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Michael A. Rapoff
University of Kansas Medical Center
Kansas City, Kansas

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To Kim
Who I always love, therefore I always need

To Lindsey and Nathan
Our hope for the future and the joys of our lives

To Andrew and Shirley Rapoff
For good beginnings

To M. A. Groff
For showing me how to love and respect children

Preface

Medications don't always work like they should, transplanted organs are rejected, bacteria develop resistance to previously effective antibiotics, and physicians are hampered in their ability to judge the efficacy of treatments they have prescribed. What factors could account for these alarming trends in medicine? One significant factor is that patients and their families don't always adhere to prescribed treatments. Why this is the case and what can be done about it is the subject of this book.

Adherence has been defined as "the extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice" (Haynes, 1979, pp. 1–2). This is the most widely quoted definition in the literature because it specifies several important elements related to adherence:

- It brings the focus on specific behaviors that are required of a prescribed medical regimen. Patients are asked to do specific things, like take medications and follow diets. Specifying behavioral requirements of regimens is a necessary prelude to assessing and improving adherence.
- The word *extent* is an important qualifier related to adherence. It conveys that adherence is not a dichotomous, all-or-nothing phenomenon. There are qualitative and quantitative differences in adherence. For example, nonadherence to medications can take many forms, such as never filling the prescription, omitting doses, doubling up on missed doses, or even overdosing.
- This definition also focuses on the concordance between what patients are being asked to do and what they actually do (if their behavior "coincides" with advice they are given). This implies that there is a standard for judging whether adherence is acceptable or not. This "standard," however, has been rather arbitrary. More data are needed to develop standards that specify the level of adherence necessary to produce acceptable clinical outcomes for most medical regimens.

Before proceeding with this discussion of medical adherence in pediatrics, several caveats are in order:

1. *It is incumbent on medical providers that they are asking patients to adhere to regimens with demonstrated efficacy.* Providers need to remind themselves of the Hippocratic oath: "I will follow that system of regimen which, according to my ability and judgment, I consider for the benefit of my patients, and abstain from whatever is deleterious and mischievous" (as cited in Cassell, 1991, p. 145).

2. *Providers need to abandon the "blame and shame" approach to dealing with medical adherence problems.* It is tempting to blame patients for adherence failures and shame them into changing their behavior. Providers need to share the blame (or better yet omit blame) and look at their own attitudes and behaviors that impact adherence. For example, failing to simplify regimens or minimize negative side effects can adversely impact patient adherence.

3. *Patients and their families are no longer (or maybe were never) satisfied with a passive role in their health care.* In fact, the term *compliance* lost favor in the literature because it implied for some an authoritarian approach to health care that required unquestioned obedience by patients to provider recommendations (DiMatteo & DiNicola, 1982). Comprehensive and effective health care requires a cooperative relationship between providers and patients and their families. It also acknowledges the following realities, particularly for treating persons with chronic illness:

"Doctors do not treat chronic illnesses. The chronically ill treat themselves with the help of their physicians; the physician is part of the treatment. Patients are in charge of themselves. They determine their food, activity, medications, visits to their doctors—most of the details of their own treatment" (Cassell, 1991, p. 124).

4. *It is possible that nonadherence to prescribed regimens may be strategic, rational, and adaptive in certain cases* (Deaton, 1985). The "culture of medical practice" rests on the assumption that patients or their parents seek medical advice and will follow this advice with reasonable fidelity (Vandereycken & Meermann, 1988). Scientifically trained providers find it difficult to understand why people would seek advice, receive empirically validated advice, and then not follow it. Indeed, this does appear to be irrational behavior on the part of patients or their families. But medical treatments sometimes have serious side effects, do not produce anticipated outcomes, or patients find acceptable substitutes. In certain cases, nonadherence becomes rational. As Cousins (1979) observed: "The history of medicine is replete with accounts of drugs and modes of treatment that were in use for many years before it was recognized that they did more harm than good."

5. *Finally, children are not little adults.* Pediatric adherence issues are arguably more complex than with adults because of the influences of family members and peers. There are also developmental processes and constraints that uniquely affect adherence for children and adolescents. Caution is in order when theoretical and empirical work with adults is extrapolated to pediatric patients.

This volume is intended to give primary and allied health care providers, researchers, and students an overview of the topic of medical adherence in pediat-

rics. Chapter 1 reviews the prevalence and potentially serious consequences of adherence problems. There is also an overview of patient, family, disease, and regimen correlates or predictors of adherence. Chapter 2 is a review and critique of adherence theories, such as self-efficacy theory, and applications to clinical examples. Chapter 3 provides a critical overview of ways to assess adherence, including drug assays and electronic monitoring devices. There are also examples of adherence assessment formats that can be used by clinicians. Because the desired outcome of adherence interventions and research is that patients get better, feel better, and do better, Chapter 4 reviews both traditional and quality of life approaches to measuring disease and health status outcomes. Chapter 5 is an overview of educational, organizational, and behavioral strategies for improving adherence to acute and chronic disease regimens. Practical strategies are outlined and actual adherence-enhancing protocols are provided for use by clinicians. Chapter 6 concludes with a summary and critique of adherence intervention studies that focus on acute and chronic pediatric diseases. There are also recommendations for improving research and clinical approaches to assessing and enhancing adherence.

I would like to acknowledge the people who have helped shape the contents of this book and my career in pediatric psychology. I appreciate the feedback and patience of the series editors Drs. Michael Roberts and Annette La Greca, particularly their challenging me to make this book clinician-friendly. I thank my mentor, Dr. Ed Christophersen, for giving me my first opportunities and training in pediatric psychology. I thank my valued physician colleague and collaborator, Dr. Carol Lindsley, for giving me the support and setting for studying ways to help children and adolescents with rheumatic diseases adhere to medical treatments and cope with the demands of a chronic illness. I am also very grateful to the patients and families who have participated in our studies and have given me more than I could give them. Former students who made significant contributions to our research program on medical adherence include Drs. Kathryn Pieper and Mark Purviance and Ms. Joni Padur. I thank them for their efforts and for tolerating me. I am also grateful to the Arthritis Foundation and Bureau of Maternal and Child Health for funding my research on pediatric medical adherence. Finally, a special thanks to my close friend and colleague, Dr. Pat Friman, who critically reviewed parts of this manuscript. Knowing him has helped me strive to be a better thinker and a better person.

Contents