The past decade has seen a marked increase in recognition of both the degree to which chronic medical conditions affect the psychological functioning of children and adolescents, and the complexity of these interactions. The inclusion of the present chapter in the second edition of this book reflects the growing awareness of the impact of illness and psychopathology on psychological development. In the sections that follow, we review the definitions, methodological issues, and conceptual approaches to considering chronic pediatric problems, from which follow prevalence data that indicate the scope of the problem. We review available evidence on the association of psychopathology, psychological symptoms, and adjustment problems with chronic medical conditions. Theoretical, clinical, and empirical data form the basis for a discussion of the impact of chronic conditions on specific developmental stages. Finally, we discuss conceptual models that usefully integrate potentially confounding issues in the field and point the way for future research efforts.

A comprehensive consideration of all the topics relevant to psychosocial aspects of pediatric chronic illness is beyond the scope of this chapter. The impact of illness on parents and siblings; particular issues regarding the dying child; ethical, legal, and policy issues affecting chronically ill children; the full range of identified and potential psychopathology mechanisms; and problems and solutions regarding psychological assessment in the medically ill are highly relevant. The reader is referred to several comprehensive monographs that deal with these topics (Pless & Pinkerton, 1975; Stein, 1988).
DEFINITIONS

“Illness,” “disease,” “disorder,” “disability,” and “medical condition” are often used interchangeably despite subtle differences in meaning. The Research Consortium on Chronic Illness in Childhood advocates the use of “condition” as the most neutral and encompassing term, avoiding the implication that active symptoms are necessary (as an “illness” or “disease”) or (as in “handicap” or “disability”) that a deficit or incapacity is inevitable (Perrin et al., 1993).

Chronic illnesses, having a duration of 3 months or more, are distinguished from acute illnesses in several important ways. With an acute illness, the diagnostic process is of primary importance and consumes considerable energy, in contrast to a chronic illness, where the diagnosis typically was made some time earlier. An acute illness is assumed to be curable in a timeframe of days to weeks, whereas a chronic illness is expected to be managed over months to years. With an acute illness such as pneumonia or appendicitis, children and their parents expect to delegate the caretaking responsibilities to the medical system, whereas parents and children with chronic conditions often gain considerable expertise and assume significant management responsibility. While these differences are important and seem readily apparent, the medical system has long been based on the acute care model. This is reflected in medical training, where residents rotate on a monthly basis (to the dismay of chronically ill patients), in the preponderance of cross-sectional research when longitudinal studies are needed, and in the way medical funding fails to deal with “preexisting conditions.” Although the medical system is gradually changing, the problems of fitting a chronic condition into a system with an acute care focus present additional challenges to affected children and their families.

In the past, children were identified as having a chronic health condition through the use of diagnostic lists: If their specific condition was on the list, they were included in public programs, educational efforts, and research protocols. Such an approach was criticized for being arbitrary, inevitably incomplete, inequitable, prone to bias, and promoting fragmentation. Stein and Jessop (1989) have proposed an alternative, “noncategorical” framework in which children with various conditions are considered together and grouped across, rather than within diagnostic categories with regard to psychological and social aspects of their chronic conditions. This approach recognizes the common experiences associated with having a chronic illness, no matter what the specific condition. It permits the inclusion of children with rare or difficult-to-define conditions, encourages the design of inclusive programs, and minimizes competition for resources. Recognizing the considerable variation in how individual children are affected even within a particular illness category, Perrin et al. (1993) have advocated applying a broad, noncategorical approach initially and then evaluating a number of dimensions with regard to their impact on a given child, as summarized in Table 15.1. This two-step evaluation maximizes the benefits of both the categorical and noncategorical approaches, while minimizing artificial distinctions.

Clearly, each of these variables cannot be examined and controlled for in every study. Acknowledging their relevance adds complexity to an already challenging area. If researchers collectively consider these variables in detail, however, progress will be made toward a comprehensive understanding of how chronic medical conditions affect the developing child.

EPIDEMIOLOGY

The prevalence of chronic illness within the pediatric population is a subject open to considerable debate. Depending on the definitions applied (severity threshold, whether psychi-