinence does become a clinical issue, e.g., according to DSM III-R criteria, a medical evaluation is advised in any case of age inappropriate urinary incontinence (Doleys, Schwartz, & Ciminero, 1981). Such an examination would be used to rule out any urological or neurological pathology. Forsythe and Redmond (1974) indicated that less than 1% of enuresis is organically based, however.

Levels of parental tolerance for bladder-control problems are quite variable; however, one should not underestimate the potential importance of this type of condition and the impact it may have on the parent–child and other social relationships. Aside from the obvious social embarrassment and restrictions this type of condition often causes, there is evidence that bed-wetting is second only to persistent crying as a precipitating event in reported physical abuse of children (Anthony, 1978).

While there is a general knowledge that emotional states such as increased stress, anxiety, or excitement can produce a recurrence of incontinence for a brief period, there does not appear to be any support for the fact that children who are enuretic possess any significant negative psychological traits. Whereas, in clinical settings, children with enuresis often present with higher than normal rates of behavioral problems both at home and at school (Berg, 1979; Berg, Fielding, & Meadow, 1977), these are most likely associated with the significant stressors responsible for the incontinent episode. Young and Turner (1973) found no support for enuretic children being more neurotic than nonenuretic children. However, they found that mothers of enuretic children tended to have higher introverted and neurotic scores than other mothers.

Toilet training can be conceptualized under two different categories. The first category deals with the normal training that takes place as the child develops in early childhood initiated by parents as a normal developmental milestone. The second category is made up of those clinical situations in which toileting has become a significant problem relative to parental and societal expectations and normal developmental process. There are a wide variety of strategies adopted by parents in developing normal toileting habits. Obviously, most of these are in fact eventually successful. The age at which such training should begin and the length of training required may vary considerably from child to child.

The age at which an active toilet training program may be most appropriate, based on maturational considerations, was addressed in a study by Madsen, Hoffman, Thomas, Koropsak, and Madsen (1969). Using four experimental groups and a maturational control group, these researchers sought to determine the utility of a urine alarm signaling device implanted in the child's pants and/or the use of positive reward in a shaping process as compared with parents' own methods. The overall sample included 70 children in four age groups, including 12–14 months, 16–18 months, 20–22 months, and 24 months and over. Results were based on the number of correct toileting episodes and the number of accidents 1 week after 4 weeks of training. The results indicated that the pants alarm system plus reward and the reward-only group obtained significantly better levels of continence than did other groups but were not significantly different from each other in the number of correct toileting episodes. The reward only group and the pants' alarm plus reward and the pants' alarm only groups significantly decreased the number of accidents as compared to the other groups but were not significantly different from each other on this measure. With regard to age groups of the children, the three older groups did better than the youngest group in the number of correct toileting episodes. Also, the oldest group did best at decreasing the number of accidents while the middle two age groups did better than the youngest aged group. These data indicate that systematic training can be successful in children under the age of 24 months, however, its use may have a less predictable outcome in those under the age of 16 months.

It was interesting to note in this study that those few parents who were successful in the "parents' own methods" group used a reward based system similar to the system outlined in the reward group in the study. While the reward only procedure and the reward plus pants alarm procedure appear to be equally effective as indicated in this study, parents in the combined procedure group reported being pleased that they did not have to rely on scheduling toilet times as a result of having the pants alarm system. This greater convenience of the combined procedure might indicate a preference for this type of training in situations where parents are already experiencing considerable time demand related stress.

The amount of time necessary for obtaining continence can vary considerably; however, a program developed by Foxx and Azrin (1973) has been demonstrated to develop such skill within a relatively short period of time. In the initial study, the researchers selected 34 of 43 children ages 20–36 months with an average age of 25 months. Nine children were excluded because of an inability to follow simple verbal instructions and imitate simple motor acts. The training program involved intensive instruction by a therapist lasting anywhere from ½ to 14 hr, with an average of 3.9 hr. The therapist used a toy doll to model the sequence of appropriate toileting behaviors along with simulated reward for appropriate toileting. These modeling sessions were then interspersed with the child's rehearsal of the same behavior and ingestion of large quantities of liquids throughout the sessions. High levels of praise and preferred edibles were used as rewards when appropriate toileting occurred for the child. Following the training sessions, the urinary accident rate decreased from about six accidents per day to approximately one accident per week, at the end of the first week after training. This low rate of incontinence was maintained at a 4-month follow-up assessment. While this intervention was directed primarily at diurnal enuresis, 30% of the children also stopped nighttime wetting as a consequence of decreased day time wetting. This initial research led to the development of a widely distributed popular book entitled "Toilet Training in Less than a Day" (Azrin & Foxx, 1974) for independent use by parents. However, subsequent research on the use of this self-help book suggests that professional supervision is necessary to achieve success levels comparable with most other initial training strategies (80–100%) and to avoid negative drift in the program that may produce significant negative side effects (Matson & Ollendick, 1977).

The problem of clinical enuresis has resulted in a variety of attempts at the development of an effective intervention. Medication therapy, hormone injections, hypnosis, and traditional psychotherapy have all been tried as a means to promote continence in enuretic children. However, none of these has been as successful as a direct learning approach to the problem (Johnson, 1981; O'Leary & Wilson, 1987). For this reason, the remainder of this chapter deals with learning-based intervention strategies to the problems of enuresis.

The issue of possible symptom substitution has been raised with the use of a learning base approach to enuresis. However, this issue has been well addressed in the review by O'Leary and Wilson (1987, pp. 72–73). These investigators cited Salk (1972) and Homan (1969) and their strong contention that the use of conditioning procedures to accomplish bladder training would result in frequent and serious negative side effects, based on traditional psychodynamic theoretical implications and personal clinical recollections. As an empirically based answer to these assertions, O'Leary and Wilson (1987) discussed data from a well-controlled study by Baker (1969) that found no evidence of symptom substitution using three different data sources (home reports, school reports, and projective assessment) for children treated for enuresis using conditioning procedures. In fact, it is more often the case that positive social and self-esteem side effects are associated with such conditioning training.

The first practical learning device for intervention with nocturnal enuresis was developed by Mowrer and Mowrer (1938). In their initial work, Mowrer and Mowrer used a specially constructed mattress pad which was sensitive to ions in the urine. When activated by urination, the pad caused a bell to ring in a box positioned next to the child's bed. The child was therefore awakened by the alarm and had to arise to turn it off. Following this, the child was instructed to go to the bathroom to finish voiding. Parents were asked to have the child wash his or her face to insure full awakening. Following this, the child returned to bed and reset the alarm after changing the bed clothes. The progress was charted, and for each dry night, a gold star was placed on a chart. Thirty children were treated in the initial study, and all reached a level of 2 consecutive dry weeks by the end of 2 months of such training.

While Mowrer and Mowrer (1938) reported 100% success with their 30 children, subsequent studies have found rates of success to be more like 80% in using this approach (Doleys, Ciminero, Tollison, & Wells, 1977; Lovibond, 1964; Young, 1965). Follow-ups as long as 4 years after initial treatment have indicated that the success achieved using the Mowrer pad method is relatively long lasting (Deleon & Sacks, 1972), however, there is indication of a relapse rate of approximately 20–30% with the bell pad method following initial treatment (Johnson, 1981; Young & Morgan, 1972a). Such relapse episodes typically are easily dealt with through booster sessions using the bell/pad method.

Attempts to improve on the Mowrer pad method that have indicated possible incremental utility include the use of intermittent signaling rather than continuous (Finley, Besserman, Bennett, Clap, & Finley, 1973), simultaneous treatment with stimulant medication (Young & Turner, 1965), and "overlearning" in the form of having the child drink 2 pints of fluids during the hour prior to going to bed following a successful pad training. (Young & Morgan, 1972b). However, more research is needed to confirm these initial findings before we can be confident that these are truly improvements on the original procedure.

Lovibond (1963) devised a system similar to that of Mowrer and Mowrer (1938) using two signals (an initial loud signal followed by a lower volume buzzer) to provide the impression that, by stopping the urination upon awakening to the loud tone, the child has terminated the more aversive signal. It was hoped that this modification would provide improved learning through a negative reinforcement paradigm. However, subsequent research (Turner, Young, &

Rachman, 1970) has shown that this modification does not necessarily lead to improved efficacy over that of the original Mowrer pad design. As the original Mowrer pad system is more readily available commercially and less expensive for parents to purchase, there seems little reason to recommend the Lovibond modification system.

One adaptation that may prove useful in certain situations involves the modification of the sensory modality through which the signaling occurs. Baller and Giangreco (1970) described an adaptation of the Mowrer pad system for deaf children. Instead of an auditory alarm, they used a light focused on the child's face as the signaling mechanism. All 21 children trained using this method were consistently dry within 30 days of initiating the procedure. Only one relapse episode was noted, which was successfully retrained under a brief reapplication of the procedure. The researchers also anecdotally reported improved social relations for the children following the toilet training. Thus, it would appear that the Mowrer system may be successfully modified to deliver bedwetting signals based on a child's sensory handicap (e.g., using strong vibration for deaf–blind children).

Starfield (1972) and Paschalis, Kimmel, and Kimmel (1972) reported moderate success using a procedure of training improved bladder retention capacity through the lengthening of the delay between initial urination and need detection and actual elimination coupled with practice at starting and stopping the urine stream. However, several subsequent studies have indicated little success when using this procedure with their clinical subjects (Doleys, Ciminero, Tollison, & Wells, 1977; Harris & Purohit, 1977). Since even the best success cited with this procedure (33–43%) is only approximately one half that obtained using the Mowrer pad method, it would be difficult to recommend this procedure to parents by itself unless there was a specific knowledge of a bladder-size problem (i.e., volume less than 200 ml). This procedure has, however, been incorporated in a number of the multi-component treatment packages that appear in the published literature.

MOWRER PAD TRAINING

In 1938, Mowrer and Mowrer proposed a model for the treatment of nocturnal enuresis based on classical conditioning principles and reported the development of a conditioning apparatus for such treatment. From their perspective, enuresis is a result of deficient habit training. Mowrer and Mowrer reasoned that the repeated sudden awakening (unconditioned response) of a child to a ringing bell (unconditioned stimulus) immediately after the onset of urination would result in an association of bladder distention (condition stimulus) and the response of awakening and inhibiting urination (condition response).

The conditioning apparatus consisted of a moisture-sensitive pad that results in a bell ringing or buzzer sounding when the pad is moistened by urine. The apparatus is currently commercially available from several manufacturers (Sears Co., model 861164; Montgomery Ward, model 53B21530). Before treatment begins, the child is fully informed of procedure and should see the apparatus demonstrated. The pad is placed under the bed sheet, and the bell or buzzer is placed near the head of the bed. The child is instructed to get out of bed and to go to the toilet the moment he or she hears the bell ring. If the bell does not awaken the child, the parent should awaken the child as quickly as possible while the bell is still ringing and direct the child to the toilet. The child completes the urination in the toilet. The bed is remade with dry sheets, the pad is replaced, and the alarm is reset so that any additional bed-wetting occurrences will awaken the child. Mowrer and Mowrer recommend that the child maintain normal fluid intake and that the bell pad procedure be used until the child has 7 consecutive dry nights on the pad. Then, for children over 5 years of age, the child fluid intake should be increased just before bedtime, and the bell and pad should be used until the child has 7 consecutive dry nights with increased fluid intake. At this point, both the bell and pad and increased fluid intake can be discontinued. If relapses occur, treatment should again be implemented until the child has 7 consecutive dry nights with normal and increased fluid intake. Once this procedure has been implemented, it should not be interrupted until the treatment is completed. Mowrer and Mowrer recommend that no additional incentives or rewards (other than privilege of not sleeping on the pad) be provided to the child.

While Mowrer and Mowrer (1938) argued for a classical conditioning explanation of the learning of bladder control using the bell and pad method, Lovibond (1964) suggested that treatment of enuresis using this method is best explained as a process of instrumental avoidance conditioning. Lovibond argued that, if the learning were based on classical conditioning, the conditioned response (awakening to bladder distention) should begin to extinguish as the inhibition of urination occurs without the bell (unconditioned stimulus). He argues, in fact, that avoidance of the loud bell (unconditioned stimulus) appears to reinforce the awakening and toileting before urination (condition response), making it extremely difficult to extinguish. Kalish (1981) supported the avoidance learning interpretation and suggested that the distended bladder (discrimitive stimulus) produces a sphincter contraction (active avoidance response) that is negatively reinforced by the child not having his or her sleep disturbed (p. 202).

DRY BED TRAINING

Azrin, Sneed, and Foxx (1974) also viewed enuresis from an operant learning perspective and developed a multimethod approach to treatment. Social and motivational factors were considered as important in this treatment as sensitivity to bladder distention stimuli in the establishment of urinary continence. The dry bed training (DBT) procedure for enuretic children was a modification of the procedures developed by Azrin, Sneed, and Foxx (1973) in treating adults who were enuretic and retarded. Major components of DBT include training in specific behaviors necessary for rapid awakening and urination, the use of a urine alarm (Mowrer bell and pad apparatus), increased fluid intake, training in inhibiting urination and increasing bladder capacity, self-correcting of accidents, self-recording of success and failures, and providing social and tangible reinforcers for correct toileting. The original DBT as described by Azrin *et al.* (1974) required one intensive all-night training session with a trained therapist in the home. This procedure was later modified so that a therapist could successfully instruct the child and parent during a single office visit (Azrin, Thienes-Hontos, & Besalel-Azrin, 1979); subsequently, a written parent guide was developed that required no direct therapist contact (Besalel, Azrin, Thienes-Hontos, & McMorrow, 1980). The final package of training methods was elaborated and published in a book entitled *A Parent's Guide to Bed-wetting Control: A Step-by-Step Method* by Azrin and Besalel (1979). Overall, the major changes from the original procedures included the shift to parental responsibility for the initial intensive training and moving this training back in time to include a portion of the day and only a portion of the first night.

The modified dry bed training occurs in three distinct phases: the intensive training day, the maintenance program, and the fading-out procedures. In beginning the intensive training day, the parent is encouraged to approach the training with enthusiastic optimism and is instructed to encourage the same attitude in the child. The various activities are to be approached in a funlike (light) manner, and many procedures are described to the child in terms of games. A "special" shopping trip is conducted on which salty snack foods, favorite drinks, and a 16-oz. graduated measuring cup are purchased for the training sessions. Then the parent reviews and explains to the child all the procedures that will be conducted during training. The child is encouraged to drink as much liquid as possible, so that he or she may practice more. Each half-hour, the child is asked to go to the toilet and sense whether he or she feels the need to urinate. If so, the child is asked to hold back on urination and go to the bed and lie down. The child is to try to hold back the urination for 2 min. If the child no longer needs to urinate, he or she will go back to playing games. If the urge continues, the child quickly goes to the toilet. The child then urinates into the measuring cup, and the bladder capacity is recorded. In repeated sessions, the child is encouraged to hold the urine longer and to beat earlier marks for the amount of urine in the cup.

The second step of the training day involves teaching the child (even those as young as 3 or 4 years) how to change the bed in case of a bed-wetting accident. Removal of the soiled bed clothing and obtaining and fitting new ones are all a part of this cleanliness training procedure. It is important for the child to accomplish this independently, as much as possible, even if the resulting bed makeup is not perfect. Also, this is a good time to introduce the child to the Mowrer pad device with an explanation and demonstration of how it works.

A positive practice component is then implemented in which the child rehearses getting up out of bed to go to the bathroom. During this procedure, the child lies in bed, waits for approximately 1 min, pretending to be asleep, gets up, and walks to the toilet and attempts to urinate. This procedure is repeated 20 times. The room should be darkened during this process to simulate nighttime. This procedure is reviewed again with the child just before bedtime, with considerable parental encouragement given. Also, at bedtime, the child is reminded of the bell and pad apparatus.

After going to bed for the night, the child is awakened on an hourly basis for 5 consecutive hours. Initially, the parents will check the sheets to determine whether they are dry or wet. If the sheets are dry, the child is gently awakened and asked to determine the need for urination. The child then decides whether to go to the toilet or to wait until the next awakening. The child is praised for having dry sheets and offered more liquid to drink (during the first three awakenings).

If bed-wetting occurs, the urine alarm sounds. The trainer verbally reprimands the child for wetting and directs the child to the bathroom to complete urination. The child is then required to change pajamas and to conduct the practiced cleanliness training procedure, including placing the soiled pajamas and linen in the clothes hamper or other appropriate place. The trainer reactivates the urine alarm. The child obtains clean sheets and remakes the bed. After the bed is made, the child is informed that the accident indicates the need for more practice in correct toileting. The child is then required to complete the positive practice procedure of getting up 20 times before going back to sleep. Twenty repetitions of positive practice is also recommended before bedtime on the evening after any bed-wetting accident.

Following the intensive training day and evening, the hourly awakening and increased fluid intake are discontinued and the parent begins the maintenance training procedure. The urine alarm continues to be placed on the bed. At bedtime, the parents remind the child of the need for the positive practice procedure if an accident occurs. The child is awakened only at the parents' bedtime and sent to the bathroom on the first night of the maintenance phase. After each dry night, the child is awakened for toileting one half-hour earlier, until the awakenings are scheduled to occur within an hour of the child's bedtime. After a dry night, the child is praised by the parents immediately in the morning and at least five times during the day. Friends and relatives are also encouraged to praise the child. After 7 consecutive dry nights the urine alarm system is removed. The parents continue to inspect the bed each morning. If the bed is wet, cleanliness training is implemented immediately, and positive practice is required that evening. The child is also to keep a "dry bed calendar" and to record daily success or failure in maintaining a dry bed. The calendar is posted next to the child's bed and reviewed frequently with the child. Tangible reinforcers may be provided after a child achieves a specified number of dry nights. It is recommended that the calendar be maintained until the child demonstrates 30 consecutive days of dryness.

While the dry bed training procedure has been demonstrated to be generally more successful than the Mowrer pad method alone in the treatment of nocturnal enuresis (Bollard & Nettelbeck, 1981), reviews of studies conducted by other researchers indicate that it typically takes longer than original reports indicate to obtain the dryness criterion (O'Leary & Wilson, 1987).

One of the major deterrents for many therapists using the original dry bed training approach has been the amount of therapist contact time involved in setting up the procedure, even when parents are to carry out the multiple components. A recent article by Houts, Liebert, and Padawer (1983) outlined a low-cost home-treatment program modeled after the dry bed training method that can be delivered to parents and children by therapists in a group format lasting only 1 hr. In the demonstration study, 60 children ages 4 years, 6 months, to 12 years, 10 months, met with the therapist along with their parents in groups of up to ten families each. The rationale for each procedure and modeling of its components were provided during the 1-hr session. The components consisted of (1) self-control attention and retention of urine training with rewards; (2) bed cleanliness training; (3) bell and pad training; (4) overlearning the fluid loading before bed time (after 14 days of dry bed achievement); and, finally, (5) a behavioral contract signed by both the child and the parents on the various responsibilities listed for items 1–4.

The results of the study indicated an 81% dry bed achievement by the end of two months. Follow-up at 1 year indicated a 66% success rate at that time. Thus, with very minimal therapist contact a relatively high success rate was achieved. It is very likely that the behavioral contract with its specific outline of responsibilities and a clear commitment to follow them by both the parent and the child is primarily responsible for mediating the lack of therapist involvement which had been demonstrated in previous studies to lead to a lower success rate. Houts *et al.* (1983) point out, however, that some families may need more therapist contact if it is felt that the behavior contract will prove insufficient.

CLEAN INTERMITTENT SELF-CATHETERIZATION

A small percentage of children because of organic problems are unable to accomplish voluntary control of voiding. Clean intermittent self-catheterization has been demonstrated by Lapides, Diokno, Silber, and Lowe, (1972) to be an effective technique in the management of patients unable to empty their bladders satisfactorily. The technique is an alternative to surgical intervention and/or the use of indwelling catheters which have been demonstrated to produce up to 95% bacteria rate in just a few days (Kass, 1956). It has been successfully taught to patients with multiple sclerosis, diabetes mellitus, spinal cord injuries and tumors, chronic cystitis, myelomeningocele and other defects of the spinal cord (Lapides, Diokno, Lowe & Kalish, 1974; Champion, 1976; Hasham, Meyer, Altshuler, Butz, Norderhaug, & Uehling, 1975; Lapides, Diokno, Gould, & Lowe, 1976; Orikasa, Koyanagi, Motomura, Kudo, Togashi, & Tsuji, 1976; Lyon, Scott, & Marshall, 1975). Notably, the direct results of the use of clean intermittent self-catheterization include decreased urinary incontinence, improved bladder emptying, and improved renal functioning (Lapides, Diokno, Gould, & Lowe, 1976; Lapides, Diokno, Lowe, & Kalish, 1973; Lapides, Diokno, Silber, & Lowe, 1971).

The self-catheterization technique has been demonstrated to be successfully taught to children (Altshuler, Meyer, & Butz, 1977; Hardy, Melick, Gregory, & Schoenberg, 1975; Kass, McHugh, & Diokno, 1979), some as young as age 5 (Hannigan, 1979) and to children with impaired cognitive function (Tarnowski

& Drabman, 1987). As a minimum criteria, Hannigan (1979) suggests that a child demonstrate sufficient manual dexterity, motivation to learn the task, and a minimum mental age of 5 years before training in self-catheterization is attempted. The multiple steps involved in the self-catheterization process require that any child being taught the method undergo an extensive training program using a systematic teaching approach. Many such training programs use dolls or drawings as a means of modeling the series of steps involved in the procedure before rehearsal of the actual procedure with the child. As with other toilet training approaches, the therapist should proceed with an air of optimism and enthusiasm, encouraging the child to proceed with the activity at their own pace. The modeling and rehearsal with dolls and/or drawings should help reduce the child's fears about the procedure (Altshuler *et al.*, 1977; Hannigan, 1979). A systematic series of procedural steps, such as the task analysis provided by Tarnowski and Drabman (1987) affords an easier method for the child to comprehend the task in that each step becomes the cue for the next step when rehearsed repeatedly. As with any learning activity, immediate corrective feedback and reward for correct performance should facilitate the learning process.

TRAINING IN SELF-CATHETERIZATION

Training a child considered to be a candidate for self-catheterization will require good rapport and patience. The length of time necessary to train a given child will vary as a function of the child's rate of learning, manual dexterity, and hesitancy/fear of undertaking the procedure.

The following steps taken from the task analysis devised by Tarnowski and Drabman (1987) should be taught to the child using the following strategies: verbal explanation of the procedure with pictures if possible, therapist modeling of the procedure using a doll, rehearsal by the child of the procedure using a doll, rehearsal by the child on himself or herself, and independent home practice with initial close monitoring.

The following steps were devised by Tarnowski and Drabman (1987) to teach cognitively impaired males with myelomeningocele the self-catheterization technique:

1. Wash hands with soap and water.
2. Wash genitals with soap and water.
3. Dry genitals with towel.
4. Open packet of lubricating jelly (water-based type).
5. Open packet of sterile gauze.
6. Put contents of lubricating jelly packet onto one side of sterile gauze.
7. Put small end of catheter in lubricating jelly.
8. Rotate small end of catheter in lubricating jelly so as to lubricate approximately 3 inches from tip of catheter.
9. Hold penis between thumb and index finger of nonpreferred hand, palm up, in approximation to within 1 inch below coronal bridge.
10. Hold penis away from body (perpendicular to torso).

11. While holding penis with nonpreferred hand, hold catheter about 1–2 inches from small end with preferred hand. (Index finger/thumb grasp with palm up).
12. Insert small end of catheter into penis about 1 inch.
13. Press catheter in slowly (about 1 inch per 10 secs), until resistance is encountered (hard to push).
14. Take large breath and exhale while continuing to insert at same, slow rate.
15. Continue to insert until urine appears (staff or parent positions a bottle for child at opposite end of catheter). (Staff or parent inserts approximately 1½ to 2 inches more).
16. Empty bladder as best as possible, by brief straining.
17. Two shifts of body position.
18. When no urine for 20–40 secs, hold as in nos. 8 and 9.
19. Remove catheter with preferred hand by holding as specified above. Remove at same rate as specified for insertion.
20. Empty urine that is in the catheter into the urine container.
21. Empty the container in toilet. (Note: if urine samples are needed for the test, the staff person removes needed amount to another container before the patient empties into toilet.)
22. Wash hands with soap and water.
23. Wash catheter and container.

For girls, the procedure is very much the same, except that numbers 9–12 are substituted with the following steps:

9. Hold labia apart with the second and fourth fingers of hand.
10. Apply considerable pressure with the third finger, palpate urethra meatus until certain you can feel the urethra without looking (many small girls can see their urethra while sitting, so there may be no need to palpate).
11. Release the pressure, but do not move finger.
12. With right hand, hold the catheter about ½-inch from the tip, directing it slightly upward, and inserting it into the urethra under the finger.

Overall, clean intermittent self-catheterization is currently viewed as a safe, effective means of accomplishing more normalized urinary function in many persons who have significant organic complications. The only subgroup group of such patients for which the procedure may not be appropriate is those who have heavily trabeculated bladders. These patients have been indicated to frequently develop urinary tract infections when using the procedure (Orikasa *et al.*, 1976).

CASE ILLUSTRATION

Brian was a 5-year, 4-month old boy with a history of myelodysplasia and neurogenic bladder dysfunction. He was referred for training in self-catheterization, as his physician and family both agreed that he was physically and emotionally ready to learn self-management. Brian was familiar with the catheterization procedure, since his parents have been performing this with him for several years.

The initial training session for the self-catheterization was scheduled to take place in Brian's home. This was done to help Brian feel at ease with learning a new procedure and to allow him to practice the procedure using the facilities in which it would be carried out every day. Although Brian was familiar with the catheterization process, I wanted to make sure that he understood why the process was necessary and exactly what was taking place. Because of his young age, I knew that it would be necessary to use simple concrete examples in explaining this to Brian. Therefore, using a drawing of a young boy with the urinary system outlined on the drawing, I explained to him, in language appropriate for his age, how the urinary system worked and how by inserting the catheter on a routine basis he could empty the bladder and help to avoid any problems with infection. To increase his motivation, I also explained how accomplishing training in self-catheterization would allow him to do various activities on his own such as staying overnight with his cousin (something his mother had indicated he has wanted very much to do). I asked him to repeat back the explanation I had just given him in his own words. He was able to do this with considerable detail, indicating a good level of understanding for the need to catheterize himself, and its meaning for personal independence.

Brian's parents had been using a #10 catheter with him, and this was used during the self-catheterization training process. Brian was given a small plastic bag containing all the materials needed for self-catheterization, including the #10 catheter, water-soluble lubrication jelly, a collapsible measuring cup, and some tissue paper. Next, an anatomically correct male doll was used, to allow Brian to practice the self-catheterization procedure.

> Brian, this is Rodney. He has a problem going to the bathroom just like you. I want to show him how to catheterize himself. Would you help me teach him?

Brian readily agreed to help, and the training session began.[1] Brian was asked to hold Rodney in front of him with the doll's back to his front, so that the doll could have the same orientation as Brian would have while carrying out the practice procedures. Next, Brian was asked to help the doll complete the following steps: Wash and rinse the doll's hands, penis, and the catheter; squeeze a small amount of lubricating jelly unto some tissue; and rotate the small end of the catheter and the jelly from the tip down, covering approximately 2–3 inches. While holding the penis erect in the left hand, Brian was to insert the catheter gently but firmly in Rodney's penis; the other end of the catheter was placed in a measuring cup. After simulation of draining the urine, measuring and recording of the urine amount was completed, and again hands, penis, and catheter were washed, rinsed, and dried with all materials being placed back into the plastic bag. On the fourth rehearsal of this process, Brian was able to complete all the steps independently without the need of prompting. This indicated his readiness to go on to the self-catheterization process.

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[1] Because Brian was already familiar with the catheterization procedure, the therapist modeling of the procedure with the doll was omitted.

> Brian, now that you have helped Rodney learn to catheterize himself, we would like for you to learn to catheterize yourself. I will help you at first until you can do it all by yourself. This will mean that you do not have to have mom or dad help you with this anymore and you can do it on your own.

Brian appeared to be ready to start with little sign of anxiety; therefore, the training was initiated. The same steps as used with Rodney were completed by Brian with verbal coaching from me. As before, he was instructed to wash and rinse his hands, penis, and catheter. He was asked to sit on the toilet and squeeze the lubricating jelly into the tissue rotating the #10 catheter in the jelly and lubricating it from the tip down, about 2–3 inches. Next, he was taught to insert the catheter:

> Brian, hold your penis up and away from you in your left hand. Do not hold too tightly or you won't be able to put the catheter in. Now, insert the catheter gently in the tip of your penis, like your mom has done in the past. . . . As you push the catheter in, you may start to feel that it gets harder to push. Keep pushing gently until it gets easy to push again, but never push real hard. . . . If you take a deep breath, sometimes that helps when you let the breath out. . . . Continue to put the catheter in until the urine starts to flow out and only go in about this much more [indicating about 1 inch with the catheter]. . . . Let the urine flow into the measuring cup so we can keep a record of how much urine is coming out each time. . . . Before you are done, try to push as much as the urine out as possible and maybe change body positions on the toilet a few times just to make sure that you have gotten it all out.

Brian had completed all the steps up to this point correctly and had totally evacuated the bladder.

> Now Brian, I want you to gently pull the catheter out, making sure that you hold the ends of the catheter with both hands to keep from spilling the urine on you or your clothes.

Brian was then shown how to empty the urine in the catheter into the measuring cup, and record the ounces of urine on a small card. He was then instructed to empty the container into the toilet and flush. Again, Brian was instructed to wash, rinse, and dry his hands, the catheter, and the measuring cup. Brian had completed the entire procedure requiring some verbal prompting, but with relatively good skill and anticipation of most of the steps. His parents lavishly praised his courage and his good work towards independence, and his parents provided him a reward by taking him out to a restaurant of his choice for dinner.

Brian's parents were asked to monitor the self-catheterization process closely over the next several days with a telephone call from me on each of the days to determine how the process was proceeding. The parents were well familiar with the appropriate catheter care, including rinsing every 2 days with full-strength distilled white vinegar, to prevent crystals from forming in the catheter. They also routinely inspected the urine for any signs of infection. The parents were provided a detailed outline of the self-catheterization procedure as practiced with Brian, and within 3 days, Brian was able to accomplish the procedure without prompting.

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CHAPTER 11

Asthma

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INTRODUCTION

The assessment and treatment of childhood asthma are best viewed from an interdisciplinary perspective. Therefore, in addition to understanding psychosocial components of the disorder, behavioral scientists must possess a basic knowledge of biomedical aspects of the disorder and its treatment. By doing so, they can successfully interact with medical scientists to develop effective interventions. The necessity of a working interface between behavioral and medical scientists will become more apparent as the chapter unfolds.

DESCRIPTION OF THE DISORDER

Asthma is somewhat peculiar in that although accurate descriptions of the disorder are found in the writings of many ancient observers (McFadden & Stevens, 1983), it has proved almost impossible to define operationally. One reason for this failure is that any definition would likely include approximately 25% of those patients with chronic bronchitis (Porter & Birch, 1971). Nevertheless, three characteristics are normally associated with asthma: the intermittent, variable, and reversible nature of attacks. Each characteristic is briefly described.

Intermittency of Attacks

Most attacks suffered by children occur on an intermittent basis. The frequency of asthmatic episodes varies from child to child and, for any given young-

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ster, from time to time. Thus, while a child may experience a series of attacks during a particular season, he or she may then remain free of the disorder for durations extending for weeks, months, or, in some cases, years. The rate of attacks experienced by a child is a function of two factors: the hyperreactivity of the airways, and the stimuli that irritate the airways. Hyperreactivity denotes that the lower airways of the child are overresponsive to various chemicals that mediate physiological and inflammatory processes and to a large number of unrelated stimuli that have the capacity to activate or release these substances (Pearlman, 1984). Stimuli that trigger attacks vary from child to child. One youngster may suffer attacks only during certain seasons, as airborne pollens, abundantly present in the child's environment during that period, serve to precipitate the attacks. A second youngster may be less fortunate, having airways that are hyperreactive to a number of stimuli, including allergens, cold air, chemicals, exercise, and air pollution; this child is apt to experience attacks on a year-round or perennial basis.

Variability of Attacks

Asthmatic episodes vary in severity from mild attacks, characterized by a sensation of tightness in the chest or a slight wheeze to fatal occlusion of the airways predominantly by mucus plugs (Williams, 1980). Attack severity varies from patient to patient and, within the same patient, from episode to episode (Creer, Harm, & Marion, 1988). At one end of the spectrum are asthmatic youngsters who occasionally suffer mild wheezing. For these children, asthma is little more than a nuisance; while they may experience some breathlessness during attacks, the condition does not ordinarily interfere to any extent with their daily lives (Creer, 1983a). At the other end of the spectrum, Jones (1976) described children who experience asthma characterized more by persistent respiratory debilitation than by discrete attacks.

Reversibility of Attacks

The airway obstruction that characterizes asthma can reverse either spontaneously or with adequate treatment. This reversible component is the *sine qua non* of asthma (McFadden, 1980); it differentiates the condition from other types of respiratory disorders, such as emphysema, for which there is no reversibility of the physical impairment. Two major problems occur because of the reversible nature of asthma. First, reversibility is a relative condition. Although there may be a total remission of the attacks of most children, there are youngsters who show reduced airflow that is irreversible, even with intensive treatment (Loren, Leung, Cooley, Chai, Bell, & Buck, 1978). Second, the fact that attacks can remit spontaneously adds a degree of uncertainty in pinpointing the factors that produced the change. Although functional relationships may be demonstrated in the laboratory between the administration of medications and the reversibility of airway obstruction, such relationships become less clear with naturally occurring attacks.

ASSESSMENT OF ASTHMA

There are two types of assessment: medical and behavioral. This dichotomy serves to guide the discussion that follows.

Medical Assessment

Basically, the aim of medical assessment is twofold: (1) to confirm the diagnosis, and (2) to measure any changes that occur in patients with treatment. The awareness that asthmatic patients comprise a heterogeneous population led to the development of a classification scheme whereby patients were diagnosed as suffering extrinsic, intrinsic, or mixed asthma (Rachemann, 1928). In this model, extrinsic asthma is usually synonymous with allergic asthma and is generally experienced on a seasonal basis, when allergens are most plentiful. Intrinsic, or ideopathic asthma, refers to attacks that occur in the absence of clearly identified precipitants, e.g., exercise or viral infections. Since Rachemann (1928) predicted that many patients would suffer attacks in which both intrinsic and extrinsic factors could be involved, he created a third category—mixed asthma—to account for such episodes.

Rachemann's (1928) model of the pathogenesis and classification of asthma has been the most widely accepted approach to conceptualizing asthma. More recently, however, Reed and Townley (1978) described a system that appears more promising in delineating both factors responsible for attacks and the physiological changes provoked by these precipitants. The model outlines three components of asthma: (1) stimuli that trigger airway obstruction, (2) variables linking the stimuli to the response, and (3) the pathophysiological responses that constitute the airway obstruction. The stimuli known to provoke airway obstruction include irritants (e.g., cigarette smoke), respiratory infections, allergens, emotional responses and situations, and aspirin-related substances. Factors linking stimuli to a pathophysiological response include immunological and neuromuscular pathways that are influenced by genetic/familial, endocrine, and nutritional factors. Finally, pathophysiological response variables include the location of obstruction, temporal pattern of obstruction, smooth muscle spasm, bronchial inflammation, and mucus gland reactivity.

The model proposed by Reed and Townley (1978) has relevance for both medical and behavioral scientists. In addition, it provides a useful means of describing the medical assessment of asthma. Generally, three methods are used to diagnose the disorder: clinical symptoms, bronchodilator response, and bronchial challenge.

First, asthma is frequently diagnosed by clinical symptoms, such as wheezing, coughing, and other respiratory symptoms. The problem with this approach is that the symptoms may be indicative of another respiratory problem, e.g., a viral infection. Under these circumstances, patients may be diagnosed as having asthma when they actually do not suffer the disorder (e.g., Pratter, Hingston, & Irwin, 1983).

Second, patients with an airway obstruction may be given a bronchodilator medication. A 20% or greater improvement in lung function with administration of the drug may warrant a diagnosis of asthma (e.g., Chai, Farr, Froehlich, Mathison, McLean, Rosenthal, Sheffer, Spector, & Townley, 1975; Taussig, Chernick, Wood, Farrell, & Mellins, 1980). A potential problem with this method, which is widely used in medical practices that may lack the equipment to perform a more sophisticated evaluation, is that the lung obstruction may not actually be asthma.

The final and most decisive method is to challenge the patient to determine whether he or she has asthma. A hierarchical progression of steps is taken with this approach, including (1) conducting skin tests to determine what stimuli, if any, induce allergic reactions in the patient; (2) subjecting the patient to bronchial challenges whereby minute amounts of substances are inhaled to which he or she is thought to be allergic; (3) determining the degree of airway obstruction that may occur when the patient inhales each stimulus; and (4) in questionable cases, exposing the patient to an exercise and/or methacholine challenge. Exercise is thought to provoke attacks in up to 90% of children with asthma (Ghory, 1975); this percentage demonstrates the significance of using exercise as a test for the disorder. Methacholine, when inhaled, leads to bronchoconstriction in patients presumed to have asthma; this drug is traditionally used as the final test to confirm questionable cases.

The measurement of treatment effects is similar to assessing the response to a bronchodilator for diagnosing the disorder. Basically, medications are prescribed and their effects assessed over a period of time. Physicians usually subscribe to a philosophy whereby asthma is controlled—there is no cure for the disorder—with the least amount of medications (Chai & Newcomb, 1973). They consider such variables as (1) the potency of the medication, (2) dosage level, and (3) the schedule on which it is taken. This may begin with the patient taking only nebulized medication on an as-needed basis and progressing, if necessary, to the patient taking maintenance medications daily to maintain his or her health. The potency of medications range from those that may be purchased without a prescription to corticosteroids, the most potent asthma medication (and the one with the potentially greatest side effects). In an investigation of decision-making in allergists, Marion, Creer, Arkes, and Kotses (1983) noted that most experienced physicians follow a systematic and stepwise procedure in treating their patients. In addition, those physicians considered the most experienced by their peers tended to treat each patient as a single-subject study in the approach they took to treating their patients.

Psychological and Behavioral Assessment

A decade or two ago, the common practice with asthmatic children was to administer psychological tests to determine whether these youngsters differed in personality from their healthier peers. Despite considerable research on the topic, no conclusive evidence emerged from this morass of data (Creer, 1979). What is now the prevailing philosophy is that asthmatic youngsters, like other children with chronic disorders (Varni, 1983), may experience either psychological/or behavioral changes, or both, as a consequence of their disorder and the treatment they receive. It is the consequences of asthma that are of major concern to behavioral scientists.

The assessment of asthmatic children takes many forms, ranging from the use of standardized psychometric instruments to direct behavioral observation. Table 1 enumerates procedures used with asthmatic children in recent years. This should not be considered an exhaustive list, but it does illustrate the variety of approaches taken to assess the disorder. Table 1 also reflects that the assessment of childhood asthma is increasingly grounded in social learning theory and related biopsychosocial models (e.g., Bandura, 1977; Engle, 1977; Schwartz, 1982). This model has been specifically applied to childhood asthma (Creer, 1983b; Thoresen & Kirmil-Gray, 1983) integrating the cognitive/ affective, physiological/somatic, social/environmental, and behavioral factors involved with the disorder. Recent attempts to assess components of the system include, for each component, the following approaches.

Cognitive/Affective Dimensions

The emphasis here has been to assess any cognitive or affective changes that occur as a result of asthma or of the treatment administered to manage the disorder. Four approaches have been taken:

Standardized Cognitive/Intellectual Instruments. Instruments such as the WISC–R and neuropsychological instruments (e.g., Halsted-Reitan, Benton Visual–Motor Retention Test) have been used in a number of recent studies to assess the validity of anecdotal reports of cognitive deficits with the use of theophylline, the

TABLE 1. Techniques for the Psychological and Behavioral Assessment of Asthmatic Children

- Cognitive/affective dimensions
  - Standardized cognitive/intellectual instruments
  - Specialized paper-and-pencil instruments
  - Behavioral checklists
- Behavioral dimensions
  - Behavioral checklists
  - Interview techniques
  - Observational approaches
- Environmental dimensions
- Asthma diaries
  - Observational approaches
- Physiological dimensions
  - Pulmonary physiology measures
  - Medication scores
- Miscellaneous morbidity dimensions
  - School absenteeism
  - Use of hospitals and medical services
  - Quality of life indices

most widely prescribed medication for asthma. Early research strongly suggests that theophylline use is linked to behavioral and cognitive deficits, although much more research must be conducted on this topic (Creer, 1987).

Specialized Paper-and-Pencil Instruments. These have been specifically developed and tested for use with asthmatic children. Two examples would be the children's Health Locus of Control (Parcel & Meyer, 1978), an instrument designed to assess any changes in the children with respect to the perceived internal/external locus of control of their disorder, and the Asthma Self-Efficacy Scale (Tobin, Wigal, Winder, Holroyd, & Creer, 1987). The latter instrument is designed to assess the beliefs or expectancies that patients can perform particular coping behaviors associated with their asthma.

Behavioral Checklists. These checklists have also been employed in an attempt to assess cognitive and affective functions in asthmatic children. Examples include use of the Child Behavior Checklist (Achenbach, 1978, 1979; Achenbach & Edelbrock, 1979) to determine whether depression in asthmatic children occurs as a result of their taking theophylline (Creer, 1987), or the Asthma Problem Behavior Checklist (Creer, Marion, & Creer, 1983), an instrument designed to elicit information on problems and potential target behaviors from asthmatic children and/or their parents.

Behavioral Dimensions

Three approaches have been taken to assess the behavior of asthmatic children: behavioral checklists, interview techniques, and observational approaches.

Behavioral Checklists. General behavioral checklists, such as the Child Behavior Checklist (Achenbach, 1978), are increasingly used in studies of childhood asthma. The Asthma Problem Behavior Checklist (Creer *et al.*, 1983) is a highly reliable and valid instrument for determining specific target behaviors in asthmatic children. Other paper-and-pencil instruments, such as the Comprehensive Problem Behavior Survey by Renne and Christian (1983), yields reliable and valid data on individual patients and groups of patients; it provides an instrument for daily monitoring of asthmatic youngsters.

Interview Techniques. Perhaps the best illustration of this method is a structured interview, described by Purcell and Weiss (1970), designed to pinpoint triggers of a patient's asthma attacks. It is useful in determining both behavioral and environmental stimuli that may result in attacks.

Observational Approaches. Observational approaches taken with asthmatic children have ranged in level of sophistication from observers monitoring and writing narrative accounts of institutionalized youngsters' behavior over brief periods of time (Creer & Miklich, 1970) to on-line computer-assisted monitoring of behavioral interactions in families where a child is afflicted by asthma (Renne

& Creer, 1985). The former approach is useful in targeting and assessing any changes that may occur as a result of behavioral intervention; the latter approach, based upon a sophisticated system of coding behaviors on portable computers, yields a morass of information about the type of interactions that take place in these families and their relationship to a youngster's asthma.

Environmental Dimensions

Two approaches taken here include the use of environmental checklists and direct observation.

Asthma Diaries. Studies by medical and behavioral scientists have relied heavily upon asthma diaries that are completed by patients and/or members of their families. These provide information on topics such as any medication side effects to the stimuli a patient perceives as triggering a particular attack. They, as well as detailed checklists that provide information about the course of a given asthmatic episode, are the mainstay of asthma self-management programs (Creer & Winder, 1986).

Observational Approaches. Direct observation of environmental antecedents, a cornerstone of any functional assessment technique, is the most desirable means of assessing environmental factors in asthma onset and management. The online computer-assisted coding system described by Renne and Creer (1985) represents one of the most advanced forms of environmental assessment seen to date.

Physiological Dimensions

Two approaches are increasingly being taken by behavioral scientists in the assessment of childhood asthma: assessing pulmonary functions in patients and calculating medication scores.

Pulmonary Physiology Assessment. Behavioral scientists discovered almost two decades ago that pulmonary physiology measures added an objective index to the assessment of asthmatic children (Purcell, Brady, Chai, Muser, Molk, Gordon, & Means, 1969). Four techniques are used: First, there has been widespread acceptance of the peak flow meter. This instrument measures airway obstruction by determining how much air a patient can exhale in a fraction of a second. Since the instrument is portable and inexpensive, it can be incorporated into studies ranging from assessing the influence of a child's parents on his or her asthma (Purcell *et al.*, 1969) to predicting the likelihood a youngster will suffer an attack within a prescribed period of time (Harm, Kotses, & Creer, 1985; Taplin & Creer, 1978). Second the spirometer is useful in that it provides data on more pulmonary variables than does the peak flow meter. The instrument has primarily been restricted to use in physicians' offices, although a portable spirometer has recently been developed. This instrument proved useful in a study by Marion (1987). He taught patients to predict, based on information gained with the spirometer, the likelihood they would suffer an attack within a specified period of time. Based upon this information, the patients could initiate early action to either prevent or abort the incipient episode. Third, the Landser Air Spectrum Analyzer (Landser, Nagels, Demedts, Billiet, & Van de Woestijne, 1976) is useful in assessing total respiratory resistance in both normal and asthmatic patients (e.g., Kotses, Rawson, Wigal, & Creer, 1987). Since this instrument provides more information than is supplied by the spirometer or peak flow meter, it is increasingly at home in a behavioral laboratory. Finally, the plethysmograph or body box, which measures airway resistance, has principally been used in the medical laboratory, primarily because of its expense. Nevertheless, it has been used widely in studies that have investigated the effect of verbal suggestion upon pulmonary functioning (e.g., Luparello, Lyons, Bleecker, & McFadden, 1968).

Medication Scores. Behavioral and medical scientists are increasingly assessing medication scores in an attempt to determine if they change as a result of behavioral intervention (Reynolds, 1988). A prime illustration is the report by Hindi-Alexander and Cropp (1983) who reported that the performance of self-management skills by asthmatic children resulted in a reduction in the amount of medications they needed to control their asthma. Medication scores are a major outcome variable of most self-management studies (Creer & Winder, 1986); such information is likely to be used more by behavioral scientists in the future.

Another way that medication scores can be used was described by Renne (Renne & Creer, 1985; Creer & Winder, 1986). He defined the severity of asthma attacks within a 5 × 5 matrix operationally according to two criteria: medication scores and the deviation of peak flow rates from predicted values. This method proved highly reliable when comparing information collected over a period of time with the matrix to the judgments of medical and behavioral clinicians.

Miscellaneous Morbidity Dimensions

These are also variables that are being added by behavioral scientists to their investigations.

School Absenteeism. Reducing school absenteeism has been an aim of many self-management programs designed for childhood asthma (Creer & Winder, 1986). When such information is obtained directly from the school, it becomes a convincing case for these procedures.

Use of Hospital and Medical Services. Because asthma is the leading diagnosis for hospitalization within the pediatric population (Reed, 1986), the reduction of the use of hospitals and medical services has been a leading outcome measure added to self-management studies (Creer & Winder, 1986). Producing changes in such services with the application of behavioral procedures, including self-management techniques, should be even more significant in the future.

Quality-of-Life Indices. Assessment of general health status or quality of life has become an important concern in all areas of behavioral medicine (Tobin, Reynolds, Holroyd, & Creer, 1986). The use of measures such as the Health Status Index allows an assessment of the number of "well-years" gained through intervention, as well as an estimation of changes in quality of life (Atkins, Kaplan, Timms, Reinsch, & Lofback, 1984; Kaplan, 1985).

TREATMENT

Recognizing that there are no medical cures for asthma, Creer, Renne, and Christian (1976) outlined five goals for rehabilitation of children with asthma:

1. Teach patients that despite the fact that they have what may be a chronic respiratory disorder, it should neither be at the center of their lives, nor dictate the quality of their well-being any more than is absolutely necessary.
2. Correct any behavioral deficits, e.g., the lack of medication compliance skills, that may interfere with medical management of the asthma.
3. Correct any behavioral excesses, e.g., panicking during attacks, that may interfere with medical treatment and exacerbate ongoing attacks.
4. Teach self-management skills.
5. Mainstream the child.

These goals, as relevant today as they were a decade ago (Creer & Wigal, 1989), may be attained by following two general strategies. First, there may be intervention by others to correct the behavioral deficits or excesses displayed by

TABLE 2. Behavioral Approaches to the Treatment of Childhood Asthma

- Operant procedures
  - Positive reinforcement
  - Negative reinforcement
  - Satiation
  - Differential reinforcement of incompatible behaviors (DRI)
  - Response cost
  - Time out
  - Extinction
- Systematic desensitization
- Biofeedback
- Modeling
- Contracts
- Family approaches
- Self-management

patients. This may entail approaches ranging from environmental manipulation to providing counseling for children and their families. Second, after behavioral problems are corrected, patients and their families must be taught self-management skills. These not only provide techniques for patients to better contribute to the management of their asthma, but they serve as a vehicle for promoting the mainstreaming of asthmatic children. A sampling of the major approaches taken with these youngsters is depicted in Table 2. Each of the various techniques will be briefly summarized.

Operant Procedures

A plethora of operant respondent procedures have proved effective with asthmatic patients (Creer, 1977, 1978, 1979; Creer, Renne, & Christian, 1976).

Positive Reinforcement

The use of positive reinforcement was the basis for the rehabilitation program established at the National Asthma Center in Denver (Creer & Christian, 1976). It provided the major way of not only managing behavioral problems in a residential treatment facility, but of correcting behavioral deficits/excesses related to asthma. Examples here included use of paper script, exchangeable for inexpensive toys, to shape behaviors related to use of the intermittent positive-pressure breathing (IPPB) apparatus (Renne & Creer, 1976), and the application of a combination of reinforcement and modeling to shape behaviors required to effectively use nebulized medications (Marion, Creer, & Burns, 1983).

Negative Reinforcement

This was the basic component of the treatment of chronic coughing in an adolescent who was repeatedly diagnosed as suffering asthma (Alexander, Chai, Creer, Miklich, Renne, & Cardoso, 1973). With this procedure, the boy avoided mild electric shocks to his forearm by refraining from coughing for progressively longer periods of time when he was presented with stimuli that elicited such responses. The procedure not only eliminated violent bouts of coughing in the youngster, but the pattern did not reappear in a 5-year follow-up (Creer, 1977). In addition, enuresis in asthmatic children was eliminated because the youngsters avoided being awakened at night by remaining dry (Creer & Davis, 1975).

Satiation

This technique was used to reduce unnecessary requests for hospitalization in children (Creer, 1977). The procedure called for children to be hospitalized for at least 3 days each time they claimed they needed hospitalization for asthma even when their physicians were somewhat skeptical about the symptoms reported by the youngsters. The use of the procedure with one child showed that in an 8 month baseline period, he was hospitalized a total of 33 days. During the month in which the satiation procedure was applied, he spent 11 days in the hospital; in the next 8 months, he was hospitalized only 12 days. While the number and frequency of his hospitalizations decreased during this latter period, however, no other changes were noted in other indices of his asthma.

Differential Reinforcement of Incompatible Behaviors

Many youngsters display signs of anxiety and panic during their asthma attacks (Creer, 1979). This is demonstrated by a wide array of responses ranging from the incessant demand for more and more medication to the youngsters remaining frozen-like in their beds (Creer, 1974). To correct this behavioral excess, children have been taught to perform relaxation exercises. In addition, Wolpe's (1958) systematic desensitization by reciprocal inhibition has been used with good success. Following this training, the youngsters showed dramatic changes in the way they responded to their attacks. The change, incompatible with panic, was always reinforced by hospital personnel at the Center. This no doubt contributed to the absence of panic exhibited in these children over a long follow-up period during which the behavior was assessed (Creer, Renne, & Chai, 1982).

Response Cost

This technique was employed in a study of two asthmatic children by Creer and Yoches (1971). The aim was to increase their attention to academic materials. The youngsters were credited with 40 points at the beginning of each experimental session; the points could be exchanged for inexpensive toys and objects, varying in value according to the number of points the children retained, at the end of each session. Each instance of nonattending behavior was signaled by the click of a counter and the subtraction of a point from the total maintained for each boy. The procedure was not only effective in increasing attending behaviors in both boys, but resulted in their improved performance in the classroom.

Time Out

Some asthmatic children attempt to be admitted to hospitals, even when they do not require such treatment. Hochstedt, Shepard, and Lulla (1980) referred to such patients as overusers of hospital services in that they verbalize their intentions either of prolonging their stay or of returning as quickly as possible once discharged. To correct this behavioral excess, Creer (1970) had hospital personnel use time out whereby the youngsters, when admitted, were (1) sequestered from other children, (2) not permitted to have TV, (3) denied comic books, and (4) permitted to only have schoolwork present. By making the hospital dull, there was a significant reduction in the amount of time children, considered as overusers of hospital services, were hospitalized (Creer, 1970; Creer, Weinberg, & Molk, 1974; Hochstedt *et al.*, 1980).

Extinction

Neisworth and Moore (1972) successfully used extinction to treat coughing in a 7-year-old boy diagnosed as having asthma. Assuming that parental attention reinforced and maintained such behavior, a procedure was introduced whereby the parents were instructed not to interact with their child when he was put to bed, the time when he usually exhibited a high rate of coughing. The result was the extinction of the coughing response.

Systematic Desensitization

Systematic desensitization was very effective when applied to the treatment of panic in asthmatic children. Basically, the procedure involved three steps: (1) teaching the youngsters skills so they could relax with a self-generated cue, (2) arranging in hierarchies situations previously associated with panic, and (3) using relaxation to extinguish panic in the face of imagined stimuli previously associated with the pattern. As a result of this procedure, panic was invariably reduced in youngsters labeled as panicking during their attacks (Creer *et al.*, 1982).

Systematic desensitization has been used to manage panic associated with asthma (Creer *et al.*, 1982), to reduce fear of needles (Creer, 1979), and to improve pulmonary functioning (Miklich, Renne, Creer, Alexander, Chai, Davis, Hoffman, & Danker-Brown, 1977).

Biofeedback

Training in the self-regulation of physiological variables in asthmatic patients has taken three forms (Creer & Kotses, 1983): (1) electromyographic (EMG) training, e.g., assessing EMG changes as recorded from the forehead; (2) respiratory flow-volume training, e.g., assessing changes in airway obstruction; and (3) airway resistance training, e.g., assessing total respiratory resistance. All three approaches benefit patients from both a psychological and physiological viewpoint; however, caution Creer and Kotses (1983), such changes are relatively modest when compared to those produced by pharmacological agents. Biofeedback, in the form of peak flow values, is likely to have its greatest impact in assisting a patient to better predict the likelihood he or she will suffer an attack within the immediate future.

Modeling

What was referred to as self-modeling was developed to correct behavioral excesses and deficits in asthmatic children (Creer & Miklich, 1970). Basically, the approach involved a child viewing videotaped scenes of himself behaving in both an inappropriate and appropriate manner; observers, blind to the videotaped manipulations, recorded whether the youngsters showed any changes in their behavior while in a natural setting. The technique proved highly effective not only in correcting inappropriate responses in asthmatic youngsters, but in other children with physical disorders (Dowrick & Raeburn, 1977). More traditional forms of modeling have been incorporated into many self-management programs developed for asthmatic children. An example is contained in *Living with Asthma* (1986). In this program, asthmatic youngsters are taught to imitate the behaviors displayed by a mythical character, Marvin Marvelous, and his physician, Dr. Q. By combining modeling and behavioral rehearsal, children and their families are taught basic self-management skills they should perform in the event of an asthma attack. As noted by Creer and his colleagues (1984), the approach has been highly effective in teaching these skills.

Contracts

For a decade before the National Asthma Center closed in 1981, a procedure was used to teach patients how to comply with medication instructions. The procedure is as follows (Creer, 1987):

> Shortly before a child was discharged, a contract was drawn up between the child and the physician. According to the agreement, signed by all involved, the child agreed to become responsible for his or her own medications. Thereafter, the child no longer reported to the nursing station at the facility for medications, but was entrusted with a supply of medications for use over a period of time. Initially, close supervision was provided by child care workers at CARIH to verify that the youngster was taking medications as directed; using a shaping procedure, control was gradually passed on to the child as he or she demonstrated competence at managing medications. The role of personnel at CARIH was gradually faded so that they only checked periodically to ensure the youngster was behaving as instructed. (p. 354)

The procedure proved effective in not only teaching asthmatic youngsters how to manage their medications while they remained at the Center, but long after they returned home.

Family Approaches

A variety of approaches have been taken to working with asthmatic youngsters ranging from separating the child from his or her family (Purcell *et al.*, 1969) to the application of family therapy (Liebman, Minuchin, & Baker, 1974). Family involvement in programs for the treatment of pediatric asthma has two aspects. First, family members gain considerable knowledge about the disorder as well as specific self-management skills to be performed to help prevent and manage asthma attacks (Creer & Winder, 1986). Second, functional analyses of family interactions in the clinical or natural environment can be used to develop behavioral prescriptions to influence behavioral deficits or excesses exhibited by the asthmatic child or other family members (Renne & Creer, 1985).

Self-Management

There is no doubt that for the foreseeable future the teaching and evaluation of self-management programs for asthmatic children and their families will be at the forefront of efforts taken with these families (Creer & Winder, 1986). The approach is not only highly developed for asthmatic youngsters, but a number of second-generation programs are currently being refined and tested; the history of the evolution of these programs is found in a conference summary by Green, Goldstein, and Parker (1983) and a chapter by Creer and Winder (1986).

PRACTICAL PROBLEMS

Problems presented by childhood asthma run the gamut from those observed in other populations of chronic illness (Varni, 1983) to those endemic to asthma. The present discussion will focus only on the most common practical problems that repeatedly occur with childhood asthma. The problems selected for discussion are enumerated in Table 3.

Asthma Medications

Compliance

Compliance among asthmatic patients is generally poor. In studies where theophylline levels have been analyzed in these youngsters, compliance has ranged from 2 to 100% (Creer, 1987b). However, the latter value is somewhat specious in that it reflects what was obtained in a study in which a small number of children volunteered from among a large population of potential subjects (Baum & Creer, 1986). In most investigations, particularly those that include random testing, compliance is apt to hover around 10% (Creer, Harm, & Marion, 1988).

TABLE 3. Practical Problems Presented by Childhood Asthma

- Asthma medications
  - Compliance
  - Misuse of medications
  - Side effects of medications
- Avoiding precipitants
- Prediction of attacks
- Symptom discrimination
- Attack management
- Consequences of asthma

Misuse of Medications

Not only can the asthmatic child misuse medications prescribed to control his or her asthma, but there is an alarming trend of other family members misusing these drugs. For example, children have long claimed they get "high" from theophylline-based medications (Creer & Christian, 1976). This misuse is understandable given theophylline's structural similarity to caffeine. This behavior is not overlooked by the asthmatic child's siblings: they also know what effect may be produced by the drug. Second, there is evidence that theophylline is frequently added as a filler in amphetamines sold on the street (Lukas, 1985). This would only serve to reinforce the effect of getting high for asthmatic children and their siblings. Finally, there is increasing evidence that theophylline is being used in suicide attempts by both asthmatic youngsters and their non-asthmatic siblings. A study by Gaudereault, Wason, and Lovejoy (1983) described 28 patients admitted to a children's hospital between 1967 and 1980 who suffered from acute theophylline overdose.

Side Effects of Medications

There are a number of possible side effects induced by asthma medications ranging from changes in psychological functioning with theophylline (Creer, 1987) to serious physical changes that occur with the long-term use of corticosteroids (Creer, 1979). Thus, many children and their parents constantly assess the cost–benefits involved in taking asthma medications to control asthma. There are many patients and their families who frequently decide it preferable to have the youngster suffer asthma than to take asthma medications. This can present an interesting dilemma to behavioral scientists who are frequently called upon to develop strategies for improving medication compliance in asthmatic youngsters.

AVOIDING PRECIPITANTS

Children with asthma may fail to heed their physicians' advice and avoid stimuli that trigger attacks. Specific examples include failing to attend to physical changes and halt exercising to avoid attacks, or continuing to play with animals when fur dander induces attacks. Self-management training can remedy many of these problems (Baum & Creer, 1986), although the problem faced in asking a family to rid themselves of a pet is often difficult. If a family will not remove a pet from their home when it is obviously precipitating serious asthma, the only solution may be that offered by Ellis (cited in Creer, 1987) who suggested the family be charged with child abuse. Exposing a child to stimuli that knowingly triggers unnecessary attacks can be as abusive as physical beatings. It is a sound basis for taking a tough stance against parents who seemingly select ol' Fido over their child.

Prediction of Attacks

It is helpful, particularly if a child's attacks are apt to become severe in a brief period of time, to teach the youngster and his family to predict attacks. A study by Marion (1987) demonstrated that youngsters and their families could take values from a portable spirometer and successfully predict the likely occurrence of an attack. This approach, detailed earlier, shows considerable promise.

Symptom Discrimination

This can be a complex matter in that the successful detection of an attack requires the reciprocal interaction of environmental, physical, cognitive, and behavioral variables (Creer, 1983b). Since a number of problems may occur, the solution of any discrimination problem requires an accurate analysis of the situation, possibly including a thorough physical examination, and any number of remedial steps. An enumeration of potential problems in symptom discrimination is found in Creer (1983b).

Attack Management

Behaviors that exacerbate an ongoing attack or interfere with medical treatment have been detailed earlier. It is here where behavioral scientists have developed techniques for managing such responses as panic (Creer, 1974, 1979), misuse of emergency respiratory equipment (Renne & Creer, 1976) or nebulizers (Marion, Creer, & Burns, 1983), and hospital overuse (Creer, 1970; Creer *et al.*, 1974; Hochstedt *et al.*, 1980).

Consequences of Asthma

Any number of consequences can result from childhood asthma. These include those experienced by the child, e.g., depression, to those expressed by his or her siblings, e.g., resentment. The full armamentarium of behavioral and psychological techniques may be brought to bear to alleviate these consequences.

CASE ILLUSTRATION

Zeke Green is a 16-year-old boy with a history of perennial asthma since age 5. He was seen at a medical university behavioral medicine clinic (BMC) at ages 7 and 14. Zeke was first referred to the BMC following three hospital admissions within six months because of uncontrolled asthma. The patient was friendly and engaging with the clinic staff, but seemed to have difficulty remembering and following directions. Also, despite his pleasant and smiling appearance, he seemed mildly agitated, frequently getting up from his chair and moving about the room. A structured interview with his parents indicated that he experienced problems with school performance. A school psychologist had suggested to Mr. and Mrs. Green that their child might have an attention deficit disorder. Cognitive assessment findings were consistent with this hypothesis; his pattern of scores on the WISC–R were suggestive of difficulty with concentration/attention. A routine review of the patient's medications was conducted so as to rule out medication side effects as an explanation for attention difficulties. His use of oral theophylline and theophylline-based inhalers since he was 5 years of age suggested a possible cause. Zeke's presence in the hospital allowed a medically supervised suspension of theophylline-based medications for 1 week. A repeated cognitive assessment at this time revealed no attention deficits, while the reinstitution of theophylline medications resulted in the reappearance of concentration problems the following week. Further difficulty in attention was attenuated by a medically supervised switch to other asthma medications (e.g., cromolyn sodium) that offered equivalent asthma management for this patient. Thereafter, Zeke's attention was noted to improve; he also began to demonstrate improved school performance.

Thus, the BMC staff were able to identify and mediate the remedy of cognitive and behavioral deficits without a behavioral or psychological intervention. However, conversations with Mr. and Mrs. Green, observation of the family in the office, and Zeke's recurrent hospitalization for severe asthma suggested other problems. Observation of the family in the office revealed the parents to be both concerned and frustrated over the apparent unmanageability of Zeke's asthma. His parents had read a number of asthma education materials and considered themselves informed parents who took an active role with Zeke's medical management. As they spoke about the past 2 years of emergency hospital visits and frantic efforts to control their child's asthma (e.g., removal of all possible allergens from the home such as the family dog), their frustration and personal suffering became evident. While their venting their feelings and the compassion of our staff seemed to provide them with renewed hope, it was clear that further assessment and intervention would be necessary if improved asthma management was to occur.

As recommended, the family followed through with six outpatient visits to the BMC. During this time, several home visits were made to provide additional data. Clinic visits and in-home observation helped establish two important patterns of family behavior. First, it became apparent that Zeke obtained an enormous amount of attention (i.e., reinforcement) for playing a sick role in the family. While the other children were often identified in family interactions by their participation in athletics, dance, or school achievement, Zeke's interactions centered around his asthma. A second feature of family behavior over the 6 weeks following Zeke's hospital discharge was the gradual unresponsiveness of parents and siblings to the patient's report of asthma symptoms (e.g., cough or slight wheezing). Thus, the family seemed to have developed the pattern of being overattentive to Zeke's asthma immediately following a severe episode and hospitalization. However, as time passed, inattention to asthma reports became more the rule.

Several factors seemed to play a role in establishing this pattern. First, Mr. and Mrs. Green seemed to feel responsible for their child's asthma, as well as guilt and fear about their inability to manage it. This led to an overattentive posture towards asthma and its symptoms immediately following an acute episode. However, the family's gradual awareness that Zeke at times used his asthma to get attention by exaggerating his symptoms led to their decreased responsiveness to his reports of asthmatic symptoms. No doubt, the intermittent and variable nature of the symptoms further promoted the parents' inconsistent response to their child's report.

Several interventions were undertaken to attempt to change the course and management of Zeke's asthma. First, the patient and his parents were trained in the use of a daily asthma diary to monitor changes in asthma symptoms and lung function (PEFR values were recorded morning and evening). Also, the family was encouraged to limit discussion of asthma until bedtime unless asthma symptoms were reported or observed. Furthermore, the family was urged to engage Zeke in discussing other issues, his behavior, or personal qualities that were unrelated to asthma. Also, the parents became involved in a support group for parents of asthmatics. Follow-up contact up to 2 years after his initial contact with the BMC revealed no recurrence of severe asthma (e.g., requiring hospitalization).

Zeke was next seen by BMC staff at age 14 after being admitted to the hospital because of severe asthma. A brief history revealed that following his BMC referral at age 7, Zeke gradually experienced fewer symptoms, with no episodes after age 12 (until the present). The patient admitted he had stopped all medications for over one year without medical supervision, and that he recently began experimenting with smoking cigarettes. He had enjoyed increased freedom in his life the last few years (e.g., increased involvement in sports) and was scared by the recurrence of asthma. Thus, he seemed motivated to comply with the recommended interventions. First, the recording of daily PEFR values was reinstituted, and Zeke was referred to an asthma support group for adolescents. Second, he was educated about the effects of cigarette smoking on lungs and its relationship to asthma and other lung disease. Third, both he and his parents were educated about the course of the disorder; it appeared that although Zeke was in the process of "outgrowing" the disorder, recurrences were to be expected. Although episodes were likely to be less frequent through adulthood, severe episodes, possibly life threatening, could still occur. It has been 2 years since our contact with Zeke at age 14; all follow-up contact has revealed no recurrence of asthma episodes, although prophylactic medication has been instituted on two occasions on the basis of fluctuations in lung function.

The above case touches on only a very few of the clinical issues found in the treatment of childhood asthma. Others include the misuse of inhalers (or other forms of medication noncompliance), overuse of hospital services, use of illicit drugs, and depression. In asthma management, the availability of a full range of assessment tools and interventions is essential to the complete treatment of the patient and family.

CONCLUSIONS

This chapter has reviewed the application of behavioral techniques to childhood asthma. Owing to morbidity costs associated with asthma, interest in its effective management will continue to increase. Fortunately, progress made during the past two decades shows asthma is particularly amenable to treatment with behavioral procedures. Thus, the foundation has been established for the development and evaluation of integrated medical and behavioral approaches for managing the disorder in the years ahead.

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CHAPTER 12

Childhood Sleep Disorders

RICHARD R. BOOTZIN AND MARK J. CHAMBERS

INTRODUCTION

Almost every child experiences a sleep problem at some time while growing up. In many cases the problem is not serious or long-lasting; an occasional poor night of sleep resulting from stress, excitement, or external disturbances is normal and to be expected. In other cases, sleep problems may have significant effects on the child's normal functioning and general well-being. Furthermore, these problems may have an impact on others as well, notably parents and siblings of the affected child.

Historically, childhood sleep disorders have not been given much attention by either researchers or clinicians. Adding to this problem is the fact that parents are often unaware that a problem exists. An unusually sleepy child, particularly one of preschool age, is rarely a concern for parents, who may be content with letting the child sleep excessively and may even welcome the peace and quiet. Often, such problems are not identified until the child enters school, where the classroom teacher notices the child's sleepiness (and its effect on the child's school performance) and subsequently brings it to the attention of the parents.

Although sleep disorders in children have not been extensively studied, effective techniques for assessment and treatment are available, many borrowing from the literature on adult sleep disorders. In some circumstances, treatment may require medical intervention such as medication, but in a number of cases, psychological and behavioral interventions can be employed with good success.

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THE ARCHITECTURE OF SLEEP

Sleep is not a unitary state but instead is composed of two distinct states, rapid eye movement (REM) and non-REM (NREM) sleep. REM sleep is characterized by heightened brain activation, autonomic arousal, loss of muscle tonus, and rapid eye movements. It is during REM that most dreaming occurs. By contrast, NREM is a relatively quiet state. Brain activity is slow and synchronized, pulse and respiration are slow and regular, and muscle tone is maintained.

For children older than about 1 year, a normal night's sleep typically begins with NREM stage 1. Sleep then gradually deepens through stage 2 until, at stages 3 and 4 (collectively referred to as *delta* or *slow-wave sleep*), the sleeper is quite unresponsive to external stimuli and is often awakened with difficulty. Sleepers awakened from slow-wave sleep are often groggy and disoriented; rarely will they report dreams or dreamlike mentation.

After a period of slow-wave sleep, the sleeper moves back into stage 2, followed by the first REM period of the night, which typically begins about 90 min after sleep onset. This REM–NREM cycle continues throughout the night, although NREM stages 3 and 4 are primarily seen only during the first third of the night.

The sleep of newborn infants, while differentiated into active and quiet sleep, does not have all the features of REM and NREM sleep until about the third month of age. Neonates may sleep as much as 17 hr/day, with up to 50% of that time spent in active sleep, the stage that develops into REM sleep. As the child matures, both total sleep time and the percentage of sleep time occupied by REM gradually decrease, such that by adolescence, total sleep time averages about 7.5 hr, 20–25% of which is REM.

BASIC APPROACHES TO SLEEP DISORDERS

Nearly all clinical sleep disturbances can be placed into one of four categories:

1. *Parasomnias:* Include nocturnal enuresis and sleep-walking, which tend to be disorders of arousal during sleep, usually from NREM sleep
2. *Sleep-phase problems:* Disturbed sleep–wake schedule
3. *Insomnias:* Shortened or disrupted sleep period
4. *Hypersomnias:* Disorders characterized by extreme sleepiness and excessively long sleep periods

A fifth category of sleep disturbance that is frequently described—sleep problems secondary to medical illness—is not discussed here. It should be pointed out, however, that in assessing any sleep problem, a physical examination to rule out potential medical disorders is usually indicated. In most cases, a routine examination is sufficient, as any illness responsible for secondary sleep problems will most likely be readily detected.

Assessment of a sleep disorder should be designed to elicit a complete picture of the problem, including its duration, intensity, and frequency. Among the variables to be evaluated are the child's physical health, medication taken, amount of caffeine in the diet (e.g., in soft drinks and chocolate), stress, psychopathology, and the sleep environment (Bootzin & Engle-Friedman, 1981). It is important for the interviewer to determine why the client(s) believe that the presenting symptoms merit professional attention. In some cases, the symptoms are not actually a problem for the child, but rather a parent is disturbed by them and is the one insisting on treatment. In other cases, the child or family members may feel that the patient's sleep patterns or habits are "abnormal," even though they may not actually present any identifiable problems.

A Sleep Habits Questionnaire (Anders, Carskadon, Dement, & Harvey, 1978) has been developed for use as a screening instrument for children with potential sleep problems, particularly for those children struggling in school for no other apparent reason. The questionnaire yields an index of sleepiness from items designed to assess latency to sleep onset, daytime naps, sleeping through alarms, sleep attacks during school, snoring, daytime energy levels, and impaired daytime functioning.

It is particularly useful to have the child or parents keep a daily diary of the child's sleep problem before treatment is instituted (Bootzin & Engle-Friedman, 1981). Once daily recording is undertaken, families often discover that the problem is not as frequent as previously believed. Daily recording can sometimes be an effective intervention by itself. It helps families adopt a coping attitude about the problem and enables them to notice whether the problem is reducing in frequency. Without daily monitoring, improvement may be unnoticed and each new incident is taken as evidence that the problem still persists.

THE PARASOMNIAS

The parasomnias, traditionally thought of as disorders of arousal, are much more common among children than among adults; when seen in adolescents and adults, these disorders are often associated with psychopathology. The most common of the parasomnias—nocturnal enuresis, somnambulism (sleepwalking), and pavor nocturnus (night terrors)—have a number of features in common. What is particularly significant, however, is that all three appear to be associated with arousal from slow-wave sleep.

Arousals associated with the parasomnias typically occur near the end of the first period of stage 4 sleep, about 1 hr after sleep onset. Physiological symptoms during these arousals reflect autonomic activation: rapid breathing, tachycardia, and profuse sweating. Behavior is usually stereotyped and automatic, and in most cases there is amnesia for the event the following morning.

Familial coincidence of the parasomnias is relatively common, suggesting the possibility of genetic transmission. There has also been some speculation that the various parasomnias may simply be different manifestations of the same general disorder; in fact, children frequently display more than one of the parasomnias, although not usually at the same point in their development.

Nocturnal Enuresis

Because of widely differing definitions of the disorder, prevalence rates for nocturnal enuresis are difficult to pin down; Guilleminault and Anders (1976), for example, report that 5–17% of children between the ages of 3 and 15 years may have bedwetting problems. For many clinicians and researchers, defining a bedwetting problem presents its own problems, particularly in determining the age and frequency at which bedwetting should be considered a disorder. Feldman (1983) argues that children under 5 years of age—boys in particular—should not be diagnosed as having nocturnal enuresis, especially considering that 14–38% of all 4-year-old boys wet the bed regularly. The best strategy, he suggests, is to consider as a disorder any problem that is disturbing to either the child or the parents. Fraser (1972), however, advises that attention be given to all frequent bedwetting, even if it is not considered a problem by the family, as regular enuretics are at a higher risk of urinary tract infection.

Assessment

A bedwetting problem may be characterized as either primary or secondary enuresis. A child with primary enuresis has always had bedwetting problems and has never had any extended dry periods. A child who has gone for a significant amount of time without enuresis and then begins wetting the bed again is referred to as a secondary enuretic. Primary enuresis is more common but is rarely seen beyond age 8; enuresis in children older than 8 years is likely to be a secondary problem. There is some evidence that primary enuretics differ from children with secondary enuresis on certain dimensions. Primary enuretics have been found to have smaller functional bladders than that of secondary enuretics (Troup & Hodgson, 1971). Some investigators have suggested that primary enuresis may have more of a genetic factor (J. D. Kales, Soldatos, & A. Kales, 1980). Organic and learning disorders are more frequently cited as causes of primary enuresis, whereas emotional disturbance is more commonly implicated in secondary enuresis. Finally, although boys are generally more likely to be enuretic than girls, this is especially true for secondary enuresis.

Parents of enuretic children often describe them as being heavier sleepers than their nonenuretic siblings (Feldman, 1983); in fact, enuretic children have been found to have more slow-wave sleep than nonenuretic children (Anders & Weinstein, 1972). Most enuretic episodes occur during the first third of the night and appear to be associated with arousal from NREM stages 3 and 4 (McClain, 1979). The accompanying phenomena during these arousals may include tachycardia, rapid breathing, increased muscle tone, decreased skin resistance, and in males, penile erection. Somnambulism is also seen more frequently in enuretic children than in the general population. However, the average age of onset tends to be later than for nocturnal enuresis (Klackenberg, 1981).

Some researchers and clinicians have proposed that emotional disturbance may be responsible for some cases of nocturnal enuresis, particularly when it is seen in older children (Fraser, 1972). According to Klackenberg (1981), bedwetters are more likely to demonstrate episodes of aggression, fear of the dark, defiance, and poor school performance than are nonenuretic children. Other studies (Hallgren, 1956; MacKeith, 1972) indicate that enuretics show a higher incidence of anxiety. However, the role of psychopathology in nocturnal enuresis has been questioned by others. Werry (1965) argued that emotional disturbance is present only in a few of cases and that when it is present, other explanations of its relationship to the enuresis may exist. Feldman (1983) echoes this argument. "Enuresis may cause emotional problems in children and families," he states, "though the reverse is usually not true" (p. 115).

Treatment

A variety of techniques are available for the treatment of nocturnal enuresis and, with the exception of organic etiologies such as urinary tract infection, treatment approaches usually do not differentiate between primary and secondary enuresis. In choosing a treatment plan, it is important to consider its potential side effects. As pointed out by Weir (1982), the sequelae of nocturnal enuresis are relatively innocuous; therefore, an attempt should be made to choose a treatment with few aversive features. Another reason for proceeding cautiously with treatment is that the rate of spontaneous remission for the disorder is as high as 20% (Forsythe & Redmond, 1974); other cases may improve simply due to placebo effects (Weir, 1982).

Because some enuretics have small bladder capacities, one treatment strategy employs bladder training, designed both to increase the child's bladder capacity and to increase general control of micturition. This treatment involves giving the child unrestricted access to fluids during the day, with the instruction that he refrain from urinating up to a point of minimal discomfort. The child is also asked to practice stopping and then resuming the flow of urine during elimination. McClain (1979) claimed a success rate of 30% for this method but, as this is not substantially higher than the rate of spontaneous remission, the actual effectiveness of bladder training has been questioned. Some investigators have disputed the claim that this technique actually increases bladder capacity (Doleys, 1977); some have suggested that it may instead simply help make the child more aware of the sensations associated with elimination and a full bladder (McClain, 1979).

Classical conditioning treatment, which uses a bell-and-pad system designed to sound an alarm when bedwetting occurs, has generally been regarded as the most effective method for treating nocturnal enuresis. Reported success rates have ranged as high as 75% (Fraser, 1972; McClain, 1979), with best results in children older than 7 years (McClain, 1979). Failure of this method is often due to inconsistent use (resulting from parent and/or child resistance), mechanical problems, or a tendency of the child to sleep through the alarm. When this latter problem arises, it may be necessary initially for a parent to sleep in the child's room and awaken him or her when the alarm sounds. In all circumstances, however, the child should be required to turn off the buzzer.

Although this treatment was developed from classical conditioning principles in which cues of a full bladder are to be conditioned to elicit arousal, it may also involve avoidance-learning principles in which staying dry allows the child to avoid being awakened by the buzzer. In support of the avoidance-learning interpretation, children who improve often sleep through the night without wetting the bed.

If the bell-and-pad treatment is to be employed to treat nocturnal enuresis, it is recommended that the apparatus be used consistently for 2–4 months, or until the child is dry for 4 consecutive weeks. If satisfactory results have not been obtained within 4 months, use of the buzzer should probably be discontinued.

A number of treatment programs for nocturnal enuresis have been described that combine information and support with reinforcement strategies. For any treatment program, it is certainly important to help inform both the child and the parents of the prevalence and nature of the disorder. All parties involved may be comforted by knowing that the problem is not an unusual one; in some cases, it may be necessary to make it clear that the child does not intentionally wet the bed, and therefore punishment is not appropriate. Involving the child in treatment planning and execution is strongly advised; in doing so, the therapist should encourage the child to assume responsibility for the problem. To facilitate this, a reinforcement system, such as stars on a calendar for dry nights, can be instituted.

Some medications, the tricyclic antidepressants in particular, have been shown to have limited effectiveness in controlling enuresis. They have been found to have relatively low success rates, while relapse rates following withdrawal from the drugs are high (J. D. Kales *et al.*, 1980). In cases in which medication is the only treatment found to be effective, its use should probably be reserved for special occasions, such as when the child spends the night with a friend.

Somnambulism

Guilleminault and Anders (1976) estimate that about 15% of all children walk in their sleep at least once between the ages of 5 and 12. As a more persistent problem, however, reported prevalence rates for the disorder range from 1 to 6%. Sleepwalking is more common in boys than in girls, and in children than adults, with the peak onset of the disorder occurring around 11–12 years of age.

Assessment

Sleepwalking episodes are typically precipitated by an arousal from NREM stage 4. At the start of an episode, the child may abruptly sit up in bed, eyes open but with a glassy appearance. Movements are clumsy and automatic, and speech is generally incoherent or monosyllabic. An episode may last from a few seconds to 30 min or more, but there is usually amnesia for the event the following morning.

Although it is commonly believed that the sleepwalker is acting out a dream, this is usually not the case; electroencephalographic (EEG) recordings during these episodes indicate a mixture of waking and NREM brain-wave patterns. Sleepwalkers have been injured by leaving the house, for example, but accidents resulting from somnambulism are rare (Klackenberg, 1982). Nevertheless, it is advisable to protect the frequent sleepwalker with basic measures such as locks on windows and outside doors and by having the child sleep on the ground floor (J. D. Kales *et al.*, 1980).

Familial studies have indicated that genetic factors are strongly implicated in the etiology of somnambulism. The prevalence of the disorder in the family of a sleepwalker has been demonstrated to be significantly higher than that of the general population (A. Kales, Soldatos, Bixler, Ladda, Charney, Weber, & Schweitzer, 1980). Moreover, monozygotic twins were found to show six times as much concordance for the disorder as dizygotic twins (Bakwin, 1970). However, environmental elements may also play a part in the occurrence of somnambulism, as factors such as febrile illness (J. D. Kales, A. Kales, Soldatos, Chamberlin, & Martin, 1979) or stress (Anders & Weinstein, 1972) have also been known to precipitate sleepwalking episodes. Furthermore, sleepwalking can be produced in children with a predisposition for somnambulism by awakening them from stage 4 sleep using an external stimulus, such as a buzzer (Anders, 1987). In adults, sleepwalking appears to be associated with psychopathology, but a consistent relationship between somnambulism and emotional disturbance in children has yet to be demonstrated.

Treatment

In most cases, treatment of somnambulism is unnecessary, particularly if the sleepwalking episodes occur only occasionally. Instead, it may be necessary to reassure the parents that there is no cause for concern and that the episodes usually disappear spontaneously with increasing CNS maturity (Klackenberg, 1982). Both diazepam and imipramine have been reported to be effective for sleepwalking (J. D. Kales *et al.*, 1980). In cases in which the episodes are frequent and disruptive, medication may be used but, since the long-term effects of psychotropic drugs on children are unknown, it is advised that, as with nocturnal enuresis, medication be reserved for occasions when the child sleeps outside the home. A more complete psychological assessment may be indicated if the onset of the disorder is later than age 12, if episodes continue on a frequent basis for several years, if there is no family history for the disorder, or if there is evidence of abnormal daytime behavior (J. D. Kales *et al.*, 1980).

Pavor Nocturnus and Nightmares

Pavor nocturnus share a number of features with sleepwalking. Most episodes occur during the first third of the night and appear to arise from NREM stage 4 awakenings. Although night terrors are often mistaken for nightmares, night terrors do not have the elaborate sleep mentation of dreams, but instead usually produce a general feeling of threat, danger, or being suffocated. Like somnambulism, night terrors are accompanied by extreme autonomic arousal, and in the morning there is amnesia for the event. There is a high rate of familial coincidence for night terrors, but not for nightmares. Although night terrors are somewhat less prevalent than sleepwalking (1.5% versus 2.5% for somnambulism), there is evidence that night terrors possess a higher degree of heritability (A. Kales *et al.*, 1980). Environmental factors are also involved in both night terrors and nightmares, as episodes have been observed in connection with febrile illness (J. D. Kales *et al.*, 1979) and post-traumatic stress (Marshall, 1975).

Assessment

Night terrors are brief, vague, terrifying sensations experienced by the child during sleep. During an episode, screaming or crying and psychomotor agitation are the most prominent behavioral signs. Verbalizations are, for the most part, incoherent, and some sleepwalking may occur. In most cases, the child appears frightened, disoriented, or confused; attempts to console the child may be met with resistance or even wild thrashing, tossing, and turning. These episodes may last 30 min or longer, but eventually the child will calm down and return to sleep.

In some instances, it may be difficult to distinguish a night terror from a nightmare. However, if the episode occurs during the latter half of the night, if the child is relatively coherent and alert immediately following the incident, or if the child reports detailed or vivid imagery, it is more likely to have been a nightmare than a night terror. The nightmares of preschool children often relate to a fear of being punished or devoured (J. D. Kales *et al.*, 1980). They are common in children between the ages of 3 and 8.

Night terrors appear to reflect a predisposition to an abnormal pattern of arousal from slow-wave sleep, although little is known about the etiology of this predisposition other than that it appears to be genetically transmitted. As with the other parasomnias, however, the question has been raised concerning a possible association with psychopathology. Most investigators seem to agree that a thorough psychological assessment is indicated if the disorder is seen in adulthood (J. D. Kales, Davis, Russek, Martin, Kuhn, & Kales, 1978), but it has been suggested that psychological disturbance may be responsible for some cases of childhood pavor nocturnus as well, particularly when episodes occur frequently (i.e., three or more times per week) over a period of months. In such cases, the child may demonstrate anxiety or behavioral problems, and there may be a familial history of psychopathology (Keith, 1975).

Treatment

The choice of treatment for night terrors or nightmares should be determined by the severity of the symptoms. Treatment is usually not indicated, particularly because the rate of spontaneous remission is high. It is important to reassure parents that nightmares in children are common and are part of normal development. Similarly, parents of children with night terrors should be assured that the night terrors will decrease as the child matures. Parents should be encouraged to be comforting to their children when an episode occurs, but not to wake them up if waking has previously produced fright and anxiety.

The treatment of night terrors with medication has proved effective in some cases. Diazepam (Valium) tends to be the drug of choice for this disorder; its effectiveness is believed to be a function of its delta-sleep-suppressing properties, as studies have suggested that the occurrence of night terrors may be related to the amount of delta sleep prior to an awakening (Fisher, Kahn, Edwards, & Davis, 1973). However, it may be possible to control the quantity of delta-sleep in the child's sleep without medication, using naps and earlier bedtimes. Because delta sleep time is frequently elevated in those who do not receive adequate sleep, either a nap or an earlier bedtime, or both, may help prevent the child from being as tired and thus relieve some of the pressure for delta sleep. Even if this strategy is unsuccessful, the use of medications should be carefully considered and should probably be reserved for special circumstances. Finally, before employing a sedating medication such as diazepam, it is necessary to rule out sleep apnea as a source of the night terrors, as diazepam depresses respiratory function (Hauri, 1982).

In situations in which nightmares or night terrors persist at a high rate, daytime factors such as stresses at school, family conflicts, or emotional disturbance may be implicated. A thorough psychological assessment should be undertaken, and individual or family therapy may be indicated.

SLEEP-PHASE DISORDERS

Many physiological functions, such as body temperature, hormone secretion, and sleep–wake cycle, follow a daily or circadian rhythm. In many circumstances involving a complaint of sleeping difficulties, a disturbance of the sleep–wake circadian rhythm may be responsible. This occurs when the body's biological clock does not correspond to usual bedtime hours.

Assessment

There are two sleep–wake rhythm problems: delayed sleep phase, and advanced sleep-phase syndrome. In the case of delayed sleep-phase syndrome, complaints typically concern an inability to fall asleep until several hours after going to bed, a tendency to sleep later than the usual awakening time, or difficulty getting up at the time dictated by the individual's schedule. Those suffering from advanced sleep-phase syndrome fall asleep hours before their scheduled bedtime and likewise awaken several hours early in the morning. In both syndromes, the sleep itself is normal, provided it occurs during the times demanded by the body's circadian rhythms.

For most people, the body's natural sleep–wake rhythm does not follow a strict 24-hr cycle, but is closer to 25 hr. The circadian rhythm is typically entrained to a 24-hr schedule by daylight, meals, and social interaction. If this entrainment fails, a sleep-phase problem may develop. Although frequent changes or irregularities in the sleep schedule are often responsible for sleep-phase disorders, the drift caused by the natural 25-hr circadian rhythm is most frequently the culprit, which is why delayed sleep-phase syndrome is more common.

Treatment

Advanced sleep-phase syndrome is uncommon, but some parents may be concerned that their child regularly wakes up earlier than the rest of the family. To correct this problem, the child's bedtime should gradually be shifted to later in the evening, perhaps by 10 min each day. As bedtime is adjusted, morning waking times will follow suit, although these changes may lag behind changes in the bedtime by a few days. These adjustments can then be continued until the desired bedtime and waking time are achieved.

Delayed sleep-phase syndrome is a much more prevalent and troublesome disorder than advanced sleep-phase problems. Bedtime can become the source of a number of conflicts between the child and other family members, notably the parents. When the child's bedtime arrives, he or she may complain of not being tired, and resistance on the part of the child to being sent to bed is not uncommon. It is important to discriminate delayed sleep-phase syndrome from a parental desire to have the child go to bed earlier than necessary. The child's morning behavior is an important cue. If the child has extreme difficulty awakening in the morning and is fatigued and irritable for much of the early part of the day, delayed sleep-phase problems are likely.

Treating delayed sleep-phase syndrome is somewhat more problematic than interventions for advanced sleep-phase problems because any attempts to establish an earlier bedtime oppose the natural tendency of the circadian rhythm. An effective approach to this problem is for parents to move the child's morning waking time earlier gradually, while discontinuing efforts to have the child go to bed before he or she is tired. If the child does not go to bed until late, the progressively earlier morning awakening times will produce some minor sleep deprivation, and the child will gradually become tired earlier. After a few days of earlier wakening times, the parents can begin advancing the child's bedtime by equivalent increments until the desired bedtime is attained. Once the goal has been reached, measures should be taken to maintain the child on a consistent sleep schedule.

Teens appear to be the most susceptible to delayed sleep-phase syndrome (Anders, Carskadon, & Dement, 1980; Ferber, 1985). One reason for this may be that on weekends teens tend to stay up late and then sleep late the next day. This practice serves to shift their circadian rhythms to a later cycle, with the result that during the week, they may find it difficult to fall asleep at night and even more difficult to get up the following morning. The strategy of maintaining a consistent waking time for all 7 days of the week is an important element in regularizing the sleep–wake schedule. Other elements can be added to facilitate wakefulness in the morning, such as letting in daylight upon awakening, having breakfast, putting on the radio or TV, and engaging in social interaction.

For children who do not respond to this strategy, stimulus-control instructions described in the section on insomnia) or chronotherapy may be appropriate. Chronotherapy (Czeisler, Richardson, Coleman, Zimmerman, Moore-Ede, Dement, & Weitzman, 1981) is a treatment for severe phase-delay problems in which the individual follows a 27-hour day, moving bedtime around the clock until the desired bedtime is reached. At that point, the child reverts to a 24-hr day. This treatment can only be followed during a period when the teen has no regular daytime obligations. Relapse rates with this method are likely to be high, unless the variables that led to the original problem (such as staying up late on weekends) are corrected.

Case Illustration

The following case, reported by Ferber (1985), describes a typical example of delayed sleep-phase syndrome in children:

> Vanessa was a 7-year-old who, although well behaved during the day, vigorously resisted going to bed at her usual bedtime, 8:30 PM. Once in bed she would complain of stomach pains or claim that she was frightened and wanted the lights left on. Most nights she would not fall asleep before 11:00 PM. In the morning, she was difficult to wake up and was groggy and irritable through most of the morning routine.
>
> On weekends and vacation, Vanessa would usually sleep late, and on those occasions would be congenial and in good spirits. Furthermore, if she was allowed to stay up late, she went to bed without objections and had no trouble falling asleep.
>
> In constructing a treatment plan for Vanessa, it was impractical to let her sleep until her natural waking time because she had to get up for school. Instead, it was suggested that she be allowed to move bedtime to 11:00 PM in order to eliminate the conflicts provoked when she was forced to go to bed earlier in the evening. She was awakened at the same time every morning, including weekends, and although this may have left her somewhat tired during the day for the first few weeks of the program, it made it easier for her to fall asleep at bedtime. Her bedtime was gradually shifted to earlier times, so that after about 3 months, Vanessa was going to bed at 8:30 PM without objections.

INSOMNIA

Compared with an adult population, insomnia is relatively rare among children, particularly those younger than 5 years of age; when present, it is often the result of transient phenomena such as illness or stressful life events (e.g., the death of a family member). When sleep problems are longer lasting, however, poor sleep habits, a disruptive sleep environment, or emotional problems should be considered possible causes. Among a general pediatric population, estimates of prevalence rates for insomnia range from 5% (Bixler, Kales, Scharf, Kales, & Leo, 1976) to 14% (Dixon, Monroe, & Jakim, 1981); among child psychiatric patients, however, these rates may be as much as three times higher. Poor sleepers have been shown to exhibit more anxiety, depression, sensitivity, and somatic concerns than do good sleepers (Marks & Monroe, 1976), and among high school students, poor sleep had been associated with mood disturbance and negative self-image (Price, Coates, Thoresen, & Grinstead, 1978).

Paradoxically, dependency on hypnotic medications may be the most common cause of insomnia among older children and adolescents (Coates & Thoresen, 1981; Ferber, 1985; Guilleminault & Anders, 1976), as chronic use has been shown to impair sleep as compared with baseline (Kales & Kales, 1974). A survey of 12- to 17-year-olds (Abelson, Fishburne, & Cisin, 1977) found that 2.9% reported having used a sedative or tranquilizer during the past month, and 6.9% claimed to have used sleeping medication during the past year. Hypnotics may initially be prescribed for short-term episodic sleep problems, but dependence and the accompanying drug-dependent insomnia can develop rapidly, sometimes in as little as 1 week. Attempts to discontinue the drug usually result in withdrawal effects, which temporarily worsen sleep and persuade patients to conclude erroneously that their sleep is better with the drug than without it.

Assessment

In assessing the nature and severity of an insomnia problem, multiple sources of information should be used in order to maximize the reliability of the assessment. Often there is poor correspondence between sleep-related complaints of children and observations by parents; many times neither provide reports that accurately reflect data obtained from sleep recordings or behavioral observations. Frequently parents and even the child may not be aware that sleep deficiencies exist. In a study of children defined by sleep recording as suffering from insomnia, most of the subjects and their parents considered the child's sleep to be of average or better quality (Dixon *et al.*, 1981). Self-reports by the patient are more likely to exaggerate the problem, however; two thirds of insomnia patients studied by Carskadon and colleagues underestimated their total nocturnal sleep time by at least 60 min, compared with measurements from objective sleep recordings (Carskadon, Dement, Mitler, Guilleminault, Zarcone, & Spiegel, 1976).

In order to get a clear picture of the patient's sleep habits and the severity of the presenting problem, sleep diaries should be used (Bootzin & Engle-Friedman, 1981). Each day the patient or the parents record information relevant to the quality of the previous night's sleep, such as the time taken to fall asleep or the number of awakenings during the night, as well as any factors that may be associated with poor sleep, such as naps during the day. Although sleep diaries still rely on self-report, they provide a more accurate record of the incidence and frequency of the presenting complaint than might be obtained by retrospective reporting. In circumstances in which self-reported information is still suspect, however, sleep recordings may be necessary.

An assessment of the sleeping environment may also help pinpoint potential causes of sleep problems. Noise and heat, as well as how much the child feels at ease in the bedroom, can all be important factors. Other behaviors and habits that may affect the child's sleep, such as diet and activities before bed, should be examined as well. In many cases, the use of caffeinated or highly sugared products late at night may be responsible for sleep problems. Coates and Thoresen (1981) also suggested that the use of antihistamines may cause daytime drowsiness, giving the impression that the previous night's sleep was poor.

Treatment

Probably the most effective means of treating childhood insomnia is to make the bedroom a comfortable, secure environment for sleep. Establishing the proper cues for sleep in the sleep environment is a major component of this process. For instance, children who are regularly sent to their rooms as punishment may come to associate the bedroom with feelings of fear and anxiety, feelings that may keep them awake at night, when it is time to sleep. Changes in bedtime routine may also affect sleep cues. For young children, parents often stay in the room until the child is asleep or may frequently let the child sleep with them in their room. However, children may come to depend on the presence of the parents as a stimulus for sleep, so that when the parents begin sending them to bed alone, they may simply lie awake crying until the parents come in to sit with them.

If a child has trouble falling asleep or awakens frequently during the night, parents should be encouraged not to establish a pattern of going into the room to attend to the child, as this attention is likely to provide reinforcement for the sleep problem. If such a pattern has already been established, the parents should keep their visits to reassure the child brief. They should make it a point to leave the room before the child falls asleep. For younger children, for whom separation issues may be a factor in the sleep problem, a substitute object such as a teddy bear or a special blanket may help ease the transition. In most instances, anxieties children may have about sleeping or being in a dark room can be alleviated by parental reassurances that they will be safe and protected. If the child desires it, there is no reason why a nightlight cannot be used.

Insomnia in young children is quite amenable to treatment. In an evaluation of treatment for 35 children aged 1–5 having persistent sleep problems, 77% improved. Individualized treatment consisted of having parents withdraw attention from the wakeful child, provide positive reinforcement for going to sleep with praise or star charts, and making a sharp distinction between daytime and nighttime activities by developing a bedtime ritual (Richman, Douglas, Hunt, Lansdown, & Levere, 1985).

In some instances, childhood insomnia may be associated with emotional disturbances, particularly attention-deficit disorder, depression, or conduct disorder (Dixon *et al.,* 1981); in such cases, these disturbances should be treated. For most, if not all, cases of insomnia in children, the use of hypnotic medication should be discouraged. Such medications rapidly lose their effectiveness and can lead to even more impaired sleep through drug-dependent insomnia (*vide supra*). Although sleeping pills are usually only given to children for temporary sleeping difficulty, they can quickly lead to dependence.

Persistent sleep problems in older children can be treated with the same treatments that have been found to be effective with adults such as relaxation training and stimulus-control instructions (Bootzin & Nicassio, 1978; Borkovec, 1982). The goals of stimulus-control instructions are to help the insomniac acquire a consistent sleep rhythm, to strengthen the bed as a cue for sleep, and to weaken it as a cue for activities that might interfere with sleep. Some teenagers may have such irregular sleep schedules that they do not acquire a consistent sleep rhythm. Another aspect of the problem is that the sleep-disturbed child may engage in activities in the bedroom at bedtime that are incompatible with falling asleep, such as reading, watching television, or worrying. Thus, the bed and bedroom may become cues for arousal rather than cues for sleep.

From the preceding analysis, a stimulus-control treatment for insomnia was developed (Bootzin, 1972, 1977) to strengthen the cues for falling asleep and separate them from cues for other activities. The following rules constitute the stimulus-control instructions:

1. Lie down intending to go to sleep only when you are sleepy.
2. Do not use your bed for anything except sleep; that is, do not read, watch TV, eat, or worry in bed.
3. If you find yourself unable to fall asleep, get up and go into another room. Stay up as long as you wish and then return to the bedroom to sleep. Although we do not want you to watch the clock, we want you to get out of bed if you do not fall asleep immediately. Remember, the goal is to associate your bed with falling asleep quickly! If you are in bed more than about 10 min without falling asleep and have not gotten up, you are not following this instruction.
4. If you still cannot fall asleep, repeat step 3. Do this as often as necessary throughout the night.
5. Set your alarm and get up at the same time every morning, no matter how much sleep you got during the night. This will help your body acquire a consistent sleep rhythm.
6. Do not nap during the day.

Stimulus-control instructions have proved effective in case studies and controlled evaluations (Bootzin & Engle-Friedman, 1987). Although the focus of most evaluations has been on sleep-onset latency, improvement in total sleep and number and duration of awakenings has also been reported.

Case Illustration

The following case of an 11-year-old girl was provided from the records of the Insomnia Clinic at Holy Cross Hospital in Mission Hills, California, by Michael Stevenson.

> Jennifer reported considerable difficulty in falling to sleep. Almost every night it took 1–2 hr to fall asleep, sometimes as long as 3 hr. She often did not fall asleep until around midnight, even though she had to be up for school at 6:00 AM. In addition, Jennifer reported that she had nightmares involving being chased by monsters two to three times a week.

Jennifer's typical nighttime routine was to watch television in the living room until 9:00 PM, at which point she would get ready for bed. Once in bed, she read for awhile before turning out the lights. She reported that she often felt sleepy while reading but would then be wide awake as soon as she turned off the lights. With the lights off, her mind would race. In particular, she worried that she would get spinal meningitis from not sleeping, apparently because of a concern expressed by her father that she would get sick if she did not begin to sleep longer. She was therefore quite worried about whether she would be able to fall asleep each night.

The treatment focused on reassurance and stimulus-control instructions. Jennifer kept a daily sleep diary to keep track of her progress. First, she was assured that she would not get spinal meningitis from poor sleep. The pressure from Jennifer's father had been substantial, as indicated by the fact that he was dissatisfied with the progress being obtained after only 1 week of treatment.

In implementing the stimulus-control instructions, Jennifer was told not to read, do her homework, or worry in bed. She was to confine her homework to her desk. If she was unable to fall asleep within 15–30 min or if she was awake that long in the middle of the night, she was to get out of bed and go into the living room until she felt sleepy or until 30 min had passed. At this point she was to return to bed and focus on relaxing. If she still could not fall asleep, she was to repeat getting out of bed as often as necessary. She was also instructed to get up at approximately the same time of the morning 7 days a week.

Within 3 weeks, Jennifer reduced her sleep latency to 10–15 min from the 1–2 hr reported at the beginning of treatment. No nightmares were reported once treatment began.

THE HYPERSOMNIAS

The primary features of the hypersomnias are excessive daytime sleepiness (EDS) and extended nocturnal sleep periods. Of these, EDS appear to have the greatest impact on daily functioning. In children, school problems often result from EDS, and usually it is not until the child experiences problems in school that these disorders are identified and correctly diagnosed. J. D. Kales *et al.* (1980) estimated that as many as 25% of infants and preschool children have some type of sleep problem. Guilleminault and Anders (1976) report that among their patients referred by teachers because of sleepiness in class, the daytime sleepiness had existed an average of 28 months, and in one case as long as 7 years.

Although a child with EDS may fight to stay awake, short periods of sleep known as microsleep may still occur. During a microsleep, which may last 5–15 sec, the child's eyes may remain open, but they take on a glassy "unseeing" look. Behavior becomes somewhat automatic and, although the child may be capable of answering simple questions with short, monosyllabic answers, more elaborate responses are likely to be incoherent and inappropriate. Most importantly, however, the child's information-processing capabilities are severely impaired during a microsleep episode. These episodes not only interfere with perception, but they also seem to disturb the integration of information from short-term memory to long-term memory, resulting in retrograde amnesia for periods as long as several hours. The effect of this phenomenon on the learning process is so great that it is not uncommon for children with EDS to have originally been misdiagnosed as borderline mentally retarded.

Narcolepsy

The defining characteristic of narcolepsy is the presence of sleep attacks, i.e., sudden irresistible urges to sleep. This is most frequently observed as EDS. However, the symptoms of narcolepsy usually extend beyond EDS. Cataplexy, hypnogogic hallucinations, and sleep paralysis have also been observed in association with narcolepsy; although only a small number of narcoleptics exhibit all these signs, most patients develop at least one of the auxiliary symptoms as well as EDS.

The onset of narcolepsy tends to occur during adolescence. Most patients first present with the disorder between 15 and 25 years of age (Guilleminault & Anders, 1976), with the mean age of onset at about age 19 (Kessler, Guilleminault, & Dement, 1974). However, cases have been observed in children as young as 3 years of age (Yoss & Daly, 1960), and some clinicians have indicated that a substantial percentage of the narcoleptic population may suffer from the early symptoms, particularly EDS, many years before identification of the disorder (Guilleminault & Anders, 1976).

Estimates of prevalence rates for narcolepsy range from 0.02 to 0.09% (Coates & Thoresen, 1981), although in children this disorder may be significantly underidentified. There is also strong evidence that narcolepsy may be genetically transmitted; incidence of narcolepsy among the family members of narcoleptics is around 5%, 60 times greater than the general population (Kessler *et al.*, 1974).

Assessment

Excessive daytime sleepiness usually is the first symptom to appear in narcoleptics, along with a tendency to sleep long at night. However, most of these patients also report signs of cataplexy, characterized by episodes during which the person experiences a sudden loss of muscle tone, resulting in temporary paralysis. In some instances, these attacks may not involve the entire peripheral musculature but may be restricted to smaller regions, most commonly the face and neck. Cataplectic attacks are often precipitated by emotional arousal, such as laughter, anger, or excitement, and their presence is considered a pathognomonic sign of narcolepsy.

Hypnogogic hallucinations and sleep paralysis are also often components of the narcoleptic syndrome. Hypnogogic hallucinations occur at sleep onset and are usually auditory, such as noises or voices. Visual hallucinations are often amorphous shapes and colors, although more detailed images have been reported. Hypnogogic hallucinations are frequently accompanied by sleep paralysis; frightened by the hallucinations, the child may attempt to escape, only to discover that he or she is unable to move. The simultaneous occurrence of these two symptoms can be an extremely terrifying experience for the child and often may lead to a stubborn reluctance to go to bed at night.

Cataplexy, hypnogogic hallucinations, and sleep paralysis are all believed to represent abnormal manifestations of REM sleep. For normal sleepers, the beginning of the sleep period begins with NREM stage 1. By contrast, narcoleptics have been found to exhibit sleep-onset REM periods (SOREMPs), i.e., REM periods occurring less than 15 min after sleep onset. Although SOREMPs are occasionally seen in normal subjects, frequent SOREMPs are considered pathognomonic for narcolepsy. Hypnogogic hallucinations and sleep paralysis result from the dreamlike mentation and suppression of muscle tone associated with these REM periods occurring at sleep onset. The muscle paralysis characteristic of cataplexy is likewise believed to be a sign of REM sleep intruding into the waking state.

In assessing a patient for the presence of narcolepsy, Coates and Thoresen (1981) suggested asking the following two questions: Does the child experience sudden and irresistible urges to sleep during the day? (2) Does the child have peculiar attacks of muscular weakness precipitated by strong emotions such as laughter, anger, or fright? An answer of "yes" to both questions strongly indicates a diagnosis of narcolepsy, although sleep recordings should be carried out to confirm the diagnosis. Particularly useful is the Multiple Sleep Latency Test (MSLT), in which the patient is recorded while falling asleep four or five times during the day (Association of Sleep Disorders Centers, 1986). Sleep recordings are helpful by revealing the presence of SOREMPs, which may appear before the first signs of cataplexy are detected. Because the appearance of cataplexy may follow the onset of EDS by as many as 10 years, this approach may lead to earlier detection of narcolepsy.

Treatment

In most cases, some form of drug therapy is necessary for the treatment of narcolepsy. Tricyclic antidepressants are often used to control the REM-related symptoms of narcolepsy (capaplexy, hypnogogic hallucinations, and sleep paralysis), primarily because of the tendency of these drugs to suppress REM sleep. These medications are usually sufficient to keep the more debilitating features of narcolepsy in check. When tricyclics alone are ineffective, however, stimulants such as methylphenidate (Ritalin) may be used to control EDS and sleep attacks.

The psychosocial consequences of narcolepsy are substantial. The family will need help in providing a supportive environment and in ensuring medication compliance. An explanation of the disorder and its symptoms can help make the transition to a new schedule and daily routine somewhat smoother. The patient will also need help in developing coping strategies for those occasions in which sleep attacks or cataplexy occur. If medication is prescribed, a medication compliance program may be necessary, particularly if the child or parents are somewhat resistant to the use of drugs. This is most important at the time when the symptoms first begin to abate as a result of the drug use, for parents may conclude that the drug is no longer necessary and discontinue its use.

The severity of the associated symptoms should be carefully assessed before drug treatment is considered for narcolepsy; in general, drug treatment is contraindicated for children younger than 10 years of age. Coates and Thoresen (1981) suggested that, in some instances, behavioral strategies may be employed to obviate or at least reduce the need for pharmaceuticals. In particular, they recommend using behavioral assessment to identify situations in which sleepiness or cataplexy might be especially likely. With the results of this analysis, the patient can then be assisted in constructing strategies designed to avoid such situations. Incorporating frequent napping into the schedule can also help reduce EDS.

Case Illustration

Although full-blown narcoleptic symptoms are rarely seen before age 10, exceptions do occur, as illustrated in the following case described by Wittig, Zorick, Roehrs, Sicklesteel, and Roth (1983).

> Danny, a 7½-year-old boy, was referred to the sleep disorders center by his mother, who complained of his excessive daytime sleepiness and a tendency to fall asleep in almost any situation, despite 10 hr of nocturnal sleep and two daily naps of 1–1½ hr each. It was also reported that during episodes of laughter or excitement, Danny would experience sudden weakness, occasionally falling down, although never losing consciousness. Danny also claimed to see faces of people in his bedroom at night, and during these hallucinations he found himself unable to move.
>
> Danny's past medical history was unremarkable, with the exception of chickenpox and a tonsillectomy, both at about age 6. Family medical history was equally free of major medical disorders. His mother, however, stated that she frequently fell asleep with inactivity and spoke of "losing her balance" with laughter.
>
> Danny's sleep was assessed with a nocturnal polysomnogram and a daytime MSLT. Both assessments revealed sleep-onset REM periods, and the average sleep latency on the MSLT was 1.5 min, which compares with an average of 19 min for children of his age. Narcolepsy was diagnosed and medications prescribed. Within a week, Danny's cataplexy had disappeared, he was more alert, and he found it easier to stay awake in school. After several months, his mother attempted to discontinue the medication, but with the return of the symptoms, the medication was resumed.

Sleep Apnea

Sleep apnea is defined by repeated episodes during nocturnal sleep in which there is a cessation of airflow through the mouth and nostrils lasting at least 10 sec. Most definitions specify that at least 30 such episodes must occur during a 7-hr sleep period to qualify as sleep apnea syndrome, although most patients suffering from this disorder experience nightly apneic episodes numbering in the hundreds. These episodes have a severely disruptive effect on sleep, as the person awakens at the end of each episode to breathe. The awakenings are not usually remembered in the morning; in fact, the person may believe that he or she had a normal night of sleep.

As a result of the frequent sleep disturbances and the impaired respiration associated with sleep apnea, a number of secondary symptoms may develop, such as snoring, morning headaches, EDS, poor school performance, nocturnal enuresis, and cardiovascular abnormalities, hypertension in particular. Other symptoms that have been seen somewhat less frequently in association with sleep apnea include emotional problems, hyperactivity, personality changes, reports of terrifying nightmares, refusal to go to bed, and significant fluctuations in weight. As with narcolepsy, the EDS that results from sleep apnea can have a profound effect on school performance; some researchers have suggested that this problem is exacerbated by the repetitive hypoxia associated with apneic episodes. Guilleminault and Anders (1976) reported that 35% of children treated by them for sleep apnea had previously been diagnosed as borderline mentally retarded.

The mean age at diagnosis for children with sleep apnea is approximately 7 years (Mauer, Staats, & Olsen, 1983). In general, however, younger children with sleep apnea are less likely to show signs of hypersomnolence and EDS than are older children. Sleep apnea is also more common in boys than girls; in the population described by Guilleminault and Anders (1976), 86% of the children with the syndrome were boys.

Three types of sleep apnea have been identified: upper airway apnea, central apnea, and mixed apnea. In upper airway apnea (also called obstructive apnea), airflow through the mouth, nose, or pharynx is obstructed despite continued contraction by the diaphragm. Central apnea is characterized by a decrease or cessation of diaphragmatic activity during sleep. Persons with mixed apnea show signs of both obstructive and central apnea, usually beginning with the central component and later developing into obstructive apnea as well. In children, mixed apnea appears to be the rule. In a study of 50 apneic children, Guilleminault, Korobkin, and Winkle (1981) reported that all their subjects showed some signs of mixed apnea, although obstructive apnea was the most common component.

Assessment

Brouilette, Hanson, David, Klemka, Szatkowski, Ferbach, and Hunt (1984) constructed a simple but effective diagnostic tool for assessing obstructive sleep apnea in children. The assessment is based on three variables: (1) difficulty breathing during sleep (D); (2) apnea observed during sleep (A); and (3) snoring (S). For variables D and S, the parent assigns the child a value of 0 (never), 1 (occasionally), 2 (frequently), or 3 (always). For variable A, possible values are 0 (no) or 1 (yes). From these values, an obstructive sleep apnea (OSA) score can be calculated using the following formula:

$$\text{OSA score} = 1.42\,D + 1.41\,A + 0.71\,S - 3.83$$

An OSA score greater than 3.5 strongly suggests the presence of OSA; for scores below −1, OSA can usually be ruled out. Polygraphic monitoring is recommended for a conclusive diagnosis.

In assessing the source of obstructive apnea, physical deformations and allergic reactions must be considered. Obesity is also sometimes a factor (resulting in the so-called Pickwickian syndrome), as fatty tissue in the neck produces a partial constriction of the trachea. Enlarged tonsils and adenoids, however, have been identified as the most common causes of obstructive apnea in children. Among 14 children with OSA examined by Mauer, Staats, and Olsen (1983), for example, 12 had enlarged tonsils and/or adenoids. Similarly, in the sample studied by Guilleminault *et al.* (1981), 14 of 24 had tonsil or adenoidal enlargement.

There has been speculation that sleep apnea might be implicated in sudden infant death syndrome (SIDS). However, only 7% of those infants having an apparent life-threatening event (ALTE) show evidence of apnea (Ariagno, 1987). Nevertheless, home monitoring to detect sleep apneas has been recommended for (1) infants with prior severe ALTEs requiring mouth-to-mouth resuscitation or vigorous stimulation; (2) preterm infants with sleep apnea of longer than 20 sec at time of discharge from the hospital; (3) siblings of two or more SIDS victims; and (4) infants with other respiratory conditions such as hypoventilation (National Institutes of Health, 1987). The available data on the benefits of home monitoring are inconclusive for other groups, such as siblings of SIDS, less severe ALTEs, and infants of opiate- or cocaine-abusing mothers. In any case, routine monitoring and asymptomatic infants is not recommended.

Treatment

Although medications and (in the case of obese patients) diet regimens have been used in limited applications to treat sleep apnea, the most common and successful solutions for serious cases of upper airway apnea have involved surgery to remove the airway obstructions. For most children, this means tonsillectomy or adenoidectomy; in 70% or more of cases, these procedures successfully relieve the apnea and associated symptoms. In circumstances in which this approach is unsuccessful, however, a tracheostomy may be necessary. Although tracheostomy eliminates the apnea, secondary psychological symptoms often develop, most notably depression. Family support and in some cases, psychotherapy may be necessary to aid in the adjustment to the surgery. However, long-term follow-up with tracheostomy patients have revealed no lasting medical or psychological side effects (Guilleminault *et al.*, 1981).

SUMMARY

Sleep disorders appear to be underdiagnosed in children, particularly among preschool children. It is often not until they have experienced severe learning deficits in school that these disorders are identified and treated. Narcolepsy and sleep apnea are by far the most debilitating, but the parasomnias, sleep-phase disorders, and insomnia can be sources of severe distress for the child as well as for other family members.

A number of techniques are available to the clinician for the management and treatment of sleep disorders. Although the treatment of some sleep problems requires medical interventions such as surgery or medication, behavioral principles may be effectively employed in a number of instances. In those cases in which surgery or medication cannot be avoided, behavioral techniques can help reduce the amount of medication needed or may aid in adjustment to surgery.

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PART III

NEWER AREAS OF CLINICAL INTERVENTION IN BEHAVIORAL PEDIATRICS

CHAPTER 13

Pediatric Burns

KENNETH J. TARNOWSKI AND L. KAYE RASNAKE

INTRODUCTION

The multitude and magnitude of medical and psychological problems caused by burns render these injuries among the most serious of childhood. During the past 25 years, considerable attention has been devoted to increasing our understanding of the coping and adjustment of adult burn victims. A substantial literature exists on the psychological assessment, treatment, correlates, and outcome of adult burn injuries. Unfortunately, less research attention has been devoted to the psychological problems of pediatric burn victims and their families. The relative lack of research with child burn victims is documented in a recent review of the pediatric burn behavioral assessment and treatment literature in which only 14 published investigations were identified (Tarnowski, Rasnake, & Drabman, 1987c).

This chapter provides an overview of the behavioral assessment and treatment approaches which have been employed with pediatric burn victims. The suggestions offered were derived from the empirical literature as well as the authors' experiences in consulting with staff and patients on pediatric burn units. The chapter commences with a brief review of the epidemiology, classification, and medical treatment of pediatric burns. This is followed by a presentation of specific assessment and treatment strategies. The chapter concludes with a case presentation involving a 12-year-old boy who had sustained serious burns.

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EPIDEMIOLOGY

In the United States, approximately 1% of the population suffers burn injuries each year. Two million persons each year sustain burn injuries that require medical attention. The United States has more deaths per capita than any other industrialized nation and of the approximately 130,000 persons hospitalized annually, one third are children. Thus, even by conservative estimate, more than 40,000 youths are hospitalized each year for burn injuries (Luther & Price, 1981). The fatality rate is 3.9 per 100,000, and children account for 1300 of these deaths (National Safety Council, 1979). Males outnumber females in a 2 : 1 ratio and children under 15 years of age account for two thirds of all burn fatalities (U.S. Fire Administration, 1978). While these statistics document the risk children are at for sustaining serious burns, they fail to reflect the profound psychological morbidity associated with these devastating injuries.

TYPES OF BURNS

Burn injuries are usually described in terms of degree and percentage of body surface affected (BSA). Injury to the epidermis is called a first-degree burn, while more severe injuries involving the dermis are labeled second-degree or partial-thickness burns. Injury to multiple skin layers, often accompanied by subcutaneous tissue and peripheral nerve involvement, are known as full-thickness or third-degree burns. Percentage BSA is calculated for patients using standard burn charts, which divide the body into specific areas of known percent body surface (Lund & Browder, 1944).

MEDICAL CARE

Wernick (1983) described the medical treatment of the burn patient as consisting of three phases: (1) emergency period, (2) acute phase, and (3) rehabilitation phase. During the first phase, medical efforts focus on stabilizing the patient. Careful monitoring is conducted to ensure appropriate electrolyte balance and adequate cardiovascular and respiratory functioning. Typically, it is during the acute phase that patients experience the most pain. Skin graftings and debridement procedures are routinely conducted during this phase of treatment. Skin grafts involve the removal of skin from healthy donor sites on the patient's body. Debridement typically involves daily tankings, during which the patient is placed in a hydrotherapy tub and the devitalized surface tissue is removed via dermabrasion. Other patient physical stressors include IV placements, dressing changes, application of topical medications, and the need for increased fluid and food intake. In addition, physical therapy is also commonly needed in order to prevent contractures and maximize range of movement and function. During the rehabilitation phase, patients often need to engage in (or parents need to perform) a variety of specific care routines in order to promote optimal recovery. Repeated hospitalizations may be required for the purpose of performing reconstructive surgeries. In sum, few health disorders pose this sort of protracted physical and psychological challenge to pediatric patients and their families. For more information concerning the medical aspects of burn management, the reader is referred to Rudowski (1976) and Bailey (1979).

BEHAVIORAL ASPECTS OF PEDIATRIC BURNS

Burned children do not typically present with a single and invariant clinical problem but rather tend to exhibit a broad array of difficulties. In their review of behavioral treatment approaches to pediatric burn victims, Tarnowski *et al.* (1987) identified studies that addressed the following clinical problems: (1) distress and compliance during medical procedures (hydrotherapy, debridement, dressing changes, and physical therapy), (2) consummatory behavior, (3) sleep-related problems, (4) self-excoriation, and (5) general stress and coping. Unfortunately, these difficulties constitute only a subset of the clinical problems evidenced by this population. To date, the focus of most research has been on problems evidenced during the course of initial hospitalization. Little attention has been devoted to other problems which these children often exhibit. For example, clinical observation of these children indicate that they, as well as their parents and siblings, are at increased risk of developing symptoms of posttraumatic stress disorder, depression, self-esteem problems stemming from profound disfigurement/loss of physical functions, social rejection, and family discord. Finally, it is well known that many children sustain burn injuries as a result of either parental neglect or abuse, or both. This listing is by no means exhaustive but is simply provided so that the reader may appreciate the range of problems that he or she is likely to be confronted with as a clinical consultant. Given the difficulties that these children and/or their families can potentially exhibit, it is imperative that clinicians conduct an adequate assessment of the unique problems of each family. We now turn to a discussion of how such a needs assessment can be accomplished.

ASSESSMENT

In Chapter 2 of this volume, Mash and Terdal present a review of the application of behavioral assessment procedures to pediatric problems. The issues discussed by Mash and Terdal are relevant to the assessment of pediatric disorders in general, including burn-related problems, and therefore are not reiterated here. In this chapter, we describe an assessment sequence that we have found to be useful.

Without doubt, one of the most cost-effective means by which to obtain patient needs assessment data is via the interdisciplinary case staffing. Typically, such staffings include representatives of surgery, nursing, psychology, social work, child life, occupational therapy, physical therapy, dietary, and pastoral care. The usual practice involves interviewing parents and child on at least two occasions before such staffings in order to obtain background information concerning the injury, family variables (e.g., support resources), and the child's premorbid level of functioning. Considerable attention is devoted to obtaining a detailed assessment of patient and parent coping. An attempt is made to survey high-probability problems for these children and their families: procedure-related pain, compromised mental status (e.g., burn-induced delirium), nutritional intake problems, compliance with physical therapy, child and parent depression, marital discord, negative sibling reactions, nightmares and trauma-related cognitive–emotional reactions (e.g., intrusive burn-related cognitions), adverse response to hospitalization, and excessive anger and guilt reactions. Self-report inventories and direct observational data are often used to supplement interview data. At the case staffing, relevant case data are presented by each discipline and a list of unique patient and family needs is established. Staff work to arrive at a consensus of who will address what specific clinical problems with what available resources. Depending on the nature of the presenting problem(s), arrangements are made with staff concerning the schedule and format for specific clinical intervention and further behavioral assessment. In many instances, it is possible to obtain tripartite assessment data, since medical information such as heart rate and drug dosages is readily available. Cases are followed throughout the course of hospitalization and are often seen on an outpatient basis following discharge.

Concerning the assessment of procedure-related pain behavior, several coding systems have been developed for use with burned children (Kelley, Jarvie, Middlebrook, McNeer, & Drabman, 1984; Elliott & Olson, 1983; Tarnowski, McGrath, Calhoun, & Drabman, 1987b). Appropriate self-report measures (e.g., visual analogue scales) and social validity measures are also described in these publications. Finally, given that inpatient consultants often rely upon nursing staff to assist with data collection and the implementation of specific behavioral procedures (e.g., token systems to increase compliance), assessment of treatment acceptability is highly recommended with staff as well as patients and parents (Tarnowski, Kelly, & Mendlowitz, 1987a). For a more detailed discussion of specific methodological issues and problems in the assessment of the burn-injured child, the reader is referred to Tarnowski *et al.* (1987c).

BEHAVIORAL TREATMENT METHODS

General Coping

The burned child is subjected to a variety of stressors, including intense pain, separation, lengthy hospitalization, and surgery. In general, these children find themselves in a largely uncontrollable and unpredictable environment. Behavioral reactions to such an environment often include agitation, depression, and anxiety. Grief reactions due to separation and multiple losses (e.g., possessions, limb, physical attractiveness) are common. In addition, children may regress behaviorally. Some professionals argue that all patients need to interact with staff members who do not conduct painful medical procedures (Wright, 1984). Research suggests that creating an environment characterized by increased predictability and control facilitates better coping and adaptation for the burned child (Kavanagh, 1983). Prediction and control can be increased by providing discriminative stimuli to signal impending medical procedures (e.g., only certain staff conduct aversive medical procedures) and allowing children to participate in specific aspects of their care (e.g., remove splints and dressings) (Kavanagh, 1983; Shorkey & Taylor, 1973; Tarnowski *et al.*, 1987b).

Demands for coping are not restricted to patients, as adjustment is required of all family members. It has been noted that the family's reaction to the burn injury has implications for patient recovery (Knorr & Myer, 1970). Parents are required to cope with the multiple stresses affecting their child as well as other personal stresses, such as guilt, financial problems, and separation from spouse and other children. In addition, a lack of understanding of, and control over, the child's medical treatments (e.g., debridement) may make the family feel overwhelmed. Daily trips to the hospital, rehospitalizations, peer rejection, parental guilt, and depression place a significant burden on families, often leading to marital and family discord. Parents of pediatric burn patients have been found to experience impaired self-esteem, loss of appropriate role perceptions, and hostility toward the child (Wright & Fulwiler, 1974). Intervention can be beneficial in helping parents cope with feelings of fear and guilt. Well-established behavioral interventions that focus on increasing communication, problem-solving, and conflict-resolution skills should be considered for these families (Wood & Jacobsen, 1985).

Treatment-Related Distress

One of the most painful experiences associated with burn injuries is daily dressing changes and debridement. These treatment procedures are associated with extreme pain and often represent the most aversive aspect of hospitalization. Researchers have employed attentional diversion (distraction) and relaxation procedures in an attempt to reduce behavioral distress during hydrotherapy, debridement, and dressing change procedures. Kelley *et al.* (1984) successfully reduced the behavioral distress of two burned children using visual distraction (cartoon viewing) during debridement and providing feedback to the patient via a star chart. Instructions in pain management (e.g., attention distraction, relaxation breathing, visual imagery, reinterpretation of the context of pain) have been shown to be effective in reducing behavioral distress if the therapist is present to coach the child (Elliot & Olson, 1983; Walker & Healy, 1980). Self-mediated debridement has proved an effective means of reducing behavioral distress during burn care. However, when control is relinquished to the therapist, an increase in behavioral distress may result (Tarnowski *et al.*, 1987b). Use of a token economy program has been successful in reducing distress and decreasing the time required to conduct dressing changes (Walker & Healy, 1980). Finally, counterconditioning procedures have been found useful in reducing fear during hydrotherapy (Weinstein, 1976).

Compliance with Adjunct Therapies

Adjunct therapies are usually necessary in the treatment of pediatric burn injuries. Most commonly, these therapies involve occupational and physical therapists working to prevent contractures and promote range of motion. Intense pain is often associated with therapeutic endeavors such as splinting and exercises. A variety of techniques have been suggested to decrease resistance and increase cooperation (Wright, 1984). Concise explanations of what is going to happen and why can be of considerable benefit. Identifying specific performance goals for each session (e.g., number of physical therapy repetitions) can be helpful. Varni, Bessman, Russo, and Cataldo (1980) described a strategy for increasing a 3-year-old child's participation in orthopedic and physical therapies. Pain behaviors that interfered with activities and treatment were systematically ignored. Cooperative behaviors resulted in attention, praise, treats,and play time. A changing criterion was established, whereby the performance expectations for the patient were gradually increased (e.g., wearing splints for 1 min, then 5 min; descending 1 step, then 2). The procedure resulted in marked improvements in patient cooperation. Zide and Pardoe (1976) used a similar strategy to increase cooperation with physical therapy and wearing of leg splints with a 13-year-old patient. Points were earned for cooperative behaviors, which were exchanged for desired items and activities. For the pediatric burn patient, noncompliance with the adjunct therapies can result in serious health and physical functioning problems. Systematic manipulation of environmental contingencies can be an effective means of increasing cooperation and addressing pain behaviors which interfere with recovery.

Associated Problems

Three behavioral problems commonly associated with pediatric burn injuries are nightmares, food refusal, and self-excoriation.

Nightmares

Disturbed sleep and nightmares are often associated with the experience of a burn injury (Noyes, Andreasen, & Hartford, 1971). Roberts and Gordon (1979) used extinction and systematic desensitization to eliminate the burn-related nightmares of a 5-year-old child. Parents were instructed to use a response-interruption procedure contingent on the occurrence of motor behavior associated with nightmares. In addition, systematic desensitization of the child's anxious reactions to fire-related stimuli such as stoves and cigarettes was included as a treatment component. The importance of eliminating all potential reinforcing consequences of the nightmares (e.g., parental attention) was emphasized. The use of minimal reassurance following nightmare occurrences and refraining from extended periods of comforting was recommended.

Food Refusal

Maintenance of high fluid and food intake is an essential component of burn treatment. An accelerated rate of tissue breakdown produces an increased need for protein and calories. Pediatric burn patients frequently evidence decreased nutritional intake. Institution of tube feedings is common due to food refusal (Bernstein, 1976). The literature contains numerous descriptions of effective behavioral treatments for childhood feeding and food refusal problems (Bernal, 1972; Linscheid, Tarnowski, Rasnake, & Brams, 1987). Positive reinforcement and time out procedures have been successfully used to increase the food intake of pediatric burn victims (Simons, McFadd, Frank, Green, Malin, & Morris, 1978; Zide & Pardoe, 1976). Zide and Pardoe (1976) implemented a token economy to increase the food consumption of a 13-year-old boy whose food refusal had resulted in dependence on nasogastric feedings. The patient earned points for intake which were exchanged for rewards. Similarly, Simons *et al.* (1978) employed behavioral contracting to increase the food intake of a 5-year-old girl with 80% BSA. The contract specified the specific responses expected of the patient and the consequences to be provided by staff. Certainly, feeding problems become more complex with patients presenting with facial burns, especially if the mouth is involved. However, the use of environmental contingencies to build appropriate eating behaviors and reduce inappropriate refusals has been shown to be effective, if applied consistently and systematically.

Self-Excoriation

Intense itching often accompanies the natural healing process of burned surface tissue and is particularly likely in the case of grafted tissue (Brodland & Andreasen, 1974). Verbal exhortations to refrain from scratching are unlikely to result in self-restraint with younger children. Multiple interventions are available for inhibiting excoriation such as mitts or gloves for the hands, complicated wrappings, medication, and tie-restraints. Another approach to this problem was described by St. Lawrence and Drabman (1983) for use with a 10-month-old infant. A response prevention device, which consisted of a colorful divider placed over the waist, was employed to preclude self-excoriation of the child's legs. Such a device represents an advancement over other techniques, since the divider does not prohibit developmentally appropriate movement and activity.

CASE ILLUSTRATION

Having considered the nature of burn injuries and the variety of behavioral approaches used in the treatment of these children, a representative case study is presented that highlights some of the assessment and treatment issues involved in the care of burned children and their families. In order to illustrate a range of interventions, the case description is hypothetical, reflecting clinical aspects of several of our patients.

Tom was a 12-year-old boy who had been admitted to the inpatient burn care unit following accidental burn injury. Tom presented with 35% BSA. The child was injured in a house fire caused by faulty electrical wiring. Tom's mother received relatively minor burn injuries which were treated on an outpatient basis. Tom's family consisted of his mother and one brother (10 years old). Psychology was consulted approximately 1 week following admission. Specifically, the consultation request noted that Tom was not coping well with his burn-care procedures (e.g., debridement, physical therapy).

The assessment process began with medical chart review. Details concerning date of admission, how the burn injury was sustained, whether child abuse was suspected, medical status, and progress notes from the time of admission were reviewed. Children admitted to this particular unit are typically screened by a social worker in order to obtain demographic information and family social history. Interviews were conducted with two primary care nurses assigned to Tom's care. The surgeon was interviewed in an effort to assess the types of treatments planned for Tom, expected length of stay, prognosis for recovery, and expected reconstructive surgeries. Tom's drug regimen was also reviewed. An initial interview was conducted with Tom's mother (Ellen) who was staying at the hospital. This first brief interview was intended to introduce ourselves and make Ellen aware of the range of psychological services available. In two subsequent interviews, a comprehensive review of Tom's developmental, medical, and behavioral history was conducted. Tom's feelings about hospitalization, staff, treatments, his injury, and so forth were assessed. The nursing staff reported that Tom was evidencing difficulty during debridement procedures. Although a narcotic was being prescribed, Tom purportedly experienced little pain relief. Direct behavioral observations of Tom during debridement were conducted using the coding system described by Tarnowski *et al.* (1987b). In addition, staff were asked to maintain a log of medication requests and Tom was asked to complete a self-report rating of his discomfort on a visual analogue scale following debridement and physical therapy. Finally, an interdisciplinary staffing was scheduled in order to maximize our understanding of the case and interface appropriately with the services provided by other disciplines. At the staffing, several problems were discussed that appeared to warrant intervention. First, data were provided that documented the severe problems Tom was experiencing during debridement and physical therapy. Despite the fact that his dosage of narcotic had been steadily increased over the past four days, pain expression during debridement was considered excessive by all involved, including Tom. Behavioral observations indicated pain behavior occurred more than 90% of the time during debridement. Because of verbal and motoric attempts to "stall" implementation of the procedures, debridement was taking almost 2 hr rather than the expected 30 min. Physical therapy was also taking an inordinate amount of time to complete as a result of stalling and noncompliance. Tom refused to speak with nursing staff, except to request pain medication. It was also observed that Tom displayed a pronounced fear response (marked tremulousness) whenever staff approached him. Tom felt that the nurses enjoyed hurting him and that he had no control over his schedule or procedures being performed. Tom's mother was experiencing considerable guilt about the accident and felt that she should have had the electrical system in the house examined when some difficulties were noted prior to the accident. In general, she could be characterized as being moderately depressed. She indicated that Tom's premorbid behavioral development was considered within normal limits. Tom was an A–B student in school and was considered a popular child who engaged in several extracurricular school activities, including football and track. Ellen's report of Tom's functioning was found to be quite consistent with that obtained from school authorities. Tom had no history of health problems and had not been hospitalized before his burn injury. Neither Ellen nor Tom's younger sibling had a history of significant health disorder.

Tom's pattern of responding to debridement and physical therapy procedures had several consequences. First, since the procedures were taking an inordinate amount of time to perform and both debridement and physical therapy were each conducted twice daily, the majority of Tom's day was spent undergoing procedures. This left little time for emotional recovery between procedures and minimized opportunities for participation in other activities (e.g., TV, visiting with parent and sibling, interacting with other children on the ward). Second, the duration of time spent undergoing procedures reinforced the notion that staff were basically present to inflict pain. Third, Tom appeared to be developing a conditioned fear response in that staff presence appeared to be functioning as a discriminative stimulus for pain. Finally, Tom's affect appeared to be deteriorating, as he increasingly felt that he had no control over his current environment. It was explained to Tom that we wanted to work with him to teach him methods that might make the medical procedures more tolerable. He agreed and Ellen and the staff supported our involvement.

First, we would like to note that burn pain differs from other types of procedure-related distress that has been reported in the behavioral literature. Certainly, while bone marrow aspirations, spinal taps, and other procedures are painful, they are relatively brief in comparison with the medical procedures employed in the treatment of burn injuries. Pain expression tends to be nearly constant as the devitalized tissue is vigorously removed. The pain is so intense that narcotic agents such as morphine often have little effect. In general, our experience has been that behavioral procedures that produce reasonable pain management effects within the context of other aversive procedures (e.g., bone marrows) do not provide equivalent pain reduction for pediatric burn victims. The lengthy duration and extreme intensity of procedures such as debridement appear to mitigate the effectiveness of standard pediatric pain management procedures. Our general approach has been to provide children with a variety of pain-management strategies tailored to their level of cognitive development. The provision of multiple strategies has been found to be useful in working with adult burn victims (Wernick, 1983). What we have often witnessed is that children and adults will use a specific procedure (e.g., breathing exercises) for a brief period and obtain some pain relief that diminishes quite rapidly, at which point they spontaneously switch (or are verbally prompted to switch) to the use of an alternative pain-management procedure (e.g., attention distraction). Tom was provided with instruction in the use of passive relaxation procedures, breathing exercises, guided imagery, and calming self-talk. In general, the multicomponent skills training package described by Turk, Meichenbaum, and Genest (1983) was adapted for presentation to Tom. Attention-distraction methods were presented and included focusing attention on (1) specific aspects of the physical environment, (2) the body part experiencing the negative sensations, and (3) specific thoughts (e.g., songs). Methods of imaginative inattention, transformation of pain, and transformation of context were also employed. Finally, Tom was taught how to employ these basic pain management skills within the context of a four phase stress-innoculation procedure: (1) preparing for intense stimulation, (2) confronting the stimulation, (3) coping with thoughts and feelings at critical moments, and (4) positive self-statements. These methods were taught to Tom between medical procedures, and a psychology staff member was always present initially to coach Tom in the use of the procedures. Several other procedures were implemented concurrent with skills training. Specifically, in order to reduce Tom's apprehension toward medical staff, it was agreed that two designated nurses would conduct Tom's debridement and have no other primary care responsibilities for him. In addition, arrangements were made with nursing and physical therapy staff for debridement and physical therapy to occur at standard times each day. A schedule was established and posted near Tom's bed. These procedures were implemented in order to reduce anxiety by providing Tom with increased predictability concerning when procedures would be conducted and by whom. These procedures aimed to reduce Tom's apprehension and increase his social interactions with staff who did not perform painful procedures. His schedule was reviewed with him by a nurse each morning. In collaboration with the nursing and physical therapy staff, it was agreed that Tom would be permitted increased control over specific aspects of his debridement and physical therapy exercises. Specifically, Tom was provided with the opportunity to remove dressings as well as perform some debridement on his left arm. In physical therapy, explicit performance criteria (e.g., number of full arm extensions) were established at the beginning of each session. Tom reviewed the number of specific exercises that needed to be performed with each of the affected body parts. The therapist provided verbal and gestural instructions for each exercise. Points were assigned for each exercise and an exchange menu created which specified the number of points needed for specific backup reinforcers (e.g., VCR movies). Ellen was followed three times weekly with brief (20- to 30-min) sessions. Sessions were aimed at providing support, increasing adaptive coping, planning for postdischarge activities, keeping her abreast of how our pain management efforts were proceeding with Tom, and providing her with consultation concerning ways she could contribute to Tom's recovery (e.g., reviewing and verbally reinforcing Tom's daily accomplishments). Hospital child-life staff were consulted in an effort to provide for recreational opportunities. In addition, Tom was being followed by a member of the hospital education staff who coordinated her efforts with personnel from Tom's school in order to provide continuity of academic instruction during Tom's protracted hospitalization (7 weeks). Finally, routine psychological supportive care was provided to Tom in order to address issues related to disfigurement, peer reactions, loss of function, school absence, and so forth.

Results of direct behavioral observation as well as child and nursing reports indicated that the multicomponent pain management intervention appeared to have a positive effect. The percentage of pain intervals observed during four observation points during the first two weeks of treatment averaged 37% below baseline levels. Self-report data indicated mean ratings of 9 on a 10-point distress scale during baseline and 5 during treatment. Nursing ratings of pain and cooperation on similar scales yielded analogous results. Of the procedures taught, Tom indicated that he found the breathing exercises, guided imagery, and attention diversion procedures to be the most helpful. The average time to conduct debridement at 2 weeks post-treatment averaged 28 min per session. In general, compliance with physical therapy had improved. Compliance with procedures averaged 69% during baseline and 88% following introduction of the token system. Tom indicated that he was employing some of the pain management skills during physical therapy. Parenthetically, it should be noted that psychology staff were not available to coach Tom in the use of pain management procedures during physical therapy. Tom's apprehension about the presence of medical staff in his room was found to dissipate quite rapidly following introduction of a predictable schedule and agreement that only specific staff would conduct aversive medical procedures. Collateral changes included improved affect and increased receptivity to social advances by staff as well as other patients on the unit. In addition, requests for medication decreased by an estimated 65% within 3 weeks despite the fact that morphine had been discontinued and replaced with fairly low doses of acetominophen with codeine. During the remainder of Tom's inpatient stay, his burn injuries healed well and discomfort decreased such that by week six he was tolerating both debridement and physical therapy with minimal levels of distress.

Upon discharge, Tom continued to receive physical therapy three times per week on an outpatient basis. In addition, he was scheduled to be readmitted for two reconstructive surgeries. Before discharge, a comprehensive interdisciplinary summary was completed and forwarded to Tom's school and to his local pediatrician. The report documented the progress made as well as detailed residual physical limitations. Explicit plans for follow-up by specific disciplines were noted. Following consultation with psychology, a representative of the burn team met with school personnel before Tom's return to school in order to discuss strategies for maximizing Tom's reintegration into the school environment. Issues discussed with school personnel included prognosis for physical recovery, educational programming during hospitalization, upcoming readmissions, teacher and peer reactions to disfigurement, planned psychological follow-up, and availability of specific hospital consultation services (e.g., nursing, psychology).

Tom was followed on an inpatient basis throughout both of his reconstructive surgeries. Pain management services were reimplemented on both occasions. The case was followed on an outpatient basis for six months post-injury. Outpatient services focused on providing Tom with methods to manage recurrent depressive symptoms related to social rebuffs, loss of ability to resume participation in specific group athletics, and facial disfigurement. Tom's sibling was also seen along with Ellen and Tom within the context of several family sessions. At 1-year follow-up, Tom's social adjustment and general affect had improved considerably. Plans were made to see Tom and his family during his surgery clinic follow-up appointments, which were scheduled at three month intervals.

CONCLUDING COMMENTS

At this point, very little is known about characteristics of burned children that predict response to specific psychological interventions. Although we attempt to individualize treatments for each patient, it is clear that such efforts are made without benefit of data-based empirical findings. The influence of age, previous hospitalization, cognitive development, percentage BSA, area of burn, degree of disfigurement and loss of function, premorbid behavioral status, parental psychological status, and a host of other factors need to be considered in order to broaden our understanding of the unique complexities of each case and better determine how these factors interact with treatment to influence behavioral outcome.

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CHAPTER 14

Tics and Tourette Syndrome

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INTRODUCTION

Tics are one of the most common behavioral problems of childhood; by some estimates, 12–24% of all children exhibit tics at one time or another (Shapiro, Shapiro, Brunn, & Sweet, 1978). Most tics are transient, disappearing spontaneously within a few weeks or months. Other tics are chronic and persist for years, even for life. Occasionally, motor tics are accompanied by "vocal" or "phonic" tics—sniffing, snorting, grunting, or swearing—to produce the condition called Tourette syndrome (Golden, 1979). Whether these tic conditions are different disorders or represent a continuum of the same disorder is unknown. What is known is that there is a relatively high incidence of tic disorders in the families of children who present with these problems. In an early study, Lapouse and Monk (1964) reported that 38% of parents of children with transient tics had a history of tics themselves; more recently, Golden (1979) indicated that 31% of the families of Tourette children had another member with Tourette syndrome, while 20% of the families had at least one other member of the family with chronic multiple tics. Similarly, Shapiro and Shapiro (1982) reported the rate of tics and Tourette syndrome to be 40.5% in the families of their sample of 650 Tourette children. Clearly, these familial rates exceed prevalence rates found in the general population, which are usually estimated to be 0.5 per 1,000 for Tourette syndrome and 1 per 100 for chronic multiple tics.

Although the issue of whether tic disorders represent a unitary syndrome or distinct entities is currently unsettled, the revised Diagnostic and Statistical Manual distinguishes among the conditions of transient tic disorder, chronic motor

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tic disorder, and Tourette's disorder. The criteria for transient tic disorder include (1) onset during childhood; (2) presence of recurrent, involuntary, repetitive, rapid, purposeless motor movements; (3) the ability to suppress the movements voluntarily for minutes to hours; (4) variation in the intensity of the symptoms over weeks or months; and (5) duration of at least 1 month but not more than 1 year. Chronic motor tics are differentiated from transient motor tics largely by their duration (greater than 1 year), intensity (unvarying), and extensiveness (up to three muscle groups at any one time). By contrast, Tourette's disorder is characterized by the following: (1) age of onset at 2–15 years of age; (2) presence of recurrent, involuntary, repetitive, rapid, purposeless motor movements affecting multiple muscle groups; (3) multiple vocal tics; (4) ability to suppress movements voluntarily for minutes to hours; (5) variation in the intensity of the symptoms over weeks or months; and (6) duration of more than 1 year. The presence of vocal tics and the duration of 1 year differentiates Tourette syndrome from transient tic disorder, whereas the variation in intensity of symptoms and the presence of vocal tics differentiates Tourette syndrome from chronic motor tic disorder. Although coprolalia, the irresistible urge to utter obscenities, is popularly regarded as the distinguishing characteristic of Tourette syndrome, its actual occurrence is quite low and varies between 30% and 60% (King & Ollendick, 1984; Shapiro & Shapiro, 1982). Indeed, only one half of Tourette's original sample evinced this symptom.

Because of the potential implications for treatment, it is important to differentiate among the three tic disorders (Ollendick & Matson, 1983). Many researchers and clinicians view transient tic disorders as more mild and, accordingly, as more responsive to psychotherapy or behavior therapy. By contrast, chronic motor tics are thought to be more complex and more resistant to behavioral change efforts. Yet, they are responsive to concerted intervention efforts and psychopharmacologic interventions are usually not necessary. Tourette syndrome, however, is more responsive to psychopharmacologic agents, especially to dopamine-blocking agents such as haloperidol and pimozide. In fact, some assert that psychotherapy and behavioral therapy are singularly ineffective in the treatment of Tourette syndrome and that their use should be discouraged for the treatment of the primary motor symptoms. In a detailed review of the literature on children treated with behavioral techniques (primarily massed practice), Shapiro *et al.* (1978, p. 356) concluded that behavioral therapy was "largely ineffective for the treatment of Tourette syndrome", while Brunn (1984, p. 128) stated that the "only benefit that I have observed from behavioral treatment methods has been in training patients to substitute a less obvious symptom for one which is socially objectionable." Later, Brunn concedes that while psychotherapy "has not been helpful" in reducing the symptoms of Tourette syndrome, it might be helpful in helping patients "cope with the symptoms they have as well as with their general adaptation and development." These conclusions seem a bit harsh, at least for behavioral techniques. In fact, behavioral techniques have been shown to be quite effective with both transient and chronic motor tics and to be valuable adjunctive aids with Tourette syndrome.

ASSESSMENT PROCEDURES

Since the question of differential diagnoses is such a pivotal one, we recommend a thorough and comprehensive behavioral assessment when working with children who display tics (Ollendick & Hersen, 1984). Aspects of this comprehensive approach are nicely illustrated in a paper by Hurley, Schaughency, and Krahn (1986) on the differential diagnosis of Tourette syndrome. Essentially, they propose a five-step process in which information about the tics and related behaviors is obtained. The five steps include (1) examining the tic behaviors for characteristic features; (2) determining the history of tic development; (3) identifying any associated features; (4) establishing a family history of tics and associated features; and (5) ruling out other disorders.

When examining a child who display tics, it is important to establish the frequency, intensity, and complexity of the tics, as well as the settings in which they occur. Unfortunately, since the tics can be suppressed voluntarily for minutes or sometimes hours, this is not an easy or straightforward task. Furthermore, at least with Tourette syndrome, the motor and phonic tics can wax and wane in severity over periods of weeks or months, as well as be affected by environmental and psychological factors such as novel or highly structured situations and increased stress or fatigue (e.g., symptoms are often worse right after coming home from school but are much diminished in a clinical setting). Although it was once believed that tics were attentuated by absorbing activities and to be nonexistent during sleep, neither of these contentions has been shown to be accurate (Brunn, 1984).

Owing to the variability in symptoms and the ability of the child to voluntarily control them, it is frequently necessary to observe the child under different circumstances and, perhaps, on several occasions. For these reasons, we observe children under four standardized conditions during the first or second assessment session: (1) a 10-min unstructured period in which the child is left alone in the therapy room with no special tasks or instructions (toys and reading materials are available, however); (2) a 10-min structured play period in which the child engages in some competitive activity such as checkers; (3) a 10-min structured academic period in which the child completes a series of achievement tasks such as reading recognition and arithmetic calculations; and (4) a 10-min period in which the child and his or her parents plan some family activity. In this manner we sample the tic frequency, intensity, and complexity under several different situations. It is not at all uncommon to see the tics under some conditions but not others, or not to see them at all. In the latter instance, we arrange for subsequent observational sessions and/or to observe the child in the home and school settings.

With the recent advent of the Tourette Syndrome Global Scale (TSGS) (Harcherik, Leckman, Detlor, & Cohen, 1984), the task of quantifying and comparing scores across children is considerably more reliable and easier. The TSGS consists of two major domains: the motor and phonic tic domain and the social functioning domain (this latter domain will be described in more detail later).

For the first domain, tics are scored according to their frequency, complexity, and degree of disruption. Tics are subdivided into four subcategories: simple motor (e.g., eyeblinking, arm jerks, head jerks, rapid kicks, jaw snaps), complex motor (e.g., rolling eyes to the ceiling, gyrating and bending, touching objects or self or others, holding funny expressions), simple phonic (e.g., sniffing, barking, grunting, clacking, hawking), and complex phonic (e.g., words, phrases, or statements like "Shut up," "How about that?" and "Here I go again" as well as coprolalia—obscene words or phrases). The frequency of each of these types of tics is rated on a six-point scale, ranging from 0—no tics of this category are present, to 5—an uncountable number of tics of this type are present. A time sampling procedure is used. Disruption is also scored on a six-point scale, from 0—the tics cause no disruption for the child and are camouflaged, to 5—the symptoms make functioning impossible when they are present. An infrequently occurring tic such as coprolalia may thus be rated with a low frequency (e.g., 2) but a high disruptive score (e.g., 5); similarly, a very frequent tic such as a throat clearing, which occurs many times per minute, may have a high frequency score (e.g., 5) but a low disruption score (e.g., 1). The Tic Domain Subscore can be derived by summing the Frequency × Disruption Scores for each of the four tic categories.

Since a time-sampling procedure is used to code the frequency of the four subcategories, this system easily lends itself to our initial observation session. Because each activity is limited to 10 min, we can easily code the frequency for each of the unstructured and structured activities. For transient tic disorder children, simple and complex phonic tics are rarely seen. More often, the tics are limited to simple motor or complex motor ones. Regardless, with this system, a quantified index can be obtained reliably and used in cross-subject comparisons as well as in treatment outcome evaluations.

In addition, to determine the exact characteristics of the tics themselves, it is also important to explore the presence of associated features. A number of features have been identified that occur more frequently in children with tics (especially Tourette's syndrome) than in the general population. Among these are compulsive behaviors, attention-deficit disorders, learning/language disorders, sleep problems, enuresis, and other behavior problems (Hurley *et al.*, 1986). Much of the information on associated features can be obtained through a careful clinical interview, parent- and/or teacher-rating forms (e.g., Quay–Peterson Behavior Problem Checklist, Achenbach's Child Behavior Checklist), and additional behavioral observation. In particular, the social functioning domain of the TSGS (Harcherik *et al.*, 1984) is useful. The social functioning domain consists of three areas: behavioral problems, motor restlessness, and level of school (or occupational) functioning. Each of these areas is rated from 0, for no problem in this area (superior functioning) to 25, for profound problems in this area. For example, motor restlessness can vary from "normal movement for task—good concentration" to "nonstop motion, impaired concentration, unable to sit still, always in motion, clearly cannot function." Likewise, the behavioral problem area can vary from "normal social relationships" to "unacceptable social behavior, no attempt at good social interaction." Scores on these areas can be obtained from informants in the child's environment as well as directly rated by the therapist in the clinical sessions.

TREATMENT APPROACHES

The treatment of tic disorders presents an intriguing challenge. Their variability and situational specificity frequently result in measurement problems. Moreover, the nature of tic disorders, especially Tourette syndrome, poses problems for the evaluation of treatment outcome. In particular, the "waxing and waning" of Tourette's symptoms suggests the need to employ no-treatment control groups and to obtain long-term follow-up. Furthermore, the important effects of life events on the course of Tourette's symptoms also require the monitoring of such events in order to evaluate treatment successes and failures. In an eloquent review, Turpin (1983) examines these and other issues in the behavioral and pharmacological management of tic disorders.

By far the most frequently used treatments for tic disorders are the behavioral and psychopharmacological approaches. We shall first briefly review the behavioral procedures. As noted by Turpin (1983), the earliest and most widely used behavioral treatment for tics is massed or negative practice. Essentially, this procedure requires the child to produce the tics voluntarily as accurately and effortfully as he or she can. The practice, or repetition, of the tic is prolonged, usually lasting up to 15 min. Brief rest periods are interspersed and are followed by additional trials of repeated practice. Theoretically, it is assumed that the prolonged practice is accompanied by fatigue and a decrease in the ability of the child to voluntarily reproduce the tic. Reactive inhibition is thought to occur (Yates, 1970), although it must be noted that the exact mechanisms are unclear. Unfortunately, this procedure has not lived up to its early promise. In fact, Turpin (1983) reported that only 3 of 22 studies resulted in successful treatment outcome at long-term follow-up. Two of these successful cases would probably be diagnosed as transient tic disorder, while the third would be a Tourette's disorder child. Unfortunately, in the latter case, psychotropic medication was used concurrently. Overall, there is very little support for the use of massed or negative practice in treating any of the tic disorders.

The next most frequently used technique has been contingency management. In this procedure, the child is reinforced for the absence of the tic and/or the practice of some substitute behavior. In other instances, the child might be ignored or punished (e.g., time out) when the tic is displayed. Again, a number of studies—primarily of the single-case genre—have been reported. A relatively safe conclusion appears to be that a variety of tics can be brought under contingency control with positive reinforcement and punishment procedures but that long-term maintenance is not produced. Another conclusion is that these procedures are more effective with transient and chronic tic disorders, but less so with Tourette syndrome (Turpin, 1983).

Although used less frequently than either massed practice or contingency management, self-monitoring and self-management procedures have resulted in more encouraging findings. Self-monitoring consists of the child recording the frequency (or intensity) of the tic in a notebook or by tallying its frequency on a response counter. As noted by a host of researchers, self-monitoring frequently produces reactive effects, resulting in significant behavior change. Illustrative of this approach is a single-case study by Ollendick (1981). In this study, a 9-year-old boy who displayed excessive eye-blinking and "cheek-bunching" of a 3-year duration was treated. Following baseline monitoring by his parents and school teacher, he was instructed in the practice of self-monitoring. He was provided a wrist counter and instructed to record each tic occurrence by pressing the counter stem. Practice in becoming aware of the tic and recording it was provided in the session itself; he was then instructed to record the frequency in school and home settings for prespecified periods of time each day. Self-monitoring was found to be highly effective. Following four treatment sessions, a near absence of tics was noted; furthermore, the gains were maintained at follow-up 1 year later. Not all cases treated with self-monitoring have been this successful. There is accumulating evidence, however, that self-monitoring procedures are effective in controlling tics in transient and chronic tic disorders, as well as Tourette's disorders (e.g., Hutzell, Platzek, & Logue, 1974; Turpin, 1983). It should be emphasized, however, that once again all these studies have been single-case studies and the necessary controlled group outcome studies have not been undertaken.

In recent years, a fourth behavioral procedure, habit reversal, has come into vogue and has been associated with rather successful outcomes, at least for the transient and chronic tic disorders. Based on the principles of positive practice overcorrection, three distinct phases are involved when using this procedure. First, awareness training is used to assist the child in accurately discriminating the onset of the tic and the recording of it. Typically, self-monitoring procedures are used for this purpose. In the second phase, the child is involved in the construction and practice of competing muscular responses. Generally, the competing response involves the isometric contraction of muscle groups that are functionally incompatible with the tic. The third phase of treatment requires the systematic practice of the competing response whenever the tic occurs. Thus, competing response practice is made contingent on the occurrence of the tic and, in this sense, may function as a contingent punisher (Azrin & Nunn, 1977). Although this procedure has not been evaluated systematically with Tourette's syndrome children, results with children with transient and chronic motor tic are truly remarkable. As stated by Turpin (1983), "the results of Azrin's studies are most dramatic and report 80% of ticquers remaining tic-free at an 18-month follow-up" (p. 227). We have found similar results with chronic tic disorder children, but we have not tested these procedures systematically with Tourette syndrome children. We are not aware of anyone who has done so at this time.

In addition to these procedures, others have examined the use of anxiety management procedures such as relaxation training and systematic desensitization in the treatment of tics. The use of these procedures assumes the critical role of anxiety in producing or at least maintaining the tics. Strong support for this assumption, or for the efficacy of anxiety-based procedures, has not been evident in the literature, however. As a result, these procedures have been used less frequently.

Overall, the efficacy of behavioral treatment procedures seems more established for the transient and chronic tic disorders than for Tourette's disorder. Even in these instances, however, firm support is lacking and, as with many other areas of application, the necessary outcome studies have not been completed (Ollendick, 1986). However, it appears that behavioral procedures are effective with the transient and chronic tic disorders and that they may be valuable adjunctive aids in the treatment of Tourette's disorder.

In this latter disorder, there is increasing evidence that a basic neurophysiological condition exists. The support for this assertion is extensive and well beyond the scope of this chapter. Briefly, the evidence centers around diffuse, nonspecific, but clearly identifiable electroencephalographic (EEG) abnormalities, the presence of neurological "soft" signs, abnormal prenatal or perinatal histories, the tendency of this condition to run in families, and the response of the condition to various psychotropic medications (Cohen & Leckman, 1984; Golden, 1979). By far the most frequently used medication has been haloperidol, a drug that has been effective with 70–90% of children with Tourette's syndrome. Since haloperidol is a dopamine-blocking agent and is so singularly effective, it suggests that Tourette's disorder involves overactivity of the dopaminergic system of the brain, either from excess production or diminished reuptake of the neurohumor or possibly from hypersensitivity of its neuronal receptors. Present data do not permit us to distinguish clearly among these three possibilities. However, it has been shown that the presumed higher synaptic concentrations of dopamine are not reflected in higher cerebrospinal fluid (CSF) concentrations of metabolite homovanillic acid (HVA), in dopamine, suggesting that there might well be a hypersensitivity of the postsynaptic receptors rather than abnormally high synaptic levels (Golden, 1979). Regardless, the effects of haloperidol are striking with this disorder, and it is clearly the treatment of choice. (Some other recent studies suggest the use of pimozide and clonidine—both of which may have fewer side effects than haloperidol. However, clear support for these other medications is less convincing at this time.)

There is now clear evidence that the early use of haloperidol resulted in many youngsters being overmedicated and experiencing serious side effects such as parkinsonian symptoms, akinesia, akathesia, and, in very rare cases, tardive dyskinesia. In some other cases, school avoidance and school phobia were noted as were an exacerbation of attentional and hyperkinetic problems. Current use of haloperidol is much more closely monitored and, hence, potentially safer. As indicated by Shapiro and Shapiro (1980), the starting daily dosage should be 0.25 mg haloperidol taken orally one hour before bedtime. To prevent the occurrence of dystonia and akinesia, they also recommend the routine use of benztropine mesylate (0.5 mg) at the beginning of treatment (some investigators disagree with this routine practice and suggest waiting to see whether these side effects actually occur). The Shapiros then recommend that the dosage of haloperidol be increased 0.25 mg every 5 days, until maximal benefits (and minimal side effects) are achieved. Although the usual dosage ranges from 2–10 mg/day and averages 5 mg/day, higher dosages may be required for some youngsters. This practice stands in sharp contrast to those of earlier days when more than 100 mg/day may have been prescribed. With these more appropriate dosages, significant side effects have been reduced substantially. Nonetheless, as with all psychoactive drugs, haloperidol should be discontinued (or at least its dosage reduced) from time to time to assess whether the youngster's condition may have ameliorated. Furthermore, since tics primarily affect the child's ability to function socially and the various medications do not possess social skill-enhancing properties, attention to the child's social behavior and the acquisition of appropriate social skills should not be ignored. It is for this reason that we particularly endorse the Global Scale of Harcherik *et al.* (1984); it allows us to monitor the tic frequency, intensity, and complexity, as well as important social and behavioral indices. This position is also consistent with Golden's (1979) sage advice: "Haloperidol (like most drugs, unfortunately) is corrective or ameliorative, not curative" (p. 97). Finally, there is little reason or support for the use of psychotropic medications for the transient and chronic tic disorders. These conditions are usually responsive to behavioral procedures. The risk of side effects associated with the various medications is too great to warrant their use with such children. They are, however, the treatment of choice for children with Tourette syndrome.

CASE ILLUSTRATION

David, an 11-year-old white boy, exhibited excessive eye-twitching since he was 5 years of age. His parents indicated that this tic developed when he entered kindergarten and his mother was hospitalized for glaucoma treatments. In the summer preceding his entry into kindergarten and mother's operation, his mother had had recurring visual problems requiring several visits to the doctor. David, the second of three children and described as "mommy's boy," was reportedly very upset about these happenings. The eye-twitching continued over the 6 years and had begun to include the mouth and cheek. The symptoms were not extensive, however, until he entered junior high school—a transition that we hypothesized to be sufficiently similar to his entry into kindergarten. Mom's condition at this time was stabilized and no recurring problems were noted.

Initially, David was seen for an intake session consisting of a clinical interview. David and his parents were seen together initially, and then David was seen alone. While being seen alone, he was observed under standard conditions detailed in our assessment section. The tics were observed to be present under both structured and unstructured situations and to occur at a rate of about three per minute. Although the tics were somewhat disguised, they did interfere with functioning at least moderately. They were viewed as simple motor tics, and he was diagnosed as having chronic tic disorder (6-year duration).

Following this session, both his parents and teacher were asked to monitor the frequency of his tics during prespecified 20-min time periods. The importance of obtaining an unobtrusive accurate recording of his tics was stressed. The tics were tallied on index cards.

During the second session (following the collection of unobtrusive baseline data for 5 days), David was instructed in self-monitoring. Basically, during the session, he was taught to become aware of the tics and to record them on an obtrusive wrist counter, used to maximize potential reactive effects (Nelson, Lipinski, & Boykin, 1978). He was to do this in the school setting only. With self-monitoring, the tics reduced to about 50% of their baseline rate in the school setting (parents and teacher continued to collect data for reliability purposes—found to be 0.88).

Since the tics had stabilized at about 50% of their baseline rate and were not being reduced further, it was decided to next employ the habit reversal procedure. The competing response practice consisted of extensive practice in tensing the muscles antagonistic to the tic. He was instructed to hold his head centered, direct his eyes forward, and to tense the opposing eye and cheek muscles until the tic abated. He was taught to hold this position for 3 minutes. During the last half of the third session, he practiced this competing response whenever the tic occurred. At the end of the session, he was told to continue to self-monitor the tics at school and to self-administer the competing response practice contingent on each tic. At home, he did not self-monitor or self-administer the habit reversal procedure; rather, mom continued to monitor their frequency. This procedure was used in order to evaluate the procedure systematically across two different settings.

The procedure was found to be highly effective, with the tics reducing to a near-0 level following 5 days of practice in the school setting. At home, however, the tics had not abated. Accordingly, these same procedures were applied in the home setting and were found to be highly effective. At 3-, 6-, and 12-month follow-up appointments, no tics were observed. Furthermore, as reported by parents, there was no evidence of tics at home, school, or other settings.

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CHAPTER 15

The Role of Behavior Therapy in Cystic Fibrosis

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CYSTIC FIBROSIS

Cystic Fibrosis (CF) is a lethal hereditary disorder affecting approximately 1 in 1500 Caucasian births in the United States (Bowman & Mango, 1976). It presents a special challenge to the pediatric health care community because of the lethality, complexity, and unknown cause of the disease. CF may affect several organ systems, including respiratory, gastrointestinal (GI), pancreas, kidney, and reproduction (Matthews & Drotar, 1984). The exocrine glands of these various organ systems produce an abnormal mucus that is thick, viscous, and sticky. The most serious complications of the disease involves abnormal mucus production in the lungs and pancreas.

In the lungs, the viscous nature of the mucus impedes the normal cleaning mechanism. This results in an accumulation of mucus in the bronchi and bronchioles, leading to obstruction and infection. Over time, this process can permanently damage the lungs, causing complications that lead to respiratory insufficiency and death (Holsclaw, 1980). Chronic pulmonary disease is the cause of 90–95% of the morbidity and mortality in patients with CF (Wood, Boat, & Doershuck, 1976).

In the pancreas, important enzymes responsible for the breakdown of cer-

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tain proteins, are either missing or not released. Thus, patients are unable to absorb a sufficient amount of proteins, fats, and fat-soluble vitamins without enzyme supplements. Even with such treatment, a substantial number of patients are chronically underweight or malnourished (Allan & Phelan, 1980; Yassa, Prosser, & Dodge, 1978).

This chapter is intended to provide a working model of the potential of behavior therapy to interface with medicine in treatment management and patient adaptation to CF. Topics discussed in this chapter include the role of a behavioral psychologist in enhancing patient compliance to treatment, providing comprehensive treatment for nutrition and exercise, and enhancing patient adaptation to the disease, even in its end stages.

ENHANCING COMPLIANCE: POSTURAL DRAINAGE

One role of the behavioral clinician in working with CF patients is designing methods of enhancing treatment compliance. This is an especially important function, given that there is no cure for the disease and consistent comprehensive therapy is the recommended means of increasing longevity.

Treatment of CF is generally complex, time consuming, and expensive. The typical regimen consists of medication, postural drainage, inhalation therapy, dietary recommendations, and exercise. Medication includes daily intake of pancreatic enzyme replacements with each meal and snack, and daily vitamins. Oral antibiotics are prescribed on an as-needed basis to combat infection. Postural drainage is a form of chest physical therapy (CPT) designed to aid in clearing mucus from the lungs. It involves the parent or patient clapping on various sections of the patient's chest while the patient assumes up to 11 different positions. The recommended number of treatments per day range from two to six, depending on disease severity (Gaskell, 1975). Aerosol inhalation therapy is often used in conjunction with postural drainage to wet and thin the mucus (Matthews & Doershuk, 1967). Dietary treatment focuses on increasing caloric intake to 150% of the recommended daily allowance (RDA) for healthy children with emphasis on foods high in protein and fat. Exercise is often recommended as an aid in preventing mucus accumulation in the lungs.

The few studies that have examined patient compliance have demonstrated consistent findings of high compliance with medication (Hobbs, Geiss, Hammersly, Kramer, & Henley, 1985; Passero, Remor, & Solomon, 1981) but lower compliance with postural drainage, diet, and exercise (Bellisari, 1985; Hobbs *et al.*, 1985; Passero *et al.*, 1981). The reasons for noncompliance are many and varied. Bellisari (1985) found low compliance with postural drainage to be associated with the patient's and/or family's perception of treatment efficacy, patient's respiratory involvement and issues of independence, self-reliance, and a sense of normality and emphasis on family quality of life over health concerns. Furthermore, a recent study by Hobbs, Geiss, Hammersly, Kramer, & Henley (1986) found higher ratings of compliance to be associated with maternal reports of lower levels of marital satisfaction and less adult social contact.

In our clinical work, we have found many of these same issues. Because treatment is aimed at disease complications rather than symptoms, patients do not experience the immediate benefit of symptom reduction by complying. The exception to this is medication taking. Furthermore, treatment frequently becomes a battle between parents and children, with parents resorting to coersive means of insuring compliance. Often, this creates tension and disagreement between the parents as well. This cycle of events may partially account for the relationship between low martial satisfaction and higher compliance (Hobbs *et al.,* 1986).

As of late, behavioral techniques have been successfully applied to increasing compliance with other medical regimens (reviewed by Dubbert & Faulstich, 1988). Thus, behavior therapy offers the technology for improving patient compliance and ameliorating some of the parent–child and parent–parent conflicts that arise with CF. Useful techniques may include positive reinforcement, shaping, contingency management, tailoring the regimen to fit the patient's lifestyle and use of contracting (Dubbert & Faulstich, 1988).

Case Illustration: Contracting to Increase Compliance

Contracting has been found particularly useful in working with CF patients because it addresses many of the barriers cited to interfere with compliance to this aspect of treatment. In a previously published case study (Stark, Miller, Plienis, & Drabman, 1987), this procedure was successfully employed to increase compliance of an 11-year-old girl with her postural drainage treatment. Several aspects of the use of contracting in this case made it especially useful and generalizable to other children and adolescents with CF.

Carol Ann was an 11-year-old CF patient who was diagnosed shortly after birth. Her disease severity was mild to moderate. She was seen regularly for clinic visits at 1- to 3-month intervals and occasionally hospitalized for pulmonary clean outs. Carol Ann was referred for poor compliance with pulmonary drainage procedures. Her physician was also concerned about Carol Ann's adjustment to her disease and family interactions. The physician had observed Carol Ann to "act" sicker than her physical examination indicated and that this behavior would distress her mother.

Carol Ann and her mother were interviewed together and separately during one of their CF clinic visits. The psychologist explained her role in the clinic as someone with experience in helping children and their families deal with difficult situations related to having a chronic disease. Carol Ann was told her doctor was concerned about her performance of postural drainage. The psychologist emphasized that postural drainage was time consuming and she understood that children often find it hard to fit in everything they want to do, with everything they are "supposed" to do. Carol Ann was especially receptive to discussing postural drainage in this manner.

Carol Ann's mother expressed a lot of uncertainty regarding the importance of regular postural drainage. She felt that Carol Ann should do it but felt very guilty making her daughter do something she disliked. She also felt guilty about allowing Carol Ann to skip treatments. Carol Ann's father was not present during the clinic visit; the mother reported that he was not involved in treatment and that he placed all responsibility for compliance with her. At the end of the interview, Carol Ann and her mother were told that they had expressed many of the same feelings that other children with CF and their parents have and that we could design a program to help make compliance easier.

However, it was explained that we would need more information about how many times a day Carol Ann performed postural drainage. Therefore, both Carol Ann and her mother were asked to record the date and time of each postural drainage treatment. This information would be collected at the next clinic visit in 3 weeks.

At the next visit, Carol Ann was hospitalized for pulmonary exacerbation of CF. She was seen by the psychologist at this time and her records were reviewed. According to her records, Carol Ann had rarely performed postural drainage more than once a day and missed treatment completely on half the days. Recording helped Carol Ann and her mother see that Carol Ann often felt postural drainage interfered with preferred activities. Furthermore, the mother did not provide contingencies to motivate Carol Ann to take responsibility for her treatment. In discussing these findings, it was explained that in their current lifestyle postural drainage was an intrusion and we needed to make it part of Carol Ann's routine, like brushing her teeth.

Contracting was introduced to Carol Ann as the first step in making postural drainage a routine task. She was told that first she should provide herself with rewards for remembering to do her treatment and these rewards should be activities she enjoyed doing. Also, it was pointed out to Carol Ann's mother that she gave many of Carol Ann's rewards away free, by allowing Carol Ann to do activities she requested regardless of whether she took proper care of herself. A list of activities Carol Ann could earn was generated by Carol Ann and her mother. Carol Ann and her mother were then told that they needed to describe exactly what behaviors were expected of each of them in order for Carol Ann to earn her rewards.

Contracting was begun during the hospital stay. This was done by Carol Ann's mother taking over performing postural drainage from physical therapy. A formal contract was written in which Carol Ann and her mother decided on the four times postural drainage was to be done each day and they specified activities they would do together following compliance, within 10 min, of the prescribed time. If Carol Ann did not participate at the appropriate time the activity was withheld. Weekly rewards were specified for completing 75% of treatments.

Thus, the program was set up in a positive way, framing it as a means of the patient taking over responsibility for her own treatment. The consequences chosen were privileges she was already receiving noncontingently. In this way, the patient was directly taught that when she took care of herself, she was able to engage in more activities, the rationale behind treatment and quality of life in CF, plus the contingent use of existing privileges avoided the parent viewing the contract as artificial or "bribery." Second, the patient was directly involved in treatment planning. She helped identify the privileges to be used and specified times to perform postural drainage. Contracting allowed the contingencies to be arranged such that the consequences for compliance were immediate and positive.

Carol Ann was very enthusiastic about the contract and readily complied to 100% of her treatments during her hospitalization. At discharge, rewards were faded from following each treatment to daily (following completion of three treatments). A new contract was drawn up specifying daily and weekly activities. Weekly activity rewards were given for 90% compliance. Over a 2-month period, daily rewards were faded to only weekly, and then formal contracting was stopped. At the end of follow-up, Carol Ann's mother reported that Carol Ann continued to specify her treatment times and follow through without prompting. Carol Ann's new approach also gave her father a positive way to become involved in treatment administration and he began performing Carol Ann's postural drainage. Her mother reported that parental arguing had ceased in addition to arguments between herself and Carol Ann.

Not only did this approach improve compliance, but Carol Ann's mother reported that it decreased conflict among all family members and allowed her father to become involved in treatment delivery for the first time. Behavioral contracting appears useful for increasing compliance, and, equally important, it may improve familial relations by decreasing parent–child and parent–parent conflicts concerning treatment.

TREATMENT PROGRAMMING: DIET AND EXERCISE

Although strategies for enhancing compliance are useful and important, there are certain components of CF treatment in which more intensive behavioral interventions may be necessary. Diet and exercise represent two such areas. Each of these components involves lifestyle behaviors that are generally difficult to modify even in healthy patients (Martin & Dubbert, 1984). Because such changes must be made within the context of a complex treatment regimen and limited clinic visits, they represent an even greater challenge to the pediatric physician treating CF. Behavioral clinicians with expertise in program design and implementation can make a valuable contribution to medicine in this area. This can be accomplished by designing programs that delineate the specific behaviors involved in diet and exercise treatment and by teaching patients a systematic approach to integrating such behavior change into their daily life. Beyond simply enhancing compliance, such an approach is more comprehensive and usually includes patient education as well as treatment programming.

As the survival time of CF patients improves, normal nutrition is considered increasingly important in patient growth, quality of life, optimal pulmonary functioning, and perhaps long-term outcome (Phelan & Landau, 1979; Chase, Long, & Lavin, 1979; Kraemer, Rudeberg, Hadorn, & Rossi, 1978). Despite recent advances in disease treatment and management, conditions of malnutrition and being chronically underweight continue to affect a substantial number of patients (Allan & Phelan, 1980; Yassa *et al.*, 1978).

The reasons for poor weight gain are many and interrelated. Weight status is affected by respiratory disease, malabsorption, and increased energy needs for bodily functioning (Hubbard, 1985). While a clinician working in this area must be cognizant of these factors a fourth factor may be insufficient consumption of calories by CF patients. Indeed, research has shown that most patients do not meet the prescribed caloric intake of 150% of the RDA, and many do not consume the RDA of calories for healthy children (Chase *et al.*, 1979; Hubbard & Mangrum, 1982; Hodges *et al.*, 1984).

To date, treatments aimed at increasing caloric intake have included nutritional advice during clinic and hospital visits and direct medical interventions. Medical interventions have included artificial diet (Allan & Phelan, 1980; Yassa *et al.*, 1978), parenteral (Mansell *et al.*, 1984; Shepherd, Cooksley, & Cooke, 1980), and enteral nutrition (Levy, Durie, Pencharz, & Corey, 1985). While these procedures have been successful in increasing weight gain in the short term, they are not practical on a widespread level because of their intrusive nature, both physically and in terms of lifestyle. Furthermore, the reported improvements have not been maintained at post-treatment. From a learning perspective, such a finding is not surprising. These treatments have usually lessened the patients' oral intake or eliminated it and thus potentially decrease either patient skills or motivation to increase their intake after intervention, or both.

The application of behavior therapy to this problem appears promising as behavioral interventions are noninvasive and have long been applied to the modification of dietary patterns in the prevention and treatment of other pediatric problems (Handen, Mandell, & Russo, 1986; Epstein, Wing, & Valoski, 1985; Coates, Jeffrey, & Slinkard, 1981; Stark, Collins, Osnes, & Stokes, 1986). At the Rhode Island Hospital CF Clinic, we are investigating the efficacy of a behavior treatment approach to increasing caloric intake of CF patients aged 7–12 years and are evaluating these effects in terms of weight gain, pulmonary functioning, and disease severity (Stark & Passero, 1987).

The current program involves six weekly and three monthly group sessions with parents and children seen simultaneously but separately. The emphasis in the child group is on teaching them to assume greater responsibility in increasing their caloric intake. This is done through sessions focusing on teaching children to identify high-calorie foods, setting caloric goals that gradually increase to appropriate standards, rewarding goal attainment, and teaching children to work cooperatively with their parents through contracting. Similarly, the parent group is designed to teach parents information about nutrition and CF, contingency management skills to motivate their child to consume adequate calories, and maintenance strategies such as contracting.

A group format was chosen as the method of intervention because of our previous success with such a format in treating other difficult populations (Stark, Owens-Stively, Spirito, Hart, & Guevremont, 1989). Many families have had a history of attempting to increase calories on their own and under the guidance of their physicians and/or a nutritionist. As with other aspects of disease treatment, many parents report such attempts have not been successful and led to further conflict between themselves and their child. Consequently, our program was designed to provide optimal conditions of motivation by giving the children and parents exposure to others with similar circumstances. Furthermore, we have found children to be highly motivated to achieve their goals when placed in a group with situations in which other children are seeking the same goals (Stark *et al.*, 1989; Stark *et al.*, 1987). If successful, such an approach may be useful in maintaining adequate nutritional status and possibly delaying progression of pulmonary disease.

Exercise

Physical activity is also a recommended element of the treatment regimen for patients with CF. Exercise is considered beneficial in raising sputum and, for some patients, may be more effective in clearing mucus from the lungs than postural drainage (Orenstein, Henke, & Cerny, 1981). Recent studies on the effects of swimming or running programs for patients with CF (Edlund *et al.*, 1986; Keens, Krastins, Wannamaker, Levison, Crozier, & Bryan, 1977; Orenstein *et al.,* 1981) have demonstrated improved exercise tolerance and, in some instances, improved aerobic capacity. However, only Edlund *et al.* (1986) found concomitant changes in measures of disease status. Modest, but significant increases in global ratings of disease status (Schwachman scores) were reported following their exercise program.

Similar to dietary treatment, exercise interventions have involved either recommendations during clinic visits for patients to increase their activity level or enrollment in highly structured programs in which patients meet at a central location several times weekly and exercise together over a period of 1–3 months. Evaluation of the effects of clinic recommendations for exercise has rarely been reported. However, in a recent study (Hobbs *et al.,* 1985), only 40% of the parents reported that they had been given an exercise prescription for their CF child. By contrast, physicians reported that such recommendations had been made for 80% of the children. The structured exercise programs cited earlier, have reported positive results and high compliance. However, these programs have not included follow-up evaluations. Given the highly structured nature of these group exercise programs, their long-range effects are questionable and need to be assessed. Since less structured patient implemented programs, which can be incorporated into the patient's normal routine and environment, have been found superior in enhancing long-term compliance with lifestyle change (Epstein, Wing, Koeski, & Valoski, 1985), such alternatives need to be developed.

Currently, at Children's Medical Center and University of Oklahoma Tulsa Medical College CF Clinic, such an approach to exercise is being evaluated. A home-based exercise program involving a number of behavioral features designed to enhance compliance with prescribed exercise regimens (Hobbs, Stratton, Geiss, Kramer, & Ozturk, 1987) has been developed. Behavioral techniques employed include self-monitoring of exercise frequency and duration, dispensing of reinforcers specified in behavioral contracts contingent on achieving specified exercise goals, and requiring children to have a partner to complete exercise sessions with them. The requirement of an exercise partner is designed especially for children who may be unable to follow an exercise regimen independently and to provide social reinforcement during exercise. For younger children, the partner typically is a parent; for older participants, the partner may be a parent, friend, sibling, or other relative.

In the home-based exercise treatment, patients, parents, and exercise partners are taught proper exercise behaviors and behavioral management strategies of self-monitoring, goal setting, and contracting for reinforcers during four clinic exercise sessions over a 2-week period. Between sessions, patients are instructed to exercise at home. Data sheets and exercise techniques are reviewed during the in-clinic sessions and corrective and/or positive feedback is given. Following the 2-week training period, the children and their parents/partners are instructed to implement all aspects of the program at home for 8 weeks. Self-monitoring forms are collected on a weekly basis. After the 8 weeks, requirements for self monitoring and contracting are removed, but participants are encouraged to continue to use these on their own.

For comparison purposes, a similar number of children with CF participate in a supervised clinic-based exercise program conducted at Children's Medical Center. Participants in the clinic-based program receive comparable instruction during scheduled exercise sessions. However, they are not trained in behavioral strategies of self-monitoring and behavioral contracting, nor are they required to have an exercise partner. In this manner, the clinic-based exercise program is analogous to previously reported programs for CF patients.

Thus far, nine subjects have completed treatment and the 3-month follow-up in the first phase of a 2-year project. The home-based exercise subjects have compared favorably to the clinic-based on number of exercise sessions per week (4.2 versus 3.3), and 97% of the home based sessions were completed with an exercise partner. The primary forms of exercise completed by participants included swimming, basketball playing, bicycle riding, running, and walking.

Owing to the relatively small number of participants to date, the subjects in the two treatment conditions were combined to form a single group for preliminary analyses. On treadmill tests conducted before and after the 10-week exercise programs, subjects demonstrated a significant improvement in maximal minute ventilation (VE). On standard pulmonary function tests administered concurrently with treadmill tests, significant improvements were observed on forced vital capacity (FVC), forced expiratory volume (FEV1), and peak expiratory flow rates (PEF). Furthermore, improvements on VE, FVC, and FEV1 were maintained at 3-month follow-up.

In addition to physiological changes, significant pre–post improvements also were observed in symptoms of depression on the Children's Depression Inventory and in somatic concerns on the Personality Inventory for Children. Mothers of participating children also reported significant improvements in their own symptoms of depression on the Beck Depression Inventory. Although small increases on these measures were observed at 3-month follow-up, treatment effects were essentially maintained.

While it would be premature to draw conclusions regarding the long range and relative efficacy of the exercise treatments, we are encouraged that the home-based subjects compared favorably with the clinic-based subjects on the number of sessions completed per week and concomitant physiological changes. These results illustrate the potential for behavioral clinicians to provide a valuable collaborative contribution in designing effective methods of implementing CF treatment. As discussed in the case study of compliance with postural drainage, such an approach can impact positively on the patient's and family's psychological functioning as well.

ENHANCING COPING AND ADAPTATION: END-STAGE DISEASE

As in other disorders requiring chronic symptom management CF raises issues of patient adaptation to the disease, quality of life, and functional limitations imposed as the disease progresses. Such issues become even more pronounced during adolescence and end-stage disease. A primary task of adolescence is achievement of greater personal autonomy and separation from parents. The development of autonomy can be substantially impaired by the continuous demands of medical treatment and health decisions that are often made by medical staff and parents rather than the patient. Previously we have discussed behavioral interventions to increase patient involvement in treatment planning and implementation. In this section, we focus on behavioral procedures to enhance adaptation during end-stage disease.

The mean life expectancy for a patient with CF is 19–20 years (Cystic Fibrosis Foundation, 1985); thus, coping with severe disease limitations and end-stage difficulties may be necessary at a time when autonomy is of paramount importance. Behavioral self-management interventions may be most appropriate at these times, as they offer patients a means of helping themselves. The ultimate goal of self-management techniques is to enhance existing, or to teach new, adaptive behaviors.

During end-stage disease, patients often experience anxiety as a result of decreased lung functioning, hyperventilation episodes, sleep difficulties, and pain associated with their disease status. Such symptoms fit into a behavioral analysis framework. For example, patients often develop inappropriate stimulus control in response to symptoms associated with pulmonary disorder. Therefore, labored breathing becomes a cue for anxiety, i.e., fear of hyperventilation attack. Self-management strategies might entail teaching the individual to relabel such an episode and respond adaptively with deep breathing instead of anxiety.

Both cognitive and behavioral self-management strategies can be employed with CF patients. These strategies may include self-instruction to reinterpret bodily cues and to guide and assist the implementation of other behavioral interventions for symptom reduction. Relaxation training to aid with anxiety reduction and sleep difficulties may also be useful. The variety of physical complications associated with CF requires a broad range of skills in implementing different relaxation procedures. Often a combination of procedures including imagery, autogenics, meditative breathing, or deep muscle relaxation is necessary.

The behavioral clinician must take medical conditions, such as frequency and intensity of coughing, ability to assume a prone position, and the use of an oxygen mask, into consideration when designing relaxation interventions. Other characteristics important when considering the use of self-management techniques with patients were reviewed by Tobin, Reynolds, Holroyd, and Creer (1986). Finally, in order to set the stage for successful treatment, the clinician should emphasize the self-control aspects of the interventions, provide a clear explanation of the patient's role in making them effective, and underscore the differences between such an approach and standard medical and psychiatric care.

The above strategies have been helpful in clinical work with CF patients at the Children's Hospital, Boston. Spirito, Russo, and Masek (1984) reported data from 23 patients, aged 13–32 years, who were referred for behavioral treatment during hospitalizations for pulmonary cleanouts. The great majority of these patients were interested and willing to learn a self-control technique, even during the end stages of their disease. Relaxation training and self-instructional training were the primary interventions taught.

A 4- to 6-month follow-up of patient satisfaction with this training indicated that the CF patients found these procedures useful, particularly in dealing with anxiety, but also with pain and sleep difficulties. In addition to the direct benefit of symptom management, the adolescents anecdotally reported an accompanying increase in their perception of control, not only of particular symptoms but of other aspects of their lives as well. Such findings are encouraging, as they occurred at a time when the patient's medical condition would presumably impair the development of such feelings of self control. Such data suggest reasonable promise that behavioral interventions may be beneficial to CF patients and that these benefits extend beyond the symptoms targeted.

Case Illustration: Relaxation

Nancy was a 19-year-old CF patient who had been diagnosed at 2 weeks of age. She did well until age 18, when she was hospitalized for pulmonary clean-outs, 10 times over the year, and referred for a behavioral medicine consultation on her tenth admission. Presenting complaints included chest pain, shortness of breath, hyperventilation episodes, and anxiety caused by pulmonary congestion.

Upon meeting the patient, the behavioral clinician described his role on the floor as a specialist in helping people deal with physical symptoms that accompanied chronic disease. He further explained that there were a variety of interventions he could teach her to do so she might better deal with symptoms such as shortness of breath and hyperventilation on her own. Emphasis was placed on the self-control aspects of these procedures, which tends to be different from most aspects of medical care during hospitalization, and on the patient's own role in making such self-management strategies efficacious.

Nancy was very interested in learning to calm herself when she had episodes of hyperventilation and sleeping difficulties. She could also identify that such episodes made her anxious and her anxiety was also disturbing. It was explained to Nancy that she would need to self monitor the intensity of her symptoms and that such an estimate would be useful in deciding which intervention would be best. This estimate would also be used to evaluate how helpful intervention was once it was implemented. Nancy agreed to self-monitor and a simple chart was used. A short baseline of 2 days was obtained. Such a brief assessment period was used because medical and nursing staff assume a consultation request will be followed by an immediate intervention. Further, as with most of the patients, Nancy required immediate attention.

In the second interview with Nancy, the self-monitoring data were reviewed. Events that contributed to the intensity of the symptoms were pointed out, and intervention techniques were discussed. The data indicated that anxiety heightened the intensity of Nancy's physical symptoms. To help alleviate the anxiety, relaxation training was chosen. An initial trial of meditative breathing and autogenic relaxation was conducted in Nancy's hospital room. She reported that this procedure helped lessen her anxiety level and decreased the intensity and duration of her hyperventilation episodes because it helped slow down her breathing. After this initial training in relaxation, an audiocassette tape was made for Nancy to allow her practice during hospitalization and later on at home. She was asked to continue monitoring complaints to determine whether relaxation had an effect on the problems.

Through continued monitoring, Nancy was able to specify other physical problems and direction for further intervention. Although the meditative procedure was helpful, Nancy reported that the muscles in her back and shoulders were sore because she was only able to breathe adequately and get comfortable when leaning forward. Consequently, a deep muscle relaxation component focusing on these muscle groups was added to Nancy's skill repertoire. She reported that this procedure, in conjunction with meditative breathing, greatly increased her comfort level. Ten days after discharge Nancy was admitted for the eleventh time. She had severe shortness of breath, chest tightness, and pleuritic chest pain. She gradually deteriorated over 16 days. Sleeping difficulties and anxiety were prominent complaints. Relaxation was only minimally helpful for the sleep problems, but she reported that deep breathing helped her "lungs feel better," which made her less anxious. Respiratory distress became increasingly severe and finally resulted in cardiac arrest.

CONCLUSIONS

The application of behavior therapy to issues of treatment management and patient adaptation with cystic fibrosis is a relatively new area. Such an application holds much promise but is relatively unexplored. As the expected life span of CF patients improves, behavioral and psychological factors are becoming of increasing importance. Thus, there is a growing need for further clinical and research activities. However, behavioral clinicians interested in this area need to develop good liaison relationships with physicians and other health care professionals working with CF, because of the complexity of the disease and its life-threatening nature. It is only through a collaborative approach that psychological interventions can be delivered in the most efficacious and nonstigmatizing manner possible.

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CHAPTER 16

Allergies

Behavioral Effects and Treatment Implications

LEE A. ROSÉN AND JULIE A. BEYERS

INTRODUCTION

Millions of people each year report personal discomfort or behavioral problems resulting from allergies (Faelten, 1983). An allergy is defined by *Webster's Dictionary* (1974) as a "hypersensitivity to a specific substance (such as a food, pollen, dust, etc.) or condition (as heat or cold) which in similar amounts is harmless to most people: it is manifested in a physiological disorder."[1] The substances most often identified as causing allergic reactions are pollens and dust. Reactions to these substances often produce hayfever and asthmatic symptoms (Patterson, 1985). In addition, physicians, psychiatrists, and psychologists frequently hear complaints from parents concerning their children's "allergic" reactions to substances such as food additives, caffeine, sugar, aspartame, and other similar substances. This chapter summarizes what researchers have concluded regarding the effects of such substances on children's behavior. Implications of these behavioral effects are addressed, and treatment approaches for dealing with children believed to be affected by these substances are discussed.

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[1] The Committee on Adverse Reactions to Foods of the American Academy of Allergy and Immunology makes a distinction between the term *food allergy,* which implies a immunological response ("a term synonymous with food hypersensitivity but frequently overused and applied to any adverse reaction to a food or food additive"), and *food toxicity* ("a general term implying an adverse reaction following the ingestion of a food or food additive as a result of a direct nonimmune action") (Atkins, 1986, p. 105). For the purposes of this discussion, these distinctions are ignored.

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PSYCHOLOGICAL REACTIONS TO TRADITIONAL ALLERGENS

Extensive data are available regarding the body's physiological response to airborne pollens, mold spores, house dust, and the like (Patterson, 1985). These substances are traditionally associated with allergic reactions such as allergic rhinitis. Allergic rhinitis (hayfever) reportedly affects up to 10% of children and 20–30% of adolescents (Ricketti, 1985). This disease involves the inflammation of the nasal membrane and is characterized by excessive periods of congestion, nasal discharge, and sneezing. Seasonal exposure to pollens and mold spores is often responsible for this condition; however, chronic rhinitis can occur in a child who is sensitive to such things as house dust, animal dander, and feather pillows. In addition, some types of asthma are caused by hypersensitivity of the airways to various allergens. Unfortunately, information regarding the individual's psychological reaction to these allergens is lacking. Although we have information regarding the contribution of emotional factors to the maintenance of asthma in children (see Chapter 11), we know little of the psychological effects that true allergic reactions can create.

It would not be unreasonable to expect adverse psychological effects to be associated with allergic reactions to these substances. Anecdotally, hay fever sufferers often report increased drowsiness, irritability, and difficulty functioning during an episode. The available evidence, however, is that emotional disturbances occurring in individuals with seasonal asthma or rhinitis due to pollen allergy is coincidental and unrelated to the allergic disease (Golbert, 1985). It has been reported, though, that more chronic asthmatic conditions can cause anxiety and fear in children (Golbert, 1985). Clearly much more research needs to be conducted in this area before we can fully understand the interaction between allergens and behavior.

FOOD "ALLERGIES"

Hyperactivity and Food Additives

Dr. Benjamin Feingold, a pediatrician and allergist, reported in the mid-1970s that he was able to reduce the activity level of several hyperactive children in his clinic through the use of a special diet which eliminated all artificial color and flavors, and all foods containing salicylates (Feingold, 1975). Feingold's hypothesis that salicylates, artificial food colorings, and preservatives could, in genetically predisposed children, produce a reaction having the behavioral symptoms of childhood hyperactivity was based on clinical observations of children in his practice (Feingold, 1975). Feingold reported that up to 50% of the hyperactive children in his clinic no longer exhibited hyperactive behavior as a result of following his special diet. He also stated that other childhood disorders, such as mental retardation, learning disabilities, and delinquency, improved dramatically while on the diet. The Feingold approach required stringent regulation of the child's diet, including elimination of processed foods. Cookies, lunchmeat, most carbonated soft drinks, and many fruits and vegetables with naturally occurring salicylates were also included in the extensive list of foods eliminated on the Feingold diet (Faelten, 1983).

Research regarding the impact of the Feingold diet on behavior associated with hyperactivity has consisted of several different methodologies: uncontrolled case studies, diet crossover studies, and specific challenge studies. Initially, many uncontrolled case studies indicated lessened behavioral symptoms of hyperactivity while the children were on the Feingold diet (Cook & Woodhill, 1976; Crook, 1980). However, when studies were conducted using appropriate experimental methodology and empirical measures, no such effects were documented (Mattes & Gittelman-Klein, 1978). Overall, the methodologically strong studies indicate only slight, if any, reductions in hyperactivity while children are on the Feingold diet (Conners, 1980; Ross & Ross, 1982). Both the challenge studies and diet crossover studies suggest that only a small number of hyperactive children may be affected by food additives (e.g., Harley, Matthews, & Eichman, 1978; Mattes & Gittelman, 1981). The number is much smaller than the 50% reported by Feingold. The overall conclusion is that food additives have not been shown to be the cause of hyperactive behavior, and the Feingold diet should not be considered an empirically supported intervention for the treatment of hyperactive children.

Behavioral Effects of Caffeine

Caffeine is a central nervous system (CNS) stimulant found in coffee, tea, cola, chocolate, and many prescription and nonprescription drugs (Bassuk, Schoonover, & Gelenberg, 1983). Studies with adults have demonstrated that caffeine can produce adverse effects, such as irritability, nervousness, insomnia, and headaches. These findings were found to be especially true for people who do not typically consume caffeine (Goldstein, Kaizer, & Whitby, 1969). In fact, adults who habitually ingest large amounts of caffeine may experience positive effects rather than negative effects (Goldstein, Kaizer, & Whitby, 1969). Other researchers have reported, however, that adults who consume abnormally large doses of caffeine can experience symptoms indistinguishable from those of generalized anxiety disorder (Gilbert, 1976; Greden, 1981).

Because of its stimulant qualities, caffeine was considered for a short time to be a possible alternate treatment for children with hyperactivity. The research investigating this possibility, however, did not find caffeine to be an adequate substitute for methylphenidate (Ritalin)—the most frequently prescribed stimulant medication for controlling hyperactivity (Schnackenberg, 1973, Huestis, Arnold, & Smeltzer, 1975). Most of the other studies of the effects of caffeine on children have addressed whether caffeine might provoke childhood hyperactivity or other maladaptive behavior. Rapoport, Berg, Ismond, Zahn, and Neims (1984), for example, found that when children were tested while abstaining from caffeine, those who usually consumed large amounts of caffeine scored higher on both the Conners Teacher Rating Scale and an anxiety questionnaire, and lower on a measure of autonomic arousal than their peers who usually consumed low levels of caffeine. However, when tested after consuming large amounts of caffeine, children who usually consumed small doses were more restless and experienced adverse side effects (although these children did not become hyperactive). By contrast, those who regularly consumed large amounts of caffeine did not experience negative side effects and were somewhat calmer than usual after receiving a high dose of caffeine.

Caffeine, therefore, does appear to have some effects on the behavior of both children and adults. The evidence, although not extensive, clearly demonstrates that children who habitually consume large quantities of caffeine are adversely affected when they are not consuming their typical dose, whereas those children who do not regularly ingest caffeine are adversely affected when given this substance.

Children's Reactions to Sugar

Parents and teachers frequently report changes in children's behavior following ingestion of foods containing large amounts of refined sugar. Many people are convinced that sugar consumption is responsible for problematic behaviors exhibited by children, especially those associated with hyperactivity (Duffy, 1975; Tauraso, 1983; Buchanan, 1984). For some, there appears to be an emotional investment in proving that sugar consumption causes hyperactive behavior. For example, in discussing the recent research regarding the effects of sugar on children's behavior, more than one half the 200 students in a general psychology class taught by the second author (J. A. B.) indicated that they believed that sugar does indeed causes behavior change in children. Furthermore, many in the class vigorously disputed the results of studies that found no connection between hyperactivity and sugar consumption.

Sugar is a substance found in many foods, including breads, fruits, and dairy products, as well as the sweets that we typically associate with sugar. In fact, monosaccharides such as glucose and fructose are biologically essential to good health. Therefore, to remove all sugar products from our diet would be both impractical and unwise. Nevertheless, many physicians continue to recommend a sugar-restricted diet for their hyperactive patients (Bennett & Sherman, 1983).

Some correlational studies linking children's diet histories and subsequently observed behavioral patterns have found evidence for a relationship between sugar consumption and hyperactive behavior (e.g., Prinz, Roberts, & Hantman, 1980). However, most of the research investigating the relationship between sugar and behavior change suggests that sugar is not responsible for increased activity levels in children.

Controlled experiments—those actually manipulating the amount of ingested sugar—have been conducted. A review of these studies indicates that, in general, sugar consumption does not cause behavior reactions of any kind (e.g., Wolraich, Milich, Stumbo, & Schultz, 1985; Milich & Pelham, 1986, Miethke, Rosén, & Burns, 1986). The few studies that have found behavioral changes associated with sugar ingestion have not been consistent in their findings. Some have shown adverse effects (e.g., Goldman, Lerman, Contois, & Udall, 1986;

Conners & Blouin, 1982), while others have found salutary effects (Behar, Rapoport, Adams, Berg, & Cornblath, 1984). No study has found that sugar consumption causes behavior changes severe enough to be considered hyperactive (Milich, Wolraich, & Lindgren, 1986).

Our own research is consistent with the above findings. In our first investigation of this issue we assessed the effects of sugar (sucrose) on the behavior of 45 children, consisting of 30 preschool and 15 elementary school (Rosén, Booth, Bender, McGrath, Sorrell, & Drabman, 1988). The amount of sucrose contained in a breakfast they received was manipulated in a double-blind within-subject challenge design. The children's responses were examined on several measures: cognitive measures, teacher-rating measures, and direct observations. The results indicated that ingestion of large amounts of sugar (approximately 50 g) caused a slight change in some aspects of the children's behavior. All these differences, however, were quite small in magnitude, leading us to conclude that sugar does not play a major role in the etiology or maintenance of hyperactivity.

Our second investigation (Rosén & Beyers, 1986) concentrated on the behavior of normal preschool children following a breakfast either high or low in sucrose or containing aspartame. This investigation focused on preschoolers ($N = 17$) because of the clear adverse effects reported by Goldman *et al.* (1986) with this group. We again assessed the behavior of the children on cognitive measures, teacher ratings, and through direct observation. Our findings indicated that there were no significant differences among the three conditions on any of the dependent measures. Given the contradictory nature of some studies, more research will need to be conducted in this area before firm conclusions can be reached. In general, however, sugar does not appear to be the powerful allergen many parents and teachers believe it to be.

The Newest "Allergen": Aspartame

Aspartame is a low-calorie nutritive sweetener that goes by the brand name Nutrasweet (manufactured by Searle). Aspartame recently received regulatory clearance from the Food and Drug Administration (FDA) for use in products such as carbonated soft drinks, frozen desserts, frozen dairy products, gelatin, dry beverage mixes, cereal, chewing gum, and candy (Homler, 1984). Aspartame is a dipeptide of the commercially produced amino acids, L-phenylalanine and L-aspartic acid (Council on Scientific Affairs, 1985). These amino acids are identical to those found in foods such as meat, vegetables, dairy products, and grains. Because aspartame contains phenylalanine, there has been some concern that children with heterozygous phenylketonuria (PKU) should be cautious when ingesting aspartame. Overconsumption of foods containing phenylalanine by children with heterozygous PKU may produce mental retardation, learning disabilities, and perceptual difficulties (Horwitz & Bauer-Nehrling, 1983). Studies have demonstrated, however, that even though children with heterozygous PKU metabolized the phenylalanine portion of aspartame slowly, the levels of phenylalanine in the body were not sufficient to produce toxic effects (Horwitz & Bauer-Nehrling, 1983).

Few studies have examined the effects of aspartame on children's behavior. Most of this research has consisted of studies examining the effects of sugar on behavior where aspartame was used as a control substance. The general conclusion to be drawn from these investigations is that aspartame causes few if any changes in children's behavior (Kruesi & Rapoport, 1986).

In summary, the evidence thus far has shown no behavioral effects of aspartame ingestion, adverse or other. However, given the beginning nature of this research and the number of anecdotal reports concerning this substance, more studies are clearly needed.

Behavioral Reactions to Other Foods

Several studies have investigated children's behavioral reactions to common foodstuffs, apart from their reactions to specific substances such as food additives and caffeine (e.g., Crook, Harrison, Crawford, & Emerson, 1961; Rapp, 1978). Foods such as milk, chocolate, eggs, and tomatoes have been implicated by these studies (Atkins, 1986). Unfortunately, almost all these studies consist of case reports of patients treated by the authors (Atkins, 1986). Virtually none of these studies used double-blind control procedures for adequate testing of the behavioral effects of the suspected foods. One study that did use appropriate double-blind control was conducted by King, Margen, Ogar, and Durkin (1984). These investigators examined the impact of specific "allergic" foods on several measures: the continuous performance test, heart rate, finger tapping, and direct observation. This study did find a moderate behavioral response to the suspect foods. In general, however, the data on food allergies do not provide pervasive or convincing evidence that common foods can cause behavioral reactions in children (Atkins, 1986; Prinz, 1985). In fact, for a number of children, "psychological factors may be the cause rather than the result of apparent adverse reactions to foods" (Atkins, 1986, p. 110).

TREATMENT OF BEHAVIORAL PROBLEMS ASSOCIATED WITH "ALLERGENIC" SUBSTANCES

Most of the research on substances (dietary or otherwise) thought to be associated with changes in children's behavior has not demonstrated that ingestion of these substances produces any significant behavioral effects. The exception may be caffeine. Among all the substances studied (e.g., foods, dyes, pollens), caffeine is the one substance for which we have the clearest evidence linking it with changes in children's behavior. Children who self-select high amounts of caffeine in their diet appear to experience no ill effects. However, children not typically consuming large amounts of caffeine appear to suffer negative effects, such as restlessness and inattention. We therefore recommend that parents limit their child's intake of this substance, especially if their child is unaccustomed to it.

In many cases, factors other than allergic reactions are responsible for the child's disturbed behavior. How, then, should assessment and treatment of a child who is displaying problematic behaviors, and whose parents suspect (or often insist) that he or she is having an allergic reaction to a particular substance (other than caffeine), proceed? The first step is to do a careful behavioral assessment of the problem behavior, problem situations, antecedents, consequences, and the like. It is also prudent at this time to question the parents carefully as to the reasons for their belief that an allergic reaction is causing their child's problem. In most cases, the parents will describe situations in which the child's problem behavior could be attributed to several factors, such as eating large quantities of sugary substances at a poorly supervised birthday party. The next step we recommend is educating the parents as to the nature of their child's specific behavior and the research findings regarding possible causes and effective treatment approaches for that behavior. Within this context, we also discuss the research findings regarding children's behavioral responses (or lack of) to food additives, sugar, aspartame, and other suspected substances. We then suggest that the parents try, at least as a first step, the treatment practice which the current research indicates is the most effective and appropriate method for treating their child's particular disorder. For example, for children displaying hyperactivity we suggest following the behavioral approach outlined by Barkley (1981). Barkley's approach involves a modification of the parent training program advocated by Constance Hanf and researched extensively by Forehand and his associates (Forehand & McMahon, 1981). Tailoring his approach to hyperactive children, Barkley's program includes instruction regarding the characteristics and causes of hyperactivity, increasing parental attention for appropriate behavior, teaching parents the use of appropriate punishment procedures (such as time out), and teaching parents how to manage behavior in public.

If, in spite of all efforts, the parents insist that the child's problem is attributable to ingestion of an allergenic substance, we recommend the following: a complete physical examination specifically aimed at uncovering allergic disorders, a full allergy history, skin-prick testing, a dietary history, and, if prudent, a double-blind challenge assessment using the substances in question. These assessments, if properly conducted, can be very time consuming and expensive and are unlikely to support the parent's hypothesis. It is for these reasons that we strongly suggest that such measures only be pursued if the parents are insistent. In fact, if these allergen assessments are conducted as an initial step the parent is likely to believe that an allergic reaction is probable even where all assessments fail to support this conclusion.

Finally, an approach we often use with families who insist that allergies are creating their child's problem is to suggest that they realistically consider the implications of this. Could they truly eliminate this substance, food additives, for example, completely from their child's diet in all situations, at all times? Most parents agree that this would be impossible. Next the parents are asked whether they would be willing to try some other approaches that may be able to help, even if their child is displaying a true allergic reaction. Given this approach, most parents accept this argument and are willing to "give it a try."

CASE ILLUSTRATION

The following case is a combination of several children we have treated. It illustrates the insistence of some parents regarding behavioral reactions to "allergenic" substances. It also demonstrates the creative measures needed to change parents' dysfunctional attributions as well as to help improve their child's behavior.

Joe was a 10-year-old white boy diagnosed with attentional deficit disorder with hyperactivity. When the case was originally referred Joe was receiving stimulant medication for his hyperactivity (Ritalin, 20 mg bid). Assessment indicated a hyperactive boy with all the typical symptoms: short attention span, impulsivity, noncompliance, situational overactivity, aggression, and poor peer relations. In addition, Joe's mother insisted that sugar consumption was at the root of Joe's difficulties. Because of this, she had restricted his intake of everything she considered high in sugar (e.g., cookies, ice cream, candy) both at home and at school. However, so that Joe might still have some access to these "goodies," she bought him dietetic cookies and sweets. Unfortunately, she continued to make available real cookies and other sweets to the rest of the family. Joe felt singled out and proceeded to deal with this problem by sneaking into the pantry during the middle of the night and stealing the "real" thing. This served to reinforce his mother's concern that sugar was the cause of his problems.

Treatment proceeded as outlined in the previous section. Joe's parents agreed to use the "most effective methods available" to deal with Joe's behavior and were thus taught several behavior-management techniques. These techniques were very effective in controlling Joe's problem behavior and included differential reinforcement of alternate behavior, time out, and home-based management of school behavior.

The differential reinforcement program involved teaching Joe's parents to attend to his appropriate behavior in a frequent, salient, and consistent manner. Specifically, each parent was told to "catch him being good" at least 10 times a day. They were instructed to use both social reward, such as praise and hugs, as well as tangible rewards, such as toys, in response to any appropriate behavior no matter how small or insignificant. In addition, they were told that the frequency could never be less than 10—even if Joe was having a bad day, they were still to find at least 10 appropriate behaviors to reward him for. This last provision was very important as some parents will use a child's "bad day" as justification to stop attending to his appropriate behavior. We explained to the parents that when Joe was having a "bad day," he needed even more incentive to help him behave himself, and "catching him being good" during those days would help him "turn his behavior around." Finally, to ensure compliance to the program, each parent was instructed to write down daily each of the 10 behaviors that they "caught" and to record the reward that they provided, be it a positive comment, hug, or special treat (we provided them with 8 × 10-inch file cards for this purpose). These lists were turned in to us for weekly inspection and discussion. This aspect of Joe's treatment continued throughout Joe's therapy; that is to say, we continued to expect the parents to provide Joe with a high frequency of consistent and salient positive consequences for appropriate behavior. We did, however, drop the data-collection requirement after a month, as a means of fading out the amount of external control of this parental behavior.

Shortly after the introduction of the differential reinforcement program the use of "prudent" negative consequences was introduced (see Rosén, O'Leary, Joyce, Conway, & Pfiffner, 1984). It has been our experience that, in many instances, hyperactive children do not begin to make significant changes in their behavior until we begin to teach the parents appropriate and effective methods to use in response to their child's inappropriate behavior. This was the case with Joe. Although his parents were doing a fairly good job of "catching him being good," Joe still seemed to get into a lot of trouble both at home and at school, especially regarding his aggressive behavior. Therefore, our next step involved teaching the parents how to use time out as an easy, effective, and prudent negative consequence for aggression and other inappropriate behavior. Time out for Joe consisted of having him sit in a chair in the dining room for 10 min immediately following each instance of aggression, noncompliance, tantrum behavior, and other inappropriate behavior (we use the rule of thumb "1 min of time out for every year of age, with a minimum of 5 min"). Joe's parents were carefully instructed to set the kitchen timer so as to signal them when Joe's time out was completed (you would be surprised at how easy it is to lose track of time) and to ignore him completely while he was in the chair. If Joe left the chair, his parents were instructed to tell Joe that his time would have to start over and 5 extra minutes would be added for his having left the chair. When Joe's time out was over, he was allowed to leave the chair, provided that he was quiet, and resume an appropriate activity. Within the space of 2 weeks, both the frequency and intensity of Joe's aggressive behavior had decreased greatly and many of his other inappropriate behaviors had improved as well.

Finally, we taught the parents how to set up a home-based program to help manage Joe's school behavior, which was still somewhat problematic. This consisted of having Joe bring to school each day a daily report card—a file card with his name, the date, and the words "Joe had no problems today" and "Joe had problems today." At the end of each school day, it was Joe's responsibility to bring the card to his teacher and to ask her to initial, in ink, the relevant statement (there was also a section for teacher comments). Joe was to bring the card home each day and, if the report was good, he was allowed to choose one item off a menu of rewards that he and his parents had previously made. This menu included such items as getting to play a special game with dad, calling grandma, getting a special snack, and playing computer games. If, however, the report was bad or Joe "forgot it" (which most often meant it was a bad report and he had ripped it up), Joe's parents chose one item off the menu of negative consequences. This included going to bed a half-hour early, no television for the evening, not being allowed to have friends over or to play outside, and having to do extra chores that night (all short-term "prudent" negative consequences). This procedure was very effective in reducing Joe's aggression and noncompliance at school. Joe's academic performance also improved dramatically; instead of getting Cs and Ds, Joe now starting getting Bs and even some As. In addition, Joe's teacher reported that he seemed to be getting along much better with his peers.

Although these behavioral techniques were very effective in reducing Joe's problems, Joe's mother continued to believe that she should restrict Joe's access to sugar, and he in turn continued to steal the goodies he was denied. Therefore, to focus more directly on the stealing problem, and to change the family's attitude regarding sugar, we asked Joe's mother to place a bowl of "real" candy right out in the open. We then asked her to carefully count the number of pieces of candy in the dish and to check frequently for any missing pieces. The others in the family were instructed not to remove any candy from this dish. In addition, Joe was told that if he did not steal any of this candy (or any other candy), he would be allowed to take a "handful" after dinner. However, if he did steal any candy, he would have an immediate timeout.

At first, Joe's mother was very reluctant to try this technique, but within a week after instituting it, Joe had completely stopped stealing candy. According to his mother, Joe never stole another piece (6-month follow-up). Most importantly, however, there was absolutely no deterioration in Joe's behavior, in spite of the fact that he was not getting a "handful" of candy every night. Consequently, without directly admitting her attributional error, Joe's mother stopped buying dietetic candy and allowed Joe access to the "real" goodies on an equal basis with the rest of the family.

SUMMARY

Parents and teachers frequently report that exposure or ingestion of certain "allergenic" substances can cause detrimental changes in the behavior of some children. Review of the evidence concerning traditional allergens (e.g., pollen, mold spores, dust), food additives, sugar, aspartame, and specific foods is clear in showing little, if any, effects of these substances on children's behavior. The one exception is caffeine; evidence is available indicating that children unaccustomed to consuming caffeine display changes in behavior following caffeine consumption. These children tend to be perceived as more emotional, restless, and inattentive than they are without caffeine (Rapoport *et al.,* 1984). Therefore, we recommend that parents restrict their children's access to large amounts of caffeine. Given the lack of detrimental effects for other substances, however, it is our recommendation that treatment for children whose parents suspect that an allergic reaction is taking place, consist of adherence to the empirically validated treatments available for that disorder. In addition, the parents should be educated concerning the research regarding children's reactions to "allergenic" substances and helped to make more appropriate attributions for their child's disorder.

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CHAPTER 17

Therapeutic Consultation in Pediatric Dentistry

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INTRODUCTION

The pediatric dental operatory is naturally a setting that is unusual for its young patients. Although the modern clinic is less foreboding than its predecessors, being cheerfully decorated with posters and housing numerous stuffed animals and other pleasant furnishings, it is not a place that is frequently visited, and it is a setting in which unusual procedures are conducted. The young child is required to lie helplessly on his or her back underneath an array of lights and instruments. Smiling adults in white coats insert strange and unusual items inside the mouth. The mouth must be kept open for long periods of time, even if it is held open mechanically. The sensations in the mouth are different, including the touch and vibration of the sharp and blunt instruments and the taste of chemicals, saliva, and blood. The sounds of the dental clinic are different. The drills whirr and the suction forcefully extracts saliva and other debris from the mouth. There is even a distinct aroma in a dental operatory. Modern dentistry has become a largely painless experience under the hand of a skilled practitioner. Yet given the assault on the child's person, it is surprising that more children do not display serious behavioral problems while visiting the dentist.

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DESCRIPTION OF CHILD BEHAVIORAL PROBLEMS IN DENTISTRY

As a consultant to pediatric dentistry, it is likely that one will be asked to provide assistance in the management of a young child who is so disruptive that dental treatment cannot be completed. This is problematic, since children who are out of control may increase the probability of their own injury, increase the probability of staff injury, increase the intrusiveness of the procedures, prolong or prevent necessary dental treatment, and compromise the quality of treatment.

Various behavioral problems are presented by children during restorative procedures in pediatric dentistry. Some of these behaviors relate to avoidance of the operatory, some to avoidance of dental procedures, and some to interruption of and escape from ongoing restorative procedures.

After extensive observation of children undergoing dental treatment and collaboration with dentists, Stokes and Kennedy (1980) described and categorized major disruptive behaviors displayed during restorative treatment. These included movement, crying, and behaviors requiring physical restraint of the child. Head movements of more than 15 mm and general body movements (e.g., legs, arms, or body, of more than 15 cm) were judged by dentists as presenting difficulty in treatment and likely to interrupt treatment or put the child at risk of injury. Excessively large and frequent movements require restraint by the dentist or dental assistant by holding the head and/or body to prevent further prevention of ongoing procedures. Crying, complaining, whining, and moaning about the procedures or pain were a further concern, sometimes interrupting ongoing procedures and certainly were unnecessary additions to the clinic. Crying tended to increase the arousal of the child and the dentist to an overbearing level.

Specific examples of behaviors observed included moving in the chair, kicking feet, waving hands, turning over to face sideways or down, sitting up in the chair, leaving the chair, shaking the body, weaving the body from side to side, turning the head away from the instruments or the dentist, clamping the mouth shut, weaving the head continuously, pushing instruments away when they were brought close to the mouth, pulling instruments out of the mouth, screaming, complaining, crying, and moaning even when there was no objective cause for pain or discomfort. Problematic behaviors do not usually occur throughout the dental appointment. An assessment of the level of disruptive behavior continuously allows an examination of disruptive behavior across time within a restorative visit (Allard & Stokes, 1980). Although there is typically maintenance of disruptive behavior from one appointment to the next without specific intervention, some children show more disruptive behavior at the beginning of an appointment (e.g., during anesthetic injection) and less near the end of an appointment (e.g., during polishing) (Allen & Stokes, 1987).

Research assessing children's behavior across dental and medical procedures has consistently found that disruptive and distressful behaviors, such as screaming and attempting to escape, increase rather than decrease across treatment sessions (Elliott & Olson, 1983; Stokes & Kennedy, 1980; Venham &

Quatrocelli, 1977). The serious behavior problems of the children are not likely to improve without specific procedures related to treatment.

ASSESSMENT OF CHILD BEHAVIORAL PROBLEMS IN DENTISTRY

Each child is likely to display a range of problems when a referral is made to a psychologist. There will be similarities among referrals, and there will be behaviors displayed by only a few children. An essential component of treatment, therefore, will be an assessment of the individual circumstances, individual behavior, and the individual history of functional contingencies that the child brings to the clinic. A child's functional history of the behavior(s) needs to be assessed. This involves an analysis of past and current operating contingencies of reinforcement, punishment, and extinction (Stokes, 1985). An antecedent stimulus or a consequence is said to be a functional event if it has an effect on the child's behavior, i.e., increasing, decreasing, or maintaining the behavior. Therefore, the functional analysis attempts to disclose previous and current factors that have developed or that maintain the current problems. It is important to note that the assessment needs to be individualized, even though some children may display the same types of behavioral problems.

In pediatric dentistry consultation, there are a number of clients. The dentist is one important client; the parents and the child are the others. Conducting an assessment of a child's behavior starts with a discussion with the referring dentist. The nature of the problems, the concerns of the dentist, management strategies that the dentist has tried, and the goals that the dentist has for the child should be considered. Dentists vary as to their tolerance of certain behaviors exhibited by their young clients; some will readily tolerate excessive crying and minor movement, whereas others will find such activity quite distressing, which results in interruption of the procedures or even a longer-term avoidance of young children. A subsequent interview with the parent obtains the parents' description of the problem and its history, as well as previous and current strategies employed to manage the behaviors. Most importantly, the child is seen to assess the problems and to determine the effect of various procedures on the child's behavior before full implementation of the procedures.

Analysis of events that precede disruptive behavior and of those that follow disruptive behavior, both closely and remotely, suggests that children's disruptive behavior may be a function of specific antecedent and consequent stimuli. Children's disruptive behavior seems to be occasioned by the sights, sounds, and sensations of the dental operatory and maintained by the consequences of that disruptive behavior. Potent consequences seem to be the temporary escape from procedures and entrapment of adult attention that occur as a result of the behavior. This appears to be true, regardless of age of the child. For older children, who typically have more extensive learning histories with rules and delayed consequences, the immediacy of escape and attention as functional consequences may be more easily overshadowed by delayed consequences (e.g., threats about health consequences, promises of reward at the end of treatment contingent on cooperation), by the provision of sensory or procedural information (e.g., description, modeling), or by distraction (e.g., cartoons, video games).

For very young children, however, limited learning histories render the most salient consequences to be those that occur more closely in time to the actual disruptive behavior. These children may require interventions that manipulate the escape or attention contingencies rather than attempting to compete with them (e.g., distraction).

CASE ILLUSTRATIONS

Case 1: Distraction Techniques

If a child attends too much to the ongoing procedures and sensations in the dental clinic, it is possible that interventions that divert the child's attention away from the procedures might function well to decrease the concomitant disruptive activity that may be produced in order to escape from procedures or to entrap other positive consequences. Various strategies have been taught to children. These include relaxation, deep breathing, and use of imagery (e.g., Siegel & Peterson, 1981). Although a package of procedures is usually implemented simultaneously, many procedures have a strong element of distraction (Stark, Allen, Hurst, Nash, & Stokes, in press).

Raymond was a 7-year-old boy referred because of his major disruptive behavior in the pediatric clinic of a university dental school. These uncooperative and disruptive behaviors included excessive movement and frequent complaints about the pain of the dental procedures. The dental operatory was furnished with one chair and dental equipment and had decorative posters, stuffed animals, and mobiles on the walls and ceiling.

During the initial assessment visits, the dentist or the dental assistant explained the procedures and provided sensory information associated with each procedure, i.e., what was going to happen and how it was going to feel. In addition, Raymond was praised for cooperative behavior and disruptive behavior was ignored as much as possible. At the end of each appointment, Raymond was awarded a colorful helium-filled balloon, regardless of his behavior.

Distraction Procedures

One component of typical distraction procedures was employed as the intervention. This distraction task allowed for an objective assessment of Raymond's use of the skill through direct questioning about the information retained by the child. Distraction was introduced following Raymond's second visit to the clinic. Improvements as a result of the distraction strategies were measured by comparison of behavioral problem frequency under the distraction procedures as compared with the initial two visits.

The psychologist explained to Raymond that he would be taught a way to relax and stay calm while at the dentist. The distraction stimuli were [0.5 × 0.5-m (19 × 19 in)] posters and a 13-min audiotaped story about each poster. The posters were colorful, depicting unusual scenes such as outer space and ship wrecks and contained children and animals engaging in various activities. The posters were purchased from an educational supply company. They were mounted on posterboard and hung about 1.5 m above Raymond's head as he laid back in the dental chair. A new poster and story presented simultaneously through earphones was used at each visit.

During training, Raymond was instructed to listen to the story and look at the poster and to remember as many things as he could by repeating them to himself. He was then given practice at this technique by first saying things out loud, then in a whisper, then to himself. Raymond achieved 100% correct answers on our 14-item questionnaire within 15 min of the introduction of this technique in the clinic, but without ongoing dental procedures. Raymond's scores on the distraction task quizzes after dental treatment were always higher than 75%, documenting his use and mastery of the task.

On Raymond's third visit, his first treatment visit, he received 5 min of refresher training on the previously used training poster and tape to ensure that he was able to complete the task. He was then told he could earn a prize if he paid special attention to the poster and story, practiced remembering during the visit, and was able to answer the questions after the visit. The prizes included inexpensive activities or items, such as a small toy car, a coloring book, and a video game. There was no discussion of Raymond's behavior during dental treatment, nor was there any discussion linking the prize to any behavior other than use of the distraction task.

Assessment of Treatment Outcome

Raymond was directly observed in the clinic using the Stokes and Kennedy (1980) observation system that noted head and body movements, crying and complaining, and restraint. Ten of the typical dental procedures were also scored during each 15-sec interval. These included use of explorer, injection, placement of rubber dam, drilling with handpiece, placement of amalgam/resin, use of suction, pulpotomy, and extraction. During Raymond's first visit, he was disruptive on 35% of the intervals observed. This increased to 67% on his second visit. Disruptive behavior occurred mostly at the beginning of the first appointment, when the anesthetic injection was given. However, during the second appointment, the disruptive behavior occurred throughout all procedures. Following the introduction of the distraction, Raymond's disruptive behavior immediately decreased from the assessment average of 57% to a more acceptable level. On each of the first two intervention visits, he displayed 29% disruptive behavior. He continued to be most disruptive during the injection at the beginning of an appointment. On the third intervention visit, the fifth and final day of dental treatment, Raymond's overall level of disruptive behavior increased from the previous two visits to 50% disruptive behavior. The disruptive behavior occurred across all procedures and was not confined to the injection.

Cooperation and anxiety ratings were also obtained from the dentist and dental assistant. These ratings could range from 1 (extremely cooperative or calm) to 6 (extremely uncooperative or anxious). Each rating between 1 and 6 had specific descriptors for decreasing cooperativeness and increasing anxiety. These ratings provided an indication of improvement from the perspectives of the dental service providers. For the first two appointments, Ray was given cooperation ratings of 2.5 and 3.5 and anxiety ratings of 3.5 and 4.5. The dental ratings during intervention parallel the observational data. Improvements to ratings of 2.0 on both cooperation and anxiety were initially shown. However, these increased to 2.5 and 3.5 for cooperation and to 3.5 and 4.0 on anxiety.

Treatment Parameters

Distraction appears to be a clinically useful strategy for children undergoing dental treatment. The present distraction task was easy to teach and Raymond was able to learn to use it quickly. Checks on the use of the technique by means of the quiz documented Raymond's actual use of the procedures. Distraction procedures have sometimes been shown to work and sometimes ineffective. When they have not worked, it is often unclear whether the child has actually used the distraction procedures or whether the child used the procedures but they were ineffective. In the present case, the use of the distraction procedures was documented, permitting an examination of whether they were effective.

The course of treatment with Raymond emphasizes the importance of programming maintenance of treatment effects. It would appear that the novelty of the distraction task may have been responsible for its initial use and that Raymond may not have continued using it efficiently beyond his first two distraction visits. That is, after the first two visits, Raymond's quiz performance declined consistently, although always staying above the 65% criterion. A concomitant decrease in his cooperative behavior was evidenced.

Thus, if distraction, or any coping skill, is to be clinically useful, it is important to continually assess the child's use of the skill and evaluate ways of motivating the child to use it. In Raymond's case, we initially set an achievable goal of 65% and scheduled the reward only to be contingent upon use of distraction. Perhaps setting a higher criterion in line with what Raymond could clearly accomplish and giving him more contact with the contingencies of obtaining or not obtaining the reward would be advantageous. Related to this is the point regarding shaping versus the use of terminal contingencies. If Raymond was to show progressively deteriorating levels of quiz performance, it would not have been the time to similarly reduce the criterion for reward. He had already shown that he was well able to complete the task. Other procedural changes are more likely to be beneficial than changing reward criteria, e.g., to examine the diversity or attractiveness of the rewards available. Alternatively, making Raymond's reward contingent on his disruptive behavior during treatment as well as providing him with a means of reducing disruptive behavior through distraction may be a more practical procedure.

It is also important to note that we are dealing with procedures that have traditionally distressed children and that have occasionally evoked pain. As with any other learned aversive phenomenon (e.g., phobias), it is unrealistic to expect one trial to reverse this learning. Thus, the effects of any intervention need to be thoroughly assessed over time, in this case across multiple visits. Modifications in the procedures may be made in its implementation as clinically indicated. Another goal of the procedures is to make the role of the psychologist obsolete for the child. Therefore, maintenance of the effects of the procedures over time is an important treatment focus.

One question frequently asked is whether the parent should be asked to stay while the procedures are being conducted. We have found it advantageous to ask the parent to separate quickly from the child and to return to, or stay in, the waiting room. This allows the psychologist and the dental staff to proceed quickly without interruption. It is important to explain to the parent precisely what will be done and what the effects are likely to be. Sometimes it has been beneficial to allow the parent unobtrusive observation of the child after the initial success of the procedures has been evident.

Case 2: Reinforcement

An analysis of the contingencies operating for children's disruptive behaviors in the clinic suggests the value of a procedure that would arrange for the reversal of the existing conditions that maintain disruptiveness. That is, escape and attention could be made available contingent on cooperative rather than disruptive behavior. These conditions may be presented in a practice visit format wherein increasingly longer periods of cooperation could be rewarded in the presence of invasive procedures. Once acceptable levels of cooperation were established, the child could be returned to actual dental treatment where necessary restorative work could continue (Allen & Stokes, 1987).

Logan was a 3-year-old boy referred because of excessive levels of disruptive behavior. During two previous visits to the dentist, Logan exhibited biting, kicking, hitting, screaming, and pinching. Previous attempts at managing his behavior using procedural information, distraction with videotaped cartoons, and prizes at the end of treatment for being well behaved had proven ineffective. Eventually, the dentist recruited three assistants to restrain Logan to control him during treatment. The dentist was still unable to complete necessary restorative procedures because of Logan's movement. Given Logan's need for multiple restorative treatment visits, and at least one extraction, the dentist referred the child's case to a psychologist.

Reinforcement Procedures

After the end of assessment dental appointments, Logan was brought into the dental operatory and was told that he would be given the opportunity to practice being a "big helper" for the dentist by using "good dentist chair behaviors." The first goal was to get Logan to lie down and remain still and quiet in the dental chair. Logan earned a small sticker after increasingly long periods of time, during which he remained quietly in his chair. Subsequently, he was required to maintain appropriate chair behavior during each of the restorative procedures. No work was actually done during the practice. However, each of the instruments was moved in and around Logan's mouth by the dental assistant, who worked closely with the psychologist. Typical sensations were provided, if possible. For example, the high-speed drill, with the drill bit removed for safety, was turned on and placed harmlessly against Logan's teeth so he could feel the vibrations as well as hear the sound. If Logan was disruptive during this practice, it continued and the psychologist and the dental assistant ignored the behavior.

After one 45-min practice session, Logan was able to demonstrate at least 30 sec of acceptable cooperation during all but two of the procedures he would contact during actual treatment. Following his second practice visit, he was able to remain quiet and still in the presence of the sights, sounds, and nearly all the sensations of each procedure he would experience during actual dental treatment. Immediately before subsequent visits, Logan was given a very brief test of procedures to ensure that he was still able to maintain cooperative behavior he showed during the practice visits. Following this assessment, the dentist entered and completed his work.

Assessment of Treatment Outcome

Direct observations using the Stokes and Kennedy (1980) system showed that during assessment visits Logan's disruptive behavior ranged from 75% to 90% of the observation intervals. There was an increasing trend toward more disruptive behavior over appointments. During the three intervention appointments, one of which included multiple injections and an extraction, Logan never went above 6% disruptive behavior for an appointment.

Cooperation and anxiety ratings were also obtained from the dentist and dental assistant. Logan's cooperation ratings during assessment appointments averaged 3.6; his anxiety ratings averaged 4.2 on the 6-point scales, where 6 represented extremely uncooperative and extremely anxious. During intervention, ratings for cooperation averaged 1.2 and for anxiety, 1.6, both with decreasing trends across appointments.

Treatment Parameters

Several practical issues appear to be critical to the successful implementation of these procedures. To enhance generalization from the practice to the actual treatment session, there should be a high similarity between what is said and what is done during the practice sessions and what happens during actual treatment. This is the generalization programming strategy of using common salient stimuli (Stokes & Osnes, in press). Small differences in the wording of certain procedural presentations were observed to make large differences in the amount of control over the child's behavior during dental treatment.

We found it most expedient to begin with a procedure the child is likely to master quickly (e.g., looking in the mouth with the mirror) and then to move to the procedure with which the child has the most difficulty. The first step allows the child to achieve some early success, while the second step seems to enhance the salience of the escape contingency.

The most difficult part of the procedure is waiting for a minimal demonstration of cooperation during practice with the procedure that has proved to elicit the most disruption by the child during treatment. The instrument must be kept in the child's mouth and practice must continue with no eye contact and only the minimal physical contact necessary to maintain practice. Minimal instructions are provided during the instrument-in-mouth procedures, because that is the provision of attention contingent on inappropriate behavior. The timing of the removal of instruments from the mouth is also very important. The psychologist provided cues to the dental assistant based on the child's previous demonstrated skills, sometimes holding out for a little more time if the child has clearly shown mastery on previous trials. The skill of the psychologist in observing and analyzing ongoing behavior while shaping with a positive and negative reinforcement contingency is critical here and should not be underemphasized.

While the procedure has proved effective, an explicit time commitment is involved in implementing the procedure, although it may vary from child to child. For this reason, we would advocate the use of proven procedures, such as contingent distraction (Ingersoll, Nash, Blount, & Gamber, 1984), filmed modeling (Melamed, Hawes, Heiby, & Glick, 1975), or live modeling (Williams, Hurst, & Stokes, 1983), with older or less difficult children. The reinforced practice procedure could be reserved for the most difficult cases where the other strategies are not likely to be effective, although we have found it quite effective with an older child (7 years) who was vomiting repeatedly during treatment. One 45-min practice visit eliminated the vomiting during subsequent treatment visits. Clearly the cost effectiveness of a procedure will determine which should be used at any time. Some children will require considerable professional time at the outset of a consultation while other children will require less time and less intrusive procedures.

Finally, it is possible that these procedures could be implemented in-operatory rather than as preparation. That is, escape and attention contingent on cooperation could be implemented as a regular feature of restorative treatment. Initial interruptions during treatment which are related to the escape contingency could gradually be reduced as the child begins to tolerate increasingly longer periods of treatment and escape becomes a natural product of the rapid completion of each procedure. The practice component could then be reserved for the most disruptive children who might benefit from a more frequent contact with the positive consequences for cooperative behavior.

GENERAL TREATMENT ISSUES IN PEDIATRIC DENTISTRY

Various procedures have been used to manage children's behavior during restorative dentistry. The cases presented here are two examples of interventions applied. The treatment research literature describes a range of other procedures. These techniques include pre-exposure through the use of filmed models (Melamed *et al.,* 1975), dental treatment involving the use of live models (Williams *et al.,* 1983), desensitization procedures (Gordon, Terdal, & Sterling, 1974; Machen & Johnson, 1974), shaping by reinforced contact with dental treatment procedures (Kohlenberg, Greenberg, Reymore, & Hass, 1972; Allen & Stokes, 1987), distraction using cartoons or television (Ingersoll *et al.,* 1984; Venham Goldstein, Gaulin-Kremer, Peteros, Cohan, & Fairbanks, 1981) and the use of inexpensive reinforcers (Melamed, Bennett, Jerrell, Ross, Bush, Hill, Courts, & Ronk, 1983; Stokes & Kennedy, 1980).

The management of disruptive and uncooperative behavior in the dental clinic is one aspect of children's oral health management (Allen & Stokes, in press; Blount, Santilli, & Stokes, in press). Other issues relate to the proficiency and regularity of brushing, flossing, using fluoride rinses, and making visits to the dentist (e.g., Blount & Stokes, 1984; Blount, Baer, & Stokes, 1987; Claerhout & Lutzker, 1981; Dahlquist & Gil, 1986; Iwata & Bechsfort, 1981; Kegeles, Lund, & Weisenber, 1978; Murray & Epstein, 1981; Poche, McCubbrey, & Munn, 1982; Reiss, Piotrowski, & Bailey, 1976; Swain, Allard, & Holborn, 1982). A comprehensive program of dental treatment management will also attend to these areas of oral health.

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CHAPTER 18

Recurrent Abdominal Pain in Children

Assessment and Treatment

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INTRODUCTION

Apley (1975) defined recurrent abdominal pain (RAP) as pain that is (1) paroxysmal (i.e., unpredictable, unexpected, and self-limited) in nature, (2) frequent in occurrence (i.e., more than three episodes) over an extended period of time (i.e., more than 3 months), and (3) severe enough to interfere with social and academic functioning. RAP can therefore be classified as chronic intermittent pain. Children typically describe it in vague terms, indicating that "it hurts" or "feels funny" in the periumbilical or mid-epigastric region. Stone and Barbero (1970) noted that recurrent abdominal pain is variable in duration and intensity across patients. Usually the pain lasts for less than an hour, but it may persist throughout the day; it rarely awakens the patients at night. Typically, children with RAP are physically well between pain episodes.

Prevalence

Estimates of the prevalence of RAP vary. Ranges of 10–17% have been reported (e.g., Apley, 1975; Oster, 1972; Parcel, Nader, & Meyer, 1977; Pringle, Butler, & Davie, 1966). The variation in rates reported may be a function of the

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way RAP has been defined by different investigators. Overall, most clinicians agree that at least 10% of schoolchildren experience RAP.

Correlates

Apley and Naish (1958) and Oster (1972) observed that girls are more likely to report RAP symptoms than are boys. This is especially true for older children (over 9 years of age). Children with RAP frequently complain of other somatic symptoms, such as nausea, vomiting, perspiration, palpitations, and other autonomic signs of arousal (Apley, 1975). Some children with RAP manifest a lactose intolerance, whereas others do not (Lebenthal, Rossi, Nord, & Branski, 1981).

Numerous investigators have sought to describe children with RAP in terms of personality characteristics (e.g., Apley, 1975; Apley & Naish, 1958; Leibman, 1978; Stone & Barbers, 1970). For example, Apley & Naish (1958) reported that children with RAP did not differ from children without RAP in terms of intelligence but were more likely to be "highly strung, fussy, excitable, anxious, timid, and apprehensive" (p. 168). Although these findings have been frequently cited, the methodology used (e.g., unmatched control group, ratings of personality were based on clinician's impressions, interviewers were not blind to group membership) render the conclusions tentative, at best.

Apley and Naish's (1958) findings were corroborated to some extent, however, in Barr and Feuerstein's more recent study (1983), in which many of the methodological flaws of the Apley and Naish study were corrected. Barr and Feuerstein compared three groups of children—(1) children with RAP (N = 80), (2) children with other types of pain (N = 17), and (3) children without pain (N = 82)—by asking parents to respond to 54 statements concerning the behavior of their children. Children with RAP differed significantly from children without pain on the following characteristics or behaviors: trouble falling asleep, cries easily, worrier, bad dreams, often sad, many fears, often tired, headaches, overeats, feels ill often, too neat/orderly, and jealousy. Although this investigation was not without its limitations (e.g., parents may have been sensitized to their children's problems in the clinic setting, statistical significance may have been reached by chance due to the large number of comparisons), the results suggest that children with RAP do differ from their peers. Because of the correlational nature of the data, however, one can not determine if these factors are causes or effects of being a child with RAP.

Several investigators have studied the family characteristics of children with RAP (e.g., Apley & Naish, 1958; Hodges, Kline, Barbero, & Flanery, 1984; Hughes & Zimin, 1978; Oster, 1972; Stone & Barbero, 1970; White, 1979). The most common finding is that children with RAP live in families in which other members also report pain symptoms (e.g., Oster, 1972). Stone and Barbero (1970) observed that the parents of RAP children often complained of gastrointestinal (GI) complaints.

Table 1 summarizes the various characteristics associated with RAP children and their family members. The characteristics are subdivided into four categories—somatic, behavioral, emotional, and cognitive—for both the RAP child and

TABLE 1. Characteristics Associated with Recurrent Abdominal Pain: Children and Their Family Members

- RAP child
  - **Somatic**
    - Frequent illness
    - Fatigue
    - Headaches
    - Lactose intolerance
    - Sleep disturbance (e.g., bad dreams)
  - **Behavioral**
    - Cries easily
    - Poor social skills (e.g., timid)
    - Perfectionistic (e.g., overly neat)
  - **Emotional**
    - Anxiety
    - Depression
  - **Cognitive**
    - Somatic preoccupation
- RAP family
  - **Somatic**
    - Pain (e.g., gastrointestinal, headaches)
  - **Behavioral**
    - Overprotective of RAP child
  - **Emotional**
    - Anxiety
    - Marital dissatisfaction
  - **Cognitive**
    - Somatic preoccupation

the family members. A child or family member may exhibit some, but not other, characteristics listed. Although the list is not exhaustive, it suggests that there may be a child–family profile for RAP.

Prognosis

Most children with RAP improve with minimal intervention (e.g., advice from the pediatrician to return to school) or even remit spontaneously. Stickler and Murphy (1979) reported that 76% of 161 children with RAP no longer exhibited symptoms within a 5-year period; 57% of the cases resolved rapidly. It appears; however, that as many as one third of RAP cases will not improve over time (Apley, 1975; Apley & Hale, 1973). Christensen and Mortensen (1975) conducted a long-term follow-up of 34 patients who had been hospitalized as children for RAP. The former RAP patients were compared with a randomly selected control group who had not experienced RAP as children. The findings were striking: one half of the former patients experienced GI symptoms as adults; the difference in symptoms was significant between the two groups. It is possible that this finding of 50%, which is considerably higher than most reports, is related to the fact that the former patients had been hospitalized. Since most patients with RAP are not hospitalized, it is likely that the cases investigated were of a more serious nature.

Etiology

Traditionally, RAP has been considered the result of organic or psychogenic factors. Most investigators agree that 5–10% of the RAP cases seen are attributable to a medical disorder, whereas 90–95% are of a psychosomatic nature. Barr and Feuerstein (1983) questioned this classification schema. They propose an alternative model that includes three potential causes of RAP: (1) organic (e.g., gastritis, neoplasma, ovarian cyst); (2) dysfunctional (e.g., chronic stool retention, lactose intolerance, irritable colon); and (3) psychogenic (e.g., school phobia, acute reactive anxiety, depression). Barr (1983) provides a detailed clinical classification system that can be used to guide one in determining the etiology of RAP. The focus of this brief review will be on the latter category.

A variety of psychological factors have been associated with RAP (see Table 1) and purported to be instrumental in the onset, maintenance, and exacerbation of RAP symptoms. Given the retrospective and correlational nature of the data presented, it is impossible to determine if these factors preceded RAP development or if they are the result of being a child with RAP. It is equally plausible to propose that a child is anxious because he or she fears a recurrence of a pain episode as it is to suggest that pain is precipitated by anxiety. In adult chronic pain patients, one frequently observes depression which is secondary to the pain problem.

Two types of psychological factors have been the focus of inquiry: personality characteristics and environmental factors. Specifically, children with RAP have been described as hypersensitive, anxious, compulsive, and depressed (e.g., Barr & Feuerstein, 1983). Their parents have been characterized as being overly protective, anxious, and as having somatic complaints themselves (e.g., Oster, 1972). This latter finding could be interpreted in two ways. Either children whose parents have somatic complaints are more vulnerable constitutionally or parents of children with RAP model illness behavior. Although this latter interpretation seems more likely, it has yet to be demonstrated empirically. With regard to environmental factors, stressful life events have been investigated in children with RAP (e.g., MacKeith & O'Neill, 1951). Pain episodes have been related to school events, social activities, excitement, and punishment, as well as to marital discord and family dysfunction (i.e., separation, divorce) in RAP children (Liebman, 1978). Although these findings are intuitively appealing, the underlying biobehavioral mechanisms which could mediate these events remain unknown (Feuerstein, Barr, Francoeur, Houle, & Rafman, 1982).

Barr (1983) considers RAP at three levels: (1) the individual pain episode, (2) the recurrence of pain episodes, and (3) the syndrome itself in the context of the child's environment. He notes that different psychological factors may be relevant to these three levels. For example, an individual pain episode may be precipitated by loss of a significant other, and the recurrence of pain episodes may be a function of social reinforcement, whereas the syndrome itself may be maintained by marital discord. Understanding RAP and developing a treatment plan therefore requires assessment of a multitude of factors that may contribute to any of these three levels of the RAP problem. This approach differs considerably from the rather simplistic one in which psychological factors are purported to cause RAP. It is more likely that chronic intermittent pain is multidetermined and that it involves bidirectional influences between a child and the environment.

BIOBEHAVIORAL ASSESSMENT OF RECURRENT ABDOMINAL PAIN

Given the complexity of the pain experience, it is recommended that a multifaceted approach be taken in assessment of RAP. A number of methods may be used in various combinations, depending on the nature of the problem being evaluated. Table 2 presents the components of the evaluation process.

The purpose of the evaluation process is to identify specific problem areas related to (1) pain itself, (2) psychosocial impact of pain, (3) factors in the environment that may contribute to maintaining or exacerbating pain, (4) premorbid psychosocial functioning, (5) interpersonal style, and (6) family functioning. The overall aim of biobehavioral assessment is to gain insight into the nature of the problem such that an individualized treatment plan can be designed for each case.

Medical Records Review

Data contained in the child's medical records are essential to the overall pain evaluation, in that the clinician can document the results of various diagnostic studies and interventions. In addition to information pertaining to the RAP problem, a positive medical history for other illnesses, as well as developmental history, are noted. This enables the clinician to obtain a more complete picture of the child.

Clinical Interview

There are several options with regard to how to conduct the clinical interview. One can choose to interview the child and parents separately or sequentially, or one can invite all members of the family in for a family interview. The child's pediatrician may be invited to attend these interviews. Usually the pediatrician's presence reassures the patients and family members that the organic aspects of the disorder have been adequately addressed. Typically, family members of the child with RAP are convinced that the child is physically sick.

The first goal of the interview is to ascertain the child's perspective of the problem. Beales (1982) notes that parents are not always reliable reporters of

TABLE 2. Biobehavioral Assessment of Recurrent Abdominal Pain

- Medical records review
  - History of RAP and other illnesses
  - Psychophysiological indices
  - Developmental history
- Psychological interview
  - **Child**
    - Pain parameters
      - Frequency
      - Duration severity (Visual Analogue Scale)
      - Quality (Revised McGill Pain Questionnare)
    - Location (pain map)
    - Peer relationships
  - **Mother/Father**
    - History of RAP and other illnesses
    - Description of child's pain behavior
    - Description of child's school performance
    - Description of child's interpersonal behavior
    - Mother's response to child's RAP
    - Father's response to child's RAP
    - Past/current stressors in the family
    - History of mother/father illness(es)
  - **Sibling(s)**
    - Description of child's pain behavior
    - Siblings' responses to child's RAP
    - History of sibling(s) illness(es)
- Psychometric evaluation
  - **Child**
    - Depression: Child Depression Inventory
    - Anxiety: Child Manifest Anxiety Scale—Revised
  - **Parents**
    - Mother: Family Environment Scale
    - Father: Family Environment Scale
- School functioning
  - Teacher's report of academic and social functioning
  - Nurse's report of RAP
  - Number of days missed due to RAP

their children's pain. He therefore recommends that children be questioned and observed directly. Ross and Ross (1984) discuss the importance of the type of questions asked, the psychological climate in which the interview takes place, as well as the format of the questions themselves. In general, Ross and Ross propose that children respond best when they are provided with a supportive environment in which they are encouraged to ask questions. It is preferable to have them respond verbally rather than in written format. Finally, children should be given an opportunity to express themselves in their own words rather than according to a fixed response set. A fixed response set (e.g., true–false questions) tends to limit the child's description of the problem.

To begin, one needs to determine the parameters of pain, i.e., its frequency, duration, quality, severity, and location. Direct questions regarding frequency and duration may be asked. To assist the child in estimating the severity of pain, a Visual Analogue Scale (VAS) may be used. A VAS is a line, usually 10 cm in length, the extremes of which are meant to represent the limits of the pain experience; one end is therefore defined as "no pain" and the other as "severe pain" (Huskisson, 1983). The child is requested to place a mark at the point along the line that best describes the pain. Scott, Ansell, and Huskisson (1977) suggest that severity of pain can be assessed using the VAS in children as young as 5 years old.

In order to determine the qualitative aspects of the pain experience, a revised version of the McGill Pain Questionnaire (Melzack, 1975), developed by Beales (1982), may be administered. This questionnaire includes 11 items describing sensory qualities (e.g., ache, pinched, squeezed) of pain. The child chooses among the words that best describe what he or she experiences during a RAP episode. In addition to the overall quality of pain experience, the child may describe its location using a Pain Map. A Pain Map is a two-dimensional graphic account used by the patient to indicate the spatial properties of pain (e.g., different colors for different sensations) or changes in pain (e.g., radiations). Pain maps are easily added to other measures of pain and contribute significantly to its evaluation.

Following the description of pain, the child should be queried about academic and social functioning. How does the child get along with other children at school and in the neighborhood? Does the child have any close friends? What changes have occurred as a result of being a child with RAP? In other words, what impact has pain had on the child's life-style, mood, and interpersonal relationships?

Subsequent to the child's description of the problem, family members can be asked to share their observations. What does the child do (e.g., complain, cry) while having a RAP episode? How do the individual family members respond when this occurs? Does the mother offer support? Is the father home during an episode? Do siblings quarrel before or after an episode? In other words, how have family members' lives been affected by the child's RAP?

Throughout the interview(s), the clinician should attend to information suggestive of a functional aspect of the problem. Does pain result in gain? If the child is being reinforced during or after a pain episode, a detailed account of the preceding and subsequent events surrounding the pain episode needs to be obtained.

In addition to information concerning RAP, parents should be queried about their child's developmental history. Did the child attain developmental milestones (e.g., walking, talking) within the normal age range? Did the child exhibit separation anxiety after 2 years of age or when first attending school? Have there been any recent or past losses of significant others?

Siblings should be requested to describe their views regarding the child with

RAP. What are their hypotheses regarding its cause? What is their perception(s) of the problem? What is their relationship like with the identified patient? Is there any indication of sibling rivalry?

If the family members are interviewed together, the clinician should note their interactional style. Who is the family spokesperson? How do the individual members relate to the interviewer? How do they relate to each other? Are the subsystems (i.e., parents, siblings) intact? Have there been any recent stressors which impact on the family as a whole (e.g., father recently changed jobs)? Minuchin, Baker, Rosman, Liebman, Milman, and Todd (1975) described four family characteristics frequently evident in family with psychosomatic illness: (1) overprotectiveness (typically for the mother with regard to the ill child), (2) enmeshment, (3) rigidity, and (4) lack of conflict resolution. Special attention should be paid to the possibility that the child's illness may serve to maintain family stability. Finally, permission to contact school personnel should be obtained in order to document academic and social functioning. Teachers and the school nurse may need to be contacted. The number of days missed at school due to RAP should be ascertained.

Psychometric Evaluation

Child

It is possible that the child's somatic complaints are related to negative affective states such as anxiety or depression. For this reason, it would be helpful to administer two brief questionnaires to the child in order to evaluate these areas directly. Kovacs (1981) developed rating scales to assess depression in schoolage children. The Child Depression Inventory is a 26-item self-report form that can be completed by children in the second through eighth grades. Reynolds and Richmond (1978) revised the Manifest Anxiety Scale as of means of measuring anxiety in children. The Child Manifest Anxiety Scale—Revised is a 37-item self-report form that consists of three factors—physiological, worry and oversensitivity, and fear and concentration—as well as a lie scale. These two questionnaires can be given to the child while the parents are being interviewed, or they can be included in the child's clinical interview.

Parents

Since the home environment may be a critical factor in the development, maintenance, or exacerbation of RAP, each parent should be requested to complete the Family Environment Scale (FES) (Moos & Moos, 1981) independently. The FES is a 90-item scale that measures the social-environmental characteristics of the family. It contains 10 subscales (e.g., cohesion, expressiveness, conflict) that measure three domains of the family; these are system maintenance, personal growth, and relationship. If there is an indication of parental psychological difficulties (e.g., hypochondriasis, depression), the clinician should use her or his judgment regarding the use of other psychometric instruments (e.g., Beck Depression Inventory) (Beck, 1972).

INDIVIDUALIZED MULTIMODAL TREATMENT FOR RECURRENT ABDOMINAL PAIN

The major goal of the biobehavioral assessment process is to identify a set of clearly delineated target areas that may respond to intervention. Table 3 lists potential target areas and treatment approaches that may be appropriate for RAP patients and their family members. Since RAP children constitute a heterogeneous population, each case should be viewed as unique. Consequently, the specific components of each treatment plan will vary. Table 3 is set up much like a menu in which column A lists target areas and column B treatment components. It may be used as follows. If the evaluation process indicates that the child's RAP problem is related to fears concerning school performance (due to

TABLE 3. Potential Target Areas for Change and Treatment Components for Recurrent Abdominal Pain

A	B
Target areas	Treatment components
Child	
Anxiety-related	Relaxation training
Fears and phobias	Systematic desensitization
Separatiuon anxiety	Self-hypnosis
Sleep disturbances	Cognitive restructuring
Ruminations/worries	Supportive individual psychotherapy
Somatic preoccupation	
Obsessive/compulsive	
Depression	Increase response-contingent positive reinforcement
Sadness	
Fatigue	Cognitive behavior therapy
Loss of significant other	Supportive individual psychotherapy
Pain perception	Self-monitoring
	Self-hypnosis
	Distraction
School avoidance	Return to school
	Social skills training
Family	
Parental preoccupation with health/illness;	Modeling
Pain behaviors	Problem-solving skills
Parental reinforcement of RAP	Operant conditioning
Parental anxiety/depression	Individual psychotherapy or family therapy
Marital discord	
Sibling rivalry	
Dysfunctional family interactional patterns	

being perfectionistic) cognitive restructuring may be indicated. If, on the other hand, marital discord is the underlying problem, family therapy may be the treatment of choice. It is possible and often advisable to combine treatment techniques. Liebman, Honig, and Berger (1976), for example, described successful combination of family therapy and behavior modification.

Berger, Honig, and Leibman (1977) discussed basic errors to be avoided in handling RAP patients and their families. First, one should resist parental pressures to treat the problem with traditional interventions (e.g., prescribing medication) once an organic basis for the disorder has been ruled out. Should one treat the problem in the traditional manner one may be unintentionally colluding with the family's view that the child is sick; this approach may even promote future symptom presentation. Second, care should be taken not to explore threatening emotional issues prematurely. Typically, families with a RAP child avoid direct communication of their affect but express their needs through physical illness. If these issues are exposed too abruptly, termination of therapy may occur prematurely. Finally, as with all pain patients, the pain must be viewed and treated as being real, even if the underlying mechanisms remain unknown. It is imperative that the clinician avoid communicating either implicitly or explicity the message that the pain is "in the child's head." By treating the pain as being real, the clinician will ensure the development of a therapeutic alliance.

Treatment Components

The RAP Child

Anxiety. Given a paucity of empirical findings demonstrating which child will benefit from a particular type of intervention, clinicians must rely on their judgment when selecting the treatment component to be used for the overanxious child. Particular disorders, such as phobias, are purported to be treated most effectively with a specific type of therapy (i.e., systematic desensitization); other problems, such as ruminations and worries, may respond well to a variety of interventions. When supportive individual psychotherapy is selected, the therapist should be accepting, firm, and consistent with the child. Individual psychotherapy may be directed at increasing the child's self-esteem and addressing her or his concerns related to maintaining self-control.

Depression. Two types of behavior therapy have been developed for the treatment of depression in adults. Beck's (1982) cognitive behavior therapy focuses on the depressed patient's characteristic negative thoughts and attitudes and seeks to modify these and the maladaptive ways in which the patient processes information. Lewinsohn's (1974) approach focuses on increasing what he terms "response-contingent positive reinforcement," which refers to the individual's perception that he or she will be rewarded when behaving in a certain way. In this type of treatment, the patient is encouraged to engage in rewarding activities in order to increase the likelihood that he or she will receive positive reinforcers (i.e., rewards). Both Beck's and Lewinsohn's interventions could be modified such that they are appropriate for treating childhood depression. Children who are not cognitively oriented may benefit more from supportive individual psychotherapy which focuses on the child's feelings of loss or other affects (e.g., anger).

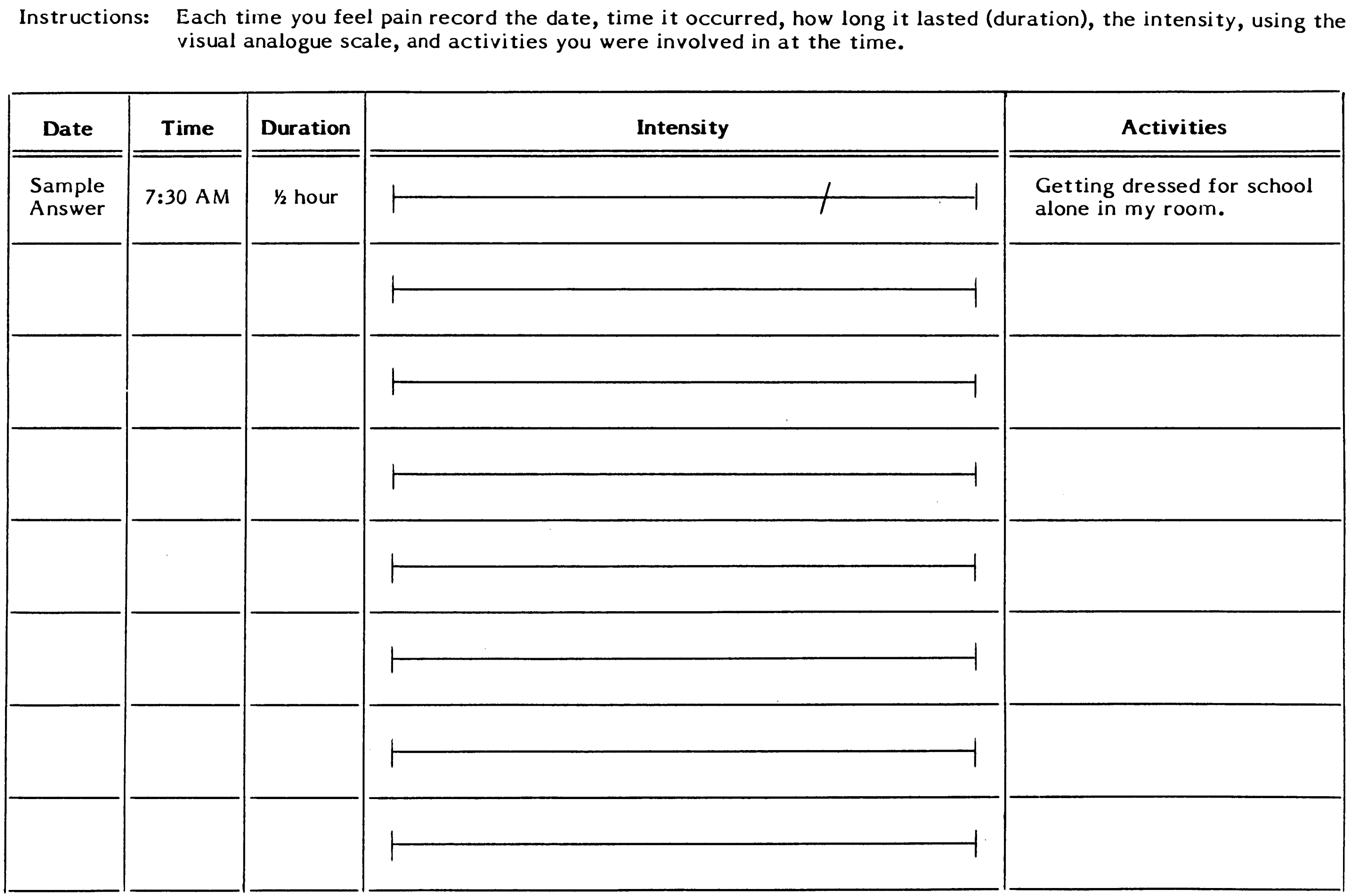
Pain Perception. The first step in altering a child's pain perception involves instructing the child in self-monitoring pain episodes in a pain diary. A pain diary consists of having the child record information pertaining to the date and time of the pain episode, its intensity level (using a VAS), and activities that preceded the pain episode. When recording activities, the child should include what he or she was doing as well as who was present. Figure 1 exemplifies this procedure. A sample answer is provided on a preprinted form. The use of a pain diary serves several functions: it increases the patient's awareness of and accuracy in recall of pain episodes, and it serves as a baseline for treatment evaluation. It can be used throughout treatment to document progress (Gaylord & Carson, 1983).

Parental involvement in assisting the child in self-monitoring should be determined by the age and maturity level of the child. The parent who is usually less involved with the patient should be selected as the parent for this task.

Pain perception per se can be altered through the use of several techniques. The effectiveness of these techniques has been investigated with an adult population or pediatric patients undergoing painful medical procedures (an acute pain) for the most part (e.g., Katz, Kellerman, and Siegal, 1980; Lavigne, Schulein, & Hahn, 1986). Unfortunately, to date, there have been no controlled experiments for the treatment of chronic intermittent pain in children.

Self-hypnosis has been used with pediatric oncology patients (Dash, 1980; Olness, 1981) with some success and may be beneficial for RAP patients. The technique consists of pairing deep relaxation with visual imagery. Since children are comfortable with the use of fantasy and are less concerned about the myths surrounding hypnosis than adults, they are usually quite responsive to this procedure. Other forms of distraction (e.g., video games) may also prove helpful in reducing the cognitive, affective, and sensory components of pain perception. For example, a child may be instructed to read a book or play a game at the onset of RAP.

School Avoidance. When assessment of RAP reveals that a child is avoiding school by exhibiting pain behaviors, it is imperative that the child return to school. This does not mean that the child's thoughts and feelings regarding school attendance are to be ignored. On the contrary, it is important to understand why the child is avoiding school. If the child is concerned about social or academic performance, social skills training or tutoring may be indicated. If the child fears separation from the mother (or father), then this will become the focal point of treatment. In the latter case, family therapy may be indicated.



Instructions: Each time you feel pain record the date, time it occurred, how long it lasted (duration), the intensity, using the visual analogue scale, and activities you were involved in at the time.

Date	Time	Duration	Intensity	Activities
Sample Answer	7:30 AM	½ hour		Getting dressed for school alone in my room.

FIGURE 1. Pain diary for recurrent abdominal pain.

The RAP Family

Family Therapy Combined with Behavior Modification. Not all families with a RAP child will require or even agree to participate in family therapy, but for some it may be the treatment of choice. Liebman *et al.* (1976) proposed three goals for the treatment of RAP with family therapy: (1) to decrease the use of the identified patient for avoiding family conflicts through the alleviation of the symptom, (2) to identify and change maladaptive family patterns that perpetuate the symptoms, and (3) to promote lasting disengagement of the identified patient from family conflicts. Liebman *et al.* (1976) discussed 10 successful cases in which family therapy was combined with a behavior-modification program. Behavior modification was used to provide the patient with a means of gaining control of the symptom. This technique reportedly resulted in decreasing the patient's and parents' anxiety levels and provided an opportunity to disengage the patient from parental conflicts. Interestingly, marital discord surfaced in seven of the 10 families. Family therapy was used to address these problems.

White (1979) elaborated on the approach used by Liebman *et al.* (1976), by outlining five stages of family therapy for psychosomatic families: (1) accepting the family's definition of the problem, (2) establishing a theme, (3) assisting the child to self-monitor and take control of her or his pain (involving the disengaged parent and blocking the overinvolved parent), (4) further restructuring the family systems (drawing individual and subsystem boundaries), and (5) helping the parents resolve underlying conflicts and establishing mutuality. (The interested reader may find Minuchin, 1975 a valuable resource.) The results reported on 10 families were impressive: pain-free status was achieved by all children. Pain control was established within 1–2 weeks and pain-free status within 1–5 weeks. All families reached stage 4 of the program. Follow-up at 15–24 months indicated a minimal recurrence of symptoms.

A cautionary note is in order concerning the above findings. Neither of the studies used a control group nor did they employ sufficient numbers to support the conclusion that family therapy combined with behavior modification is an effective treatment for RAP. Subject selection criteria were not indicated, nor were there independent raters for treatment outcome (conclusions were based on therapists' judgments). These factors limit the internal and external validity of these investigations.

Operant Conditioning. One purpose of the clinical interview is to determine whether there is a functional aspect to the child's RAP problem. That is, the child may be inadvertently reinforced either positively (e.g., gaining attention) or negatively (e.g., avoiding aversive social situations) when exhibiting pain behaviors. If, in fact, this is occurring, treatment based on operant conditioning theory may be indicated.

Sank and Biglan (1974) reported treatment success when operant conditioning methods were employed with a 10-year-old boy who had a 2½-year history of RAP. In this case, when the boy had severe pain attacks (at least once a day), his mother gave him aspirin or Maalox, took his temperature, stayed with him, and often administered back rubs in an attempt to soothe him. He was absent from school 45 of the 75 days of the year prior to treatment. When he stayed home from school because of pain, he was allowed to read, watch television, and get out of bed if he felt up to it. Thus, the boy received positive reinforcers (social, engaging in pleasurable activities) as well as negative reinforcers (school avoidance) when in pain. A token system was initiated whereby the boy received a point for every half-day in which he had no severe attacks and when he maintained an average pain rating below a setpoint. As treatment progressed, the criterion for pain ratings gradually was reduced. The boy also received a point for every half day of school he attended (but he could not attend school, unless he was below the pain criterion and had had no severe attacks just before going to school). Points had an immediate cash value of 5 cents and, in addition, could be exchanged for other positive reinforcers (e.g., toys, favorite meals, family outings). The parents were advised to provide attention and approval when points were awarded. Results indicated that severe pain attacks declined steadily until they ceased completely; school attendance increased steadily. These positive changes were attributed to the token system.

Two other case studies (Miller & Kratochwill, 1979; Wasserman, 1978) support the contention that operant conditioning techniques can be effective in the elimination of RAP symptoms. Miller and Kratochwill (1979) treated a 10-year-old girl with a time out procedure. When the girl complained of pain, she was deprived of attention from others and was removed from pleasant activities. Despite a 1-year history of RAP, she was symptom free following this procedure. This approach may be promising for some RAP patients and should be used when there is a clear indication of reinforcement contingent on RAP symptom presentation.

Modeling. Social learning theorists (e.g., Bandura, 1977) have demonstrated that children learn vicariously through observation even when they are not reinforced directly. Since several investigators (e.g., Apley & Naish, 1958; Oster, 1972; Stone & Barbero, 1970) have noted a high incidence of somatic complaints and preoccupation with health and illness in the parents of children with RAP, it is logical to assert that some RAP children may have learned to exhibit the same behaviors as their parents (Craig, 1980). If this is true, one component of the treatment should involve teaching parents the effect their behavior has on their children and encourage/teach them to engage in well behaviors. It is important to be cognizant of the fact that this may be a sensitive issue. Parents bring their child in for treatment; they do not expect to be the focus of intervention. Unless tact is used judiciously by the clinician, parents may feel they are being criticized or even attacked. This issue is similar to the one related to broaching emotional topics too early in treatment—if it is not done well, the parents may discontinue treatment prematurely. If parents use somatic complaints as a means of coping with problems, they may benefit from learning problem-solving skills. If, on the other hand, their somatic complaints reflect psychopathology, individual psychotherapy may be indicated.

Summary

Children with RAP may experience pain episodes for a variety of reasons. A thorough multidimensional assessment is required in order to delineate those factors that precipitate, maintain, or exacerbate pain episodes. Once these factors are identified, an individual multicomponent treatment plan can be designed to address these problems. The clinician needs to choose appropriate treatment components based on an understanding of the child and the family members.

CASE ILLUSTRATION

K. H. was a 12-year-old girl presenting with recurrent episodes of abdominal pain. The pain was reported to occur approximately 4 days per week with each episode lasting 20–40 min. The patient was referred by her pediatrician for evaluation and possible treatment of frequent abdominal pain.

Medical Record Review

The medical record was essentially unremarkable. All diagnostic workups were within normal limits. The patient did not display lactose intolerance.

Clinical Interview

The patient reported that the pain has increased in frequency from 1 to 2 days per week to "almost everyday" over the past year, and the duration of each episode was about 1 hr. K. H. also reported that her hands were sweaty and that it was difficult to breathe when the pain was at its worse. K. H. indicated that when the attacks occurred she tended to sit still, very tense until the pain subsided. She preferred to leave the room if other children were around because she did not want to "look stupid."

K. H. reported no significant problems at school or home and indicated that she got along with everyone. Her grades were good, and she was actively involved in a number of extracurricular activities (e.g., band, choir, student council).

An interview of her parents revealed a dual-career professional couple with three children (ages 3, 8, and 12). The father had very high expectations of K. H. and felt that the "stomach aches" were interfering with her school performance, although he "would never say anything to her." Both parents thought the pain must have been caused by some physical factor and that the pediatrician and other specialists just "haven't found the real cause yet."

Psychological Testing

Psychological testing revealed a high level of anxiety (Child Manifest Anxiety Scale) with items reflecting high levels on the physiological, worry, and oversensitivity items. The Child Depression Inventory indicated the absence of depression. The Family Environment Scale (FES) revealed significant discrepancy between both parents on the expressiveness and conflict subscale with mother reporting lower levels of expressiveness and higher levels of conflict than father.

Summary of Evaluation

The findings from the interview and testing revealed a fairly anxious young girl with multiple somatic complaints (i.e., RAP and headaches). The pain episodes were associated with an increase in sympathetic arousal, as suggested by her report of "sweaty hands," along with significant muscular tension and motor inhibition. She reported experiencing a tension-like headache two to three times a month. There was also some evidence of stress in the family as reflected in the discrepancy between the parents on the FES with regard to perceived levels of conflict and expressiveness. The interview also indicated a significant potential source of stress in the area of school performance where the father indicated high expectations for his daughter. Another potential source of stress included the multiple extracurricular activities K. H. was involved in, which interfered with time to unwind.

The results of the evaluation were reviewed with K. H. and her parents. Treatment goals included (1) teaching K. H. relaxation skills with the aid of skin-conductance biofeedback to help with the autonomic reaction to pain; (2) working with K. H. to identify factors associated with pain episodes and possible reinforcers of pain episodes; (3) helping K. H. establish priorities; (4) teaching communication skills; and (5) helping the parents improve family problem-solving and communication skills.

Treatment

Treatment included eight 40-min visits with K. H. directed at the above goals, as well as five sessions with both parents. Two visits with all three family members was also planned. The appointments with K. H. involved first teaching her progressive muscular relaxation and cue-controlled relaxation, using breathing as the cue to evoke the relaxation response. After two sessions, K. H. was loaned a GSR-II home training unit to assist her with relaxation and help her monitor how well she was reducing sympathetic arousal (the device measures relative changes in skin conductance). Cue-controlled relaxation was achieved over a 4-week period.

While the initial five sessions were directed at learning relaxation skills, K. H. also monitored her pain episodes and potential sources of stress at school and home. Patterns began to emerge, and these were discussed. Increases in the frequency of pain attacks were associated with days in which she was very active in extracurricular activities. Prior pain attacks were also stressors for her. During the attacks, she became quite upset. These pain episodes were followed by recurrences of pain. The link between stress and pain and pain and stress was discussed, and a pain-innoculation approach to the pain episode itself was taught to K. H. In addition, we discussed her busy schedule and talked about whether anything could be eliminated from it. We also discussed what needs each of the activities served and whether she could prioritize these needs and activities so as not to overwhelm herself. Sessions 2–5 were divided in terms of emphasis, with 20–30 min directed at enhancing relaxation and pain-innoculation skills and 30 min spent working on increasing her awareness of the sources of stress in her life and her reaction to them, their influence on her symptoms, and how she could deal with these stressors more effectively.

Sessions 6–8 were primarily directed at teaching K. H. direct communication skills particularly in relation to her parents. Modeling and role playing were used to teach K. H.

how to communicate her feelings to her parents, primarily feelings she thought might not be acceptable to her parents (e.g., anger, frustration).

Both parents were seen for five visits. During these sessions, efforts were directed at improving communication between the couple. Initially, topics were related to K. H. (e.g., school performance, extracurricular activities), but subsequently areas more central to the couple's relationship (e.g., frequency of sexual relations, responsibilities at home) were dealt with. The couple's strong "disease conviction" regarding their daughter's pain disorder was also focused on in an effort to redirect attention away from doctor shopping and reduce the couple's emphasis on their child's "illness."

Two sessions with all three individuals was also provided. The emphasis of these sessions was on direct communication. Specific problem areas were discussed and problem-solving and communication emphasized. This provided K. H. and her parents the opportunity to practice communication skills under the guidance of a neutral party.

By the end of the treatment program the recurrent episodes of abdominal pain were greatly reduced in frequency and severity (> 70% reduction in both dimensions of pain). Anxiety levels were down, and K. H. reported that she was much better able to cope with the pain when it did occur. K. H. effectively used her relaxation techniques and coping statements. She also continued with whatever the ongoing activity was at the time of the pain. K. H. displayed an ability to discuss with her parents how she felt emotionally and why. She could also make specific requests of her parents. She also reduced the number of extracurricular activities. Her parents appeared to be less demanding.

At 1 year follow-up, K. H. continued to do well. Pain episodes were no longer present and her relationship with her parents continued to improve. Her parents reported continued problems between themselves at times, but felt they could now solve them more effectively.

CONCLUSIONS

This chapter focuses on the assessment and treatment of the child (and the family) with recurrent abdominal pain. It has emphasized the heterogeneity of this population and the necessity of treating each case individually. This approach has been applied to adult chronic pain patients with success. Its application with children is relatively new and will require systematic evaluation. Since most research efforts have been directed toward describing and testing the use of biobehavioral interventions with pediatric patients undergoing painful medical procedures, little is known about how to help children with a recurrent chronic pain problem (Lavigne *et al.*, 1986).

Our current understanding about developmental aspects of pediatric pain is quite limited. This lack of knowledge may confound both the assessment and treatment procedures employed with RAP children in different age groups. Unfortunately, few of the measures described in this chapter have been examined in well-controlled experiments. It is likely that they will require modification in order to accommodate different age groups. For example, very young children may comprehend the use of a "pain thermometer", describing pain by rating it along a thermometer-like scale with gradations of 0–100, better than a Visual Analogue Scale without numerical markings (Jay, Ozolin, Elliott, & Caldwell, 1983). Older children may find learning relaxation skills easier than younger children because they are better able to concentrate and remain on task for longer periods of time compared to their younger counterparts.

Given the fact that treatment outcome studies reported for pediatric pain in general, and RAP in particular, have been uncontrolled investigations or anecdotal reports, little is known about the effectiveness of psychological interventions for this population. This chapter is based on the state-of-the-art understanding of the etiology and treatment of chronic pain. Well-controlled studies are required to establish its efficacy. Once this has been accomplished, attention may be focused on the various treatment components in order to determine which aspects of the multicomponent treatment plan are most important. Considering the uniqueness of each case, this will clearly be a challenging task.

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CHAPTER 19

Elevated Blood Pressure

CRAIG K. EWART AND SUSANNA CUNNINGHAM

INTRODUCTION

Behavioral interventions to modify diet, activity, and emotional stress constitute the recommended initial treatment for mild essential hypertension in children and should accompany pharmacological therapy in more severe cases (Task Force on Blood Pressure Control in Children, 1987; referred to hereafter as the Second Task Force). The first concern is to ensure that the blood pressure evaluation process itself does not generate excessive anxiety and negative self-labeling on the part of child and family (Bloom & Monterossa, 1981; Bergman & Stamm, 1967). If, upon repeated assessment, the child's blood pressure is found to be significantly elevated, this can usually be presented as a timely cue to start changing life-style patterns that could lead to health problems later on. Behavioral assessment and intervention efforts then focus on modifying diet habits, increasing physical activity, and reducing excessive emotional stress.

DIAGNOSIS

Negative self-labeling reactions can be prevented in large measure by adopting a conservative approach to diagnosis and by emphasizing the potential to manage the health threat through early intervention. It is important to remember that the prevalence of clinical hypertension is of a much smaller magnitude in children than in adults and that, in most instances, elevated pressures are simply a warning signal that the child is at risk of developing hypertension in

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later life. Parents should be reassured that an occasional high blood pressure reading is not tantamount to a diagnosis of essential hypertension. Emphasis is placed on evaluating longer-term patterns or trends. If a trend toward elevated blood pressure is detected, the appropriate response is not to panic but to cope by following a program of regular surveillance and implementing lifestyle changes that are consistent with good cardiovascular health.

Behavioral clinicians who treat children should be thoroughly familiar with guidelines for pediatric blood pressure measurement and evaluation set forth in the Second Task Force Report. The first step in preventing excessive emotional reactions is to ensure that the child is not misdiagnosed on the basis of (1) too few readings, (2) inadequate measurement procedure (e.g., incorrect cuff size or placement), or (3) examiner failure to consider the child's height and body composition. The child should be permitted to relax and adjust to the measurement equipment before measures are taken. The examiner should explain that he or she will have to repeat the procedure several times, so as not to alarm the youngster when a second or third reading is taken. The last value obtained during an office visit should be recorded on the chart recommended by the Second Task Force. If this last value represents a systolic or diastolic pressure above the 90th percentile (P90) for age and sex, using percentile norms in the Second Task Force Report, blood pressure should be measured again on three additional office visits. Systolic and diastolic pressures recorded on these subsequent visits are to be separately averaged; if the average systolic and average diastolic values fall below the 90th percentile, blood pressure is considered normal and should be checked again in 1 year.

The Second Task Force Report includes a new algorithm for evaluating blood pressures persistently above P90. If the average systolic or diastolic pressure over several visits is between P90 and P95, the child is said to have high-normal blood pressure, and age-adjusted percentiles of height and weight are consulted. If the child is above P90 for height but not above P90 for weight, the blood pressure probably reflects the fact that the child is unusually tall for his or her age and is not considered abnormal. Annual surveillance is then indicated. If the child is obese, weight control is instituted, and blood pressure is monitored regularly. If the high blood pressure cannot be explained by height and weight, the child is scheduled for surveillance at 6-month intervals.

If a child's blood pressure persistently averages above P95, he or she is considered to have high blood pressure. If obese, the child is placed on a program of weight control and blood pressure monitoring. Children with high blood pressure who are not obese or in whom weight loss does not reduce pressure below P95 are recommended for diagnostic evaluation to rule out secondary hypertension and to consider initiating or adding nonpharmacological treatment and possibly drug therapy. This approach is designed to be somewhat conservative, to ensure that children who do not really need treatment will not be mislabeled or exposed to potential harm. Inclusion of behavioral intervention to lower blood pressure by means of diet or exercise is important even when treating severe hypertension, as this may permit lower doses of adrenergic blocking agents or diuretics whose effects on physical functioning, metabolism, and growth are unknown.

WEIGHT CONTROL

The relationship between body weight and blood pressure is well established in children and adults (Brownell, Kelman, & Stunkard, 1983; Berchtold, Jorgens, Kemmer, & Berger, 1982; Stamler, Stamler, Riedlinger, Algera, & Roberts, 1978). In a child who is obese, a persistently elevated blood pressure is usually attributable to excessive ponderosity (Clarke, Woolson, and Lauer, 1986). Weight control is recommended as the initial approach to blood pressure management. It is desirable to involve the entire family in a weight-reduction program, as this creates an environment supportive of the child's weight-loss efforts. Considering that obese children with high blood pressure are likely to have parents and siblings who are either obese or hypertensive, or both, weight control may be medically indicated for other family members. An effective way to introduce weight-control intervention with a child is to conduct a cardiovascular risk assessment with all family members.

The Second Task Force Report recommends that determination of child obesity be based on clinical judgment. Typically, this will involve consideration of the child's weight in relationship to his or her height. A widely used indicator is Quetelet's body mass index, which equals the child's weight divided by the square of his or her height. When weight is measured in kilograms and height in meters, a body mass index of 25–30 is frequently characterized as indicating that the patient is "overweight" (Bray, 1986). Body mass indices within this range may occur due to unusually large lean muscle mass and do not necessarily indicate excess adiposity. Examination of body fatness as opposed to muscularity can help decide the question. Adults with a Quetelet's Index above 30 are generally considered obese; in such persons, excess adiposity is almost invariably found. This rule of thumb does not necessarily apply in younger children, however (Epstein, 1986).

Detailed guidelines for treating childhood obesity are available in several excellent recent reports and reviews (e.g., Epstein, 1986; Epstein, Wing, & Valoski, 1986; Epstein, Wing, Koeski, & Valoski, 1985; Dietz, 1983; Brownell, 1982). These investigators emphasize that weight loss is best achieved through a program that combines increased calorie expenditure with reduced calorie intake. Increasing physical activity is extremely important as a means to consume calories and accelerate metabolism. A plan integrating calorie reduction and activity components can be developed after initial consultation with a dietician to establish dietary guidelines individually tailored to each family member's nutritional needs.

Development of the plan begins with diet and activity monitoring to identify problem situations and behavioral patterns. It is recommended that monitoring focus on behavior (eating, activities) instead of weight, on the consideration that these behaviors are the actual targets of intervention. Patients are told that blood pressure control is more attainable if they work on developing and maintaining good cardiovascular health habits, rather than simply concentrating on trying to lose a given amount of weight.

Analysis of eating and activity data collected during the monitoring phase makes it possible to identify obstacles to behavioral change, as well as potential resources for overcoming these obstacles. It is critical to determine when and under what circumstances eating occurs, as well as to identify who plans menus, does the shopping, prepares the meals, and is present when food is consumed. Does the family eat at home, or are many meals eaten elsewhere (e.g., fast food restaurants, take out)? Is there more than one food purchaser or preparer? At home, is food consumed only at meals, or is there extensive snacking during other activities (e.g., watching TV, playing games)? Whose participation will be essential in developing plans to restrict eating to specific times and places, control food selection and storage, or change preparation and serving habits?

During this preliminary assessment period, it is important to assess factors that may influence various family members' willingness to attempt change. How strong is their desire to reduce disease risk and improve their health? Is the time and cost involved in altering food purchase and preparation patterns going to be a problem? Will there be significant pressure from relatives or friends to persist in old habits? We find it useful to examine these issues to be constructing a Contingency Grid. This is accomplished by listing all the potential consequences of changing a particular problematic behavior, including physiologic, emotional, social, and financial outcomes. These potential consequences are then sorted into four categories created by crossing the behavioral dimensions of immediacy (immediately experienced consequence versus delayed consequence) and valence (desired consequence versus undesired consequence). The grid focuses attention on the consequences that are most likely to encourage a behavior (e.g., those that are desired and tend to be experienced immediately after doing the desired behavior), those consequences that are likely to discourage a behavior (e.g., those that are undesired and tend to be experienced immediately after doing the behavior), and consequences that are likely to have less influence (e.g., desired or undesired consequences experienced infrequently or long after the behavior has been performed).

The challenge is then to find ways to support desired behaviors by increasing immediately experienced positive consequences (e.g., introducing tasty lower calorie foods) and reducing or eliminating immediately experienced unpleasant consequences (e.g., showing how recommended foods can be prepared more quickly and inexpensively). We find it helpful to involve family members in the Contingency Grid exercise as a means to challenge them to reflect on (1) their motives for changing, and (2) things they might do to make changing easier and more fun. This discussion also focuses on situational or stimulus-control factors that make dieting difficult (e.g., "I always get the urge to snack when I watch TV"). Family members are encouraged to think of ways to restrict eating to specified times and places and to remove stimuli that elicit the urge to eat.

A final component of the plan is an implementation schedule. Once problem areas have been identified and family members have committed themselves to a plan to overcome them, it is necessary to set realistic behavioral goals. The guiding principle here is the notion of shaping successive behavioral approximations rather than demanding radical and immediate change. Changes should be made gradually and in small enough increments to ensure success. Avoiding large or quick alterations in diet is important on both behavioral and nutritional grounds. Behaviorally, there is greater danger of early relapse when weight loss is achieved quickly (Brownell, Marlatt, Lichtenstein, & Wilson, 1986). From a nutritional perspective, sudden or excessive changes may be harmful. The weight-loss plan should be reviewed by a dietician or qualified nutritional consultant. Epstein and colleagues have developed a "Traffic Light Diet" to help children identify foods that are consistent with weight loss and good nutrition (Epstein *et al.,* 1986). Foods are categorized on nutritional and caloric criteria into three groups as "green" (eat freely), "yellow" (eat cautiously), or "red" (eat only rarely). The system facilitates learning of sound nutritional and weight-loss principles in young children.

PHYSICAL EXERCISE

A plan to increase physical activity is an important part of the weight-loss program. In addition to increasing calorie expenditure, exercise may independently protect against high blood pressure. A 10-year longitudinal study of 14,998 middle-aged men showed that men who did not engage in vigorous activities (e.g., running, swimming, handball) were at 35% greater risk of developing essential hypertension than were men who participated in these sports (Paffenbarger, Wing, Hyde, & Jung, 1983). Significant risk reduction was achieved by playing vigorous sports 1–2 hr/week, but longer or more frequent exercise did not reduce risk further. Men who had played vigorous sports in college did not experience reduced hypertension risk unless they continued to exercise regularly during their post-college years. Early benefits of physical exercise in childhood are supported by recent epidemiological evidence that schoolchildren who are more active in their leisure time tend to have lower blood pressures than do more sedentary children (Strazzulo, Cappuccio, Trevisian *et al.,* 1988). These findings imply that exercise interventions should begin early and should promote exercises and activity regimens that are possible to maintain over the course of a lifetime.

The guiding principle in promoting exercise is that any increase a child's activity level is desirable, assuming it is not offset by increased calorie consumption. Epstein and colleagues distinguish lifestyle exercises from programmed exercises. Lifestyle exercises include physical activities performed in the course of one's daily routine (e.g., walking to school instead of riding, climbing stairs instead of using an elevator), whereas programmed exercises are exertional activities designed specifically to increase strength, improve flexibility, or build aerobic power. Epstein and associates have shown that lifestyle activity changes integrated into daily routines are more likely to be maintained than are programmed exercised, hence are more effective in promoting sustained weight loss (Epstein, 1986).

This is not to say that children with elevated blood pressure should not be encouraged to become involved in more programmatic exercise. Considering that vigorous exertion is associated with a wide range of cardiovascular benefits, regular participation in aerobic activity is recommended, especially with children who have high blood pressure but who are not obese. In view of the child's elevated blood pressure and possible family history of cardiovascular disease, a careful medical screening and fitness evaluation is indicated before an exercise plan is developed. The vigorous exercise chosen should be one that appeals to the child and that can be easily integrated into the family's weekly routine. Wherever possible, siblings and parents should be encouraged to participate in similar activities. Emphasis is placed on beginning with a gradual shaping phase, during which the child learns how to exercise at the proper intensity while making the activity as enjoyable as possible. Exercise can be made more enjoyable by exercising with friends, listening to music via portable recorder/radio, and selecting from a "menu" of activities (e.g., running, swimming, cycling, basketball, aerobic dance) to enhance variety (Martin & Dubbert, 1982).

SODIUM RESTRICTION

Although the role of dietary sodium in hypertension is controversial, it is believed that most patients probably benefit from moderate sodium restriction. There is evidence for wide variation in sodium sensitivity, but no test is available to identify those most likely to benefit from reducing salt intake. Factors that appear to interact with dietary sodium to elevate blood pressure include family history of hypertension, African ancestry, and emotional stress (Voors, Berenson, Dalferes, Webber, & Shuler, 1979; Falkner, Onesti, Angelakos, Fernandes, & Langman, 1979). Sodium restriction may be especially helpful to children with these characteristics.

A realistic goal for restricting sodium intake is to reduce consumption to about 2 g/day. An effective program to achieve this has been developed by Frank and colleagues for the Franklinton dietary intervention trial (Frank, Farris, Ditmarsen, Voors, & Berenson, 1982). The program teaches elementary school children to understand the role of electrolytes in health, to read labels to identify sodium sources, to monitor daily sodium intake, and to make low-sodium snack choices. Additional instruction is provided to enable children to measure food quantities and estimate portion sizes.

The challenging task of monitoring sodium consumption is facilitated by using a microcomputer-assisted diet recording and analysis system such as the Diet Inventory of Nutritional Experience (DINE) (Dennison, Frauenheim, & Izu, 1983). The program can be used by 10-year-old children yet permits sophisticated assessment of dietary sodium, protein, fat, saturated fat, carbohydrate, and cholesterol from 24-hr food records. A coding system enables the child to indicate the specific food item by its familiar name (e.g., "Big Mac" versus a

"Whopper"). The interactive program provides a printout with the diet entered by the child and summary of total calories, sodium, cholesterol, vitamin C, and iron. The printout compares the actual diet with an ideal diet based on standards set by the American Heart Association, National Academy of Sciences, and the U.S. Dietary Goals.

Sodium monitoring provides information needed to develop a plan to alter eating habits. This plan is developed following principles described above for achieving weight control. As snacks from vending machines and fast foods are a major source of dietary sodium, it is important to help patients and families identify healthier low-sodium foods for snack choices.

STRESS REDUCTION

Chronic anger or anxiety may play a role in elevating blood pressure, both directly via sympathetic adrenal-medullary fight or flight activation (Henry & Stephens, 1977) and indirectly by association with early cigarette smoking and possible substance abuse (Boekeloo, Mamon, & Ewart, 1987). Among adolescents with high normal blood pressure, those at greater risk due to positive family history of hypertension have significantly increased diastolic pressure and reduced pulse pressure during emotional stress (Ewart, Harris, Zeger, & Russell, 1986). Recent experiments in Baltimore public high schools demonstrate that both black and white adolescents with high normal pressure can master stress reduction techniques (relaxation and biofeedback), enjoy practicing them daily in class, and achieve significant blood pressure reduction after a 12-week training program.

An important objective of behavioral intervention thus involves determining whether a child or adolescent is frequently angry or otherwise upset, and whether he or she is experimenting with tobacco, marihuana, alcohol, or other substances. Preventive intervention to discourage the latter is essential. Conflict among family members has the potential to increase blood pressure significantly, and while these changes are transient, they may contribute to chronically higher pressure. Ewart and associates have shown that mastery of interpersonal problem solving and communication techniques derived from social learning theory can help patients lower their blood pressure during family arguments (Ewart, Taylor, Kraemer, & Agras, 1984; Ewart, Burnett, & Taylor, 1983). Adolescents who report frequent anger also tend to report (1) feeling less supported by family and friends; (2) more frequent use of tobacco, alcohol, and marihuana; (3) engaging in fewer physical and social activities; and (4) feeling unhappy with school and life in general (Ewart, Peyrot, & Harris, 1989). Frequent anger or smoking/substance use should alert the provider to the possibility that these behaviors may belong to a constellation of difficulties requiring multicomponent intervention.

Relaxation techniques have proved useful in treating adolescent depression and anxiety (Reynolds & Coats, 1986) and may be helpful in controlling emotional reactions leading to smoking or drug use. A comprehensive stress-reduction program should be developed to identify and alter stress-producing life circumstances (e.g., poor academic or social skills, family conflict), to discourage substance abuse, and to impart relaxation and self-management skills.

Relaxation techniques effective for training a wide range of adolescents subjects have been developed by Ewart *et al.* (1987). The adolescent is first taught to tense and relax each of 17 major muscle groups according to a standard instructional script (Ferguson, Marquis, & Taylor, 1977). Next the subject is taught to warm his or her hands by relaxing and using visual imagery. We have found it very important to provide feedback of hand temperature, both to enhance mastery and to provide a visible consequence to maintain the adolescent's involvement in the training regimen. Feedback is provided initially by taping an inexpensive alcohol thermometer to the index finger. When the subject has demonstrated the ability to increase finger temperature above 95°F during three successive relaxation sessions, he or she is given an attractive metal thermometer ring (Bio-Q [TM], Bensalem, PA), which serves both to prompt and reinforce relaxation in other settings.

In our school-based studies, we found that students practiced relaxation willingly in the classroom on a daily basis but had trouble performing the required exercises at home. Lack of privacy as well as interruptions and competing attractions (TV, friends, sports) were commonly cited reasons for not adhering to the home assignments. This should be considered when using relaxation or biofeedback in clinical settings. Relaxation training may be worth the time and trouble only if a patient is sufficiently motivated to practice at home and if the family is willing and able to provide an undisturbed setting and time for practice.

CASE ILLUSTRATION

The following case is presented to illustrate how the techniques described above can be applied to help an adolescent achieve lower blood pressure and reduce cardiovascular risk.

R.T. was an 11-year-old boy referred to the hospital's behavioral medicine unit for dietary treatment of elevated serum cholesterol and high blood pressure associated with moderate obesity. R.T. was 4 ft., 11 in. tall and weighed 112 lb., placing him at about the 75th percentile for height but well above the 90th percentile for weight. Subcutaneous fat contributed significantly to R.T.'s relative overweight. His systolic pressure had averaged 125 mm Hg over three visits, while his diastolic pressure had averaged 84 mm Hg. Serum cholesterol values averaged over two visits revealed a mean low-density lipoprotein (LDL) level of 151 mg/d. Consultation with R.T.'s parents showed them to be worried about heart disease. R.T.'s father, a house painter in his mid-30s, was mildly hypertensive and overweight. His father (R.T.'s grandfather) had recently suffered a myocardial infarction. R.T.'s mother, a secretary in her early 30s, had normal weight and blood pressure but wanted to lose "a few" pounds. R.T. had a 7-year-old sister whose serum cholesterol was slightly elevated (80th percentile) but whose weight and blood pressure were normal.

The initial session with R.T. and his parents introduced the importance of understanding family eating habits and situations in which eating occurred. Daily monitoring forms were explained in detail, and family members practiced listing their recent food intake on a sample form. The next evening, the psychologist called the family to ask how they were doing with the forms, underscoring the importance of daily monitoring while offering assistance. Subsequent evaluation of the week's data showed that R.T. had ample opportunity to consume foods high in calories and fat. Breakfasts typically consisted of sugared cereals with whole milk or jelly doughnuts. Lunch at school consisted of fast foods, such as french fries, cheeseburgers, pizza, and chocolate milk. After school, R.T. went to his grandmother's house until his mother returned home from work. Grandmother provided snacks consisting of cake, cookies, or ice cream. Evening meals were often fast foods that R.T.'s mother purchased on her way home from work. After supper, the family enjoyed salted snacks (popcorn, potato chips, pretzels) or cookies while sharing an evening of TV.

R.T. got little exercise. His mother reported that he spent most of his time at home watching TV or playing video games. He occasionally played baseball with friends or went roller skating at a local disco rink on weekends when he had allowance money and someone to take him. R.T. was a well-adjusted child with many friends, although he complained that they teased him about his weight. His school work was generally above average, although he often performed below the level of his true ability.

Following a review of eating behaviors and situations from the daily records, R.T. was interviewed by a dietician who obtained a 24-hr food recall. She then helped R.T. enter the food items into the DINE analysis program on a microcomputer. A print out of the dietary analysis was given to R.T. and his parents, together with an explanation of nutrient values and recommended dietary goals. The family was asked to continue recording eating behaviors.

At the next session, review of recent eating and the previous DINE analysis provided the basis for developing behavior change goals. The Traffic Light diet concept was introduced and family members were asked to identify snacks low in fats and sodium to replace their usual snacks. Mother agreed to ask grandmother to provide apples, carrots, or bananas after school. Evening snacks were to consist of fruits, carrots, or juice and were to be consumed in the kitchen instead of in the living room, where the family gathered to watch TV. Initial sodium reduction was to be achieved by reducing purchase of fast foods and by switching from bread products high in sodium to low-sodium pasta and rice products. Information on reducing sodium from canned goods, soups, and condiments was provided. R.T.'s parents decided to attend a "Healthy Heart" cooking class (low sodium, low fat) offered in connection with the grandfather's cardiac rehabilitation program.

By the fourth session, the family had become aware of problem eating habits and situations, had experimented with healthier alternative foods, and had identified dietary goals that included reducing snack frequency and type, increasing their use of low-fat and low-sodium foods, and increasing physical exercise. The therapist reviewed diet and exercise goals and helped the family complete a Contingency Grid to evaluate inducements and obstacles to implementing their plan. One result was that family members noticed there were no immediate positive consequences to encourage R.T.'s exercise. This was addressed in several ways. First, a type of exercise was selected that would be enjoyable for R.T.: He was to help his grandfather walk the dog after school, an activity that generated a number of positive consequences. R.T. enjoyed spending time with his grandfather and walking the dog was fun. His grandmother was happy with this arrangement because it allowed grandfather to carry out a prescribed walking regimen in the company of his grandson. Moreover, R.T.'s father agreed that time spent walking would earn time for father and son to work on a model train set together in the evenings, with the understanding that no snacks were to be eaten in the basement room where their railroad was under construction. In addition to reinforcing R.T.'s walking, the evening model building sessions helped remove R.T. and his father from the setting (TV) where snacking usually took place. Additional reinforcement was provided by giving R.T. extra money to go roller skating, although this plan had to be modified when it was discovered that pizza and other fast foods were available at the roller skating rink.

As the family began to implement diet and exercise changes, the psychologist and dietician showed them how to record their weight and minutes spent exercising on a graph. They first showed them graphs that other adults and children had completed, making the point that weight reduction was achieved gradually with occasional plateaus and reversals (often coinciding with vacations and holidays) but that, as exercise increased, weight showed a downward trend over time. This underscored the important point that occasional "slips" need not be viewed as signs as failure but instead are temporary set backs on the journey to better health. As family members became more adept at eating desired foods in appropriate amounts, treatment focused more on monitoring the weight and exercise data and attacking problems that posed barriers to further progress.

These barriers included the father's lunch and snacking habits, and the mother's work-related tension and fatigue. The father's work routine was frequently changing; his painting jobs seldom kept him long in one location and often he ate lunch whenever and wherever it was most convenient. Fast foods were the usual fare. This problem was approached by developing a plan that involved gradually reducing the number of lunches purchased at fast food restaurants from 5 per week to 1 per week. Fast foods were replaced with lunches prepared at home and carried to the job. At least a portion of the lunch was to be eaten early enough in the work day to prevent the intense hunger that made fast foods harder to resist. These changes, together with a walk–jog program undertaken after work and on weekends, proved important weight-loss aids.

R.T.'s mother played a pivotal role in her family's success at reducing risk. Through participation in the Healthy Heart cooking class, she developed a strong commitment to a low-fat and low-sodium diet and even experimented with vegetarian cooking. Although she enjoyed cooking, new food preparation practices were often a burden. She frequently came home exhausted with a headache and in no mood to embark on a new recipe. The headaches appeared to be partly muscular in origin and usually occurred on days when she was forced to spend most of her time working on the computer at the accounting firm where she was employed. The psychologist suggested preventive measures, such as obtaining a more suitable chair and taking brief breaks from work. He also introduced relaxation as a coping strategy to reduce tension and make the evening routine more enjoyable. In a session with the entire family, the psychologist introduced muscle tensing and relaxing exercises and deep breathing techniques to be practiced regularly for brief periods during the following week.

While the mother was the primary target of this intervention, other family members were included to provide support for the notion of taking time to relax at the end of the day. Later, hand warming was introduced with feedback to be provided by means of a finger thermometer ring. At this point, R.T. became interested in practicing relaxation and graphing his finger temperatures on the form he used to record exercise and weight loss. As a result, the family was successful in establishing a short "quiet time" to be enjoyed immediately after mother got home from work. Usually this meant that mother could take a few moments to relax quietly by herself, although R.T. occasionally took this opportunity to practice relaxation too. The quiet time intervention proved extremely helpful in sustaining the mother's commitment to diet-management activities.

After 6 months, R.T. had managed to lose 11 lbs., which meant that his weight was now below the 80th percentile for his age. His blood pressure was 118 mm Hg systolic and 76 mm Hg diastolic, placing him at the 80th and 85th percentiles, respectively. His LDL cholesterol had dropped below the 75th percentile. Other family members showed comparable improvements. The father had lost 13 lbs.; his blood pressure now averaged 131 mm Hg/85 mm Hg. R.T.'s mother registered a 9-lb. weight loss, and his sister's LDL cholesterol had fallen below the 75th percentile.

SUMMARY

Behavioral assessment and intervention occupy a central place in the evaluation and treatment of elevated blood pressure in children. Initial emphasis is on ensuring that behavioral influences (e.g., excessive anxiety) do not lead to misdiagnosis and that child and parents do not overreact when informed that the blood pressure is elevated. If the child is judged to be overweight or obese, behavioral intervention to achieve weight control is indicated, before or in conjunction with drug therapy. This is best achieved by modifying eating habits (decrease consumption of high-calorie foods) while increasing physical exertion by enhancing lifestyle activities that are part of the child's normal routine. Additional benefits may be gained by restricting dietary sodium intake and implementing a program of frequent aerobic exercise (after appropriate medical evaluation). Intervention to prevent/reduce smoking or drug use, and to reduce emotional stress via environmental changes and relaxation training may be indicated for some patients.

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CHAPTER 20

Prematurity and Low Birthweight

Clinical Behavioral Intervention

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AND KAY A. TOOMEY

INTRODUCTION

Prematurity and low birthweight (LBW) constitute frequently occurring perinatal complications with potentially risky implications. Although the terms prematurity and LBW have been around for some time, the precise meaning of these terms is often confused, giving rise to misunderstanding and inaccuracies. Historically, the terms prematurity and LBW were used interchangeably (Caputo and Mandell, 1970). These investigators were referring to a gestational age of ≤ 38 weeks or less and a birthweight of ≤ 2500 g. More recently, the term very low birthweight (VLBW) has been used to designate a birthweight of ≤ 1500 g. Using the terms prematurity and LBW synonymously leads to some confusion, since every premature infant is not LBW and every LBW infant is not premature. Owing to these discrepancies a more accurate terminology has been introduced and takes into account the relationship between gestational age and weight at birth. The new designations include small for gestational age (SGA), average for gestational age (AGA), and large for gestational age (LGA). These terms distinguish an infant within the statistically normal range for gestational age or outside the normal range. Although there are additional descriptions

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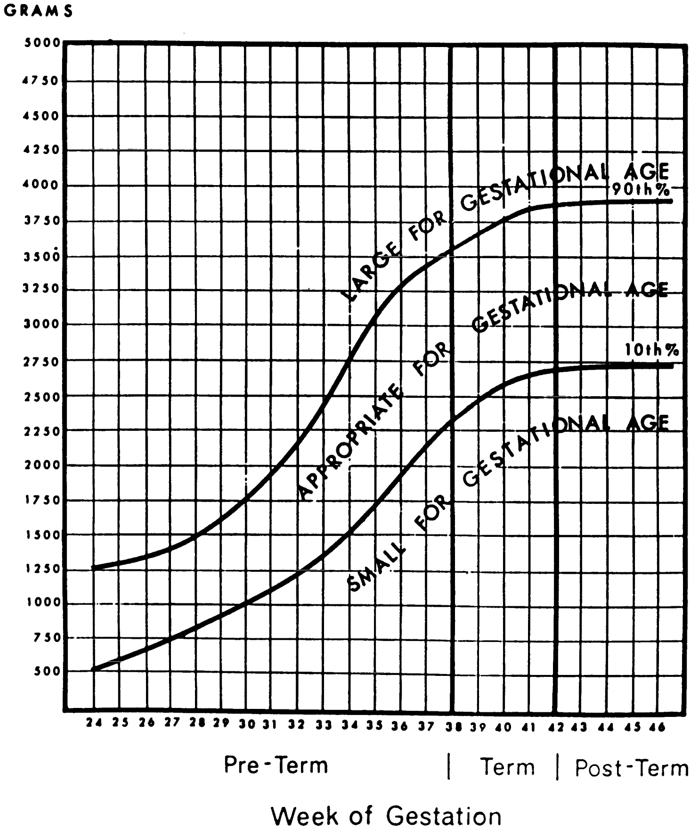


FIGURE 1. Classification of newborns by birth weight (BW) and gestational age (GA). GA–BW distribution: GA to be estimated from first day of last menstrual period (LMP) and classified by completed weeks: 37 weeks ÷ 0 days = 37 weeks; 37 weeks ÷ 6 days = 37 weeks. GA: subdivided along abscissa into three categories: Preterm (Pr), All infants less than 38 weeks GA, i.e., 37 weeks ÷ 6 days or less; term (T), All infants between 38th and 42nd weeks GA; post- term (Po), All infants of 42 or more weeks GA. BW: Within each GA group, three subgroups of infants are defined by BW: LGA, Infants above 90th percentile; AGA, Infants between 90th and 10th percentile; SGA, Infants below 10th percentile. Thus, nine groups of newborn infants are defined and coded as follows:

Pr-LGA, Born before 38th week, BW above 90th percentile.
Pr-AGA, Born before 38th week, BW between 10th and 90th percentile.
Pr-SGA, Born before 38th week, BW below 10th percentile.
T-LGA, Born between 38th and 42nd weeks, BW above 90th percentile.
T-AGA, Born between 38th and 42nd weeks, BW between 10th and 90th percentile.
T-SGA, Born between 38th and 42nd weeks, BW below 10th percentile.
Po-LGA, Born at or after 42nd week, BW above 90th percentile.
Po-AGA, Born at or after 42nd week, BW between 10th and 90th percentiles.
Po-SGA, Born at or after 42nd week, BW below 10th percentile.

From "A practical classification of newborn infants by weight and gestational age" by F. C. Battaglia and L. O. Lubchenco, 1967, *Journal of Pediatrics, 71,* p. 159. Reprinted by permission.

related to gestational age–birthweight interactions (Lubchenco, 1976), SGA, AGA, and LGA are most frequently used. The cutoff point for the SGA infant is a birthweight below the 10th percentile for its gestational age. Conversely, the cutoff point for the LGA infant is a birthweight above the 90th percentile for its gestational age. All other infants are regarded as average for gestational age, regardless of their age status. In this way, clinicians and researchers can determine whether an infants' growth is within the expected range for its age (Fig. 1). Many SGA babies suffer from what has been called intrauterine growth retardation (IUGR). IUGR may be a result of varying prenatal factors, but one that is commonly associated with IUGR is a small or insufficient placenta. These infants are commonly referred to as small-for-dates. These infants are suspected of having possible central nervous system (CNS) compromise as a result of insufficient nutrition and possibly oxygen deprivation throughout pregnancy. As such, these babies may be at exceptionally high risk of developmental difficulties that are often relatively uncorrelated with life-threatening perinatal risk factors. It is important to remember that while many premature infants will also be SGA, full-term infants who weigh ≤ 2500 g are also SGA as well as LBW (Fig. 2). Premature infants who weigh ≤ 2500 g may not in fact be SGA, but simply LBW. Depending on its gestational age, the preterm infant may have adequate growth, but has simply been born early. A determination of gestational age therefore cannot be made on the basis of weight alone but will include an assessment of posture and flexion of upper and lower extremities (Fig. 3).

Historically, LBW infants, many of whom have been premature or SGA, or both, typically have a number of adverse circumstances associated with their development. These include poorer performance on infant behavioral examinations, lower intelligence scores during school, and higher rates of other developmental deficits, such as hyperkinesis, autism, language problems, and poor academic achievement (Caputo & Mandell, 1970; Emory & Walker, 1982; Field, 1979; Lubchenco, 1976; Parmelee, 1975; Scarr & Williams, 1973). Recent studies have also found that maturity at birth and birthweight are related to fetal heart rate patterns during labor. Fetuses whose heart rate tends to drop or decelerate with uterine contractions generally have lower birthweight and are less mature than those fetuses whose heart rate rises or accelerates with contractions (Emory & Noonan, 1984a,b). While the overall outcome for premature infants, regardless of weight percentiles, has been associated with a higher incidence of developmental difficulty than that for healthy term newborns, the mortality rate for preterm and LBW infants has shown a steady decline. By the late 1970s, a declining trend of about 25% in infant mortality before 28 days of age was reported for black and white infants born in the United States (Manniello & Farrell, 1977). More infants whose nervous system had been compromised pre- and perinatally were surviving, yet many, especially those at the lower end of the gestational age and birthweight distributions, were exhibiting long-term developmental delays or disabilities. The medical and technical advances that had promised better odds for survival of high-risk newborns were ironically a major precursor of the proportional rise in long-term infant morbidity. Recently Cohen, Parmelee, Beckwith, and Sigman (1986) suggested that social

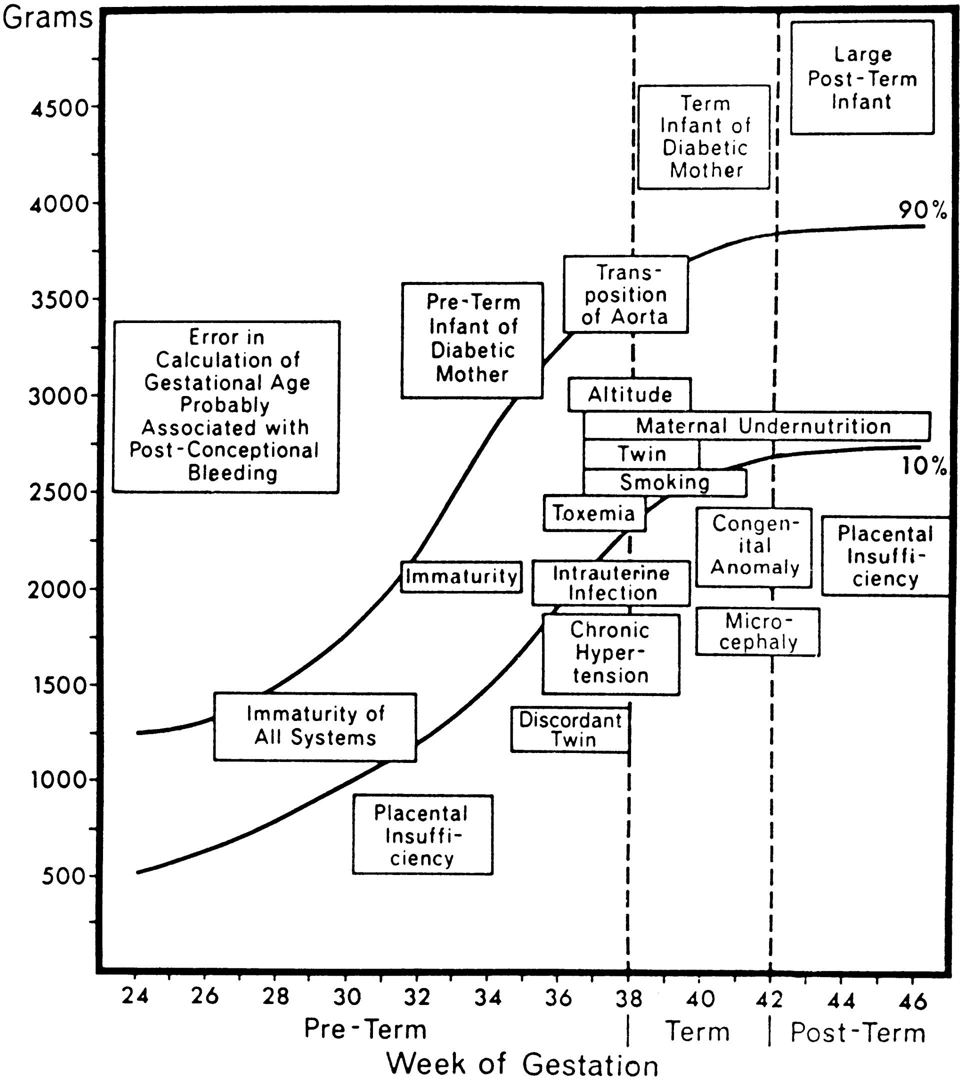
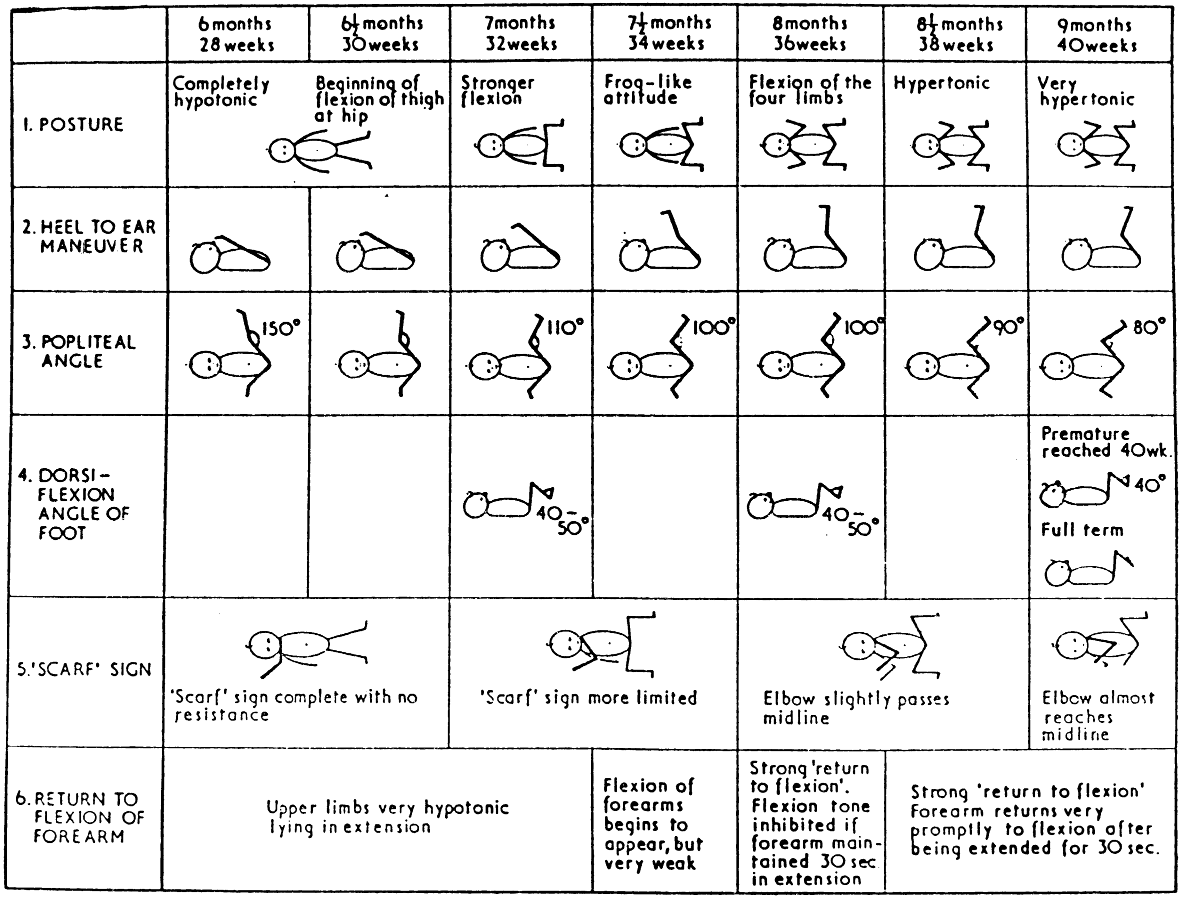


FIGURE 2. Deviations of intrauterine growth. Neonatal morbidity by birthweight and gestational age. The boxes indicate the morbidities likely to occur at the various birth weights and gestational ages. From "Factors influencing fetal growth" by L. O. Lubchenco, C. Hansman, & L. Backstrom, in *Aspects of prematurity and dysmaturity* (pp. 149–164) by J. H. P. Jonxis, H. K. A. Visser, & J. A. Troelstra (Eds.), 1968, Leiden: H. E. Stenfert Kroese, N. V., and Springfield, IL: Charles C Thomas. Adapted by permission.

factors play a major role in determining the outcome of preterm infants regardless of neonatal complications. Mortality and morbidity rates remain higher for black American babies than for their white counterparts.

Prematurity and LBW constitute an escalating medical problem with significant implications for behavioral development. Unfortunately, the magnitude of the problem is increasing, rather than decreasing, partly because of the im-



	6months 28weeks	6½months 30weeks	7months 32weeks	7½months 34weeks	8months 36weeks	8½months 38weeks	9months 40weeks
1. POSTURE	Completely hypotonic	Beginning of flexion of thigh at hip	Stronger flexion	Frog-like attitude	Flexion of the four limbs	Hypertonic	Very hypertonic
2. HEEL TO EAR MANEUVER							
3. POPLITEAL ANGLE	150°		110°	100°	100°	90°	80°
4. DORSI-FLEXION ANGLE OF FOOT			40–50°		40–50°		Premature reached 40wk. 40° Full term
5. 'SCARF' SIGN	'Scarf' sign complete with no resistance		'Scarf' sign more limited		Elbow slightly passes midline		Elbow almost reaches midline
6. RETURN TO FLEXION OF FOREARM	Upper limbs very hypotonic lying in extension			Flexion of forearms begins to appear, but very weak	Strong 'return to flexion'. Flexion tone inhibited if forearm maintained 30 sec in extension	Strong 'return to flexion' Forearm returns very promptly to flexion after being extended for 30 sec.	

FIGURE 3. Passive tone. Increase of tone with maturity illustrated by means of six clinical tests. "Neurological evaluations of the maturity of newborn infants" by A. Amiel-Tison, 1968, *Archives of Disorders of Childhood, 43,* p. 89. Reprinted by permission.

proved survival rate for many newborns who would have previously expired during the neonatal period. In this regard, the developmental implications for pediatric clinical psychology, and more generally behavioral pediatrics, take on added meaning. Documenting the relative behavioral, cognitive, and social deficits among high-risk infants will continue to be a much-researched area. More important, perhaps, is the need for new methods and techniques for enhancing development among these infants. Otherwise, they simply add to the growing number of children with developmental impairments.

TREATMENT IMPLICATIONS

Providing routine clinically oriented treatment to premature and low birthweight infants is not a well-defined area for psychologists. Treatment implications of prematurity and LBW for the pediatric clinical psychologist basically fall into two areas. These include intervention focusing primarily on parenting and family processes, as well as direct assessment and behavioral management of the premature or LBW infant. Each of these areas is briefly discussed.

PARENT AND FAMILY INTERVENTION

Working with new parents and families of LBW or premature infants, as well as those with other medical problems, will constitute a major investment on the part of the pediatric clinical psychologist. Intervention can be geared in three specific areas. These include (1) management of apprehensions and anxiety, (2) parent education, and (3) parent training.

Apprehension and anxiety among expectant and recent parents, especially primiparous women, represent a common problem for clinicians. Anxieties are usually focused on the health and well-being of the child but may also include dynamic issues among mother, father, and extended family. Our clinical investigations and experience suggest that among intact families, a pattern of anxieties among expectant parents includes three major interrelated themes. The first theme is a concern by both parents for the health and well-being of the unborn or newborn child. The second theme revolves around the mother's concern for her child's health and her need for emotional support. The primary source of emotional support is usually the child's father but may extend to any significant other. The mother's continuing need for reassurance from the child's father is seen as a major psychological factor contributing to maternal adjustment and ability to complete an uncomplicated course of pregnancy and delivery. The third major theme is the father's concern for the health and well-being of his wife and his concerns regarding financial stability. Although concerns for the child's health exist, they are usually secondary to those related to the mother. These dynamics are operative under the most optimal perinatal circumstances. Obviously, added stress is placed on the family unit when high-risk conditions exist. Prematurity and LBW, while themselves not typically life-threatening conditions, serve to heighten anxiety and stress, altering the dynamics of the parental relationship and family unit. Perinatal stressors may alter the course and outcome of the pregnancy as well as early childrearing patterns. The pediatric clinical psychologist should be aware of these dynamics. They should be prepared to help parents adjust and cope with perinatal stressors and complications, regardless of their long-term implications. Intervention within this context is aimed at reducing tensions and anxieties in an effort to help parents become effective caregivers for the newborn child.

Working with parents during the perinatal period should also focus on parental education. For professionals working in the area of clinical behavioral pediatrics, it is essential to know the fundamental aspects of infant development as they relate to behavior. The pediatric clinical psychologist or developmental psychologist can be very effective in assisting parents in acquiring a knowledge base about newborn infant behavior and development. This intervention is aimed at helping new parents (1) anticipate developmental milestones, (2) understand how their premature or LBW infant may be different from other infants who were born at term, and (3) understand the nature of the parenting effort as it relates to changing life-style and feelings of being overwhelmed. One of the most useful and effective messages that can be conveyed to new parents, especially those whose perinatal complications are of a relatively mild and nonsignificant nature, is to reassure them that the problems they currently experience will pass in time. They need to be reassured that as the child continues to develop, it will be more responsive to their efforts at social interaction and will become less demanding in terms of feeding and other routines unique to the newborn period. A few didactic sessions with a group of new parents related to early infant behavior and development can go a long way in helping them understand the nature of infant behavior and anticipate how the child is likely to react to its new environment. Parent education gives new parents a sense of control and, to some extent, mastery over a new situation. They will have a better sense of knowing what they are doing and can feel that they have a source of professional information and support, should they need it. Bromwich (1981) offered a potentially useful classification of problems as points of departure for describing interventions. The five problem categories defined by Bromwich (1981) include social–affective, cognitive–motivational, language, motor, and those common to caregiving (e.g., feeding, sleeping, safety).

Working with parents of newborn infants also includes parent training. In many research centers, parents are routinely taught how to elicit certain behaviors from their newborn infants. Some of this work has actually been published as a way of helping parents become familiar with their babies as well as facilitate parent–infant interaction, bonding, and general infant development (Field, 1977, 1979). In our setting, we have used the Brazelton Neonatal Assessment Scale as a vehicle for engaging parents in learning how to stimulate and recognize typical responses from newborn infants. In some instances, the Brazelton Scale or other infant behavior scales have been used to demonstrate infant capabilities. This method can be a major asset in helping pediatric psychologists teach new parents to feel more comfortable interacting and handling their newborn infants. To summarize, the major areas of clinical behavioral pediatric work with parents of newborn infants, especially those with perinatal complications, tend to revolve around managing their apprehensions and anxieties, providing them with formal and informal information for educational purposes, and training specific behavioral skills and techniques for working with their newborn infants.

DIRECT ASSESSMENT AND BEHAVIORAL INTERVENTION

Pediatric clinical psychologists and other people working in the newborn nursery environment can also be effective via direct intervention with premature and LBW infants. These direct intervention activities are grouped into specific domains, which include behavioral assessment and diagnostic work, along with stimulation and conditioning techniques. Behavioral assessment has been the primary area of direct involvement among nonmedically trained behaviorally oriented practitioners. It has the purpose of determining the behavioral status of the infant by observing spontaneous and elicited behavior during a standardized evaluation. The use of these techniques has been invaluable in charting the developmental course of sick or otherwise compromised infants and in monitoring the effects of certain medical interventions, including drug therapy. Infant behavioral responsiveness over the course of hours, days, or weeks can assist in helping determine the effectiveness of many routine interventions. The common functional pathway for the expression of nonoptimal or high-risk conditions, as well as recovery from those conditions, is often spontaneous and responsive behavior (Emory & Walker, 1982). An infant recovering from a serious medical condition or specific therapy will usually display some type of behavioral change. While more immediate normalization of homeostasis may reassure the primary attending physician that a crisis is under control, the ultimate effect of these interventions will be demonstrated by an overall improvement in organized behavior. Therefore, the behavioral technician is an invaluable part of the health care team in monitoring the course of development as well as the efficacy of treatment.

Behavioral intervention may also include stimulation techniques and conditioning procedures. Infant stimulation has been used for a number of years with the expectation that such intervention will enhance growth and CNS development through sensory input (Girolami, 1983; Nelson, Heitman, & Jennings, 1986; Scarr & Williams, 1973). Infant stimulation typically involves auditory, visual, and tactile sensation. Applied behavioral technology is uniquely well suited for developing specific stimulation procedures and to chart their effects on behavioral change. Although stimulation procedures may have a positive effect on some aspects of early development, its effect on weight gain was recently reported as insignificant (Nelson *et al.*, 1986).

Infant stimulation will sometimes involve more formal use of conditioning procedures. Such strategies can be used to enhance acquisition of novel responses or to counter the negative effects of certain medical interventions. Typically, high-risk infants, including premature and LBW newborns, often have frequent intervention encounters during their hospital stay. Much of this intervention is aversive to the infant. It often disrupts the infants quiescence and not infrequently inflicts pain. Infants can and do develop aversive conditioning experiences with humans if most of their contact involves painful or unpleasant stimulation. Conditioning procedures can be used to counter such negative treatment effects as well as to improve the nature of environmental contact for the newborn infant. In terminal situations, radical conditioning procedures have been effective in prolonging life. A group of researchers working with a hypoxic infant suffering from central hypoventilation were successful in prolonging the infant's life through the use of avoidance conditioning when O_2 saturation fell below a specific point (Beck, Sulzbacher, Kawabori, Stevenson, Guntheroth, & Spelman, 1980). Although this example is a rare and unusual application of behavioral techniques in the neonatal period, the possibility exists that continued refinement and improvement of behavioral interventions will be routinely employed along with more traditional medical procedures. The use of such procedures would most likely begin by targeting serious conditions that carry a high risk of mortality or major developmental disability. The following discussion focuses on two case studies illustrating the use of behavioral pediatric techniques with high-risk infants.

CASE STUDIES

Case 1

The subject was a full-term AGA infant girl delivered to a narcotically addicted mother. The medical center at which this baby was delivered had limited experience treating infants going through narcotic withdrawal. As pediatric clinical psychologists, we were asked to assist in monitoring the effects of treatment with this infant. After discussion with the attending neonatalogist, it became apparent that a standard protocol for treating a narcotically addicted infant was not available. The infant's symptoms included withdrawal, characterized by jitteriness, hypersensitivity, and excessive irritability and crying. Sleep patterns were inconsistent and maternal involvement minimal. The infant had been put up for adoption on the second day after delivery. Our approach to this case was to determine the behavioral status of the neonate. This was accomplished by administration of two Brazelton Neonatal Behavioral Assessments, 12 hr apart, within a 24-hr period. This established a baseline from which to evaluate the effects of treatment, which was to consist of a trial of phenobarbital. On day 2, the infant was started on a very small dose of phenobarbital to determine its effect on mitigating the symptoms associated with narcotics withdrawal. Eventually, the dose was titrated up to a level where the symptoms were no longer present. Because of a desire to wean the patient from medication as quickly as possible, daily Brazelton Assessments were performed. On days 2, 3, 4, and 5 after the initial baseline, the infant was administered repeated Brazelton Assessments. The assessment results were used to determine how much to titrate medication down to a level where the patient's symptoms were no longer present. They also helped determine the minimal dosage required for alleviation of symptoms. The Brazelton information was effective and helpful to the attending physician, as it described specific change scores in the behaviors that had defined the symptom picture. As the infant became less irritable, jittery, and hypersensitive to stimulation, the dosage was continually reduced. Within 1 week, the infant was weaned completely from the medication; the clinical decision to do so was based largely on daily behavioral feedback generated by scores obtained with the Brazelton Scale. We found the approach to be a clinically beneficial use of behavioral assessment during the neonatal period.

Larger medical centers will undoubtedly have more experience with treating and managing offspring of narcotically addicted mothers. It may be that these centers inadvertently used a nonstandard measure of behavioral responsivity or in fact used a formal approach, such as the Brazelton Neonatal Behavioral Assessment Scale. Regardless of the procedures involved in particular settings, it seems appropriate and beneficial to incorporate regular behavioral monitoring of the neonate who is undergoing narcotic withdrawal. Such an approach provides continuing baseline behavioral data that are indispensible in evaluating symptoms related to narcotic withdrawal in the newborn. Medical personnel, particularly the attending physician, find such information extremely useful and beneficial to them, easing their concerns about medication dosage and helping them appreciate the benefits of behavioral pediatric techniques.

Case 2

The second case is very different from the first. This infant was a premature boy, weighing approximately 1500 g at birth, and born at 27 weeks gestation with multiple problems, including respiratory difficulties, intraventricular hemorrhage, and hydrocephaly. This infant was maintained in the neonatal intensive care unit (NICU) for more than 3 months, during which his condition was gradually stabilized, but the prognosis for a normal outcome was discouraging. In this situation, a number of biomedical and social factors came into play, and more than one application of behavioral principles was used. Clinical skills in this situation were indispensible, in that regular contact with the parents and nursery staff comprised much of the clinical pediatric psychologist's responsibilities. The parents of this infant were highly motivated but very anxious about his condition and eventual outcome. They lived more than 25 miles from the medical center, and daily visitation was an added burden on their time and stress on their emotions. In addition to providing regular psychological and emotional support to the parents during the initial acute crisis, we encouraged and facilitated parent–infant interaction during intubation, monitoring devices, and other interventions. Parental involvement helped effect a treatment plan while the infant was in the NICU. The treatment plan called for infant stimulation, with the aim of involving both parents. Facilitation of bonding was viewed as an equally important goal. The plan included having the parents make an audio tape every other day that consisted of verbal interaction between themselves and their child while they were at home. The parents found that making the tape allowed them to express their concerns with each other as well as giving them a feeling of direct communication with their infant, even though they were not physically present in the nursery. The tapes were approximately 45 min to 1 hr in length and were provided to the nursery staff on each occasion of parental visitation. The parents acknowledged that the process of making the audio tape and talking to each other and their child helped alleviate their anxiety. They also understood the limitations of the program. We subsequently determined that the assumption that the tape-recorded messages would not be a direct benefit to the infant may have been erroneous. The tapes were provided on a regular basis. The parent would visit with the infant and provide caregiving appropriate to the circumstances. When the parents departed, they would leave the audio tape for the staff to play to the infant later that day and the next day. The infant was exposed to the tape-recorded message for approximately a 4-hr interval, which tended to coincide with the normal routine of feeding in the nursery. Given that this infant remained in the NICU for several months, the nursery staff and the patient were provided with a number of taped messages that could be interchanged during the course of intervention.

The infant's response to the taped messages was quite remarkable. At 30 weeks and thereafter, it was apparent that the auditory stimulation provided the infant via the tape-recorded message was having a positive effect. There seemed to be improvement in the infant's ability to maintain an alert state and to attend to the auditory information being presented. On several occasions, we personally observed behaviors associated with orienting as described by Brazelton and others. Moreover, although not systematically recorded, it appeared that the infant became accustomed to the procedure, tending to alert just before playing of the tape. We have tentatively chosen to refer to this procedure as parent–infant interaction through tape-recorded messages (PIITTRM).

A small audio cassette recorder was placed near the infant's head and played at a decibel level within the normal speaking range. The procedure was simple, since the same tape recorder was used on a daily basis, and only the tape itself was removed from the nursery.

There were a number of interesting outcomes from this case study. The first important outcome from this intervention was the pleasure and joy it brought to the parents by giving them a sense of involvement with their infant, even when they were not in the hospital. Second, although the infant's medical condition eventually stabilized, the auditory stimulation enhanced the infant's responsiveness after the acute stages of his illness. Third, the nursing staff found the procedure beneficial but noninvasive. It did not require a tremendous amount of time on their part, nor was it an encumbrance in terms of space utilization. The nursing staff also observed the infant's improvement, which they believed was augmented by the taped procedure. Fourth, it gave the attending physician a sense that he had addressed the emotional and psychosocial aspects associated with the development of this very ill infant and his parents' ability to form a close, bonded relationship. Finally, the pediatric clinical psychologists had developed a treatment plan for a critically ill neonate without interfering with the priorities of basic medical care.

These are just two of many cases in which pediatric clinical psychologists can bring their skills to bear on the care and management of the critically ill newborn infant. These experiences make it clear that the role of the pediatric clinical psychologist is expanding and promises to add a significant dimension to the overall care and treatment of newborn infants.

PROFESSIONAL TRAINING

Preparation for professional work in a clinical behavior pediatric unit is not well defined. Traditional training in clinical psychology provides adequate preparation for dealing with anxiety, family dynamics, and appreciation of clinical diagnostic issues. However, such training does not ordinarily include a strong grounding in applied behavioral analysis and, less often, supervised experience with newborn infants. By contrast, traditional training in applied developmental psychology will not include clinical practicum and supervised experience in therapy, counseling, case management, or clinical diagnosis.

The role of the pediatric clinical psychologist is one that necessitates formal exposure to the problems and issues faced by persons working in these settings. The pediatric clinical psychologist will function as a full-fledged member of the health care team and should therefore be qualified and eligible for state licensure as a provider of psychological services. Additional exposure to special issues related to high-risk infants and their families is essential.

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CHAPTER 21

Short Stature

The Special Case of Growth Hormone Deficiency

CAROL LEWIS

GROWTH HORMONE DEFICIENCY: BACKGROUND

Before approximately 25 years ago, growth hormone-deficient persons could not find successful treatment to increase their height. Without endogenous growth hormone production by their pituitary glands, these individuals missed the opportunity to grow during childhood and adolescence. Their ultimate height was generally comparable to that of children in kindergarten or early elementary school. Their bodies were proportionate despite their small size. Before the advent of successful treatment these people were known as midgets.

Growth hormone deficiency is only one of the reasons for short stature. Some children are short as a result of genetic or familial factors. They may simply be short children of short parents. It is not uncommon to have children brought to medical clinics to have their short stature investigated only to find that their parents are both 5 feet tall. Thus, some children merely resemble their parents in stature. Other children grow at a rate much slower than that of their peers but eventually catch up with them in height. Many of us have known boys in their late teens who were quite short when they entered college, yet grew to 6 feet tall or greater before graduation. These growth patterns are variations of normal growth.

Several pathological processes may also result in short stature. Impoverished environmental conditions sometimes result in retardation of what would

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otherwise be normal growth. Children subject to these conditions may appear to be growth hormone deficient. Laboratory tests will find them deficient in growth hormone because they are not producing it in the offending environment. These children do not respond to growth hormone replacement therapy. However, when they are removed from the offending environment, these children resume normal growth. This condition is called growth retardation caused by psychosocial deprivation.

Other pathological conditions that cause short stature include Turner's syndrome (a genetic disorder), achondroplasia (a bone and cartilage disorder), craniopharnygioma (a tumor), and pituitary growth hormone deficiency. This latter condition is the subject of the following discussion.

Reports of the prevalence of growth hormone deficiency have varied greatly from 1 in 30,000 (Parkin, 1974) to 1 in 4000 (Vimpani, Vimpani, Pocock, & Farquhar, 1981). The large discrepancy between available figures has been explained by one reporter as the result of underreporting by professionals. Growth hormone-deficient children often are not brought to the attention of professionals until grade school age. As children progress through the elementary school grades, lack of growth is noticeable as peers continue to grow. Parents often notice growth problems only at this critical point.

The criterion for short stature varies somewhat in different published investigations. A commonly found criterion is height below the 3rd percentile for age and sex (Schaff-Blass, Burstein, & Rosenfield, 1984). The diagnosis of growth hormone deficiency usually can be made only after at least two tests designed to stimulate growth hormone secretion show a deficiency. The diagnostic tests measure serum growth hormone after either insulin-induced hypoglycemia, arginine infusion, L-dopa stimulation, or glucagon administration (Ad Hoc Committee on Growth Hormone Usage, 1983). In terms of actual growth, the growth hormone-deficient child may grow less than 2.5 ± 0.8 cm/year (Kaplan, 1975), while the normal child generally grows at least 5 ± 1.5 cm/year (Daughaday, 1974).

Approximately 25 years ago, growth hormone replacement therapy became available. This treatment involved taking injections of costly human growth hormone several times a week. The human growth hormone was obtained by purifying growth hormone from the pituitary glands of human cadavers. The treatment resulted in increased growth rates for most children who received the human growth hormone, although ultimate height is often less than "average" height for men or women. Treatment often continued through the critical growing years and stopped when the child neared adulthood, after which height is relatively stable. Some children received human growth hormone for as long as 10 or more years.

In 1985 human growth hormone was taken off of the market by the Food and Drug Administration (FDA) after several deaths from Creutzfeldt–Jakob Disease (CJD), a degenerative neurological disease, were linked to treatment with human growth hormone. The organism responsible for CJD may have contaminated some of the human growth hormone used by growth hormone-deficient children during the past 25 years. When this was discovered, several major pharmaceutical companies were already developing biosynthetic growth hormone. It has recently been approved for sale and distribution by the FDA.

Like human growth hormone, biosynthetic growth hormone is very expensive. While many insurance companies will pay for this treatment, some have been hesitant to do so, claiming that growth hormone deficiency is not a critical illness (i.e., you will not die from it). Parents and support groups like the Parent Council for Growth Normality (PCGN) have argued that treatment for growth hormone deficiency is not purely cosmetic.

PSYCHOSOCIAL PROBLEMS ASSOCIATED WITH GROWTH HORMONE DEFICIENCY

Size versus Age

Growth hormone-deficient children are very often treated according to their size instead of their age. Parents, other family members, teachers, and others often think that the height of the very short growth hormone deficient child is "cute." The child is often carried instead of allowed to walk, has an inappropriately young wardrobe, and participates in activities more appropriate for size rather than age. An example of this latter problem is the 14-year-old boy who spends most of his time collecting comic books and playing with 7- and 8-year-old friends. The wardrobe issue is a very difficult one for the very short child. The most accessible clothes may be the ready-to-wear outfits available for much younger children. Yet these outfits may contribute to the "cute" age-inappropriate image of the growth hormone-deficient child.

This problem also manifests itself in many other ways. Short children are often not encouraged to achieve to their full potential. They may not be encouraged to participate in age-appropriate sports activities because of their size. While the short-statured child may have difficulty handling some sports equipment, arrangements should be made to allow the child to participate. In other areas, short-statured children may not be given reasonable household responsibilities, encouraged to achieve academically, or to make decisions for themselves. As a consequence, short children are often overdependent on their parents. This may be in part attributable to the child's fear of independence in a rather threatening world or to the parent's need to provide for their "disabled" child. The parents may be afraid to have their child strive and fail at things and thus do things for them that they could actually do for themselves.

Academic Difficulties and Learning Disabilities

Research has shown that growth hormone-deficient children generally have average intellectual functioning (Pollitt & Money, 1964; Rosenbloom, Smith, & Loeb, 1966; Money, Drash, & Lewis, 1967). However, more recent investigations have found that growth hormone-deficient children may tend to have specific learning disabilities (Siegel & Hopwood, 1986), particularly visual–motor integration problems (Frankel & Laron, 1968; Abbott, Rotnem, Genel, & Cohen, 1982). Further investigations in this area need to be done and specific recommendations for remediation provided.

Despite a normal distribution of intellectual functioning in this population, research has also found that the academic achievement of growth hormone-deficient children is relatively poor. Teacher comments have described these children as showing a lack of interest in schoolwork as well as poor study habits (Pollitt & Money, 1964). In one sample (Siegel & Hopwood, 1986), 52% of the growth hormone-deficient children showed poor academic achievement despite the mean full-scale IQ (Weschler Intelligence Scale for Children—Revised) of the group falling within the average range. One explanation for some aspects of poor academic achievement is the presence of specific learning disabilities as suggested earlier (Siegel & Hopwood, 1986). Overall poor self-concept does not appear to explain the low achievement (Siegel & Hopwood, 1986). However, specific areas of low self-esteem could affect academic achievement, as could behavioral problems in the classroom and lack of motivation to achieve.

Interpersonal Problems

Growth hormone-deficient children often experience social difficulties. A very frequently noted problem for short-statured children is being teased about their size. A child's short stature is often considered "cute" when the child is preschool age or younger. However, short stature generally loses its attractiveness as the child gets older. One way that growth hormone-deficient children continue in the "cute" role as they mature is by assuming the role of a "mascot." The child may then develop a group of friends who protect him or her from the ridicule of other children.

Many growth hormone-deficient children cope with their social problems by withdrawing from peers. A recent investigation (Lewis, Johnson, Knuth, & Silverstein, 1986) found that growth hormone-deficient children are rated as much more withdrawn by their classmates than are control children. There are several possible explanations for this phenomenon. The growth hormone deficient child may withdraw in response to actual or perceived ridicule by peers. The child may withdraw because of feelings of inferiority and incompetence. Conversely, the child may not be given the opportunity to become fully integrated with peers because the peers are unwilling to interact with the child. The child may perceive this peer rejection and decide to put little further effort into social interaction. Regardless of who initiates this cycle, the results are the same. The growth hormone-deficient child is left on the periphery of the social circle.

Early adolescence may be a crisis time for many growth hormone-deficient children. Whether or not they have successfully resolved the social difficulties they previously encountered, the beginnings of heterosexual attraction may prove traumatic. Other same-aged peers begin to have boyfriends and girlfriends. Growth hormone-deficient children may feel pressure from peers to develop heterosexual relationships. However, they may not feel that they are as attractive to opposite-sex children as their peers. Studies looking at growth hormone-deficient adults previously treated with growth hormone have found that compared with normal-height persons, this group is not as likely to date, marry, or participate in sexual activity. Thus, heterosexual difficulties beginning in childhood contribute to less than adequate adult heterosexual adjustment.

Research has also found that parents of growth hormone-deficient children rate their children as less socially competent than do parents of normal height children (Lewis *et al.,* 1986). Both mothers and fathers rated their growth hormone-deficient children low in the number of activities in which they participated, their frequency of participation, and skill. They were also rated low by both mothers and fathers on frequency and depth of social contact. Thus, growth hormone-deficient children may not have the social skills necessary to interact successfully with their peers. This may be a result of a failure of overprotecting parents to encourage the growth hormone-deficient child to participate in independent activities outside of the home environment. Conversely, the children themselves may withdraw from social activities or be rejected by peers.

Fear of Needles

A fear of injection needles is also seen in these children occasionally. During treatment with growth hormone, children are required to have injections of growth hormone several times per week. Many children balk at this and act up at injection time.

TREATMENT STRATEGIES

The psychological treatment of the growth hormone-deficient child should involve both the parents and the child. Sometimes other adults who have a significant impact on the child are also included.

Parents

There are several issues that should be addressed with parents and other significant adults. These adults should be helped to encourage appropriate levels of independence in the short-statured child. Parents of these children often are very overprotective and may need to learn how to release some of the control they have in their child's life. They should be helped to discover ways to treat their child according to his or her age, and not size. It is sometimes necessary to convey this information to other important adults in the child's life. These other adults may undermine the parents' efforts.

Many growth hormone-deficient children have a deficit in social competence. Parents should be shown how to work with their child in order to improve their competence as much as possible. They could teach their child sports skills, facilitate activities with same-aged friends, encourage their child to participate in extracurricular activities, and the like. The child should be equipped with sports equipment and clothing that fit and that are not too dissimilar from those of the child's peers. Parents will need encouragement and emotional support from the therapist as the growth hormone-deficient child becomes more independent.

Child

The therapist should spend some time with the growth hormone-deficient child as well as the parent. Social skills can be taught to the child through role-play in the therapeutic setting. A related therapeutic goal with growth hormone-deficient children is to increase their assertiveness skills through assertiveness training. Once again, role-playing is a very useful technique to use in teaching a relatively timid child assertive behaviors. The specific situations to be role-played should be relevant to the individual child. They can include difficulties with family members, friends, and strangers at home, at school, and elsewhere.

It should be noted that parental and peer expectations for competency in children vary, depending on the sex of the child in question. Boys are generally expected to be competent and even competitive in sports. They are also expected to be assertive in many situations, particularly with the opposite sex, and aggressive when provoked. Adequate height is often viewed as a sign of masculinity. Conversely, short stature in girls is sometimes associated with femininity. Girls have not traditionally been expected to be competent in sports skills, although this is changing somewhat. Assertiveness has not been as expected or valued in girls as in boys, and aggressiveness is often viewed as a negative characteristic in girls. Nevertheless, short-statured girls and boys may be extremely withdrawn or overly aggressive and generally do benefit from social skills training aimed at either increasing appropriate or decreasing inappropriate skills. The success of such training rests in part on parents encouraging their child to use and refine newly learned social skills in the home and school environments.

Ideally, increasing a child's social competence and assertive behavior will be self-esteem enhancing for the child. The child's view of himself or herself should be explored and relevant self-esteem enhancing activities encouraged. This generally requires facilitation by the parents. With therapist support, parents can encourage their child and ease the child into previously threatening activities. The child's expectations for growth with growth hormone therapy should also be explored. Both the child and parents may have unrealistic expectations for the child's ultimate height. While some optimism is indicated, growth in response to growth hormone therapy is variable. Unrealistic expectations may lead to disappointment and at some point undermine the therapeutic outcome.

School Intervention

Because many growth hormone-deficient children have academic difficulties and learning disabilities, educational intervention is often indicated. If there is any evidence of these difficulties, appropriate assessment should be pursued. If there appears to be academic difficulty in the absence of any learning problems, motivational issues should be discussed. Intervention in this area may be necessary.

CASE ILLUSTRATION

Sean was a 12-year-old boy with growth hormone deficiency. He lived with his parents and numerous siblings. Sean was very short for his age despite receiving growth hormone replacement therapy. He was very quiet. Members of his family spoke for him most of the time. Sean was not allowed to participate in many activities away from home. His parents feared that strangers would take advantage of him. Sean did not know how to play basketball or many other sports. His clothes, including his shoes, were much too large for him, often showing many areas of gathered material around his waist. In addition, Sean was placed in a classroom for physically impaired students because of his short stature. Sean was identified by medical personnel as in need of psychological intervention. Treatment involved weekly therapy sessions with Sean and his parents over several months.

The first goal was to improve Sean's sports competency. An assessment of Sean's sports abilities was done, and it became apparent that his skills were poor for such sports as basketball and softball. He and his parents were shown some of the proper motions for these sports in a number of different sessions and were asked to practice playing the various sports or their component parts (e.g., throwing a ball, catching a ball, batting, dribbling a basketball, making basketball shots) between sessions. The aim was not to make Sean an exceptionally good athlete, merely proficient. By the end of treatment, Sean's athletic abilities were adequate.

The second goal was to improve Sean's social skills in a more general way. Several techniques were used to address this goal. Problem areas were identified through interview. Of great importance were areas identified by Sean in which he felt particularly lacking (i.e., low self-esteem). It was apparent that Sean was a very quiet, even withdrawn, child. He did not maintain good eye contact with others and would play by himself under most circumstances if allowed to choose activities for himself. Social situations were role-played with Sean. They included using direct eye contact with others, initiating conversation with peers, and asking to join in activities or to initiate activities with peers. Corrective feedback was provided. Practice was conducted within almost every session. Sean and his parents were asked to involve Sean in activities with peers. He joined a church youth group and was encouraged by his parents to play with same-aged children in the neighborhood on an almost daily basis. By the end of treatment, Sean was using more direct eye contact and was interacting more comfortably with similarly-aged peers.

A third and related goal was to increase Sean's assertiveness with peers. Role-playing with corrective feedback was the major method used to accomplish this goal. Sean and his parents identified teasing by peers about his short stature as his major source of peer-related conflict. Situations in which Sean was teased were role-played with Sean initially in the role of taunter and the therapist as Sean. Appropriate and inappropriate responses were modeled, after which Sean was asked to role-play the situations as himself. Corrective feedback was given. In-session practice with the problem situations and appropriate responses was conducted over the course of therapy. Sean was asked to use the newly acquired responses in *in vivo* situations. By the end of treatment, Sean was able to provide more appropriate responses to role-played teasing and reported that he used these responses in settings outside of treatment.

A fourth goal was to teach Sean's parents and extended family to treat him according to his age rather than his height. Situations were identified in which family members tended to treat Sean as if he were a preschool child. For example, he was not allowed to walk to the school bus stop without an adult and was generally encouraged to be overly dependent on his family. In addition, his clothes were too large for him, and their style contributed to his looking as if he were preschool age. Discussion with the family over the course of treatment focused on becoming aware of their behavior in these situations (i.e., carrying Sean instead of letting him walk) and the effects of their behavior (i.e., encouraging excessively dependent behavior). Alternative courses of action were developed, and the family was requested to use these new behaviors at home. They were also encouraged to continue to look for other similar situations and to change their behavior accordingly.

The two final goals were school-related. The first was to improve Sean's school performance. Intellectual testing indicated that Sean was functioning within the average range of intelligence without significant variability in performance. He was moved to a regular classroom, to which he adjusted quickly. He was required, and indeed was able, to work at a faster and more reasonable pace than he had been in the physically impaired classroom. Sean's academic performance improved, although he continued to have difficulty in two subject areas. Plans were made for Sean to receive remedial help in these areas in summer school. All the components of treatment discussed thus far can be viewed as self-esteem enhancing.

The second school-related goal was to decrease the number of unsubstantiated physical complaints at school. Before treatment, Sean complained of fatigue, headaches, and various aches and pains while at school on an almost daily basis. He was allowed to go to the office and either remained there or was taken home. With physician approval, a plan was instituted whereby Sean was allowed to stay out of class only if he had a fever of specified magnitude. Within several days of initiation of this new program, Sean remained in class without complaint of physical symptomatology.

SUMMARY

Growth hormone deficiency is one of the causes for short stature. It is currently treated with one or more injections of biosynthetic growth hormone per week over a number of years. Children with growth hormone deficiency may experience a number of psychosocial problems. They are often treated according to their size rather than their age. They may not be allowed to engage in age-appropriate independent activities. Growth hormone-deficient children often have specific learning disabilities, particularly in the visual–motor domain. Socially, these children are often withdrawn from their peers. Their social competence is often poor. Adolescence may be especially traumatic for growth hormone-deficient children as heterosexual relationships become an issue.

Treatment to address these difficulties generally involves the child, parents, and sometimes other family members. Assertiveness training and encouragement of age-appropriate behavior while discouraging a sick role are generally targets of intervention as are self-esteem issues and social skills training. Academic problems should also be addressed.

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PART IV

GENERAL ISSUES

CHAPTER 22

Preparing Children for Hospitalization and Threatening Medical Procedures

LIZETTE PETERSON, JANET FARMER, CYNTHIA HARBECK, AND JOHN CHANEY

INTRODUCTION

Early observations of children's behavioral and emotional reactions to hospitalization were grim. Practitioners noted a gamut of negative affective reactions stemming from hospitalization, ranging from anger, irritability, and increased aggression (e.g., Jensen, 1955) to panic, screaming, and crying (e.g., Prugh, Staub, Sands, Kirschbaum, & Lenihan, 1953) and listlessness, negativism and apathy (e.g., Jessner, Blom, & Waldfogel, 1952). Behavioral disruptions of sleep (such as increased nightmares, insomnia, and fear of the dark), eating problems, separation anxiety, and regression were also reported (e.g., Jackson, Winkley, Faust, & Cermack, 1952). Some concerned clinicians suggested in the 1950's that childhood hospitalization could result in lasting effects on personality development and negative reactions toward medical procedures (e.g., Chapman, Loeb, & Gibbons, 1956). Later Douglas (1975) documented long-term effects 20 years after hospitalization, which included behavioral problems, learning difficulties, and delinquency.

If one examines early hospital practices, it is not surprising that children exhibited distress when hospitalized. Hospitals were characterized by immaculate white walls, sinks, sheets, and uniforms. They smelled of medicine and

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disinfectant. Parents were regarded as germ laden trespassers who often interfered with medical routines. They were tolerated once or twice weekly, during visiting hours. Most medical staff believed that knowing what was in store would only frighten the child, so most children were not told what to expect in this clearly foreign environment. They were physically restrained during threatening or painful procedures, usually without warning.

Thus, the child was exposed to a world that visually, olfactorally, and kinesthetically differed from previous experience, was subjected to painful or frightening procedures, and at the same time was deprived of the most important source of emotional support, the parent. To add to the difficulties, children were often uninformed or misinformed about what was to happen next, so they became most wary and vigilant after their first venipuncture or injection.

The first improvement in hospital routine came about when some practitioners began to argue that the child should not be separated from the parent (Vernon, Schulman, & Foley, 1966). Early studies demonstrated that children recovered more rapidly and with fewer psychological side effects if they were accompanied by a parent (Brain & Maclay, 1968) and gradually, hospital policies changed. By the mid-1970s, hospitals had moved from allowing parental visiting for only a few hours a week to allowing 24-hr contact (Hardgrove, 1980). Some physicians now state categorically that no child should be placed in a hospital in which full-time parent contact is not allowed (e.g., Gabriel, 1977). However, there are still hospitals in which rooming-in is not encouraged and many parents do not take advantage of opportunities to room-in (Roskies, Mongeon, & Gagnon-Lefebvre, 1978). In a recent study, we found that parents who had not taken advantage of the rooming-in policy rated the overnight separation as more stressful for their child than postoperative pain, vomiting, or bleeding (Peterson & Shigetomi, 1982). Thus, one of the important tasks of preparation for hospitalization and invasive medical procedures is to underline the importance of parental presence and support. Roskies et al. (1978) found that a special program for parents increased visitation time spent with hospitalized children.

The next large improvement in the psychological treatment of young children came about when practitioners found that the simple provision of information concerning what to expect, when given to the parent (Skipper & Leonard, 1968) or to the child (Haller, Talbert, & Dombro, 1967), decreased children's negative reactions to hospitalization. Initially, the impetus for informing both children and adults about what to expect in medical settings came from several sources. These included the field of nursing's concept that procedures which are congruent with the patient's expectations are less anxiety provoking than those which are not (Johnson, Kirchoff, & Endress, 1975), the growing tendency in pediatrics to focus on education and anticipatory guidance (Davidson, 1988), and legal requirements that patients be fully informed concerning physician's decisions to intervene. In psychology, findings that predictable discomfort is often rated as less painful than the same sensation if not predictable (e.g., Pervin, 1963), that predictability enhances coping (Miller, 1980), and that information may have a desensitizing effect all contributed toward establishing preparation programs for children.

Optimal preparation for any medical procedure undoubtedly involves provision of information, some degree of desensitization to the threatening aspects of the procedure, and suggestions for coping both physically and psychologically. The optimal balance of these techniques likely depends on many factors, including the nature of the medical procedure itself. Peterson and Harbeck (1988) suggested that there are many categories of medical procedures which a child may encounter. Examples include: threatening but nonpainful procedures such as cast removal (Johnson *et al.*, 1975), and anesthesia induction (Vernon & Bailey, 1974), very brief but painful and threatening procedures like injections (Ayer, 1973; Eland, 1981) and venipunctures (Fernald & Corry, 1981), painful but short term (usually under 20 minutes) diagnostic procedures such as lumbar punctures and bone marrow aspirations (Jay, Elliott, Ozolins, & Olson, 1983), and longer and very painful intervention procedures such as tanking and debridement (removal of dead tissue) in burn patients (Elliot & Olson, 1983). All these procedures have at least some empirical research (cited above) demonstrating that distress can be diminished through appropriate preparation.

Peterson and Harbeck (1988) also note that special preparation is needed for unusual medical sites such as the emergency room (Alcock, Berthiaume, & Clark, 1984), intensive care facilities (Cataldo, Bessman, Parker, Pearson, & Rogers, 1979), and isolation suites (Kellerman, Rigler, & Siegel, 1979). There are no studies which have clearly documented useful preparation for these settings, but techniques employed in other preparatory studies (described later in this chapter), such as procedural and sensory information, the use of incentives, coping skills training, and modeling techniques, are all likely candidates for preparation for unusual medical settings.

The bulk of the empirical literature on children's preparation for medical procedures has focused on preparation for pediatric elective surgery. This generic preparation typically involves preparation for a variety of individual medical procedures, such as physical examinations, venipunctures, presurgical injections, anesthesia inductions, and postoperative recovery room procedures, as well as preparation for a number of special settings such as the blood lab, the examination suite, the pediatric ward, the operating room, and the recovery room (e.g., Melamed & Siegel, 1975; Peterson & Shigetomi, 1981). Thus, this short review will focus primarily on the surgery preparation literature, while acknowledging that the techniques and issues described are also highly relevant for other medical procedures and settings. This is particularly clear when discussing the goals for preparation.

BASIC ISSUES

Goals for Preparation

One of the important points of interception between research and practice is in the selection of dependent variables. At least in theory, the dependent measures should give a good indication of the degree to which the preparation accomplishes what is desired. We have argued elsewhere (Peterson, 1984) that when planning a preparation program, establishing a unique goal should be the first step. Optimally, a procedure will have a variety of influences on the child, including alleviating the three commonly measured systems of subjective, behavioral, and physiological distress. However, because disconcordance in these systems is more common than synchronous change (Lang, 1978; Lick & Katkin, 1978), it seems important to select a given response system within a specified period of time as the primary goal for treatment impact. For example, for medical and dental checkups, the logical target may be long-term self-reported distress because internally felt distress might limit help-seeking in these situations later in life. In fact, more than one third of people over age of 45 have lost all their teeth to preventable gum disease, many because they have avoided dental treatment (U.S. Public Health Service, 1979). For procedures in which demand characteristics or young age might invalidate self-report data or where muscle tension or heart rate is the central issue, physiologically measured distress may be the appropriate target. However, for most pediatric procedures, behavioral indices of distress during the actual procedure are likely to be an important primary target. During diagnostic tests such as lumbar punctures or cardiac catheterizations, lying quietly and breathing normally (i.e., without disruptive sobbing or screaming) not only connotes less distress but also avoids tissue damage. Similarly, during anesthesia induction, cooperative, nondistressed behavior can avoid serious respiratory complications (Eckenhoff, 1953). Physical therapy is also more effective with a relaxed, cooperative child (La Greca & Ottinger, 1979).

The selection of a treatment goal will have a great deal to do with the type of interventions selected, as well as the manner in which its success is evaluated. For the first decade or so, research examined the effectiveness of single procedures in comparison to no treatment controls. Recently, however, research demonstrating the comparative value of different treatments for differing response measures has been conducted (e.g., Ferguson, 1979; Peterson & Shigetomi, 1981), and such research will prove useful to the practicing clinician's selection of the most appropriate intervention. Another important recent issue is the degree to which individual characteristics of the child may interact with treatment effectiveness. There is some evidence that the child's age, level of prior medical experience, and characteristic way of coping all may mediate the influence of some treatments.

Child Characteristics

Age

Most research studies demonstrating the effectiveness of preprocedure preparation have treated elementary school aged children (Peterson & Brownlee-Duffeck, 1984), despite the fact that younger children are more distressed by medical procedures and are more likely to be admitted to the hospital (Azarnoff & Woody, 1981). However, there is no evidence to suggest that typically employed preparation tools would not be effective with very young children. Some of the most demanding techniques such as self-induced imagery, relaxation, and detailed sensory information have been used effectively by preschool aged children (Siegel & Peterson, 1980; Siegel & Peterson, 1981). Thus, traditional preparation techniques are probably appropriate for very young children, although the "fit" between various preparation tools and young children remains to be established.

The language employed in preparing young children may need to be more simplistic, more repetitive, slower, and presented with greater inflection than might be the case with an older child. Similarly, younger children have a much more primitive understanding of illness and health (Bibace & Walsh, 1980; Burbach & Peterson, 1986). They are more likely to harbor a number of misconceptions about medical procedures (such as failing to understand that one cannot bleed to death from a venipuncture, that being "put to sleep" before the operation is not the same treatment their injured dog received, and that their illness is not punishment for wrongdoing; Korsch, 1961; Sheridan, 1975) than are older children. Thus, explanations of medical procedures offered to very young children must be sensitive to their level of cognitive and affective development.

The preparation of adolescents is another area that has not received much research attention. Some techniques to be described later in this chapter such as sensory information provision or coping skills training have been used successfully with both adults and children (although the bulk of such studies are focused on adults), while other techniques such as play therapy or modeling have been used almost exclusively with children. The ideal combination of techniques for use with adolescent patients also has not yet been determined empirically, but is likely to in some part resemble the intersection of the child and adult literature.

Pre-Experience

Because it is very difficult to match subjects across treatment groups on the degree of prior experience they have had, most sound empirical studies have treated only naive subjects. It might be anticipated that procedures would be equally effective with experienced or inexperienced pediatric patients, but with some techniques this appears not to be the case. For example, investigators have reported that modeling preparations that are typically very effective with naive children are relatively ineffective with experienced child dental (Ginther & Roberts, 1982; Klorman, Hilpert, Michael, LaGana, & Sveen, 1980) and surgery (Melamed, Dearborn, & Hermecz, 1983) patients. Peterson and Harbeck (1988) argued that modeling procedures may focus on information that is either redundant with, or in conflict with, the child's own previous experience, and may therefore be a poor choice for affording preparation for a child's second or third medical procedure. Johnston and Salazar (1979) suggested that preparation for an experienced child should be keyed to the child's perception of that prior experience in order to "detoxify" any negative aspects of that experience. There is some evidence that coping skills based training may be useful for experienced child dental patients (e.g., Nocella & Kaplan, 1982); this remains to be demonstrated with child surgery patients.

Coping Characteristics

One of the most controversial areas in children's preparation today is the extent to which all children benefit from similar preparatory information. Some studies with adults have suggested accelerated physiologically measured distress (but not self-reported or observable distress) when adults who typically cope by denying or "repressing" medical distress are presented with procedural information (e.g., Shipley, Butt, & Horwitz, 1979). There are no similar studies with children showing clear treatment by coping type interactions, but a number of empirically based studies have examined dispositional types of coping in children. These studies have concluded that children who tend to seek out information (Peterson & Toler, 1986) cope by using intellectualization rather than denial or displacement (Knight, Atkins, Eagle, Evans, Finkelstein, Fukushima, Katz, & Weiner, 1979); select medically relevant toys before an impending hospitalization (Burstein & Meichenbaum, 1979); play actively with medically relevant toys, acting out integrated sequences of coming procedures (Tarnow & Gutstein, 1983); and are attentive and oriented toward a modeling film (Melamed, 1982). All show more adaptive responses to hospitalization and surgery. LaMontagne (1984) suggested that more actively coping children she observed had a more internal locus of control; she argued that the coping disposition influenced the locus of control rather than vice versa. Lambert (1984) reviewed several case studies which similarly identified coping strategies from active to passive to resistant. In general, children who cope actively seem to have an advantage. The extent to which children who do not cope actively but are passive or denying may be helped or hindered by information is not clear.

Our own reading of the literature suggests that all children have the right to be offered information about what will happen to them. Some children effectively block out the proffered information by changing the subject, becoming fascinated with the bottom of their shoe, or unraveling the carpet edge when a medical instrument is shown. Until better evidence is in, such children should probably be offered preparation which emphasizes blocking out any bad feelings when they occur. Such children should probably not be forced to contact any information they wish to avoid. Additional research on this fascinating topic is badly needed. It may be that some techniques, such as coping skills training, would be more effective with children who cope by using denial than would other techniques (such as sensory information). On the other hand, perhaps intensive preparation of denying children to afford them the same information already obtained by their information seeking, more adaptive peers is required.

Procedures

Peterson and Ridley-Johnson (1980) found that most pediatric hospitals in this country routinely employed preparation procedures with children. However, the techniques that were most commonly employed were the preoperative tour, narration, and play therapy, none of which has any research support of their effectiveness. In a preoperative tour, the parents and the child are exposed to the gamut of settings specific to the child's hospitalization experience. A tour might include the admissions area, the examination room, the pediatrics ward, the operating room, and the recovery room (because of sterile conditions exposure to the latter two rooms is often made by peering through a window or simply viewing the entrance). Peterson, Ridley-Johnson, Tracy, and Mullins (1984) completed a component analysis in which they contrasted a hospital tour with a puppet modeling procedure as well as a no-treatment control. They found that the tour alone was no more effective than the no-treatment but experimenter-contact condition. Obviously, tour narratives could contain a variety of procedural information (e.g., "the lab technician will use a rubber band as a tourniquet"), sensory information (e.g., "the band will feel snug and tight, it will not hurt; the alcohol will feel cool and smell like this"), coping skills training (e.g., "you can take a deep, slow breath and think of eating an ice cream cone"), modeling (e.g., "you can hold your arm like this"), and desensitizing contact (e.g., "this is what the rubber band tourniquet looks like—want to feel it?"). However, it is our impression that a tour alone, the most frequently employed preparation technique, is relatively ineffective.

Similarly, play therapy may involve various kinds of procedural and sensory information plus modeling and desensitization. Cassell (1965) described the successful use of puppets to clear up children's misconceptions and deliver information about cardiac catheterizations. However, play therapy is also sometimes regarded as a more dynamic, expressive tool. Some practitioners have discussed retaliatory play (e.g., Chan, 1980) and expressive play in which children are encouraged to act out their anger or fear. In the absence of any experimental data, it is our impression that such techniques must be used with the greatest care. In exhorting a child to act out emotions, the therapist must be careful not to suggest such emotions should be present or that rehearsing anger or fear is adaptive.

The bulk of research support has focused on modeling techniques. In contrast to a tour or dynamic play, a modeling program is typically either prerecorded or operates from a script. Information is much more likely to involve details about the medical procedure or adaptive emotions and behaviors. In one of the earliest and best known tests of a modeling film, Melamed and Siegel (1975) showed children a film of an 8-year-old actual hernia repair patient in each stage of hospitalization up to anesthetization, and then recovery. Children viewing the film were much less distressed during their own hospitalization and surgery, showing less behavioral distress and reporting less fear. Peterson, Schultheis, Ridley-Johnson, Miller, and Tracy (1984) demonstrated similar findings for a videotaped child actor and a Teddy Bear model.

Peterson and Shigetomi (1981) contrasted a modeling preparation alone with coping skills training in which children and their parents learned cue-controlled deep muscle relaxation, self-instruction, and distracting imagery. These coping skills added significantly to the modeling preparation alone. Zastowny, Kirschenbaum, and Meng (1986) taught parents stress inoculation methods to use with their children, including relaxation and imagery. Children whose parents received such training had more adaptive responses to hospitalization and surgery than children whose parents did not receive such special preparation. This was particularly true when faced with a very threatening procedure, such as an injection.

Some recent investigations have targeted particularly painful and upsetting diagnostic and treatment procedures. Hypnosis, a special and particularly potent combination of relaxation, instruction, and imagery, has been reported to be very effective preparation for techniques such as bone marrow aspirations with oncology patients (e.g., Kellerman, Zeltzer, Ellenberg, & Dash, 1983; LaBaw, Holton, Tewell, & Eccles, 1975) and treatment techniques for child burn victims (Bernstein, 1965; Wakeman & Kaplan, 1978). The use of incentives for adaptive, cooperative responding has also been shown to be helpful for child burn victims during painful hydrotherapy (Kelly, Jarvie, Middlebrook, McNeer, & Drabman, 1984). Some psychologists have used multimodal treatment procedures such as relaxation, imagery, and incentives for children undergoing lumbar puncture and bone marrow aspirations (Jay, Elliott, Ozolins, & Olson, 1983). For such procedures, our own experience would suggest that information or modeling alone are likely to be less effective than techniques which focus on increasing motivation and ability to actively cope with the procedure. There is no empirically based research as of yet to document this belief, however.

Thus, there is sound empirical evidence that certain preparations are effective for specific medical procedures. It remains for future research to specify the ideal match of which child at which time should receive which preparation for which medical procedure. Clinical experience with the differing techniques as well as the availability of differing requirements for preparation (e.g., skill in inducing hypnosis, time to allow relaxation training, or equipment to show a modeling film) is likely to dictate selection of a technique for now. The following section will briefly address other pragmatic concerns in preparing a child for a medical procedure.

Practical Problems

Timing

The research literature is not clear on the most appropriate time for preparation. One isolated study suggested that for physiological distress (but not observable or self-reported distress) preparation was more effective for younger children if applied the day before than the week before. The reverse was true for older children (Melamed, Meyer, Gee, & Soule, 1976). Another series of studies suggested that coping techniques add to the efficacy of modeling techniques if trained the week before hospitalization (Peterson & Shigetomi, 1981), but not the night before (Peterson, Ridley-Johnson, Tracy, & Mullins, 1984), although ceiling effects may have influenced the latter findings. Preparation for surgery on the day of surgery may be substantially less effective than preparation the day before (Faust & Melamed, 1984), although nonrandom assignment to groups and other differences may have obscured these results.

Trying to arrange for parents to bring their children in a week prior to surgery appears preferrable to us, but this is not always possible. For example, we currently operate a preparation program in a regional health center. To ask a parent to drive with an ill child hundreds of miles solely for a psychological preparation program seems an unreasonable request to many parents. On the other hand, if preparation takes place the night before surgery, anxiety is high and the child must be "shared" with other health care specialists who must have contact prior to surgery. Ensuring that the preparation program is not repeatedly interrupted requires prior negotiations and patience.

Presentation

A program has the greatest chance for success if it is conducted in the same way at a prespecified time each day or week. This means to us that there must be a responsible professional, not a kindly volunteer, to conduct the preparation. Any equipment needed must be reserved in advance, as must the space in which the preparation is to be conducted. Backup tapes, props, and the like must be obtained, carefully stored, and made quickly available should the original materials be lost or damaged. Someone must take responsibility for such items on a permanent basis.

Presentation must have some flexibility built in for special cases. We have already discussed the needs of very young children or adolescents. There are also problems with non-English speaking children or hearing-impaired children. In such cases a *very* skilled interpreter is helpful and a personal rather than automated (i.e., film or tape) presentation seems most effective to us. Mentally retarded subjects also require special care; simply responding to the mental rather than chronological age will not suffice. A blind child must be helped to experience the information in a relevant, kinesthetic fashion. In all cases, there must be room for dialogue and a time for questions.

Parent Issues

Allowing the parents to see the importance of the roles they can play with their child is most important. Many of the classic modeling preparations have not portrayed the parent in a helping role and this is an unfortunate deficit. As noted previously, helping a parent arrange visitation, staying overnight if possible and being present during stress points such as the presurgical injection and trip to the operating room, seem vital.

Sometimes children express more discomfort and fear if parents are present during a medical procedure rather than absent (Gross, Stern, Levin, Dale, & Wojnilower, 1983; Shaw & Routh, 1982). This probably does not mean that the parents provoke fear but rather that the child is signalling, by crying or complaining, for the parent to intervene. However, sometimes parents do behave in ways that increase the child's anxiety (Bush, Melamed, Sheras, & Greenbaum, 1986). We recall one mother who announced loudly, in front of her child, "If you are going to give him a shot, I'll leave. Needles terrify me and he always screams and carries on." The mother left after having effectively sensitized her son, who complied by screaming at the sight of the needle. Special preparation for such parents is strongly indicated.

Staff

In addition to arranging timely and uninterrupted access to the child, it is important to have good working relationships with all of the staff who will have contact with the child. If the preparation program specifies that a finger-prick blood test will take place on the pediatric ward and the child experiences a venipuncture in the laboratory instead, not only is the child unprepared for the venipuncture, but the credibility of the entire preparation is diminished. In a recent study, Peterson, Farmer, and Mori (1986) found that one third of child surgery patients reported they had been told very little and one fifth said they had been told distinctly untrue information before hospitalization. Children who believed their information to be untrue showed more maladaptive responding before and after hospitalization. Thus, the veracity of information is essential and this is often in the hands of the staff rather than the preparation agent.

The other most common complaint we have received about staff is that they often operate in a routine fashion which precludes the positive benefits of preparation. For example, many parents have complained that they had effectively prepared their child to deal with an injection cooperatively and calmly, only to have two nurses enter the room and one of them physically restrain the child while the injection is given by the other. Negotiating such issues beforehand and preparing the child for such staff behavior, if staff cannot be dissuaded from the routine use of restraint, is essential. Anesthesiologists often have their own preparation presentation. Ensuring compatibility with that presentation is especially important. There are many other pragmatic issues to consider that cannot be described in detail here. Some of these are illustrated in the following brief case presentation.

CASE ILLUSTRATION

I arrange the props and read the children's files ahead of time, and then greet each of the four children with a name tag as they come through the door. Now, they are seated on the floor in a semicircle in front of me with their parents in back on chairs. The youngest girl (Nametag: Mindy) is sucking her thumb and keeps trying to climb back on her mother's lap, but the mother is insistent that she sit with the other children. I try to find a way to signal the mother that it is O.K. to hold the child without the child seeing me, so that I do not appear to be contradicting the mother. Parents are very sensitive about the legitimacy of their authority in this kind of setting.

Preparing the children in a group has both pros and cons. The peer support among both the kids and the parents is a big advantage. They are already getting acquainted and sharing emotions. Also, it is economical both in terms of my time and space, both of which are currently very tight. However, if a child reacts fearfully, it can sensitize the other children, and if one begins acting silly, the others will also, and will miss some of the most essential information. Thus, I need to really be on top of the group.

I begin my narrative with some familiar aspects the children can identify with—I act out the puppet, Teddy, packing to come to the hospital. When I mention what the child should bring, I glance up at the parents to make sure they understand. The language is pitched at the children, but the message is important for the parent too. I narrate driving, parking, and admissions and show this all with the puppet. I talk about the feelings of leaving home, the excitement and some trepidation. When I get to the blood lab part, I get four different reactions. The blond boy, Steven, on my left is frankly interested. His eyes sparkle and he examines his arm for the vein I describe. The next child is a girl, named Laurie, who begins tickling her mother's knee and giggling. I touch her arm gently and wait. If she doesn't want to accept the information, I won't force it but I want to give it a chance. She turns to look and I continue. The boy next to her, Aaron, is wide-eyed, but not distressed looking. I cannot read him well yet. The youngest girl's thumb is in her mouth and she nods as I look at her, saying "See? This is where Teddy's blood will come from."

When I pass around the alcohol pad so that the children can become familiar with the smell, I pass it to the blond boy first. He is interested and most likely to be cooperative. Still, I model sniffing it first. If he had refused it, I would have given it to his mother to model sniffing. Most adults will not refuse and the child is more likely to comply if a familiar adult emits the response. Mindy refuses to sniff, even after the other children sampled the smell, but I reassure her mother that this is O.K., that I'll leave the pad near her to try in case she changes her mind.

I narrate the entire surgical stay, talking about the emotions Teddy is experiencing and the sensations caused by various procedures. Teddy models adaptive responding in a familiar, gender neutral personage. Afterward, the parents have some pragmatic questions about forms and urine tests.

The children are now authorized to handle the equipment. Steven is still fascinated with the anesthetic mask that looks like a pilot's oxygen mask. He repeatedly practices breathing through it. He should have smooth induction. I am pleased that Mindy is applying the alcohol pad to Teddy's arm. She seems much less fearful. Aaron is still not interacting and seems quiet and withdrawn. His mother does not seem to know quite how to support him. I am still not sure what is going on with him, so Teddy and I approach and Teddy "talks" to Aaron about the program.

Aaron is not verbalizing much but smiles shyly at me and scratches Teddy's ears when Teddy "asks." I learn from Aaron's mother that he has had no medical interventions except for routine well baby visits and immunizations. The immunizations were regarded by both Aaron and his mother as very traumatic. No one has given Aaron any information concerning what an "operation" is prior to this program and neither he nor his mother seem to have any established method of coping with distress. I decide to present a coping "package" to them and let them select the techniques they prefer.

"Aaron," I begin, "Do you know how Superman can just make bullets bounce off of him?" He nods. "Well, Teddy and I would like to teach you some things you can do that will make bad feelings in the hospital bounce off, like bullets bounce off Superman." He nods again.

"Let's sit down over here. The first thing is to learn to make your muscles go all loose like spaghetti. You know how spaghetti is all limp and loose? Teddy makes his arms, legs, and neck all loose and quiet like that. . . ." I demonstrate, first with Teddy and then with my arm. After we work for about five minutes, Aaron can show me fairly good muscle relaxation. If he had experienced difficulty, I would have had him make his muscles tight and then let them all loose at once. However, he did not need the contrast or the fatiguing of the muscles to get good relaxation.

Next, we work on deep, slow breathing: "Teddy takes a slow deep breath and, as he lets it out *sooo slooowly,* he says a special word, 'calm,' to himself, inside his head. What will your special word be? Calm? Quiet? Peaceful?" Here I glance up at Mom to signal her that she needs to help Aaron choose. She understands and briefly they talk. Aaron chooses "Peace." We practice breathing in slowly (six or seven seconds, to the count of three) and out even more slowly if possible, thinking "Peace" as loud as we can, "in our minds."

Next, we think of a peaceful image. I tell him, "When you close your eyes, you can see your special place like a movie in your mind. Teddy Bear likes to think of a sunny meadow. There is warm sunshine everywhere, and he can feel it all over his fur. There is a cool breeze blowing, and he feels that too. He can hear a stream flowing past and birds calling. Wildflowers of all colors sway slowly and gently in the breeze." I say all of this very slowly, almost hypnotically, because this is the way I want Mom to introduce the image. "This is how you want your image to be, quiet, peaceful, and clear. You want to imagine colors, sounds, and temperatures. Get so you can really be there. Let's choose a scene for you." Again, I glance at Mom and she begins her undertone discussion with Aaron. They begin talking about swimming in a lake but I interject that we want a peaceful, quiet scene. This is my bias, as I believe it is most compatible with muscular relaxation that will make intramuscular injections less painful and facilitate anesthesia induction, where inducing a change in consciousness is the goal. Aaron and Mom settle on floating on an air mattress in cool, blue water with a bright, warm sun overhead, just the kind of image he needs.

Next, I often introduce self-instruction or a series of internally generated calming self-statements. The literature has used phrases such as "I am a brave boy," but I am uncomfortable having a child make what may be very obviously a nonveridical self-statement. Thus, I suggest things like "This will all be over in a little while" and "Everything is going to be all right!" I decide against using self-statements with Aaron. He is not a very verbal child, his mother relates to him more through physical gestures than through words, and he has been much more responsive to my kinesthetic cues than my verbal ones. Rather than overload the system, I stick with our muscle relaxation, deep breathing with a calming, mantra-like cue word, and visual imagery package. We practice all these techniques together a couple of times, then I recite to Aaron and his Mom the occasions during the hospitalization when Teddy's Mom helped him use the special tricks. These stress points, like before the presurgery injection, before leaving for the O.R., before induction, in the recovery room, when swallowing or voiding postsurgically, and any time he feels especially "bothered," have been identified by other investigators as times requiring special intervention.

I give Aaron's Mom a quick "You are the therapist, I am the consultant" talk. She is to practice the techniques with Aaron several times each day before coming back for the surgery and will cue Aaron to perform them as needed when she is with him in the hospital. I stress the value of her rooming in and am relieved that she plans to do so. I offer to be available by phone before she returns to the hospital (and give her my card) and on the ward when she returns with Aaron for surgery. I praise Aaron's new coping "tricks" and he seems pleased. Mom seems relieved too. I think they will follow through on practicing and will use the techniques effectively when they need to actively cope.

Each child I saw today was so different in terms of receptivity to information, typically used coping strategies, and expectations for the surgery. The program is constructed so that different children take away different skills and information from the experience. I try to be available during the day of surgery to fill in any gaps that remain between expectations and the actual experience.

One by one, the children filter out to return to their own homes and later their own surgical scenario. I hope knowing what is to come and having some suggested ways of coping will help. Most of all, I believe that labeling the experience as a chance to cope will help some of the children look back on the experience with some degree of pride (our research suggests this is an unexpected but common reaction). As one experienced child surgery patient said to me once: "It isn't any fun, that's for sure. Some parts hurt like crazy. But you figure out that after the hurt and all, you're still there. You're still yourself, you know? You can take it." That is the essence of self-efficacy for a child.

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CHAPTER 23

Patient Compliance

Pediatric and Adolescent Populations

JACQUELINE DUNBAR AND LOUISE WASZAK

INTRODUCTION

Adherence to treatment regimen in the pediatric and adolescent populations is equally problematic as it is among adult patients. In studies published before 1982, adherence rates ranging from 20% to 80% have been reported (Dunbar, 1983; Litt & Cuskey, 1980). An examination of more recent studies indicates that adherence continues to be problematic, although we know more about the factors that contribute to nonadherence and about methods to improve adherence rates. In addition, adherence rates continue to be quite variable across studies and regimen. For example, adherence rates among control groups or during baseline conditions in 15 adherence intervention studies published between 1982 and 1986 showed adherence levels ranging from 0% to 80%. Six of those studies reported the proportion of children judged to have acceptable adherence, although the criteria for being categorized as such varied between studies. The proportions ranged from 26% to 83% of children (see Table 1).

With adherence rates so variable, the question is whether this variability can be explained. Of particular interest is whether adherence varies according to the type of regimen or health behavior examined. An examination of studies published between 1982 and 1986 suggests that it may. For example, adherence rates tended to be poorest for parental compliance with immunization programs (13%) and for compliance to blood glucose monitoring among children with insulin-dependent diabetes mellitus (IDDM) (0%–30%) (Carney, Schechter, &

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TABLE 1. Reported Adherence Rates among Pediatric and Adolescent Populations

					Baseline or control group adherence	
Investigators	Year	Disease	Age	*N*	% of medication taken	% of subjects adherent
			Use of dental rinse			
Cipes	(1985)	Dental care	2nd grade	23	71%	
Cipes & Miraglia	(1985)	Dental care	2nd grade	56	67%	
Lund & Kegeles	(1982)	Dental care	7–8 grade	~125	67%	62–68%
			Immunization			
Yokley & Glenwick	(1984)		≤5 yr	227	13%	
			Appointment keeping			
Parrish *et al.*	(1984)	Varied	2–20 yr	99		45%
			Medication taking			
Finney *et al.*	(1985)	Otitis	6 mo–6 yr	39	79%	
Williams *et al.*	(1986)	Otitis	2 mo–2 yr	90		78%
Rapoff *et al.*	(1984)	Arthritis	7 yr	1	59%	
Baum & Creer	(1986)	Asthma	6–16 yr	16		83%
Smith *et al.*	(1986)	Asthma	6 mo–16 yr	103	55%	
Weinstein & Cuskey	(1985)	Asthma	1–18 yr	39		26%
		Self-monitoring: Symptoms; urine(*); blood glucose(**)				
Finkelstein *et al.*	(1986)	Cystic fibrosis	<6–>18	111	75–80%	64%
Carney *et al.*	(1983)	Diabetes**	14 yr	1	~20%	
			11 yr	1	<5%	
			10 yr	1	<5%	
Gros *et al.*	(1985)	Diabetes**	9–13 yr	4	30%	
Daneman *et al.*	(1982)	Diabetes*	8–12 yr	20	76%	
Gross *et al.*	(1985)	Diabetes*	5–13 yr	1	0%	
Gross *et al.*	(1982)	Diabetes*	10–12 yr	4	~35%	
Schafer *et al.*	(1982)	Diabetes*	18 yr	1	~47%	
			16 yr	1	~33%	
			Exercise			
Schafer *et al.*	(1982)	Diabetes	18 yr	1	~50%	
			16 yr	1	~40%	

Davis, 1983; Gross, Magalnick, & Richardson, 1985; Yokley & Glenwick, 1984). Only two single cases of exercise compliance were reported, and these were among adolescent children with diabetes. The rates were 40% and 50% (Schafer, Glasgow, & McCaul, 1982). Adherence to appointment keeping was similar, with just 45% of appointments kept in the single study reported (Parrish, Charlop, & Fenton, 1986). Compliance with a dental rinse was somewhat better with 62–71% of doses used (Cipes, 1985; Cipes & Miraglia, 1985; Lund & Kegeles, 1982). Compliance with self-monitoring of symptoms was at a similar but slightly greater level for children with cystic fibrosis (75–80%) (Finkelstein, Budd, Warwick, Kujana, Wielinski, & Ewing, 1986). Adherence to urine glucose testing among diabetic children seemed most variable, with rates ranging between 0% and 76% (Daneman, Epstein, Siminerio, Beck, Farkas, Figueroa, Becker, & Drash, 1982; Gross, 1982; Gross *et al.*, 1985; Schafer *et al.*, 1982). Compliance with medication also varied substantially, with rates ranging from 26% to 83% (Baum & Creer, 1986; Finney, Friman, Rapoff, & Christophersen, 1985; Rapoff, Lindsley, & Christopherson, 1984; Smith, Seake, Ley, Shaw, & Bracs, 1986; Weinstein & Cuskey, 1985; Williams, Maiman, Broadbent, Kotok, Lawrence, Longfield, Mangold, Mayer, Powell, Sayre, & Webb, 1986).

According to these studies, at least one half of children will have problems with glucose testing, medication adherence, exercise, and appointment keeping. In order to reduce these noncompliance rates, it is important to identify those children at risk of noncompliance so that appropriate intervention measures can be taken. Of particular interest is the identification of factors that raise the risk of compliance problems among children and adolescents.

ISSUES IN PEDIATRIC COMPLIANCE: REVIEW OF ASSOCIATED FACTORS

A number of factors have been examined as potential contributors to problems with compliance among the pediatric and adolescent groups. These include (1) family functioning, (2) social support, (3) psychological characteristics of the parent, (4) psychological characteristics of the child, (5) age, (6) sex, (7) symptomology, (8) type of medications and dispensing system, and (9) satisfaction with care. A discussion of the influence each of these factors has on patient compliance follows.

Family Functioning

A number of characteristics are related to the ability of the family to support adherence. In general, the family that is more dysfunctional is less likely to be able to support compliance efforts. For example, Korsch, Fine, and Negrete (1978) reported that children most likely to default on immunosuppressive drugs following renal transplantation came from families that were fatherless, that had lower income, and that had more communication problems within the family, and the child felt closer to and most helped by someone outside of the family. Indeed, in some of the families, the parent(s) were unaware that the child was noncompliant until the child revealed that information to the parent. This suggests that in less functional families, the mother was not able to provide adequate supervision for the child. The problem of noncompliance was sufficiently serious that eight of 14 cases of failure to take the immunosuppressive medication led to allograph failure and a return to hemodialysis for the child. Similarly, Friedman, Litt, King, Henson, Holtzmann, Halverson, and Kraemer (1986) reported that noncompliance with antiseizure medication among children with epilepsy was more likely in families with less preceived harmony.

In contrast to these findings, Brown, Borden, and Clingerman (1985) reported that dropping out of treatment among hyperactive children was more likely to occur in intact families. Interestingly, the adherent children came from families that reported greater family conflict. One might speculate that the hyperactive behavior of the child may have been more disruptive to the family with other stressors promoting a greater incentive to reduce that behavior through compliance with medication. Compliance with chronic medical disease regimen may have a less immediate effect making the effort to comply less rewarding to the parent or child.

Family functioning has a relationship to adherence. That relationship, however, appears to interact with the type of disorder, though not with the type of regimen. In each of these studies, the regimen consisted of medication taking. Yet compliance in medical conditions seemed to be adversely affected by family dysfunction while medication compliance in behavior disorders seemed to be adversely affected in intact families. In light of the limited number of studies in this area, the effect of family functioning on adherence across a variety of conditions is worthy of further investigation. Meanwhile, family functioning should be considered in efforts to address adherence in the clinical setting.

Social Support

While social support has been examined extensively with regard to adult adherence, it has not been studied with regard to adherence in the pediatric population. Two studies have suggested that social support may be important, however. Korsch *et al.* (1978) reported that lack of support from community and other social resources characterized families of children noncompliant with immunosuppressive medications. These families also tended to be single parent families of low income, those families most in need of supportive resources. Shenkel, Rogers, Perfetto, and Levin (1985) reported that the indirect support of significant others was important in moderating the intentions, although not necessarily the behavior, of adolescents with diabetes. That is, the intentions of adolescents to comply varied according to their perceptions of parental expectations and their motivation to comply with those expectations. Thus, social support appears to play at least two roles, provision of needed resources and establishment of behavioral standards. Just what the value of social support would be to families and to children themselves in supporting medical compliance, however, remains an open question.

Psychological Characteristics of the Parent

Undoubtedly, parents play a crucial role in the compliance of children and adolescents. For the children, the parent is likely to be the administrator of the treatment regimen; thus, adherence in the pediatric group may really be parental adherence. For the older child or adolescent who may be developing responsibility for regimen management, the parent's role is still crucial as a supporter and at times supervisor of compliance efforts.

A number of studies have reported that the beliefs of the mother are important factors in the compliance of their youngsters. For example, Radius, Becker, Rosenstock, Drachman, Schuberth, and Teets (1978) reported that mothers were more compliant with asthma medication regimen for their children if they had a preventive orientation, believed in their personal capabilities, considered the regimen efficacious, felt better when following the physician's advice even though they tended to be skeptical about physicians, and did not encounter deterrants to carrying out the regimen. In addition, they were more compliant if they believed that noncompliance made the child susceptible to an asthma attack. This belief in susceptibility has been supported in other studies. Becker, Drachman, and Kirscht (1974) noted that beliefs about the risk of resusceptibility to ear infections was a factor in mothers' compliance with medication regimen for children with otitis media. Mothers' beliefs in the susceptibility to the health consequences of obesity was also a factor in the success of weight loss among their children (Becker, Maiman, Kirscht, Haefner, & Drachman (1977a) and belief in susceptibility to illness was a factor in keeping well-child clinic appointments (Becker, Nathanson, Drachman, & Kirscht 1977b). The perception of the seriousness of the consequences of noncompliance was also a factor in mothers' compliance to prescribed regimen for their children (Becker *et al.*, 1974, 1977a, 1977b). This would suggest that educational efforts need to stress the risks associated with noncompliance.

Little is known about the characteristics of noncompliant parents aside from the role of their beliefs. Blotcky, Cohen, Conatser, & Klopovich (1985) noted that mothers who refused cancer treatment for their children tended to have greater religiosity and greater trait anxiety. It is not clear whether these parents are more fatalistic, find greater relief of anxiety through religious intervention than medical intervention, or use denial of the seriousness of the illness, or whether some other phenomena are operating. Other parental characteristics may also be important influences on compliance. For example, children with attention-deficit disorder who dropped out of treatment tended to have fathers who were more depressed but mothers who were less depressed. As with family functioning, it may be that the parental characteristics associated with noncompliance vary with the nature of the child's disorder. Nevertheless, these studies suggest that an assessment of parental beliefs regarding the consequences of noncompliance, level of religiosity, level of anxiety, and level of depression may be worthwhile pursuits in identifying the child at risk of noncompliance.

Psychological Characteristics of the Child

A number of psychological characteristics of the pediatric or adolescent patient have been examined in relationship to compliance. Among these are self concept, locus of control, autonomy, and depression. Self-concept has been examined in six studies, of which five found positive relationships between self-esteem and adherence (Durant, Jay, Linder, Shoffitt, & Litt 1984; Friedman *et al.,* 1986; Gross *et al.,* 1985; Jamison, Lewis, & Burish, 1986; Korsch *et al.,* 1978; Neel, Jay, & Litt, 1985). Lowered self-esteem was associated with poor compliance among children with renal transplants, epilepsy, contraceptive use, and cancer. No relationship was found for children with diabetes, although the children with diabetes tended to have lower self-esteem than a comparison group of normals (Gross *et al.,* 1985).

It is not clear how self-esteem moderates compliance. Durant *et al.* (1984) suggested that those noncompliant adolescents with lower self-esteem also reported that it was "no use trying to get anywhere," noting a relationship between pessimism or hopelessness and the prevention of pregnancy. Hopelessness is a characteristic of depression. While depression was not examined in this study, depression was found by Brown *et al.* (1985) to be associated with poorer compliance to medication among children with attention deficit disorder. Thus, hopelessness may be related to lowered self-esteem independently or as a component of depression and may serve to inhibit compliance.

Independence and autonomy have also been examined in relationship to compliance. Adolescents, scoring higher on tests of autonomy or personal freedom, have been shown to be more compliant with appointment keeping, antiseizure medication, and contraceptive use (Friedman *et al.,* 1986; Litt & Cuskey, 1984; Neel *et al.,* 1985). Similarly, Durant *et al.* (1984) found that adolescents who made their own clinic appointments were more likely to comply with contraceptive use. It has been postulated that for those adolescents whose home environment encourages and supports their growing independence, compliance is easier. For those whose families inhibit the development of autonomy, noncompliance may become an assertion of autonomy (Friedman *et al.,* 1986).

Locus of control is a further factor that has yielded interesting findings among the pediatric and adolescent group. Jamison *et al.* (1986) noted a negative relationship between external control and cooperation with treatment among adolescents with cancer. Similarly, Blotcky *et al.* (1985) reported that adolescents with cancer were more likely to refuse cancer therapy if they were higher in external locus of control. An increase in religiosity was also noted among this group, suggesting perhaps they externalized control over their outcome to a power beyond themselves. The relationship of locus of control and diabetic control was less consistent. Gross, Delcher, Snitzer, Bianchi, & Epstein (1984) found no relationship at all. Hamburg and Inoff (1982) reported an interaction between sex and locus of control and diabetic control. Internally oriented girls and externally oriented boys appeared to do better in this study. These studies further suggest that the effect of locus of control on adherence may vary with the disease of the child.

Sex

The findings of studies examining sex and compliance report differing results. Friedman *et al.* (1986) reported finding no relationship at all among epileptic children. Summey (1979), however, found that as far as compliance with prescription glasses was concerned, girls were more likely to obtain and to wear them. By contrast, Korsch *et al.* (1978) reported that of 14 children who were noncompliant with immunosuppressant medications, 12 (86%) were female. Females represented just 54% of the total group of 80 renal transplant children studied. Thirteen of the 14 were adolescents. The adolescent girls reported that the cosmetic side effects (e.g., weight gain, cushingoid features) were the reasons for their noncompliance. Hamburg *et al.* (1982) noted a sex-by-age interaction, but without any effect for sex itself among children with diabetes. These investigators reported that the diabetic control of older girls tended to worsen, while that of older boys tended to improve. Given these findings, when the effects of cosmetic side effects and of age are set aside, there does not appear to be an effect of sex on compliance rates.

Age

Age seems to bear a complex relationship, if any, to compliance. As noted, improvement in diabetic control was found among older boys, although older girls worsened (Hamburg *et al.,* 1982). Thus, this study reported a interactive relationship between age and sex. Two studies reported a worsening of adherence with age (Korsch *et al.,* 1978; Jamison *et al.,* 1986), and two found no association between age and adherence (Friedman *et al.,* 1986; Litt & Cuskey, 1981). The most reasonable conclusion to draw from these studies is that age is not a factor in noncompliance.

Symptomatology

The appearance of unattractive cosmetic side effects can serve as a deterrent to adherence, at least among adolescent girls (Korsch *et al.,* 1978). Cosmetic issues were also found important in a study of attendance in an adolescent clinic. In an examination of initial complaint and appointment keeping, Neinstein (1982) reported a 55% no-show rate for well-child care, 37% for noncosmetic problems, and 0% for cosmetic problems. Personal appearance seems to be an important factor in adolescent compliance. Other than this issue, no other symptoms were reported as being related to noncompliance.

Regimen

While the effect of the regimen itself has been examined in a number of studies among adults, that is not the case among the pediatric and adolescent group. Indeed, just one study was found that examined the regimen influence on adherence. Tinkleman, Vanderpool, Carroll, Page, & Spangler (1980) in a comparison of long acting (12-hr) with shorter acting (6-hr) theophylline in the treatment of asthma found that compliance was better with the long-acting medication. This form of the medication required fewer doses per day, a phenomenon that has been associated with better adherence among adult populations.

Satisfaction with Care

Satisfaction with care has been studied among adults, but limited investigations have been directed toward the pediatric population. Satisfaction with care and appointment keeping was examined by Litt and Cuskey (1984) in an adolescent clinic. They found that the two were related. Furthermore, they reported that those adolescents who were most likely to be satisfied with their care were female, older, had a more positive body image, were high in personal freedom, and made their own appointment. Compliance to specific prescribed regimen was not examined in this study, however.

Overall, a number of factors seem to be fairly consistently related to noncompliance. Specifically, compliance is likely to be poorer in the face of poor communication or disharmony within the family, parents who do not believe in the child's susceptibility to ill effects or in the seriousness of noncompliance, an external locus of control, a poor self-concept, restriction of independence (adolescents), and negative cosmetic effects (adolescent girls). While more research is needed in the area of identifying children at risk of noncompliance, these factors, and possibly such factors as satisfaction with care, intrusiveness of the regimen, and level of family support, should be considered in evaluating the risk of a child for noncompliance.

COMPLIANCE PROCEDURES: OVERVIEW OF INTERVENTION STRATEGIES AND PROBLEMS OF INPLEMENTATION

Most compliance interventions have arisen out of a behavioral framework. Nine strategies in particular have been investigated as procedures for preventing or remediating noncompliance: (1) educational interventions, (2) self-monitoring, (3) graduated goal setting, (4) self-management, (5) reminders, (6) reinforcement, (7) contingency contracts, (8) increased supervision, and (9) increased parental involvement. A discussion of each of these follows.

Educational Interventions

Many of the earlier educational interventions tended to focus on education about the disease and its consequences with the assumption that this information would facilitate compliance. This assumption has proven to be erroneous. Education regarding the conduct of the regimen itself, however, is crucial.

How education is offered also appears to be important. Verbal instructions alone have not tended to be effective; the combination of verbal and written instructions have (Kruger & Rawlins, 1984; Mattar, Markello & Yaffe, 1975). However, it is not a simple matter of adding written instructions to enhance those supplied verbally. For example, Mattar *et al.* (1975) found that the combination of procedures raised medication adherence among children with otitis media to 51% compared with 8.5% in an uninstructed group. This study included the use of a self-monitoring medication calendar among its experimental procedures. Kruger & Rawlins (1984) found that the combination of instructional procedures was also effective in raising knowledge of follow-up appointment time, diet instructions, and special instructions among a group of children discharged from hospital. However, the combination was not more effective in improving medication adherence than verbal instructions alone.

In a three-group comparison study among children with otitis media, Williams *et al.* (1986) included a slide-tape instruction group. This group did no better than the group that received a combination of verbal and written instructions. In the slide-tape group, 68% reported 100% compliance, while 66% of the other group reported 100% compliance. Both groups also received a sticker to place on the refrigerator reminding them about medication administration, perhaps contributing to the overall good rates of adherence in both groups.

Taking the notion of instruction a step further, Sergis-Deavenport and Varni (1983) developed an extensive behaviorally based education program on the management of factor replacement among the parents of children with hemophilia. Modeling, observational learning, behavioral rehearsal, corrective feedback, and social reinforcement were used as instructional strategies. Proficiency increased as did long-term adherence to correct technique among the instructed parents contrasted with a group of experienced parents who did not receive the training package (97% versus 65% correct, respectively). The behaviorally based training clearly impacted positively on adherence behavior, although it is not clear whether such intensive training is critical with regimens requiring less management skill.

Considerations need to be given to more than the method of presenting instructional material, however. For example, Lund and Kegeles (1982) found an interaction between educational instructions and socioeconomic status. Action instructions regarding the use of a dental rinse were effective with urban lower-income adolescents, while they tended to have a negative effect with suburban upper-middle-income adolescents. While no one would argue that patients need to be instructed on what they are to do, the best procedures for providing that education still need to be determined. Considerations need to be given to whether one is interested in knowledge or behavioral improvement or a combination, to how education combines with other techniques, and to how particular types of instruction will interact with patient characteristics.

Self-Monitoring

Mattar *et al.* (1975) used a form of self-monitoring in a remedial effort directed to short-term medication compliance. This appeared to have the effect of boosting the educational intervention also used in the study. In another study among children with otitis media, Finney *et al.* (1985) compared a package consisting of self-monitoring, education, and a reminder with usual care, controlling for experimenter contact by administrating a child-behavior inventory to the usual care group. The experimental subjects were more compliant than the usual care subjects. However, within the experimental group, the self-monitoring calendar users were no more compliant than nonusers. Baum and Creer (1986) also boosted a self-monitoring strategy with education among children with asthma. While children in the education/self-monitoring group were better able to manage asthma attacks, no differences in compliance were found between these children and those who only self-monitored. Indeed, compliance was high in both groups. The children, however, had not been selected initially on the basis of low compliance. Thus, self-monitoring may be a useful adjunct to other strategies. It does not, however, appear to be particularly efficacious in raising compliance when used alone.

Graduated Goal Setting

Graduated goal setting essentially follows the principles of shaping. It may be used in the form of a gradual increase in medication dosage both to reduce the probability of side effects, in the case of chronic disease medication, as well as to improve adherence in a complex regimen in which the rapid attainment of full dosage is not crucial. Graduated goal setting may also be used for the initiation of behavioral regimen such as diet and exercise. Schafer *et al.* (1982) examined the use of graduated goal setting with three nonadherent adolescents with diabetes. The behaviors included urine testing, insulin injections, exercise, wearing identification, and home blood glucose monitoring. The procedure was successful in improving all targeted goals (wearing identification, exercise, and urine testing) for one subject and for two of three targeted goals in a second subject (exercise and urine testing). Insulin injections did not respond to this procedure for the second subject and required additional interventions. The third subject missed several meetings and had questionable self-monitoring, making the collection of follow-up data difficult. Thus, graduated goal setting appears promising but is not sufficient for all patients nor does it appear to be sufficient for all behaviors within a given patient.

Self-Management

Self-management basically relies on a combination of self-monitoring, self-reinforcement, and some problem-solving. As conceptualized in the research on pediatric compliance, self-management involves self-monitoring with varying levels of independence in problem-solving and self-reinforcement. For example, in a study of procedures to improve compliance with a dental rinse among second-grade children, the children were taught to record daily mouthrinsing on a calendar using colorful stickers, were given experimenter feedback on their performance, were given suggestions on convenient times to use the mouthwash and to use the calendar, and were mailed appointment stickers (Cipes, 1985). There was very active involvement on the part of the investigators in the actual management of compliance with these children.

Gross (1982) and Gross *et al.* (1985) used both detailed instruction and practice with behavioral techniques to induce self-management among diabetic children. In both studies, the program included information, modeling, and role-playing on such topics as measurement, reinforcement, punishment, extinction, shaping, self-management, negotiating, and contracting. The children were also required to complete a self-management project with some aspect of their diabetes regimen. The programs were 6 and 8 weeks long. Both studies were successful in promoting improved adherence. In the Gross (1982) study, compliance with urine testing went from 9% to 74%. In the Gross *et al.* (1985) study, five of the seven children met their own self-management criteria. Self-management shows promise as a compliance enhancing procedure, although it is important to describe just what is included in the self-management package. It is reasonable to assume that the level of responsibility that can be assumed in a self-management program will be a function of the child's age and capabilities.

Reminders

A number of studies have incorporated reminders into intervention packages designed to improve compliance. Williams *et al.* (1986) used reminders alone in one of four groups in a study of compliance in otitis media. This reminder consisted of a telephone call on the fourth day after prescription to ascertain whether there were any medication-related problems and to encourage compliance. Although this group reported slightly more children with 100% compliance than a written instruction or a slide-tape group, the differences were not statistically different, with compliance rates being high for all three groups. All three groups received a sticker medication reminder to place on the refrigerator or other conspicuous place. Thus, the study actually examined the additive effect of a telephone reminder on a sticker reminder.

Reinforcement

A variety of reinforcement procedures have been examined in efforts to improve pediatric compliance. Parrish *et al.* (1986) evaluated a lottery system for improving appointment keeping in an outpatient pediatric psychology clinic. Parents received an appointment reminder including a statement that the parent would receive a coupon to enter into a lottery for a $10 cash-equivalent prize. This group kept more initial appointments than a usual care control group. However, the group most successful in keeping initial appointments was one in which, in the event of three missed appointments, the parent's name was placed on the bottom of the waiting list, and the case was not activated or reactivated until the name again reached the top of the list. Although both intervention groups were equivalent and better than the control condition in maintaining appointment keeping for the parent training appointments, the differences did not reach statistical significance. Yokley and Glenwick (1984) also used a lottery leading to a $100, $50, and a $25 cash prize in one condition to improve compliance with immunization among preschool children. The prompt plus lottery incentive condition led to more immunizations than control conditions, prompt alone, or prompt plus improved access to the clinic through the opening of specific blocks of off-hours time, which included child care. Thus, it appears that the opportunity to win an incentive is a useful strategy in promoting appointment keeping, while simple prompts and improved convenience are less useful.

The opportunity to earn incentives through token systems also have been evaluated for their efficacy in improving compliance with the treatment regimen. For example, Rapoff *et al.* (1984) reported that tokens were used as a means to promote compliance to medication taking, splint wearing, and prone lying in a 7-year-old girl with juvenile rheumatoid arthritis. Tokens were exchanged for privileges. Compliance was improved in all areas: medication compliance went from 59% to 95%, splint wearing from 0% to 77%, and lying-prone from 0% to 71%. Gains were maintained following treatment when the token system was withdrawn. Magrab and Papadopoulou (1977) also used a token system to improve compliance to diet among four children on hemodialysis. The children could exchange the earned tokens for various toys and other prizes. During use of the tokens, through a point system, all the children lost weight. In this case, treatment gains were not maintained when the token system was withdrawn. Carney *et al.* (1983) also used a point-token system to improve blood glucose testing among three diabetic children. Earned points could be exchanged for negotiated rewards. Of the three families, two actually used the point system. In the third, the family found contingent praise to work well and so did not institute the point system. In all cases, compliance improved. Daneman *et al.* (1982) also used a point-token system with children with diabetes, but in this case to regulate compliance during a 12-week period of self-management training. Compliance during this training phase was 76% with urine testing.

In general, token systems appear to be effective in improving compliance and can be used in a variety of ways (e.g., as an intervention itself) as an adjunct to other interventions and to instill good compliance habits before moving on to other forms of behavioral regulation. These studies raised areas of concern in using a token system, including management of the child who feels too old for such a system, parental resistance to the use of reinforcement for behaviors that the child should be engaging in, and lack of utilization by the family.

Contingency Contracts

Schafer *et al.* (1982) used behavioral contracts as an additional procedure when self-monitoring and graduated goal setting failed to improve compliance to diabetic regimen among adolescents with diabetes. Contracting was used for two of three children. In one case, the child was successful in improving two regimen behaviors but failed with a third: regularity of insulin injections. Contracting was initially successful although the child experienced some reactance to the contracting and the behavior later regressed toward baseline. Contracting was instituted with a second child who failed to perform blood tests. However, following this, the child and mother argued and the child failed to appear for several sessions. Contracting was not successful in this case. Cipes (1985) and Cipes and Miraglia (1985) also reported the use of contingency contracting to increase compliance with a dental rinse among second grade children. Parents were advised as to how to set up a contract with the child, set a goal, choose a reward with the child, and reward the child contingently when the rinse was used. A second group combined the contracting procedure with a self-monitoring procedure. Cipes (1985) and Cipes and Miraglia (1985) report that overall contracting depressed compliance. On further examination, they reported that those families asked to contract who did not accounted for the adverse effect. Those families asked to contract and those not asked to contract did not differ in compliance. Thus, contracting did not seem to be a successful procedure; in fact, negative effects were found when the family was asked to contract and did not. These studies would suggest that contracting is not a particularly successful means to achieving patient compliance, at least in the pediatric and adolescent population.

Increased Supervision

Smith *et al.* (1986) added increased supervision to a combined educational–behavioral package that consisted of tailoring the timing of administration to the patient's routine and the use of written instructions. The increased supervision consisted of having the physician discuss compliance problems as well as the rationale and importance of the medication with the family. This package showed an enhanced compliance rate over a no-intervention control, 78% versus 55% respectively. It is impossible to tease out the role of increased supervision. However, the effect of this package was greater than that of other primarily educational packages, suggesting that increased supervision may enhance compliance.

Increased Parental Involvement

As noted in many of the above procedures, the parents play an active and important role in the compliance of the child or in the institution of strategies to improve compliance. It is not always clear, however, how parents can best be involved beyond actual administration of the regimen to the young child. Contracting studies suggest that this may not be the best way. The reinforcement studies, however, suggest that token systems and–or praise from the parent may be effective, at least for some children. However, Cipes's (1985) study of methods to enhance compliance with a dental rinse among second-grade children suggested that parental reinforcement had no added benefit over self-management alone. Weinstein and Cuskey (1985) used increased parental encouragement and/or supervision as an adjunct to intervention in children who persisted with compliance difficulties. The effects of this involvement could not be determined, however.

The influence of the parent may be more indirect than that of interventionist with regard to the child's adherence. For example, Gross *et al.* (1985) taught parents of children with diabetes a self-management curriculum in parallel with a course undertaken by the child. Parents reported a substantial reduction in the number of parent–child conflicts, from 1.6 conflicts per week to 0.2 conflicts per week during treatment, and to 0.1 conflicts per week at 2- and 6-month follow-up. Waszak (1987) evaluated parent training in communication skills with their children with diabetes, focusing particularly on setting clear expectations, avoiding power struggles with the child, reinforcement techniques, and motivation strategies. She noted improved compliance with diet, insulin administration, and glucose monitoring when contrasted with a no-intervention control group, e.g., 96% versus 88%, respectively. Thus, parent involvement may be focused on supporting autonomy or self-management in the child and/or reducing family conflicts, including improving parent/child communication patterns.

A variety of procedures are therefore available for improving compliance in the pediatric population. With children able to be responsible for their own regimen, self-management procedures, including self-monitoring and graduated goal setting, seem useful. When self-management is not working, involvement of the parent is crucial, particularly through reinforcement strategies or actual conduct of the regimen itself. Useful adjuncts to these interventions seem to be reminders, supervision, educational programs, and parent training programs. With any intervention, however, it is important to ascertain the acceptability of the intervention to the child and/or family and to ascertain the skill of the individual in carrying the program out. Poorly implemented programs can have negative effects.

CASE ILLUSTRATION

Denise was a 12-year-old girl who was diagnosed with insulin-dependent diabetes mellitus at the age of 10½ years. She was residing with her mother and younger sister. Her parents had been divorced for 6 years and, although there was some discord between the parents, they remained in contact.

Denise was referred for evaluation because of ongoing problems with management of her diabetes, resulting in frequent hospitalizations for ketoacidosis (10 admissions in the preceding 18 months). Her problems included (1) noncompliance with her diabetic regimen, i.e., precipitating ketoacidosis by refusing to eat or drink, administering incorrect insulin doses, skipping snacks or not following her meal schedule, and purging after meals; (2) dysphoric mood, crying, and wishing she were dead; (3) temper tantrums, oppositionalism, and disobedience; and (4) social withdrawal.

Denise's problems were complicated by the fact that neither parent felt capable of managing her noncompliance at home. Initially, she lived with her mother but, shortly after being diagnosed with diabetes, she requested to live with her father. The mother supported this change hoping it would help Denise's adjustment to the diagnosis. This arrangement did not last when it became apparent that she was going between her parent's homes and neither parent knew what was happening with her diabetes management.

Denise's appearance was that of an attractive, well-groomed girl who was markedly underweight. Her mood was dysphoric and her affect bland. When questioned about her diabetes, she demonstrated a good understanding of her illness and its treatment. She also voiced her impression of the lethality of diabetes, stating that death could result in a couple of hours if a single dose of insulin was missed. Her feelings of anger about having diabetes were quite evident and she viewed her illness as punishment for wrongdoings or God's way of testing her worthiness. In addition, she indicated that her caretakers were continually making decisions for her but were unable to help her. Denise was of normal intelligence (full-scale IQ of 110). She scored within normal limits on the Children's Depression Scale and very close to the norm on the Internal–External Locus of Control Scale. The Self-Esteem Inventory revealed a markedly low self-esteem, nearly 3 standard deviations (SD) below the mean (34, contrasted with a norm of 72.2 ± 12.8). The Moos Family Environment Scale—Form R, revealed scores well above the norms on family cohesion and moral-religious emphasis and well below the norm on conflict. Other subscales were within 1 standard deviation of the means.

Denise was admitted to an acute-care child psychiatry inpatient unit for further assessment, particularly regarding her mood and purging, for management of her noncompliance, and for individual work with the mother focused on improving the parent–child relationship. The inpatient milieu focused on consistency of management and on limit setting. In addition, a token economy was used to assist her with self-management skills regarding her diabetic regimen.

During the course of hospitalization, Denise was introduced to the token economy, earning points for urine and blood glucose testing, self-administration of insulin, self-monitoring of food intake, as well as the usual ward behaviors, such as school attendance, participation in group activities, and basic activities of daily living. In addition, the use of peer pressure was incorporated into her program. For example, if Denise was late with her blood glucose testing before meals, the whole peer group was detained from the meal until she completed her testing. Denise was also encouraged to discuss her diabetes in group therapy, as she felt unliked because of it. Denise and her mother were also seen in individual therapy. Denise was in a cognitive-therapy program, while her mother was in a parent-training program. Following a 2½-month intervention program, Denise had gained to goal weight, eliminated food refusals, routinely performed urine and blood glucose testing without prompts, routinely self-administered insulin without refusals, and self-monitored as well as selected food items appropriately. Thus, the token economy used with peer pressure and with cognitive therapy were effective for Denise in improving her compliance. Unfortunately, family problems had not been sufficiently resolved, so that Denise's mother was unable to sustain improvements at home. Denise was placed in temporary foster care until her mother was able to manage Denise's behavior at home.

SUMMARY

Compliance among the pediatric and adolescent populations poses a problem of a magnitude comparable to that found among other age groups. A host of factors seem to impact upon compliance with this age group. Among these are family functioning, social support, symptomatology, the level of depression or anxiety in the parent, various personality characteristics of the child (particularly the adolescent's self-esteem, level of autonomy, hopelessness and anxiety), the type of regimen, and the degree of satisfaction with care. Multiple strategies have been evaluated to improve the compliance rates. These fall primarily within a behavioral framework. Combinations of strategies seem most useful. Most promising are those centered around either a self-management program, including self-management and gradual goal setting, or around a parental involvement program, with promising elements in the use of reinforcement strategies and in communication skills training. As with any intervention program, care must be taken to adapt the program to the patient/family skill level and their acceptability of the intervention strategy.

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CHAPTER 24

Accident Prevention

Overview and Reconceptualization

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INTRODUCTION

The term *accident* has traditionally implied that injuries are random, unavoidable, and unpreventable, or acts of God. By contrast, the term *nonintentional injuries* implies that injuries are predictable and quantifiable and may be prevented. Several investigators have argued that the distinction of these two concepts in many cases is relative rather than absolute. For example, Elmer (1978) found when comparing cases of child abuse and accidental injuries, little distinction between abused/neglected and accidental injury groups existed. Furthermore, it was concluded that most accidents could have been prevented by simple engagement of safety devices. Notwithstanding, the similarities of these concepts, the fact that accidents are the leading cause of death in children (National Center for Health Statistics, 1978), and unintentional injuries are the number one killer of children (Gratz, 1979), the need for research attention to this area is crucial. The focus of this chapter is on unintentional injury due primarily to the number of injury-related deaths that most often result from unintentional injury (Cataldo, Dershewitz, Wilson, Christophersen, Finney, Fawcett, & Seekins, 1986). This chapter has several specific goals, including the identification of the following: (1) common factors correlated with unintentional injury, (2) major categories of unintentional injuries, (3) common conceptualizations of childhood injury prevention strategies, (4) a complementary model for conceptualizing

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future injury prevention strategies, and (5) fertile areas for future research. It is hoped that this discussion will add to the dearth of literature on the topic of childhood injury on two counts: first, to provide a better understanding concerning the scope and breadth of injuries occurring in children; and second, to provide an overview of the major categories and causal factors correlated with injury. In addition, it is our intent to shed light and provide meaningful insight into definitional and conceptual issues confronting this area. Ultimately, the need for integration efforts to enhance the quality of future preventive and interventive strategies will be highlighted.

While a detailed review of the number and types of injury is far too voluminous for inclusion in this chapter, an attempt is made to discuss several categories of major unintentional injuries. This section in no way exhausts the number of categories but it provides a broad overview of some of the common types of injury.

CATEGORIES OF MAJOR UNINTENTIONAL INJURIES

Fall-Related Injuries

Fall-related injuries refer to those in which a person has fallen from a structure or fallen onto an object. Falls are the major cause of childhood injuries (Spiegel & Lindaman, 1977). From January 1965 to September 1976, 12% of all accidental deaths of children under 15 years in New York City were attributed to falls from heights. More specifically, 123 deaths were due to falls from windows (Spiegel & Lindaman, 1977). Many childhood injuries caused by falls occur on the playground with hard surfaces and equipment (O'Shea, Collins, & Butler, 1982). Most abrasions, contusions, dislocations, fractures, and lacerations are due to these types of falls (Gratz, 1979).

According to research in Great Britain and the United States, the most common causes of childhood deaths are due to injuries occurring within the home, predominantly in "working class" families (Colver, Hutchinson, & Judson, 1982). Of all the home injuries reported to hospitals, 70% involved bruises, burns, cuts, poisonings, and scalds, with more than one half related to falls (Colver *et al.,* 1982).

Product-Related Injuries

Product-related injuries include such injuries as those that can occur on playground equipment or during various sports and recreational activity. The category of product-related injuries can be divided into lacerations and contusions (e.g., scraped knees or bruises), poisonings, and burns. Males have an increased injury rate within certain product categories. One such category is injuries occurring on sports and recreational equipment. Males have received more lacerations and contusions than have females. Given that significant numbers of injuries are associated with sports including football, baseball, and wrestling, in which males are more frequently involved, this finding may not be surprising. Ingestion of foreign objects, poisonings, and burns indicates no significant sex differences.

Toys are a major cause of injury in children. Of 10,000 children, 595 will injure themselves with a toy (Rivera, Bergman, LeGerfo, & Weiss, 1982). In addition, each year, bicycles are responsible for the deaths of 1000 children between the ages of 5 and 14 years (Baker, O'Neill, & Kerpf, 1984). Home furniture, structures, and fixtures, as well as recreational equipment, also pose threats of injury.

Fire

Fire is responsible for 6000 deaths and 90,000 severe burn injuries annually. Most fire victims are either young children or elderly people (Baker *et al.*, 1984). Of all people admitted to hospitals for burns and scalds, 45% are children under 4 years of age, and approximately 200 deaths per year are attributable to burns and scalds. While most fire-related deaths and injuries occur in the home, sources frequently responsible for such occurrences include matches, stoves, and heaters. Hot beverages such as coffee are often responsible for many of the reported scalds (Baker *et al.*, 1984).

Pedestrian-Related Injuries

Pedestrian-related injuries are those injuries whereby a person is struck by a moving vehicle (an automobile, bus, motorcycle, or bike). Included in this type of injury are incidents such as a child running into a vehicle or any part of the vehicle striking the child. Each year, 8000 Americans die in auto-pedestrian accidents. Most are 18 years old or younger (Baker *et al.*, 1984), with the majority of pedestrian-related injuries occurring between 5 and 8 years of age. More boys are involved in these types of injuries than girls.

Poisoning

Poison-related injuries include the ingestion of toxic substances, such as household chemicals, or other harmful materials such as plants. For the <1- to 4-year-old age group, poisoning deaths have decreased from 445 to 73 yearly; yet during the 20-year period 1963–1983, poisoning was responsible for 295 accidents per 100,000 children (Rivera *et al.*, 1982). Although there is a consistency in that poisoning most often occurs in toddlers (Matheny, 1980), there has been no evidence of any significant sex differences in reported poison injuries (Rivera *et al.*, 1982).

Firearms

Nearly 75% of American families have guns in their homes. Within the age group of children aged 10–19 years, the third leading cause of accidental death is unintentional shootings. Of those children under 15 years of age, almost one fifth are slain in firearm accidents. Six times as many of these deaths occur in boys aged 13–17, as opposed to girls. Just over one half of accidental shooting deaths occur in the home, with about 30% of victims being children under 15 years of age.

The data on deaths due to firearm injuries are deficient in quantity. For all age groups in 1972, there were approximately 155,000 nonfatal shootings. Spinal cord injuries and blindness are examples of severe disabilities caused by such shootings.

In 1973, emergency rooms treated 11,000 injuries caused by toy guns operated by gas, air, and springs (e.g., BB guns, pellet guns, and air rifles). These spring-operated guns produce fatal, as well as nonfatal, injuries.

Drowning

Drowning-related incidents include deaths where a person has been immersed or fallen into some source of water. Of 5000 non-boat-related drownings per year, 10% involve children under 5 years of age (Baker *et al.*, 1984). Of the total yearly drownings, only 10% are caused by swimming pool accidents; 70% of these victims range from 1 to 10 years of age, with 2 years the most frequent age (Davis, 1984).

COMMON FACTORS CORRELATED WITH INJURY

Sex

Correlations of sex and injuries vary widely. There exist several categories of injury for which no significant sex differences emerge, including foreign-body ingestions, poisoning, and burns (Rivera *et al.*, 1982). However, fairly strong relationships between sex and several categories of injury do exist. For example, pedestrian-related injury rates are more common in males than females (Baker *et al.*, 1984). Similarly, lacerations and contusions often resulting from sports and recreational equipment occur significantly more among males than among females.

Age

The age distribution for childhood injuries is bimodal, with injury rates being high in the first year of life and again in adolescence (Haddon & Baker, 1981; McCormick, Shapiro, & Starfield, 1981; Rivera, 1982). For example, it has been found that poisoning occurs most often in toddlers (Matheny, 1980), and the most frequent age for drowning injuries is 2 years (Davis, 1984). Furthermore, epidemiological data indicate that 45% of all hospital admissions for burns and scalds are for children under 4 years of age (Baker, O'Neill, & Kerpf, 1984). The peak years for child pedestrian injuries range from 5 to 8 years of age (Baker *et al.*, 1984).

Behavior

Behavioral functioning of the child is also associated with childhood injuries. Changes in a child's motor development may place the child at risk for exposure to health hazards as well as the ability to safeguard personal health (Maddox, Roberts, Sheldon, & Wright, 1986). Manheimer and Mellinger (1977) reported a significant relationship between "accidents" and *injuries* of anxiety and extroversion. They also found that children who were explorative or who engaged in rough-housing were likely to be exposed to hazards. Others have also found that active children had a higher incidence of injury (Langley, McGee, Silva, & Williams, 1983).

Cognitive

Several cognitive factors are associated with injury occurrence. Langley *et al.* (1983) found that emotional reactivity, temperament, and attention span are correlated with higher frequencies of "accidents." In addition, other studies have found that children at risk for injury are less attentive to ongoing tasks and are also more distractible (Matheny, Brown, & Wilson, 1971). It has also been found that children with more serious "accident" histories committed more errors on a visual–perceptual exploration test (Matheny, 1980).

Family

Characteristics related to the family have been associated with childhood injury. For instance, the limited supervision and monitoring of children by their parents have been associated with fire-oriented injuries (Patterson, 1982; Siegelman & Folkman, 1971). With regard to family status, Manheimer, Dewey, and Mellinger (1966) reported that "accident" rates are highest among children whose fathers' occupations were classified as professional. Conversely, those whose fathers' occupations were classified as either skilled or semiskilled showed lower accident rates. Several studies have reported a relationship between family moves and childhood injuries (Knudson-Cooper & Leuchtag, 1982; Maragos, Greene, & Mitchell, 1971). Maternal health has also been correlated with injury rates in children. Beautrais, Fergusson, and Shannon (1981) reported that injuries requiring medical attention were significantly associated with maternal age, problems with the child, life events, accommodation changes, and maternal use of tranquilizers and/or antidepressants.

Socioeconomic Status

In the United States and Great Britain, injuries that occur in the home are the most common cause of death, especially in working-class children (Colver, Hutchinson, & Judson, 1982). Other British studies have found that there is a significant relationship between low socioeconomic status (SES) and injuries which result in death (Adelstein & White, 1976; McFarlane & Fox, 1978). Conversely, there are data to suggest that SES may have minimal influence on childhood deaths due to injury (Chamberlain & Hill, 1970). Closer to home, here in the United States, studies have shown that a significant relationship between low SES and "accidents" resulting in death exists (McFarlane & Fox, 1978). But here as well, the impact of SES has been shown to largely disappear when race was controlled for (Manheimer *et al.*, 1966).

CONCEPTUALIZATION

Major Models of Prevention Intervention

One of the most widely used models for conceptualizing children's injury prevention strategies has evolved from the public health perspective of injury control (Margolis & Runyan, 1983). The identification of the host (e.g., the child), agent (e.g., mechanical, electrical, thermal, or chemical), environment (i.e., home, playground, school), and vehicle (i.e., person, object) has been of extreme value in describing causative factors, categorization, incidence and prevalence of injuries. While a major advantage of this approach is its ability to apply empirically derived strategies to large groups of individuals, its use of education and mass media procedures has often led to equivocal levels of behavior change (Peterson & Mori, 1985). Not only has the overall effectiveness of these strategies been wanting, the breadth and scope of such strategies have been somewhat limited.

A second model recently proposed by Peterson and Mori (1985) advocates a preventive intervention conceptualization. This model identifies three factors. The first factor is the target or focus of intervention, which is usually the harmful agent itself, including the child or caretaker. The second factor is identified as the methods of intervention that can be categorized as mandated/legislated or educational/persuasive. Both passive and active methods are discussed. Tactics through which the methods can contact the targets make up the third factor. Tactics include population-wide prevention, milestone prevention, and high-risk group prevention (Peterson & Mori, 1985). This model, which borrows heavily from the discipline of psychology, holds much potential for the treatment of child injury.

A third model recently used in the domain of childhood injury emerges from the area of pediatric psychology. The earliest conceptualization of pediatric psychology appeared in 1967 by Logan Wright. According to Wright (1967), the pediatric psychologist is "any psychologist who finds himself dealing primarily with children in a medical setting which is nonpsychiatric in nature. . . ." (p. 323). Most attention in practice has been given to the treatment of existing physical and psychological problems in order to enhance normal developmental functioning (Roberts, 1986). Roberts also states that throughout its existence, pediatric psychology has maintained a basic orientation toward promotion and prevention. Both goals have included the application of psychology to the prevention and remediation of psychological disorders and the prevention of injuries and illness in one's childhood (Roberts & Peterson, 1984). Applications evolving from this approach frequently embrace a behavioral framework. While research efforts reflecting this model have only recently surfaced, they have produced encouraging results.

Broadening the Boundaries

While the preceding discussion focused on the identification of frameworks that have met with varying levels of effectiveness in preventing and/or lessening the untoward consequences of injury, this section focuses on a related concern of extreme urgency. Previous writings in the childhood injury area have focused primarily on unintentional childhood injuries, which have been posited to result from active exposure to physical chemical agents (Haddon & Baker, 1981). While research attention to unintentional injury is indeed warranted, given that it has been designated as the number one killer of children (Gratz, 1979), an equally compelling case can be made for the examination of other types of injuries that extend beyond the boundaries of unintentional injury. Although it has been stated that most injury-related deaths (66%) are unintentional (Cataldo *et al.,* 1986), a growing recognition of the dramatic rise in the reported incidence and prevalence of other forms of injury is becoming apparent.

Burgeoning literature in the areas of child abuse (Garbarino, 1984; Rosenberg & Reppuci, 1985), child abuse and neglect (Cohen, Gray, & Wald, 1984), child sexual abuse (Finkelhor, 1984), and maltreated children (Belsky, 1980) have revealed the epidemic proportions of this problem. In addition, these scholarly efforts have been most valuable in identifying the causative interactive and mediational variables that may be correlated with the various types of injury. Moreover, precise theoretically based intervention efforts have emerged from several of these efforts (Rosenberg & Reppucci, 1985).

Although growing attention has been paid to the area of unintentional childhood injury, to have done so in relative isolation of other forms of injury (child abuse, neglect) may have led to several conceptual and empirical limitations. For example, in identifying causal factors and conceptualizing related intervention efforts only within the context of the unintentional injury framework may have seriously limited the depth and level of analysis. That is, in identifying the causal agent of a child seriously burned in a residential fire, two agents may be considered, i.e., the fire or the "neglectful" parent. The former cause (fire) is more likely to be selected than is the latter (parent) when adopting the unintentional framework. While this conclusion may have been more fitting some years ago, given the alarming increase in incidence and prevalence of other forms of injury over the past decade, it may be highly invalid and misleading. For example, interventions rather than targeting both risk factors, the fire and the "neglectful" parent, would only target the former. Conversely, when viewing this incident from a broader perspective, taking into account the possible role of a human agent, both causal agents (fire and parent) and intervention efforts are more likely to be correctly identified.

In sum, as a consequent of the somewhat narrow emphasis of unintentional childhood injury, healthy integration and cross-fertilization with conceptually as well as heuristically related literatures and disciplines have been lacking. For example, a dearth of research attention from a psychological perspective has been given to the area of childhood injury. The disciplines of pediatric psychology, clinical child psychology, ecological psychology, and health psychology have much to offer, not only in the areas of etiology, but also in the areas of assessment, conceptualization, and application of intervention for children and their families who have either suffered or are at risk of varying types of injury.

A pressing two-pronged question that arises is: Why have the areas of intentional and unintentional injury been considered largely in isolation, and how might the negative consequences resulting from this situation be resolved? There may be several explanations for their separate consideration, which may include turf issues, conceptual differences, and boundary restrictions. More specifically, three major factors that may have contributed to this situation are (1) definitional ambiguity surrounding the term *injury*, (2) the relative lack of input from related fields of psychology, and (3) social consciousness.

One reason for definitional ambiguity stems from the nature and causes of "injuries" which result from various forms of abuse and neglect. Unlike unintentional injuries, which are commonly caused by acute exposure to physical and chemical agents (Haddon & Baker, 1981), frequently resulting in physical harm, these injuries are often a result of intentional psychological maltreatment, neglect, and/or abuse inflicted by a significant other that results in psychological and emotional harm. Consequently, it has been quite difficult to define these types of injuries (Wald, 1975).

A second reason is related to the relative lack of input from members of the psychological community with regard to intervention. While several models stemming from public health arenas have been useful in conceptualizing childhood injury prevention, they have been less useful in generating effective intervention strategies (Peterson & Mori, 1985). For example, whereas educational approaches have been helpful in making the general public aware of potentially hazardous situations, change in actual behavior has often been lacking. Additional discussion on this issue are dealt with in the next section.

A third explanation for this lack of attention to intentional injury may involve issues surrounding social consciousness as opposed to the lack of theoretical/conceptual weaponry to deal with the problem. For example, the recognition of the increasing rates of injury in the form of sexual assaults on children may be a source of extreme social embarrassment. Further statistics indicating that only 15–20% of all assaults are perpetrated by strangers (Mrazek, 1983), with the other agents either parents, friends, or relatives of the family, make this issue even more sensitive. In a time of such advancement in the areas of the social and physical sciences, as well as sociocultural enlightenment, the recognition and acceptance of this disconcerting fact is at times quite difficult.

Notwithstanding the apparent merit of the above explanations for the separate consideration of two types of injury, integration of the two is in order. Such an integration is likely to provide clarity of definition, enhance input from related disciplines, and encourage an acceptance and recognition of the magnitude of the problem. In addition, the integration of efforts targeting "injury" incurred by children may lead to more theoretically based methods to study this growing phenomenon. More specifically, the areas of conceptualization, assessment, and intervention may be greatly improved.

An Integrative Model

In an integrative effort, a complementary model for intervention is being proffered.[1] The model not only embraces a number of cardinal features of the aforementioned approaches but also underpins a growing number of effective empirical studies targeting prevention of the occurrence of injury.

This prevention model (Jones & McDonald, 1986) draws from three related frameworks: prevention, behavioral, and community psychology. The prevention framework provides the timing (primary, secondary, and tertiary) and goals of intervention efforts (Bloom, 1977), while the behavioral conceptualization ensures the objective identification of target responses, the specification of behavioral change strategies, and the methodology for assessment and evaluation of procedures (Mahoney, Kazdin, & Lesswing, 1974). To facilitate the widespread usage of empirically derived intervention procedures, the community psychology perspective is adopted (Glenwick & Jason, 1980).

In addition to the heuristic value of the prevention model for the domain of childhood injury, several recent research efforts demonstrate various aspects of its application to a variety of potentially injurious occurrences. For example, a series of studies have targeted coping with home emergencies (Jones & Haney, 1985), and confrontation with strangers (Poche, Brouwer, & Swearington, 1981), as well as potential child sexual abuse (Wurtele, Marrs, & Miller-Perrin, 1986).

There are six components of this prevention model of childhood injury. While this integrative model provides several advantages over previous approaches, the need to incorporate developmental considerations when attempting to affect maximally behavior change is highlighted.

1. *Document the need for intervention.* The initial step in this model is to document the need for intervention. After selecting the target area, relevant information may be obtained from a variety of sources. For example, at the local level, information may be obtained from elementary schoolteachers, parents in the community, and hospital community mental health clinics regarding the incidence and prevalence of injury resulting from a particular agent. At a national level, information may be obtained from various national sources. For instance, in our program of research targeting fire emergencies, the National Fire Protection Association and the National Commission of Fire Prevention and Control were contacted to obtain such information (Jones, Kazdin, & Haney, 1981). If sexual abuse was being targeted, data may be obtained from the Department of Health and Human Services as was done by Wurtele *et al.,* 1986.

2. *Decide what skills to teach and validate them.* Determining what skills to teach

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[1] Thanks are extended to Janelle Haney for her contributions on an earlier version of this model.

is a crucial component of this model. Such information may be readily obtained from national and federal agencies, mental health professionals, teachers, parents, and children. Also, examination of existing materials may be useful in accomplishing this goal. Modification of existing procedures may be of benefit. To ensure that the appropriate steps have been selected, objective evaluation by "experts" in the particular area is essential (Kazdin, 1977). Once this has been accomplished, pilot work should be carried out to ensure that the target population is able to perform the steps appropriately. It is important that consideration be given to children's developmental levels.

3. *How to teach skills.* The third step in this model consists of deciding how to teach the target skills. A variety of teaching methods exist that have been categorized as either mandated/legislated or educational/persuasive (Peterson & Mori, 1985). Selection of passive or active methods should be based on several factors, including the type of target response, the child's development level, and the availability of change-agent (i.e., caregiver, parent, or teacher). The model adopted need not be based on a single conceptualization (i.e., educational or behavioral). For example, while the behavioral approach served as the primary model in enhancing a variety of personal safety skills (Peterson, 1981; Poche, Brouwer, & Swearington, 1981; Rivera-Tovar & Jones, 1988; Wurtele *et al.*, 1986), recent efforts in the areas of fire safety and drug refusal have combined cognitive and memorial conceptualizations to this model to enhance desired behavioral and cognitive skills and lessen levels of reported fear (Jones, McDonald, Foire, Arrington, & Randall, in press; Jones, Ollendick, McLaughlin, & Williams, 1989; Jones , Ollendick, & Shinske, 1989; Jones & Randall, 1987; and Williams & Jones, 1989).

4. *When to teach skills.* The decision of when to teach skills may be as important as the decision of how to teach skills. For example, in our experience in consulting with teachers and parents, we are often asked to teach safety skills to children who are not behaviorally or cognitively ready to learn such skills. Attempting to teach 3-year-olds fire evacuation would result in failure because of their behavioral and cognitive limitations. Several investigators have pointed out limitations resulting from developmental levels that prevent certain groups of children from mastering various skills (i.e., Robertson, 1983). An additional consideration surrounding this component is the timing of the teaching (i.e., primary, secondary, or tertiary). The primary prevention conceptualization has been adopted to guide our thinking in the teaching of fire-evacuation skills. That is, the timing of training has been based primarily on suggestions stemming from this model. The psychologist can decide whether one should prevent a particular behavior or train individuals how to cope with a behavior after it occurs. The reduction or prevention of the occurrence and incidence of untoward consequences resulting from fire emergencies has been our overall goal by training competencies to enhance functioning in fire emergencies.

5. *Selection of change agents and training setting.* Who are the best trainers of various skills? How one responds to this question has important implications for the acquisition and generalization of skills. For example, the ability to transfer acquired skills to settings other than the setting in which they were originally

acquired (i.e., classroom, home, community center, fire department) is often directly related to the change-agent (i.e., teacher, parent, firefighter). The phenomena referred to as response maintenance (continuation of acquired behaviors following treatment withdrawal) is also highly correlated with certain types of change agents. While several references have been made advocating the usage of parents to enhance both types of generalization, few investigations have actually engaged this strategy (Karoly, 1980). One exception is in the area of childhood obesity, in which children's parents served as change agents (Brownell, Kelman & Stunkard, 1983) and enhanced levels of generalization. A need for continued efforts of this nature is seriously in order.

6. *Communitywide involvement.* The extent to which community involvement is maintained may have significant implications for the development and generalization of desired skills. As pointed out in the behavioral literature, the lack of community involvement often limits the overall effectiveness of treatment programs. Caplan's notion of populationwide prevention is certainly an appropriate approach to enhance the overall effectiveness of a given program (Caplan, 1964). Both passive and active methods should be engaged, depending on the type of skill(s) to be trained as well as the target population (child or parent). For example, while legislative action may lessen the degree of abuse inflicted on children by caregivers, educational messages may enhance children's awareness and ability to cope with various threatening situations. Obviously, the need for complementary approaches stemming from clinical and behavioral psychology is in order given the limited success of these and related methods. For instance, while television spots have been successful in increasing children's awareness of fire emergency, only actual behavioral training has resulted in marked improvement in functioning in simulated situations (Jones *et al.*, 1981).

DEVELOPMENTAL CONSIDERATIONS

The need to integrate developmental considerations into the preventive interventive efforts, as well as its underlying conceptualization, are of paramount importance. Given the psychological, cognitive, emotional, motoric, and other differences of children (at various levels of the developmental life span), the need to match these person variables with types of interventions is crucial.

The application of the developmental perspective in conceptualizing childhood injury prevention efforts is threefold. It may assist in (1) indicating when and what particular types of efforts may be most efficacious, (2) when such prevention efforts are most needed in light of one's level of development, and (3) what types of training methods would be most effective (Roberts, Elkins, & Royal, 1984). With respect to these three interrelated concerns, each may be addressed by drawing from several relevant literatures. For example, developmental and epidemiological sources can be used to determine when a particular type of intervention is called for. Given that the types of injuries associated with various developmental levels have been determined, such information may be forthcoming. For example, since poisoning is more common in toddlers than in children of older ages (Matheny, 1980), higher rates of pedestrian injuries occur among children between the ages of 5 and 9 (Yeaton & Bailey, 1978) and fire victims are disproportionately represented by children (Jones, 1980), the timing for each type of training should obviously be precisely selected. Regarding the impact of injury, Hart and Brassard (1987) stated that a specific age or developmental level may be an important factor in determining the degree and the severity of injury resulting from psychological maltreatment. Therefore, a convincing case can again be made for the necessity of teaching certain skills at specific times along the lifespan. Similarly, several studies have presented data that may be useful in guiding efforts likely to be effective in changing behavior. For instance, knowledge concerning a child's cognitive development can be quite useful in determining what modes, styles, and format of instruction will be most effective in producing desired behavior. Limits in young children's causal reasoning, cognitive style, and restrictions on ability to process information may suggest one mode of instruction over another.

A related finding concerns children's understanding and perceptions of harmful situations. For example, Wurtele and Miller (1987) found that children between the ages of 5 to 7 and 10 to 12 have different conceptions of sexual abuse, descriptions of the abuser and victims, and perceptions of the consequences of sexual abuse. Children's ability to comprehend hazards was also found to be age related by other investigators (Robertson, 1983). In summary, these findings highlight the importance of considering and evaluating injury-related factors within a developmental context when conceptualizing, assessing, and treating children's injury.

FUTURE DIRECTIONS

There are several conceptually meaningful and heuristically appealing directions for future work in the area of childhood injury prevention. Important goals include early identification of children at risk of injury, concise categorization of at-risk children, broader conceptualization of causal agents of injury, and clarity concerning the definitional ambiguity of the term *injury*. Of particular importance is the early identification of children at risk.

The early identification of those children at risk of injury is crucial. The greater extent to which we are able to identify such children, the more rapidly preventive measures can be taken. Although several factors that place children at risk both of unintentional injury (i.e., behavioral functioning) and of intentional injury (i.e., family characteristics) have been cited, little has been done of an integrative nature to identify groups of children at risk of both types of injury. There may exist specific causal factors that lead to both types of injuries. For instance, family practices including limited supervision or monitoring of children by their parents have been correlated with increased rates of unintentional injury (Patterson, 1982), whereas similar practices including isolating and ignoring have been found to be closely tied to more intentional forms of injury (Garbarino, Guttman, & Seely, 1986). Thus, both unintentional and intentional injury may well be a function of the same causal agent, namely family practices.

When identifying groups of children who are more likely to incur injury, it is important to specify factors that make them particularly vulnerable to injury. For example, among various groups that were recently identified as at risk of injury are *latchkey children,* defined as children under the age of 13 who return home from school to no adult supervision (Garbarino, 1980). Within this group, several general characteristics have been reported (Long and Long, 1983). A high incidence of fear, stress, and conflict has been reported, along with problems with peers, feeling lonely, and difficulty in studying and doing homework. It has also been stated that because of less adult support, these children are more likely to succumb to negative peer pressure (Steinberg, 1986).

With regard to precipitating factors, a major predictor of injury appears to be the quality of the parent–child relationship. Some investigators have asserted that both child abuse and neglect have been associated with isolation of the parent–child relationship whose nurturance and feedback frequently provided by this relationship is absent (Garbarino, 1977, 1980). It has been reported that unsupervised children are more likely to be the victims of accidents such as fires, poisonings, and sexual victimization (Garbarino, 1980). This assertion seems to be supported by claims in the areas of child abuse and neglect as well as psychological maltreatment of children. All in all, the proper identification of children at risk is likely to enhance greatly the quality of our interventive efforts.

Future research should address the task of identifying major categories of injury and factors correlated with each. The adequacy of existing and evolving models of prevention interventions should be thoroughly and systematically evaluated. Determination of the risk status of children for injury should be a top priority of investigators in this area. The ascertainment of origins, precursors, and consequences of injury is essential for development of effective preventive measures. Consideration of the separate and interactive roles of child and parent characteristics that may serve as determinants of injury should be more fully explored.

Victims' perceptions of injury, causal attributions, as well as their cognitive, behavioral, and physiological reactions to them, should be systematically assessed. The impact of injury on their short- and long-term functioning as well as overall development should also be evaluated. Ways to prevent and cope with threats or the actual occurrence of injury should be clearly articulated and empirically tested. Future conceptualizations of childhood injury should embrace the literature on stress, coping, risk, vulnerability, and protective factors to ensure a thorough understanding and appreciation of the growing phenomenon of childhood injury.

CASE ILLUSTRATION

To teach safe evacuation from a burning house and reduce the fear typically experienced by children in this situation, our team of researchers entered a local elementary school and selected a group of approximately 15 to 20 second- and third-graders. The selection process consisted of the administration of several pretest questionnaires that assessed the degree of fear experienced by each child. In addition, a pretest in which all children were assessed behaviorally in three situations (nothing blocking the path, fire blocking the path, and hot air rushing) followed. The children were assessed in a simulated bedroom within the school. The bedroom contained a cot with a pillow, a rug, an adjustable window, a chair, a door, and a t-shirt. Outside the bedroom were a hallway and stairs (marked with masking tape) leading down to the front door. For training purposes, subjects were broken down into smaller groups of three or four children. While several studies have been carried out to assess the relative impact of various treatment procedures, for illustrative purposes, only one procedure is discussed, i.e., the elaborative procedure.

Trainers met with three or four subjects for three consecutive days for a period of approximately 50 min/day. On each of the three days, a new situation was introduced. On day 1, nothing was blocking the path; on day 2, fire was blocking the path; and on day 3, hot air came rushing in through the bedroom door. The subjects were trained in fire emergency skills in a small room within the school that was identical to the room in which they were assessed. The first half of the training session (approximately 25 min) was spent teaching the behavioral steps to escape from a burning house (Fig. 1). The second half of training consisted of elaborative rehearsal where rationale as well as questions and answers were provided concerning various steps (Q: Why should you close the door behind you? A: Firemen tell us that you should close the door behind you to keep the fire and smoke out of your room.). The subjects were allowed to respond to the questions after raising their hands and being called on by the trainer. The trainer then read the correct response from the script and had the subjects repeat it after her. The subjects were asked in a systematic fashion whether they had any questions; they were also presented with pictures of certain situations, as they were being discussed. This procedure is engaged because of its hypothesized impact on long-term retention (Jones, Ollendick, McLaughlin, & Williams, 1989).

The following excerpt illustrates a typical elaborative training procedure. After greeting each of the four children, I asked them to sit along the back wall so we could begin. I began my introduction by giving the children an overview of what they would be doing over the next 3 days. The mention of tokens elicited an especially positive response in all the children, as did learning more about fire safety. As a group, we then decided that we wanted stickers to serve as the reinforcers. I then inquired whether anyone had ever been in a fire. One small boy waved his hand proudly, so I suggested that he share his experience with the group. With great enthusiasm, Jason described that his stove had caught on fire last winter. Jason further recollected that his mother had called the fire department and the firemen came to save his house from burning down. After the other children indicated that they had not been in a fire before, I asked whether anyone had ever been trained in fire safety skills. Ben raised his hand slowly, so I asked him to tell us who had trained him and how. Ben told us that his father had taught him to climb out of his bedroom window if he ever smelled smoke. Jason then said that they had practiced this safety procedure only once. Other than fire drills, none of the other children remembered having ever been trained.

Now we were ready to begin learning the anticipated safety skills that I had mentioned earlier. I explained to the children that when there is just a little smoke in their room, it might be safe to leave through the bedroom door, down the stairs, and out through the front door of their house. After reciting the ever-familiar cue (It is late at night and there is just a little smoke in your room. You are not coughing, and your eyes are not burning. You hear a smoke detector "bzzzzzz"), I proceeded to perform behaviorally and verbally the 11 appropriate steps in this situation. My crawling around on the floor had completely captivated my audience. When completing the sequence of steps, I announced assertively, "I'm done" to indicate to the children that there were no more behavioral steps.

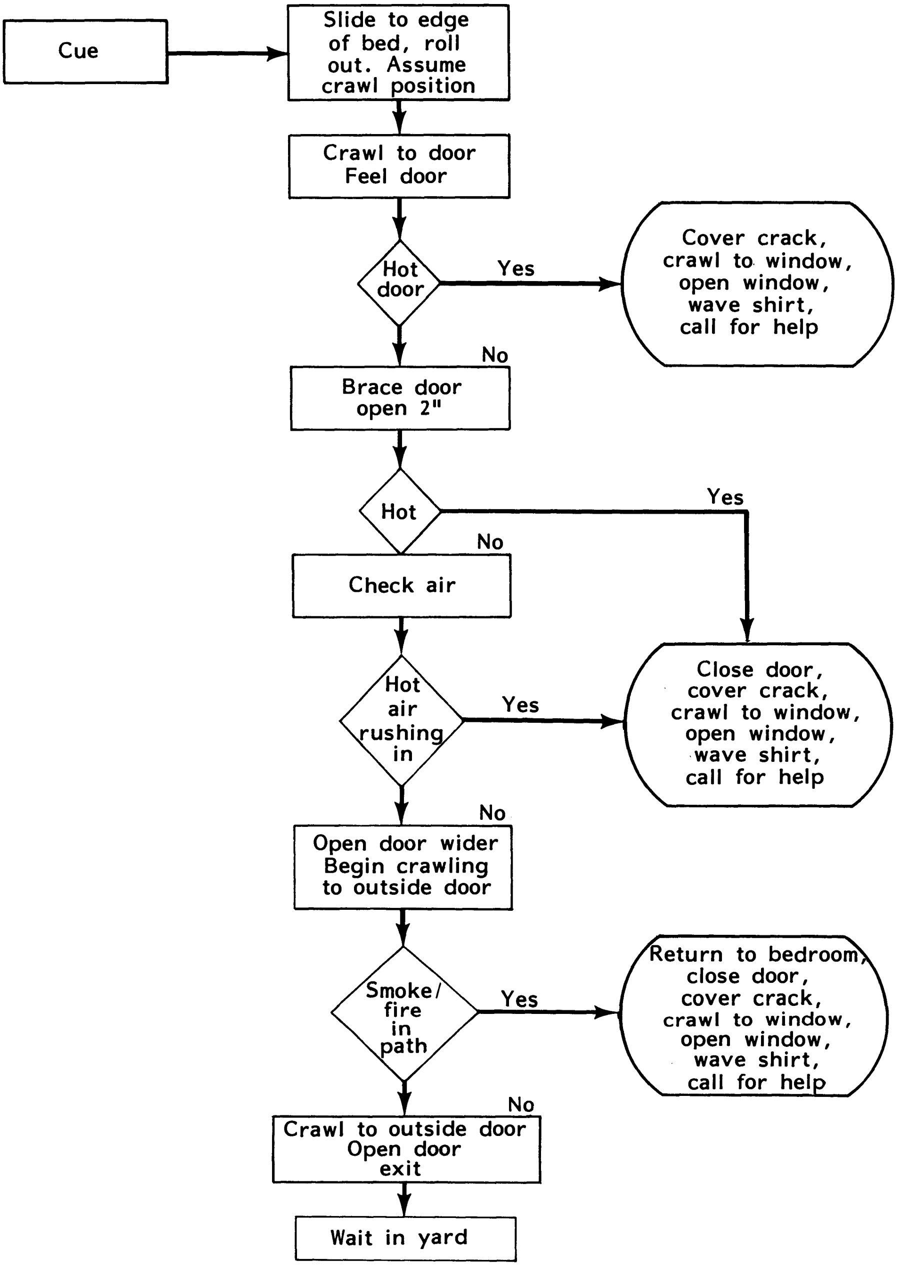

FIGURE 1. Flowchart analysis of emergency escape skills in the home during the night. (◇) Decision points, (□) responses, (⬭) termination points.

The children were pleasantly surprised when they found out that each of them would have an opportunity to perform the newly learned skills. I chose Jennifer to be first, because she gleamed with enthusiasm. I was certain that other children would model her enthusiasm. Throughout each of the children's attempts, I positively reinforced correct behaviors verbally as well as with tokens. When Ben had difficulty bracing the door, I got into a crawl position and demonstrated the step. He then tried again but still had some difficulty. Once again, I demonstrated the step very slowly and clearly. He was then able to perform this step correctly. At this point, each of the four children had earned one token, and all were ready to proceed to the next phase of the procedure.

I then announced that I wanted each child to rehearse the steps two times. This time Amy was first. After reading the cue, I asked Amy to "show me what you would do first." After rolling out of bed, I stopped her and asked for her to "show me what you would do next." We proceeded in this manner until she had completed all of the steps. I reinforced Amy's performance (both verbally and with tokens) and told her that I wanted her to rehearse once more. She successfully followed my instructions, as did all the other children during their respective turns.

It was time now for the final section of the training procedure where we discussed the rationale for why it is important to do each step. I asked the children to listen carefully and raise their hands if they knew the answer to a question ("Why should you roll out of bed and get into a crawl position?"), after which I held up a small diagram/picture of the situation. Jennifer's hand flew into the air, so I chose her to answer the first question. Her answer, "so you can see and breathe better," was correct, so I reinforced her verbally. I read the correct answer as it was stated in the script, after which I allowed the children time to repeat the phrase, "Firemen tell us that you should roll out of bed and get into a crawl position because it helps you to see better and breathe better."

The next question, "Why does rolling out of bed and getting into a crawl position help you to see better and breathe better?" was a bit more thought-provoking, and Jason answered the question incorrectly. I corrected his answer and then had all of the children repeat the correct answer (i.e., "Well, Jason, that was a good try but this is the correct answer: rolling out of bed and getting into a crawl position helps me to see and breathe better because smoke rises to the ceiling and makes it hard to see and breathe."). We continued in this fashion until we had discussed all the questions. I reinforced the children throughout the entire session for correct answers as well as for paying close attention.

The end of the first day of training had come, and so I thanked the children. I told them that I would see them the very next day to learn what to do when hot air rushes in the bedroom door. We went through this second situation on the next day and the third situation, fire blocking the path, on the third day. Each situation was trained in a manner similar to that of the first day of training. The children responded very well to the program and told me that they enjoyed it very much. After the third training session, the children were allowed to trade in all their tokens for stickers. Soon after, the children underwent a post-test to assess the behaviors learned during the training program in the same manner as the pretest. They were also asked to fill out the same questionnaires as they did at pretest to determine any reduction in the level of fear. Three-month and 6-month follow-ups were also obtained to determine the degree of response maintenance in the behaviors as well as in the reduced levels of fear.

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CHAPTER 25

Psychology and Pediatrics

The Future of the Relationship

DONALD K. ROUTH

INTRODUCTION

It was my assignment in this chapter to provide comments about how the field of clinical behavioral pediatrics is likely to develop in the future. The chapter was difficult to plan for two reasons. One, it was a bit unclear whether the particular term *clinical behavioral pediatrics* would communicate most accurately what I hoped to say. This field is still unsettled enough in its terminology that a variety of labels are used for overlapping parts of it: developmental pediatrics, pediatric psychology, and behavioral pediatrics, to name a few. And not all people who use the same terms mean the same things by them. The second reason the chapter was hard to plan was that it called for predicting the future of a rather fast-changing interdisciplinary field. I realize that psychologists are supposed to be experts at predicting behavior, but my track record in predicting the course of the relationship between psychology and pediatrics is no better than anyone else's (e.g., Routh, 1980b). What I have done in the chapter, therefore, is to try to describe some of the different models that have been discussed for the relationship of the two disciplines. Table 1 outlines the main models that have been proposed. In discussing each model, I note certain predictions that have been made about the development of the field as a whole and try to evaluate the extent to which these have actually come to pass.

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TABLE 1. Models of the Relationship of Psychology and Pediatrics

Model	Reference
Individual Practitioners with Common Interests: Clinical Psychology and Pediatrics	Witmer (1896)
Two Disciplines in a Single Skull: Developmental Pediatrics	Gesell (1948)
Individual Researchers with Common Interests: Child Development	Anderson (1930)
Clinical Child Psychologists in a Pediatric Setting: Pediatric Psychology	Wright (1967)
Interdisciplinary Researchers and Practitioners: Behavioral Medicine	Schwartz & Weiss (1978)

INDIVIDUAL PRACTITIONERS WITH COMMON INTERESTS: CLINICAL PSYCHOLOGY AND PEDIATRICS

Probably the first person to write about the relationship between psychology and pediatrics was Lightner Witmer, the founder of clinical psychology. Witmer (1896) wrote an editorial in the journal *Pediatrics* (he was, in fact, on its editorial board at the time) on "the common interests of child psychology and pediatrics." That same year (1896), Witmer set up a psychology clinic at the University of Pennsylvania in which he worked with children, primarily those with academic difficulties or mental retardation, though he was interested in children's emotional and behavior problems as well. Witmer often worked collaboratively with physicians, including pediatricians, and also with school teachers. He did not, however, as far as I am aware, make any explicit predictions about the future relationship of pediatrics and psychology. He merely noted that the two types of practitioners have a common interest in children's cognitive, behavioral, and emotional problems. (I hope this will always be so.)

TWO DISCIPLINES IN A SINGLE SKULL: DEVELOPMENTAL PEDIATRICS

The next historic figure to be considered in any discussion of the relationship of psychology and pediatrics is Arnold Gesell. He received a Ph.D in psychology in 1906 at Clark University under G. Stanley Hall (the founder of child psychology) and an M.D. at Yale in 1915. He identified himself professionally with pediatrics throughout his subsequent career, though he was a researcher rather than a practitioner. He founded the Yale Clinic for Child Development in 1911, the forerunner of the present-day Child Study Center there (Senn, 1975). Gesell was a meticulous research worker and contributed to the field a large array of findings concerning sequences of development in infancy and early childhood, conceived as the expression of underlying biological growth processes. Gesell's growth norms captured the attention, not only of pediatricians (who began to use them in their clinical evaluations), but of the general public as well. Gesell had a role in training some psychologists, notably Elizabeth Lord who did some of the early research on the behavioral sequelae of lead poisoning in children (Byers & Lord, 1943). However, Gesell wished his work to be considered medical rather than psychological. For example, he would only allow physicians to enter the training program to administer the standardized Gesell developmental examinations (Senn, 1975, p. 34).

At about the time of his retirement, Gesell (1948) made a number of statements about how what he called "developmental pediatrics" should be conceptualized. He defined this as "a form of clinical medicine which is systematically concerned with diagnosis and supervision of child development, normal and abnormal" (p. 331). He noted that shortly after the American Board of Pediatrics was established in 1935, it set up a basic requirement for specialty certification that included knowledge of growth and development. In contemplating the future of developmental pediatrics, Gesell was "tempted to paint it in utopian colors" (p. 333). "It is difficult to see," he continued, "how any other branch of clinical medicine is in a position, in itself or as a coordinator, to take over the vast work of mental hygiene implicit in the pediatric supervision of infants and young children" (p. 333). Besides growth, development, and mental hygiene, Gesell considered developmental pediatrics to include a concern with psychosomatic medicine. (He did not have much to say concerning the role of psychology or psychiatry in relation to these areas, however.)

What about training? Gesell recommended that medical school coursework include more genetics and embryology for all students, and thought that interns and residents wishing to become development pediatricians should have 1 or 2 years of "intimate participation in a diagnostic and guidance service dealing with the whole gamut of developmental problems in their human context" (p. 333).

How influential has Gesell been as an example or as a prophet? There have certainly been at least a few pediatricians since his time with both an M.D. and a Ph.D. in psychology, and their influence has been disproportionate to their number. One well-known pediatrician with an M.D.–Ph.D, for example, was the late Herbert Birch, who did research relating to reading disabilities, temperament, and brain damage in children, among other topics. Of the 291 individuals who (as of 1986) were members of the Society for Behavioral Pediatrics, only seven (or about 2%) were M.D.–Ph.Ds, including Bonnie Camp of the University of Colorado Medical School, and Marvin I. Gottlieb, the former editor of the *Journal of Developmental and Behavioral Pediatrics.* (It is not known how many of the other five of these individuals had their Ph.D. in psychology, so the 2% figure should be regarded as an upper bound estimate.) The 1987 *Directory* of the Society for Research in Child Development lists more than 4200 members. Seventy-five (about 2%) of these are identified as pediatricians, but only four of these were listed as having the Ph.D. in psychology in addition to the M.D. (and three of these are also members of the Society for Behavioral Pediatrics). Wright (1967), the well known pediatric psychologist, optimistically predicted that "the psychologist pediatrician will be a scholar–professional trained both as a physician and as a behavioral scientist. He will emerge from the growing number of medical school programs that now combine the residency in a medical specialty with the Ph.D. in a related academic area" (p. 323). However, during the late 1960s, when the University of Iowa was funded by the National Institute of Child Health and Human Development to train M.D.–Ph.Ds, it was not possible to find even one appropriate candidate for these particular trainee positions (Routh, 1969). The idea of such an M.D.–Ph.D program is still quite alive, however. Its most recent reincarnation is described by Julius Richmond (1985) as a program combining the M.D. with a Ph.D in the social sciences under the auspices of the Department of Social Medicine and Health Policy at Harvard. The content of this program includes material from the neurosciences, cultural anthropology, sociology, and psychology, conceived as the basic science building blocks of developmental pediatrics.

In recent years, a somewhat separate specialty of developmental pediatrics has begun to emerge centered around the care of mentally retarded and developmentally disabled children. There was an impetus to the emergence of this field from the resources made available to it during the time John F. Kennedy was President of the United States, for example, federally funded mental retardation research centers and university-affiliated facilities. An organization of developmental pediatricians has been formed, with its founders including well known individuals such as Arnold Capute of Johns Hopkins University. In a statement presented by Cohen (1985) at a conference in Easton, Maryland, the question was raised whether a distinction ought not to be maintained between "developmental" and "behavioral" pediatrics. Cohen said that he thought developmental pediatrics had established a more firm identity within the practice of pediatrics and a more formalized training structure. He noted that developmental pediatrics had a constituency in the families of the developmentally disabled and a base of funding support stemming from this. As he put it, "why then should we merge with the new behavioral specialists who now come to town, particularly when many of them have displayed a limited interest in children with disabilities" (p. 213).

Others, such as Julius Richmond (1967), have a much broader view of the scope of developmental pediatrics. In this much cited paper, Richmond elaborated upon the theme of child development as a basic science for pediatrics. He noted that some of the original child development institutes in the United States were established under medical auspices, for example those administered by Alfred Washburn in Denver, Harold Stuart at the Harvard School of Public Health, and Lester Sontag at the Fels Institute in Ohio. He called for a new strategy "for incorporating teaching and research in child development into the mainstream of pediatrics" (p. 656), stating that this would necessitate the establishment of postresidency fellowships in child development for pediatricians. He noted that a few fellowships of that kind were already available. This fellowship model has proved more feasible than the notion of M.D.–Ph.D training. Friedman (1970) noted that the 1969 listing of fellowships appearing in the *Journal of Pediatrics* included 16 programs in behavioral sciences, or 2.1% of the fellowships offered. Yancy (1975) noted that the 1973 list of fellowships appearing in the same journal listed 86 programs in the behavioral sciences and related fields, or 9.4% of the programs offered. Presumably even more such programs are being offered today.

INDIVIDUAL RESEARCHERS WITH COMMON INTERESTS: PSYCHOLOGISTS AND PEDIATRICIANS IN THE SOCIETY FOR RESEARCH IN CHILD DEVELOPMENT

One conventional model for the relationship between psychology and pediatrics is simply that the psychologist does research on child development, and some of the implications of these research findings are then be applied in practice by the pediatrician. One of the earliest expressions of this model was a paper by John Anderson (1930), the founding director of the Institute of Child Development at the University of Minnesota. Anderson noted that the field of child psychology was more likely to develop by gradual increments rather than by dramatic breakthroughs. He noted that its contributions to pediatrics at that point were relatively modest but included intelligence testing and some principles on which advice on childrearing to parents could be based.

Of course it is also possible that a pediatrician, even without formal Ph.D. training or a fellowship in the behavioral sciences, could contribute to the scientific study of child development. The pediatrician C. Anderson Aldrich (1934) demonstrated how careful records including behavioral as well as health information could be kept even in a private pediatric practice and showed how they could contribute to longitudinal child development research. The story is told for example of an infant described by Aldrich 6–8 hours after birth as the "terrible-tempered Mr. Bang" who later became "a prominent tycoon in Chicago with exactly that caricature" (Senn, 1975, p. 59). The award given by the Section on Child Development of the American Academy of Pediatrics is called the C. Anderson Aldrich Award.

The main theme here is that research can be done by either psychologists or pediatricians on problems of interest to both. The frequently cited paper by Jerome Kagan (1965) on "The New Marriage: Pediatrics and Psychology" fits this model. Kagan expected this marriage of research interests to produce "a corpus of cognitive products," specifically (1) research on the relationship between prenatal and perinatal anomalies and later infant or preschooler behavior, (2) work on the early detection of severe childhood disturbances such as schizophrenia, (3) research on the early detection of psychosocial problems, and (4) research on behavior therapy, e.g., for children's phobias. Indeed, research on all of these topics has continued. Kagan's own research on infant visual attention prefigured some of the contemporary advances in the assessment of intelligence in infants (e.g., Fagan, 1984).

CLINICAL CHILD PSYCHOLOGISTS IN A PEDIATRIC SETTING: PEDIATRIC PSYCHOLOGY

I was recruited into pediatric psychology in 1966–1967, when I was a psychology intern at the University of Oklahoma Medical Center. The most influential of my clinical supervisors there was Logan Wright, a psychologist in the Department of Pediatrics at Oklahoma who originated the term "pediatric psychologist" (Wright, 1967). According to Wright's concept, a pediatric psychologist was a psychologist delivering clinical services to children in a nonpsychiatric medical setting. Indeed, the Society of Pediatric Psychology later defined its membership in terms of work setting—it was an organization for clinical psychologists who worked in such settings as children's hospitals, developmental clinics, and group pediatric practices. In fact, other than its identification with the medical setting, pediatric psychology resembles the concept attributed to Witmer (1896) of common interests in service delivery to children by psychologists and physicians. In any case, the Society of Pediatric Psychology founded in 1968 by Wright, Lee Salk, and Dorothea Ross, is now Section 5 of the Division of Clinical Psychology of the American Psychological Association, and full membership in it is open only to psychologists eligible for membership in the Division—typically persons with doctoral degrees from APA-approved clinical psychology programs and with APA-approved psychology internships. The organization is somewhat narrow in that it leaves out pediatricians and other physicians, developmental psychologists, and many kinds of research psychologists and behavioral scientists.

One of Wright's (1967) statements about pediatric psychology was that "ideally the pediatric psychologist should feel that cognitive development represents an area in which referral questions can best be answered, and he should welcome the opportunity to respond at a higher level of confidence than is usually achieved in many other areas of assessment" (p. 323). My own employment as a pediatric psychologist after internship was primarily in interdisciplinary medical settings concerned with mental retardation, learning disabilities, and related behavioral problems of children, and much of my research concerned the related problem of hyperactivity in children. The two physicians who had the greatest influence on my thinking, Gerald Solomons and Harrie Chamberlin, could both be best described as developmental pediatricians in the sense described above. At the time, cognitive disability seemed like the mainstream issue in pediatric psychology to me, although it has since been partly shunted aside by the field in its concern for more direct relevance to children's health.

Later, a decade after my first initiation into the field, I had the opportunity to serve as editor of the *Journal of Pediatric Psychology*, a publication of the Society of Pediatric Psychology, during its formative years (1976–1982, volumes 1–7). One of the interesting aspects of editing a journal in a new specialty area such as this was the chance to watch the area try to define itself. Indeed, at one point, I tried to do some citation analysis of the early issues of the journal to see who the authors of articles it published considered the most influential persons in the field (Routh, 1980a). The individuals cited included five psychologists, three child psychiatrists, and two pediatricians. Only one person on the list was unequivocally identifiable as a "pediatric psychologist," namely John J. Spinetta, who was recently given the research award of the Society for his work on the psychological aspects of cancer in children. One of the psychologists, Tiffany Field, is best known as a developmental psychologist; another, Byron Rourke, as a child neuropsychologist; and the other two, Keith Conners and Gerald Patterson, as research clinical psychologists. The presence of three well known psychiatrists on the list (Magda Campbell, Leo Kanner, and Michael Rutter) emphasizes how important traditional child mental health issues were from the outset in pediatric psychology, despite its identification with "nonpsychiatric" settings. Of the two pediatricians, one, T. Berry Brazelton, is well known for his research on infant development, and the other, C. Henry Kempe, for his pioneering work in the field of child abuse and neglect. So the actual content of the field of pediatric psychology, as indexed by this preliminary citation analysis, suggested somewhat more breadth than did Wright's original concept of it.

Let us look at some of Wright's (1967) other predictions concerning pediatric psychology to see how accurate they proved to be. Wright said that "Ideally, the pediatric psychologist is a person who is competently trained in both child development and in the child clinical area" (p. 323). Interestingly enough, a recent survey of members of the Society of Pediatric Psychology by LaGreca (personal communication, May, 1987) showed that this kind of graduate training, namely a joint Ph.D program in developmental and clinical child psychology, was still considered ideal by the respondents. Whether there are increases in the number receiving this kind of training is, however, uncertain.

Wright (1967) voiced the hope that pediatric psychology would emerge as a frontier for research in the areas of the prevention of emotional disorders and the study of effective personality. Although I do not have quantitative measures of research emphasis in the field, it does not strike me that either of these has been a conspicuous emphasis in pediatric psychology research. Prevention of health problems, e.g. accidental injuries, has however, become a major research focus.

Wright stated that "some formal organization such as a special interest group within existing divisions of the American Psychological Association (for example, Division 7 or Division 12) would seem to be in order" and thought that a "newsletter or other forms of intragroup communication" should be brought into existence (1967, p. 324). These predicted events definitely came to pass with the formation of the Society of Pediatric Psychology (which started with 300 members and now has about 800) and the founding of the *Journal of Pediatric Psychology*.

Finally, Wright (1967) wrote that he thought "pediatric psychology will not soon attain a sufficient identity or an extensive enough body of knowledge to warrant anything like a 1- or 2-year postdoctoral program" (p. 324). I am sure that Wright was happy to be proved incorrect in this prediction in that a number of 1- and 2-year postdoctoral programs in pediatric psychology now appear to be thriving.

INTERDISCIPLINARY RESEARCHERS AND PRACTITIONERS: BEHAVIORAL MEDICINE

An important conference on behavioral medicine was held at Yale University in 1977. As described in Schwartz and Weiss's (1978) revised definition (developed at a meeting sponsored by the Academy of Behavioral Medicine Research), behavioral medicine is "the interdisciplinary field concerned with the development and integration of behavioral and biomedical science, knowledge and techniques relevant to health and illness and the application of this knowledge and these techniques to prevention, diagnosis, treatment and rehabilitation" (p. 250). Since the most frequent causes of death in adults are heart disease, stroke, and cancer, behavioral medicine researchers have been most concerned with the reduction of behavioral risk factors for such diseases, for example cigarette smoking, overeating, lack of proper exercise, Type A behavior pattern, and so on. For children, the number one cause of death is accidental injuries, which also has many identifiable behavioral components.

My personal contact with the field of behavioral medicine came through service as a reviewer (1980–83) and subsequently as chairman (1983–85) of the Behavioral Medicine Study Section of the National Institutes of Health. This is one of the many NIH initial review groups that evaluates grant applications for scientific merit before they are considered for funding by the various institutes, such as the National Institute of Child Health and Human Development (the main one concerned with pediatrics), the National Heart, Lung, and Blood Institute, and the National Cancer Institute. Reading grant applications and going on site visits certainly provides a unique perspective on trends in a broad interdisciplinary area.

I am not sure precisely when the term behavioral pediatrics was first written, but it seems to have been in common use well before there was much talk about behavioral medicine (e.g., Friedman, 1970). One force driving the rapid development of behavioral pediatrics was changing the pattern (and the changing economics) of pediatric primary care. For example, Roghmann, Hoekelman, and McInerny (1984) documented changes over 30 years in one well-studied community, Rochester, New York. During the late 1970s, for example, as compared with the 1960s, there were fewer children, and much less acute care per child, so that pediatricians were freed up to focus increasingly on preventive, developmental, and psychosocial needs as well as on the care of chronic disease in childhood. Problems of manpower shortage and inadequate access to care for inner city residents had long since disappeared.

Haggerty (1982) stated that the goal of behavioral pediatrics training was to develop pediatricians who remained identified as pediatricians but who became skillful in dealing with the problems of children's behavior. He indicated that while a few training programs were started with this goal in the early 1970's, the major program in behavioral pediatrics was initiated by the W. T. Grant Foundation in 1977. Eleven residency programs were given funds to support teaching staffs in behavioral pediatrics as defined above. The training was to be mandatory for all residents and not restricted to a few interested ones. The concept of behavioral pediatrics came into even greater prominence after the Task Force on Pediatric Education published its report on *The Future of Pediatric Education* in 1978. In this report, the number one priority was for changes in pediatric education was in the area of "biosocial and developmental problems, such as early family adjustment difficulties and school failure, as well as those deriving from abnormal growth and development in the child who is chronically ill or is socially, mentally, or emotionally disturbed" (p. 20). According to Green (1983), the American Board of Pediatrics now requires that in order for a residency program to be accredited, behavioral and developmental aspects of pediatrics be adequately addressed in its training.

Richmond (1985) traces the growth of behavioral pediatrics as follows: In successive 5-year periods from 1960 to 1985, the following number of books were published on behavioral pediatrics: 0, 1, 0, 4, 13, and 24. The number of journals covering behavioral pediatrics topics grew from 1 in 1930 to 24 in 1985. The percentage of articles in *Pediatrics* concerned with behavioral pediatrics was 9% in 1950, 6% in 1960, 16% in 1970, and 16% in 1980. Another indication of the growth of the field cited by Richmond includes the formation of the interdisciplinary Society for Behavioral Pediatrics. (Among its founders were the training directors of the original 11 residency programs funded by the W. T. Grant Foundation).

A National Conference on Behavioral Pediatrics was held in Easton, Maryland, in March, 1985, sponsored by the Society for Behavioral Pediatrics and the U.S. Division of Maternal and Child Health. One of the papers, by Friedman (1985) discussed the role of psychology in behavioral pediatrics. Friedman predicted that the role of psychology would continue to increase in relationship to service, teaching, and research; other fields, such as social work, child life, and nursing, would be involved primarily in relationship to service provision and teaching; and child psychiatry would continue to be involved in helping deal with the more severe behavioral and emotional problems presented by patients.

The growth of behavioral pediatrics was shaped much more by forces internal to pediatrics than by the broader conceptualization of behavioral medicine. However, psychology seems to have been much more affected by the Yale Conference and related events. Psychologists interested in behavioral medicine soon organized themselves into the APA Division of Health Psychology, which now publishes a journal, *Health Psychology*. These organizations (e.g., the Society of Pediatric Psychology) fail to include physicians as full members and thus are unrepresentative of the field of behavioral medicine. (There is an interdisciplinary Society of Behavioral Medicine, which includes physicians as well as behavioral scientists.) Unlike the Society of Pediatric Psychology, however, the Division of Health Psychology has welcomed nonclinical members, for example, many physiological and social psychologists and in fact has been dominated mostly by this academic and research constituency. The Division has a special-interest group in what might most aptly be defined as child health psychology (it welcomes researchers as well as practitioners).

Health psychology and pediatric psychology have recently had a considerable impact on each other. In 1986, the *Journal of Pediatric Psychology* devoted one special issue to disease prevention and health promotion in children. That same year, *Health Psychology* published a special issue on child health psychology and began a general increase in the number of child-oriented manuscripts it published. The most commonly cited author in the *Journal of Pediatric Psychology* in 1986 was Michael C. Roberts, especially his work on the prevention of accidental injuries. One interesting thing about such research is that although it is indisputably concerned with child health, the research and the interventions it involves do not involve physical examinations, medication, or surgery and are generally not carried out in a "pediatric setting" at all but rather in a school or other community locations. Thus, though Roberts is a well known pediatric psychologist, he does not generally work in a pediatric setting. Pediatric psychology is being redefined in terms of impact, not setting. The most frequently cited child researcher in the 1986 volume of *Health Psychology* is Karen Matthews, a personality–social psychologist studying the Type A behavior pattern in children, which is presumably a predictor of cardiovascular risk for these children over the long term. Like risk for injury, Type A is a condition for which a child would not normally be taken to a pediatrician. In short, pediatric and child health psychologists have been moving away somewhat from their previous level of direct contact with pediatricians.

If the Schwartz and Weiss (1978) revised definition of behavioral medicine were simply extrapolated downward to childhood, behavioral pediatrics would concern itself only with the biobehavioral aspects of child health and illness. In fact, as we have seen from this chapter that behavioral pediatrics actually concerns itself with a far broader spectrum of issues, including normal child development, developmental disabilities, and the behavior disorders of childhood as well as behavioral aspects of child health and illness.

THE FUTURE

The time has come for me to take my assignment seriously and to try to look into the future. I do not promise that my predictions are any more correct than when I have tried this on other occasions (e.g., Routh, 1980b). Five different models of the relationship of psychology and pediatrics have been presented. Can it be said that some of the models are more viable than others? No, I think not.

Clinical psychologists and pediatricians are going to go on having some common interests, probably more so as pediatricians become more deeply involved in children's development, behavioral, and emotional problems, and the behavioral aspects of physical illness.

Some M.D.–Ph.D types are going to be trained in both pediatrics and psychology in each generation, and although few in number they will make some of the more noteworthy contributions to the development of the field. I think the M.D.–Ph.D program at Harvard under the leadership of Leon Eisenberg (described by Richmond, 1985) sounds particularly exciting and hope that it succeeds in its goals.

Developmental pediatricians with fellowship training emphasizing developmental disabilities are also not going to go away soon. I think Cohen (1985) was correct in saying that they have a solid constituency in the parents of handicapped children and federal support in terms of funding from the Maternal and Child Health Program and others. Perhaps it should be added that there are also a significant number of research and clinical psychologists who have a particular identification with the field of developmental disabilities as well, who have the same constituency and base of federal support.

Research in child development will certainly continue in the future. It is indeed a basic science for pediatrics, as Richmond has stated, and also one for child practitioners in psychology. Child development research is dominated by developmental psychology, but pediatricians and members of other disciplines continue to be involved, whose importance is disproportionate to their relatively small numbers.

Pediatric psychologists will continue to thrive in the future, I think. Paradoxically, one of their meal tickets as practitioners will be the fact that the behavioral science aspects of pediatric practice are so inefficient in terms of time. Pediatricians in office practice are used to spending only about 15 min per child and cannot financially afford to extend this too much. Psychologists working in pediatric settings, who earn lower salaries, can therefore more easily spare the 30 to 45 min per session it might take to deal with a developmental, behavioral, emotional, or family problem presented by the child. Similarly, psychologists, social workers, and nurses are more likely than pediatricians to be able to spare the time needed for group parent meetings, which is an efficient way to address preventive issues.

Behavioral pediatrics is certainly doing well, too, and will expand in the future. It encompasses several diverse aspects. One of these is generic, in that the behavioral science aspects of the residency training of all pediatricians are receiving increasing emphasis. A second aspect is the necessary emergence of a group of academic pediatricians qualified to train these residents in the behavioral science aspects of the field. These faculty will not generally be psychologists or child psychiatrists because the residents need role models they perceive as pediatricians like themselves. The third aspect of behavioral pediatrics is its existence as an "interdisciplinary field concerned with the development and integration of behavioral and biomedical science," to quote the definition of behavioral medicine once more (Schwartz & Weiss, 1978, p. 250). Here, psychologists have a definite role both because of their knowledge of behavioral science and their research training. The particular area of psychology in which they were trained is less important than its applicability to the biobehavioral research problem at hand. They might or might not be clinically trained, but they must obtain the specific medical knowledge necessary to their research problems and must be able to get along in a medical environment—not always the easiest task, but one that can be very rewarding.

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