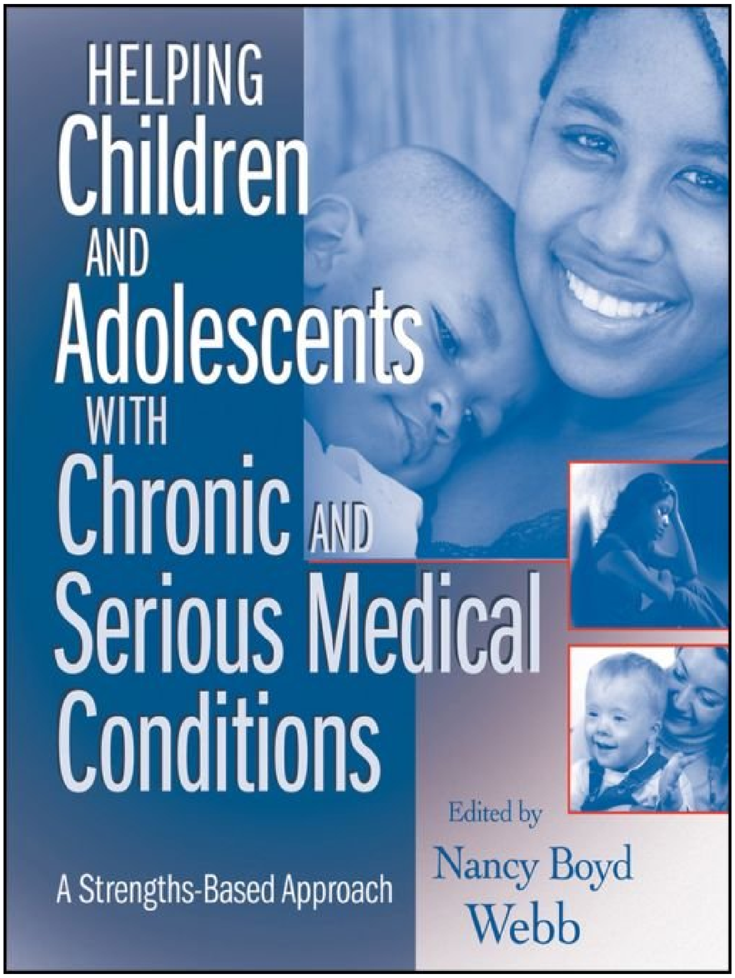
HELPING Children AND Adolescents WITH Chronic AND Serious Medical Conditions

A Strengths-Based Approach

Edited by

Nancy Boyd Webb



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Nancy Boyd Webb, Editor

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Summary: “Many practitioners lack the training to deal competently with acute and chronic health issues presented by their young clients and students. Providing an innovative inter-professional model, Helping Children and Adolescents with Chronic and Serious Medical Conditions provides a multi-disciplinary approach so that practitioners from a diverse range of helping fields, working in hospitals, out-patient clinics, agencies and schools, may be better equipped to foster children’s resilience and build on their emotional strengths. This is a vital tool for a broad range of health care professionals, including social workers, school counselors, play therapists, nurses, and many others”-Provided by publisher.
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To all the children and youth who manage to carry on their lives
despite serious health conditions . . .
and
to the professionals whose committed work with these youth
contributes to their resiliency and determination to live their lives to the fullest

Foreword

Barbara Sourkes, PhD

> If kids are normal, not sick, they like to be treated special. But if kids have a disease, they want to be treated normal.
>
> 11-year-old child (Sourkes, 1995, p. 82)

> I've had a closer relationship with my family than most other kids because I've needed them more these last years.
>
> 11-year-old child (Sourkes, 1995, p. 87)

These wise and incisive statements capture the essence of children's experience living with a serious medical condition. They long first and foremost to be seen as children, with the assurance that their identity remains larger than the "special" status of being a vulnerable patient. In fact, many of these children live a double life: They long for the normalcy of daily life and at the same time they live with the "abnormal" presence of illness (Sourkes et al., 2005, p. 370). From looking to feeling to being normal, the concept has implications for the child's sense of competence, coping, and self-esteem. The 11-year-old girl quoted in the epigraph continued: "Once you have a disease, people treat you as if you're not capable. Even though it's not true, it makes you feel really bad about yourself (Sourkes, 1995, p. 82).

Most of these children recognize the impact of their illness on the entire family, and instinctively reflect upon the child-in-the-family as a unit of its own. Each family has its own identity, strength, and vulnerability, and it is within this framework that the child struggles to withstand and integrate the illness. Children’s ability to cope is greatly influenced by their family—the individual and collective responses of its members. Under optimal circumstances, “the interior of the family assumes a central role in preserving the . . . [child’s] . . . psychological integrity” (Rait and Holland, 1986, p. 4).

The face of childhood illness is changing rapidly in the light of medical and scientific advances. Many diseases that were once uniformly fatal are now life-threatening in nature, with longer-term survival or even cure as an outcome. Chronic conditions that used to necessitate long-term hospitalization are now treated primarily on an outpatient basis. For those children who are facing death, hospice care has enabled many children to be at home for this last chapter. As a result of all these factors, children who are living with medical illnesses are far more visible in the community. It is therefore incumbent upon health and mental health professionals to broaden our concept of care to include the children’s reintegration into that wider world.

The newly emerging interdisciplinary field of pediatric palliative care encompasses many of these children. Palliative care is defined as comprehensive care of children with life-threatening conditions (i.e., where prognosis is uncertain). It focuses on quality of life for the child and support for the family, including respite and bereavement care, if appropriate. Pediatric palliative care covers a much broader spectrum than the traditional and narrow definition that referred almost exclusively to the (imminently) dying child.

Helping Children and Adolescents with Chronic and Serious Medical Conditions is an important contribution to the evolving literature in psychosocial aspects of pediatric conditions. It is particularly timely given the increasing attention to the interaction between physical and mental health. Furthermore, children's psychological distress is now more often conceptualized as a symptom that must be addressed and can be ameliorated. Dr. Webb has assembled authors from a broad range of disciplines (including social work, psychology, pediatrics, nursing, chaplaincy, child life) and settings (hospital, clinic, hospice, home, school) to address ways to enhance the quality of these children's lives, as well as that of their families.

The opening section of the book provides the foundation for all that follows. Dr. Webb stresses from the outset that these children and families are facing extraordinary challenges and that an optimal clinical approach should focus on their strength and resilience rather than on pathology. Furthermore, the experience of these children and families must be viewed from an ecological perspective: As the child is embedded in the family, so the family is embedded within a social, cultural, and economic context. Access to care is a critical issue, and barriers within the current health care system render children and families even more vulnerable. Also addressed in this section is the impact of the illness on the healthy siblings. These children live the illness experience with the same intensity as the patient and parents; yet all too often their needs are underestimated or neglected in the dramatic focus on the ill child. In the words of a group of siblings, “Don't brothers and sisters count too?” (Sourkes et al., 2005, p. 371).

The following sections of this book present a multifaceted portrait of clinical approaches: practitioners from a variety of disciplines who treat children with a variety of medical conditions across a variety of settings. The reader is struck by both the unique and overlapping nature of these interventions, a reflection of the need for specialization within an integrated and seamless continuum of care for these children. The focus on school as a primary setting for care (along with the medical and home environment) reflects how profoundly school defines the “normal” structure of children’s day-to-day lives. Its constancy can provide an anchor to the child who is coping with significant illness.

Helping Children and Adolescents with Chronic and Serious Medical Conditions provides a wellspring of knowledge, from the theoretical to the clinical. The many vignettes and transcriptions enrich immeasurably the reader’s understanding of the interventions and their broader applicability. The focus on the experience of the professionals who work with these children—the challenges, the sadness, the triumphs—adds a rich dimension to the volume.

Thank you for giving me aliveness. Six-year-old child

(Sourkes, 1995, p. 167)

“Giving aliveness” to children whose lives are impacted by illness is the overarching goal for all of us. Dr. Webb and her colleagues have contributed significantly to that mission in the pages of this book.

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PREFACE

In my 30 years of clinical practice as a play therapist with children I often encountered young people who were grappling with physical health problems in addition to the emotional and psychological issues that had prompted their referral. I remember vividly one nine-year-old boy who was having a lot of difficulty dealing with his parents' high-conflict divorce and his need to adjust to a new stepparent and step-siblings. One day when he was in my office describing to me his frustration at having to sleep in a stepbrother's room during a weekend visit and interact with this new sibling he didn't like, my client began to wheeze and gasp for air. I realized that he was having an asthma attack, but I had no idea what to do! His mother had dropped him off and would not return for another half hour. Fortunately, the boy pulled an inhaler out of his backpack and took some deep breaths, thereby relieving his symptoms. Although I had been working with this boy and his parents for more than a month, no one had ever informed me about his compromised health condition, and I immediately realized how the family stress over the divorce and remarriage was affecting his physical well-being. I also became aware that I had been remiss in not obtaining a health history when I took the boy's psychosocial history at intake, focused on detailed information about the family and about his academic and social adjustment. Unfortunately, this example is not unusual. Many children who are referred for help with their psychological difficulties also have accompanying health problems that interfere with their optimal adjustment in school, with peers, and within the family. Mental health practitioners must ask questions to learn about children’s physical and medical as well as their emotional status.

This example, like many of the cases in this book, illustrates how even a potentially life-threatening condition such as asthma can take a backseat when a child and his or her therapist are focusing on family issues. The same example could have been used with a youngster with juvenile diabetes. Medical conditions that are not immediately evident can nonetheless have a huge impact on the child’s quality of life, and it behooves therapists to be alert to a child’s effort to ignore or minimize a serious health problem. In the case described here, it would have been incumbent on the therapist to have spoken directly to the boy about his medical status, about how he manages in school and after school, and to tell him that she wants to get updated information from his parents about it, since that could be important in her efforts to help him.

The intent of this book is to help practitioners better understand the stresses of children and adolescents, as well as their families, who must find a way to adjust to their youngsters’ physical constraints related to their particular medical condition at the same time they are coping with other emotional pressures. It will serve as a resource for the various professions that work with medically compromised children and adolescents in settings such as hospitals, outpatient clinics, and schools. Because the content of the book focuses on the emotional component of illness for the youth and the family, it will help practitioners understand the impact of ongoing stress as it impacts the young person’s usual developmental trajectory.

When acute or chronic health problems emerge in infancy, or later, they may seriously derail a child’s developmental progression and create daunting problems for the young person and his or her family. This book illustrates the important collaborative role of social workers and other practitioners in helping such a chronically or acutely disabled young person and his or her family achieve the best quality of life possible under the reality of the specific circumstances. Grounded in a strengths-based perspective as it pertains to bio, psychosocial, developmental, and ecological factors. The book promotes ways to help the youth and the family focus on abilities and possibilities rather than on the limitations that accompany acute and chronic health conditions. The book will serve as a resource for social workers and practitioners in medical, school, and community settings where medically compromised children participate in educational and recreational programs and encounter health-related procedures. For example, most children who have asthma and diabetes attend school and engage to the best of their abilities in the regular routine, despite their need for medication, an inhaler, and/or other types of assistance. Children who are seriously disabled may require special education programs. Still other children with previously healthy backgrounds may suffer acute heath crises, such as accidents that require hospitalization, followed by periods of physical therapy and other remediation. Social workers, child life specialists, and school counselors often work together in these situations to facilitate the youth’s optimal adjustment. This book highlights the separate and collaborative roles of these professionals on behalf of youth coping with serious health and medical challenges. The role of interdisciplinary collaboration is emphasized because professionals from different specialties must share the complex challenge of helping medically compromised children and adolescents at home, at school, and in the community, as well as in the hospital.

The book surveys the range of psychosocial, familial, and clinical services that social workers and other practitioners provide for children and adolescents and their families who are coping with various acute medical and health crises and ongoing conditions.

Part 1 provides an overview and theoretical framework for collaborative practice. Part 2 highlights the special contributions of practitioners in different settings who are specialists in the different areas that provide services to youths with acute and chronic medical conditions. The chapter authors in this section discuss the explicit role and contribution of their particular profession and its approach to helping. Chapters in Part 3 demonstrate the special challenges and issues that are associated with chronic medical conditions at various stages of the life cycle. Part 4 focuses on acute health crises and the need for interprofessional collaboration in work with the young person and the family. In order to fully understand this challenging helping task, the book’s content reflects both general topics, such as dealing with ongoing stress, as well as very specific subjects, such as preparing a child for a surgical procedure. A strengths and empowerment philosophy integrates the various chapters with their unified emphasis on helping young people achieve optimal functioning, as outlined in Chapter 18.

This book will be an important resource in advanced college courses that train students to work with medically compromised children and adolescents in settings such as hospitals, outpatient clinics, and schools. At least three professions will find the book valuable as a required text in courses related to health, young people, and families. The professions are social work, child life, and school psychology and counseling. Pediatric nurses, pediatricians, and pastoral counselors will benefit from the content dealing with the emotional component of illness, and special education teachers will also appreciate this detailed focus on the young person’s inner life and struggles to cope with various medical limitations.

The book covers basic information such as establishing relationships and helping clients accept restrictions while striving for as much healthy functioning as possible. It also deals with the unique situation of stress on the family system and the various stages of acceptance of a medical diagnosis, including the management of terminal illness. Cultural, ethical, and spiritual factors are emphasized as applicable to coping with life-and-death issues and to the numerous losses involved in medical situations.

As previously indicated, my interest in this topic grew from my outpatient child therapy practice, in which I encountered youths with medical conditions that were complicating their lives. My own medical experience at the time I initially proposed this book consisted of three different hospitalizations (two for childbirth and one for a broken ankle). It is ironic that in the six-month interval since I delivered the manuscript to the publisher I have had three additional hospitalizations. These have been for more serious conditions and have given me the opportunity to ponder how a young person might experience a hospitalization that potentially could change his or her life in a major way. My own sensitivity to this topic has increased manyfold as a result of my recent personal experience, and my hopes for the book have expanded as I have become more aware of its potential to reduce anxiety and increase adaptation. Hopefully, this will be a useful resource that will help practitioners more effectively help children and adolescents survive and thrive despite their serious medical conditions.

Nancy Boyd Webb

Acknowledgments

I am happy to take this opportunity to thank some of the people who have contributed to this book, although it probably never is possible to identify all the people, programs, and resources on whom the authors and I have drawn. An edited volume relies on the expertise of many individuals, and its value may be directly related to the different viewpoints and perspectives represented by the various chapter authors. Since this book is intended to demonstrate collaboration among different professionals, I am very grateful to this group of chapter authors who agreed to write about their specialized roles in helping medically compromised young people. My own circle of professional contacts has widened considerably as a result of working with this group of specialists, and, despite our different backgrounds, I became acutely aware of our unifying purpose in providing services to medically ill youth.

All of the authors cooperated in following my detailed chapter outline and completed the necessary revisions in a timely fashion. An edited book such as this moves at the pace of the slowest author, and although there were bumps along the way, we did manage to submit the edited manuscript within a reasonable time frame. I thank all the authors most genuinely for their willingness to share their specialized expertise for the overall good of the various helping professions that will rely on this book for information and guidance.

In addition I want to mention specifically my gratitude to the people at Maria Ferrerea Cancer Center in White Plains New York for their willingness to permit me to visit their outstanding program and to attend a staff meeting. The helpfulness of Rose Bartone, MSW, in facilitating this was especially appreciated.

All of the clinical cases used to illustrate various situations and interventions have been disguised. Some are composite cases, and others are used with signed permissions of parents who want their child’s experiences to be used to help others. We are grateful to them.

On a personal level, I wish to thank my husband, Kempton, for his constant support and understanding. He transports my boxes of files, books, and office machines to my work places in Vermont and Florida, and he often responds to my request that he read a paragraph about which I want some independent input. He helps keep me grounded and happy.

This is my first experience working with the staff of John Wiley & Sons, and I have found them to be unfailingly responsive and professional in all our undertakings. I thank the dozens of individuals involved in the production process and look forward to having this book come into print so that it can add to the process of helping medically compromised children and youth.

Part I

Overview and Introduction: Theoretical Framework for Collaborative Practice

Chapter 1

When a Young Person’s Health Becomes Problematic

Nancy Boyd Webb
Rose A. Bartone

In the best of all possible worlds children would not develop serious health problems. We associate youth with vigor, energy, and well-being. Whereas all parents expect their children to acquire an occasional cold, earache, stomachache, or even a childhood disease such as chicken pox, they typically do not consider the likelihood that their child will develop a serious illness that has no cure and that will require continuous adaptation due to compromised bodily functioning. Similarly, young children, who are normally egocentric and bursting with feelings of strength and invulnerability, are even less likely to understand or accept the constraints of a serious illness or disability. The child thinks that older people sometimes get sick and have to go to the hospital, but not “kids like me.” Therefore, the first challenge in working with medically compromised youth and their families is to help them deal with their initial fear, denial, and sense of unfairness in having to cope with all the pain and disruptions that accompany a serious health condition.

This book presents helping approaches to assist young people and their families handle in a positive manner the stresses involved in living with an illness or disability. Some conditions are evident at birth, and others may arise in early or later childhood or adolescence. The chapter authors discuss the multiplicity of factors that impact the coping ability of the child and family as they struggle to adapt to different acute and chronic health conditions, some of which may be life-threatening. Selected helping approaches that encourage positive attitudes and stimulate family and individual strengths are presented, together with developmental considerations that influence the patient, his or her siblings, and the parents.

Interprofessional Collaboration

Because helping a medically compromised child or adolescent inevitably involves input from a variety of professionals in different settings over many years, this book emphasizes the importance of interprofessional collaboration. Pediatricians, teachers, social workers, pastoral counselors, child life specialists, nurses, and many others typically are involved in any single health crisis. Part 2 of the book highlights the separate and collaborative roles of different professionals on behalf of youth who are coping with serious health and medical challenges. Each profession has its own focus, training, and language, but if children and families are to receive the best possible bio- psychosocial care it is imperative that all helpers be able to communicate with one another and acknowledge and appreciate their distinctive roles and contributions. This can be key to a positive outcome for the patient, the family, and the staff. We hope that the book will serve as a resource for social workers and other practitioners who counsel physically challenged children in medical, school, and community settings where they receive care and participate in various educational, recreational, and counseling programs.

The Incidence of Children's Health Conditions

Estimates indicate that between 10 and 15 percent of the children born in the United States have chronic health impairments of some kind. Many of these require lengthy and/or repeated hospitalizations and treatments that interfere with the child's usual activities (Clay, 2004; Phelps, 1998). In addition, several million children are admitted to hospital emergency rooms following severe and catastrophic injuries or illnesses. "Although many of their conditions [are] life-threatening, the large majority of clinically ill or disabled children survive to adulthood" (Perrin, 1989, p. xi).

A national survey of children's health (U.S. Department of Health and Human Services, 2005) collected data on more than 102,000 households in the United States with children under 18 years of age. Parents were asked to rate their child's health status in terms of five possibilities: excellent, very good, good, fair, or poor. The majority of parents (84.1 percent) reported that their children's health was excellent or very good. In contrast, the parents of 7.9 percent of children reported that their child currently had, or had had, at least one of a list of chronic health conditions that they ranked as moderate or severe. It is interesting that the percentages rose with the age of the child, from 4.4 percent among children from birth to age 5, to 9.1 percent among children ages 6 to 11, to 10 percent in the ages 12 to 17. Despite the many achievements of modern medicine, the fact remains that in the first decade of the twenty-first century a substantial number of children and their families continue to be burdened by serious health conditions.

The Most Frequent Pediatric Illnesses

According to Clay (2004), the most common high-incidence pediatric illnesses are the following:

- Asthma. Affects nearly 5 million children under the age of 18 in the United States.
- Diabetes. Occurs in about 15 to 20 children out of 100,000 under the age of 20 in the United States (Daneman & Frank, 1996).
- Juvenile rheumatoid arthritis. Estimated to affect nearly 200,000 children in the United States under the age of 18, with onset occurring as early as infancy and with most cases diagnosed between the ages of 1 and 4 (Cassidy & Petty, 1995).
- Cancer. May take the form of a blood cancer (e.g., leukemia or lymphoma), a solid tumor (e.g., neuroblastoma), or a brain tumor. Although all are being treated with increasing success, in some children the cancer is fatal.

Lower-Incidence Pediatric Medical Conditions

This list is selective and includes conditions that are not as frequent as those already mentioned but that also make physical demands on the child and require sensitive management in schools and other locales where the young person functions:

- Heart conditions. Congenital heart defects affect 8 to 10 children per 1,000; other conditions include heart murmurs and hypertension. Most congenital heart conditions are associated with other congenital conditions, such as Down syndrome (Clay, 2004, p. 26).