

Preface

Advances in treatment and management of pediatric chronic illness have resulted in substantial improvements in the health of children and youth. But, to paraphrase former U.S. Surgeon General C. Everett Koop, treatments don't work in patients who don't follow them.

Nonadherence—not following a treatment regimen as prescribed—is believed to be the single greatest cause of treatment failure, resulting in significant morbidity and mortality, and costing hundreds of billions of dollars per year. It is also one of the most challenging and frustrating problems facing clinicians, who often do not know not how to help their patients struggling with adherence. Over the past 20 years, there have been significant advances in our understanding of nonadherence and in the development of empirically-supported interventions, yet there has been virtually no change in overall rates of nonadherence. The reasons for this discrepancy between research findings and population health form the core of this book, which is intended to help bridge the gap between research advances and lagging improvements in children's health. This volume provides a comprehensive educational resource for physicians, nurses, psychologists, social workers and any other healthcare professionals who work with children and adolescents and their families and try to help them with the often overwhelming task of managing a chronic illness.

In this volume we argue that progress in reducing nonadherence has been limited by intervention efforts that have been fragmented and poorly integrated, targeting one or at best a few of the factors known to affect adherence, to the relative neglect of others. For example, interventions may target patient motivation without addressing contributing family factors or barriers to access to care. While this approach is sensible in the research setting, it neglects the co-morbidities and complications that characterize most patients who present with adherence difficulties in “real world” clinical settings. Managing these complexities requires a systematic approach that addresses all the major contributing factors to nonadherence in a comprehensive, integrated fashion. The overarching theme is that successful illness management depends on developing “healthcare partnerships” between patients, families, and healthcare providers, and on providing support for families to navigate the complex healthcare system.

This volume includes practical guidelines for clinicians to screen for nonadherence; a model for patient triage to different levels and types of intervention; best practices for interventions for different problems; suggestions for fostering family teamwork; and education for professionals on how best to promote and support health-maintaining behaviors in their patients. As such it should be of value to all clinicians who wish to help children and their families be more successful with illness management. The book also provides a rough blueprint for developing an integrated system for promoting good adherence and preventing or reducing nonadherence that should be of significant interest to clinical directors, administrators, and policy-makers.

In Part I, we provide a broad but detailed overview of the topic of pediatric adherence. **Chapter 1** provides the background into the concept of adherence and the scope and impact of nonadherence. It also discusses some barriers to adherence inherent in the healthcare system as it is currently constituted, and introduces the partnership model. **Chapter 2** selectively reviews important theoretical models of adherence and relevant constructs, laying these out from initial adaptation through the different processes that underlie patient adherence. **Chapter 3** provides an up-to-date review of the research literature on barriers and facilitators of adherence, and **Chap. 4** reviews the research on effective interventions for nonadherence. In Chaps. 5 and 6 we discussed developmental issues as they pertain to illness management. **Chapter 5** discusses management in early to middle childhood, while **Chap. 6** focuses on adolescence, the period when adherence is at its worst. In the latter chapter we review recent research from developmental neurobiology and focus on risk taking, and argue that poor adherence in adolescence is likely to be the norm, as a result of normal aspects of adolescent development. In **Chap. 7** we discuss the critical role parents play in helping their children manage a chronic illness. In the next two chapters, we focus on some of the most vulnerable patients with chronic illness. **Chapter 8** focuses on families struggling with poverty. Poverty creates significant challenges to managing a child's chronic illness, leading many authors and clinicians to despair of finding effective solutions to help these vulnerable families; however, we believe that progress can be made by focusing on reducing chronic stress and fostering the buffering relationships within families. **Chapter 9** discusses health disparities in adherence for racial/ethnic minorities, and focuses on provider-family communication as both a contributor to problematic adherence and as an important variable to target for intervention.

In Part II, we present a conceptual model of collaborative care around pediatric adherence. In **Chap. 10**, we begin by arguing for a reconsideration of the idea of self-management, and join other authors in support of a more collaborative, family centered approach. The idea of a triadic partnership between patients, parents, and their healthcare providers is discussed in **Chap. 11**, with many practical suggestions for how pediatricians and other providers can foster such partnerships with their patients.

Finally, in Part III, we present a comprehensive, integrated model for improving the care we provide to children with chronic illness and their families in promoting better adherence. **Chapter 12** discusses methods for screening for nonadherence

and contributory psychosocial problems in children with chronic illness, and in **Chap. 13** we present a model program for providing comprehensive assessment and intervention services based on level and type of assessed risk/need. The model cuts across different modalities, addressing patient, family, and provider factors in an integrated fashion. **Chap. 14** provides a brief summary of the main clinical implications of the literature reviewed in this volume.

A Few Notes

Acute versus chronic illness. Adherence issues affect both acute and chronic healthcare management. Adherence to medications for acute illnesses such as infections is an important health issue, especially at the population level, but the focus of this book will be primarily on adherence in chronic conditions. Nonadherence is generally higher in chronic conditions and is associated with greater patient morbidity. More importantly from the perspective of this volume, managing a chronic condition is qualitatively different from managing an acute illness. Acute illnesses by definition are time-limited, and place different demands upon families and family resources. As discussed later on, chronic illness becomes a chronic *stressor* which requires continual readjustments from patient and family, and unfortunately management burnout is common, contributing to a host of complicating factors including parent-child conflict and depression.

A note on the word “parent.” Throughout this volume we use the term “parent” to refer to the child’s primary caregiver or caregivers. We recognize that many children are actually being raised by other adults, whether they be grandparents or other relatives, foster parents, or others *in loco parentis*, and we do not mean to diminish the importance of these individuals. In fact, we wish to highlight their importance by using the term *parent* to refer to anyone in the parenting role—i.e., in the role of caring for the child. In our experience, these other persons are often thought of as parents by the child in their care, and think of themselves in this light as well. We have opted against using the more generic term *caregiver* as we believe that it places too much emphasis on the functional role and too little on the emotional role that comes with parenting.

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Promoting Collaborative Management for Pediatric
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