

Issues in Research on the Young Chronically Ill Child

John W. Hagen and Barbara Anderson, *University of Michigan*,
and Craig R. Barclay, *University of Rochester*

A major goal of research on chronic illness in children is to determine how the illness interacts with developmental processes. The child must be studied within the context of the family, the school, and the health care system. Problems in research include the use of appropriate control groups and matching on control variables. The generic, or cross-categorical, approach has led to the identification of factors affecting children regardless of particular illness. Adjustment to school depends on coordination of the family and health professionals with personnel within the school.

Researchers have begun to recognize that chronic illnesses in children are a major problem affecting between 5% and 10% of all children in the United States (Gortmaker & Sappenfield, 1984; Haggarty, 1984). Research has tended to focus on specific illnesses and to be either biomedical or psychological, but seldom both. Recently, several regional and national conferences have been aimed at issues involving chronically ill children and their families. A base of data is emerging upon which decisions can be made concerning the availability and delivery of services (Perrin & Ireys, 1984). It is clear to those working within this area that reform is needed in legislation, policy, and practice if these children are to have the medical, educational, and social services they need in order to have the opportunity to develop maximally and become productive adults.

The purpose of this paper is to consider research issues concerning chronic illness and its impact on the child and family as the child reaches the age of school entry. Our perspective comes from a developmental psychological model. The concerns are with the continuities as well as the discontinuities in the young child's personality, cognition, and behavior. Like youngsters without illnesses, children with chronic illnesses are growing and experiencing their world. They are individuals who happen to have an illness that may modify development and experiences. A major goal of research, then, is to discover how chronic illness interacts with developmental processes and with those significant persons in the child's environment who contribute to development.

The chronically ill child must be studied within the context of three systems that affect development: the family, the school, and the health care delivery system. The younger the child at the time the illness is diagnosed, the more involvement from significant adults in the child's life is required. Since chronic illnesses are of long duration, typically require specialized treatments and daily regimens, and often involve certain restrictions or modifications in activities and diet, parents and teachers must be educated in terms of the specifics of medical management for a certain illness as well as about the more general impact of chronic illnesses on developmental processes.

Use of Controls

From the standpoint of design and methodology in research, there are serious problems in much of the psychosocial literature on chronically ill children. Some of these problems stem from the nature of the diseases. They are low frequency and it is often difficult to recruit sufficient numbers of children for study. Further, it is difficult if not impossible to meet the requirement of random selection from the larger population pool. Space does not permit a consideration of all the cautions and potential pitfalls concerning research in this area, but a few points are raised here to illustrate some of the more serious problems.

The use of control groups has recently been recognized as a problem with which the researcher must reckon. Frequently, comparable measures on children constituting a control group are simply not provided in published research on chronically ill children. When control groups are provided, information concerning matching characteristics is often lacking. Factors such as family socioeconomic status, particular

schools attended, and geographic location are apparently often not considered to be relevant.

One way of recruiting control groups for research on chronically ill children has been to use healthy siblings (McKeever, 1983). It has become clear that siblings are affected in a wide variety of ways, and thus it is important to study the siblings of children with chronic illnesses. However, for this very reason, siblings should not be assumed to be appropriate *controls* (Breslau, 1983), in spite of the fact that certain genetic and environmental factors are held constant by using this strategy. After studying the families of children with a variety of chronic illnesses, Breslau (1983, p. 390) concluded: "disabled children *and* their siblings have greater disorder . . ." as compared to the general population of children on a variety of measures. Thus, if one is interested in the impact of having a chronically ill child in the family, then siblings should be certainly included. However, if one is interested in matching healthy youngsters to a sample of children with particular chronic illnesses, one must find a nonrelated sample, matched carefully on chronological age, sex, intelligence, and family indicators such as ethnicity, education, and economic status.

An argument can be made that it is not always necessary to include a matched, "healthy" control group (e.g., Drotar, 1981). One problem in using controls is that the results often emphasize differences, and even deficiencies, in the group of children who are chronically ill. Yet, we need information on these children in terms of how they are functioning, what their strengths are, and how their environments can be modified to maximize their development. Research on chronically ill children *per se*, using differences among them as a way of obtaining information on predictor variables, is sometimes the only way to answer the questions.

Generic Model of Chronic Childhood Disease

Most of the chronic illness literature has focused on specific diseases. "A disease-specific approach has been the cornerstone of research on both biomedical and psychosocial aspects of illness to the point that there is great reluctance to make generalizations or to study issues across diseases" (Stein, 1983, p. 54). Moreover, generalizations across studies are difficult because such basic information about the subjects as chronological age or sex is frequently not reported.

Information on developmental levels, such as mental age, social competency, or linguistic level, as well as information on the family, such as parental education or family structure, is typically missing. Yet, we know from recent research (e.g., Pless & Pinkerton, 1975; Stein, 1983) that these factors are critical to the child's adjustment to *any* chronic disease.

Pless and Pinkerton (1975) have argued that knowledge of the diagnostic label adds nothing to our knowledge of how to treat the psychological and social needs of chronically ill children. Taking the view that there are important commonalities among children with different chronic illnesses because of the universals of development and the similarities in need for effective care, the burden is placed on the researcher to (1) pay attention to important descriptive information about ill children and their families (e.g., age, income level, etc.), and (2) develop approaches that identify the relevant dimensions that cut across illnesses (see Stein, this issue). This approach has become known as the Generic Model. Examples of dimensions that cut across specific diseases include the age at which the diagnosis occurred, the temporal course of the disease, specific requirements for care and management, the extent of the visibility of the condition, and the economic burdens of the disease.

In our attempt to construct a model for researchers studying chronic illness in children, we have identified three sets of dimensions to consider: specific diseases; factors that cut across diseases; and developmental level. As indicated in Figure 1, the first dimension, specific diseases, includes all long-term, serious medical conditions of childhood, such as type I diabetes, seizure disorders, cancer, asthma, juvenile rheumatoid arthritis, and cystic fibrosis, among others.

Second, we have identified factors that cut across those diagnostic categories, such as etiology or duration of disease, that have emerged as critical in the consideration of the impact of any disease or physically disabling condition. For example, the etiology or cause of a chronic disease can profoundly influence parental adaptation (McCollum, 1981). In contrast to illnesses such as cancer, for which there is frequently no genetic etiology, diseases that do have a genetic component, such as cystic fibrosis, diabetes, or hemophilia, exaggerate parental feelings of guilt about the illness. Another example of a factor that cuts across diseases and has important implications for understanding child and family adaptation is the duration of the illness (McCollum, 1981). For some diseases such as asthma and seizure disorders, the child's prognosis improves after adolescence. For other illnesses, such as diabetes, the

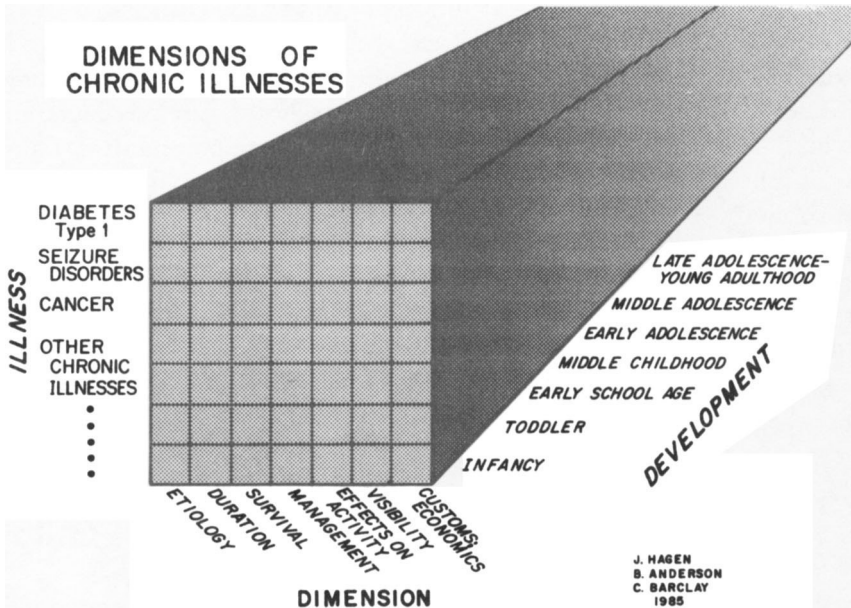


Figure 1. A model for the study of chronic illness in childhood: Specific diseases, factors across disease categories, and development level.

probability of experiencing serious physical complications of the disease increases with age. Moreover, children with cystic fibrosis face a dramatically shortened life span and until this decade seldom survived beyond adolescence (Gortmaker & Sappenfield, 1984). Duration of disease and its relationship to prognosis, therefore, clearly influence the experiences of stress and the coping processes of ill children and have repercussions for parents and other significant adults such as health care providers and school personnel.

The third dimension is the developmental level of the children studied. The chronically ill infant poses a very different challenge to the adults in his or her life that does the chronically ill adolescent! Recent reviews of research with chronically ill children have pointed out how infrequently investigators have studied the psychological impact of the disease at different developmental stages (Anderson, 1984; Perrin & Gerrity, 1984). For example, researchers have gathered data from samples of "ill children" without regard for the different developmental stages represented in the sample. There are at least three reasons why developmental information is critical. First, we must learn how to design effective treatment plans for children of all ages. Since children face

specific developmental tasks at different age periods (Erikson, 1950), a treatment plan presents distinct social and psychological challenges to ill children at different ages. Second, the child's developmental stage influences responses of other family members, health care providers, and school personnel toward the child and treatment responsibilities. Third, basic physiological processes change with age, and biological changes such as those that occur at puberty can strongly influence the child's psychological response to illness (Coupey & Cohen, 1984). It is essential that we recognize the impact of the child's developmental stage, especially during periods of rapid growth when management of the illness may be more difficult. This model provides a framework within which the three dimensions can be studied as well as interactions between and among them.

School Entry for the Young Chronically Ill Child

The introduction of a generic or noncategorical perspective into chronic illness research has helped to identify dimensions of illness that are similar across different disease groups. With respect to stresses on families specifically, Stein and Jessop (1984) have pointed out that chronic disease causes severe strain in economic, emotional, marital, and social areas of family life. Family roles and responsibilities change dramatically with the onset of chronic illness in a child and continue to change as the child grows and develops. For certain chronic illnesses such as cystic fibrosis and diabetes, responsibility for disease management or treatment is transferred to the family soon after diagnosis. In the case of diagnosis at a very young age, this means that parents assume the enormous task of clinical decision making and implementation of treatment plans at home. Attention to medications, special diets, restrictions on physical activity, and other therapeutic procedures are added to, and interact with, the typical responsibilities and concerns faced in raising young children.

One common responsibility faced by all parents, whether or not the child has a chronic illness, is successful negotiation of the child's transition from the family system to the school system at age 5 or 6 years. For many parents and children, school entrance marks the first major separation experience, with anxiety realistically heightened for both parent and child when there is a serious medical condition (Leaveron, 1979). Also, this may be the first time the child's appearance, skills, and behavior will be compared by parents, or by the child him or herself, to

peers who do not have this disease. Moreover, for many chronic conditions in which parents have had the primary "burden of care" for disease management, during the preschool years, school entrance marks the first major transition of responsibility for monitoring and managing the child to someone *outside* the family.

To date, no specific empirical studies have examined this important developmental milestone in the lives of young chronically ill children and their families. It should be understood that a developmental perspective is relatively new to chronic illness research (Perrin & Gerrity, 1984) and that the lower incidence of some chronic diseases in the first 6 years of life have made it more difficult to study families with children in this age group. Yet we feel it is important in this paper *to identify* the complex issues and interrelationships among family and ill child, educators and the school system, and health care providers that come into play when a chronically ill child enters school or when a diagnosis is made in the early elementary years. For this we can turn to several recent comprehensive reviews of policy issues in the education of all chronically ill children (Hobbs & Perrin, in press; Walker, 1984). Four parameters of the problem of chronic disease and the schools that are very pertinent to the developmental milestone of school entry have been identified:

1. School personnel are currently not adequately prepared to handle the behavioral or medical management issues raised by the young chronically ill student in the classroom (e.g., Gadow, 1982).
2. School policies are not in place regarding education decisions about school absences, home-bound instruction, make-up work, or special scheduling considerations for chronically ill youngsters (Walker, 1984).
3. Parents of chronically ill children have the total responsibility on a yearly basis for educating teachers and other relevant school personnel (secretaries, administrators, food service personnel, coaches) about their child's illness and needs (Barbarin & Chesler, 1982; Walker & Jacobs, in press).
4. Health care providers have no formalized channels of communication with school staffs. Teachers must initiate contacts with physicians to get information about each child's capabilities and condition (Baird & Ashcroft, 1982; Weitzman, 1984).

These conclusions from policy studies document the profound need for empirical research involving families, educators, and health care providers as chronically ill children *begin* their school careers. The need now is for research in each of these areas that focuses on the

identification and documentation of the *specific factors* affecting children, family members, and the professionals with whom they interact. A prospective approach, where the research begins at the point of diagnosis and continues over the years including school entry and adjustment to the school environment, would be especially fruitful.

It has been well established that while most chronically ill children function within the normal range on standardized tests of intelligence, the incidence of underachievement and social adjustment problems in school continues to be disproportionately higher among chronically ill children than their healthy classmates (Weitzman, 1984). A recent survey of Michigan pediatricians practicing in tertiary health care settings indicated that while these physicians are informed and concerned about the school-related problems of their young patients with chronic illnesses, they have almost no direct contact with school personnel (Ponte, 1985). Moreover, we know from basic studies in our laboratory on cognitive and academic functioning of children with seizure disorders and with diabetes that children diagnosed in early childhood are at increased risk for special education class placement and for repeating a grade in their early school careers (Anderson et al., 1984; Hagen et al., 1985). Thus it is clear that prospective studies monitoring the entrance to school and adaptation to the classroom environment by young chronically ill children and the roles played by parents, educators, physicians, and others in this important process should be given the highest priority.

References

- Anderson, B.J. (1984). The impact of diabetes on the developmental tasks of childhood and adolescence: A research perspective. In M. Natrass & J. Santiago (Eds.), *Recent advances in diabetes* (pp. 165-171). London: Churchill Livingstone.
- Anderson, B.J., Hagen, J.W., Barclay, C.R., Goldstein, G., Kandt, R., & Bacon, G. (1984). Cognitive and school performance in diabetic children. *Diabetes*, 33 (Supplement 1):81A (abstract).
- Baird, S.M., & Ashcroft, S.C. (1982). *Education and chronically ill children: A need-based policy orientation*. Nashville, TN: Center for the Study of Families and Children, Vanderbilt Institute for Public Policy Studies, Vanderbilt University.
- Barbarin, O.A., & Chesler, M.A. (1982). *The school experiences of children with cancer: Views of parents, educators, adolescents and physicians*. Ann Arbor: Center for Research on Social Organizations, University of Michigan.
- Breslau N. (1983). The psychological study of chronically ill and disabled children: Are healthy siblings appropriate controls? *Journal of Abnormal Psychology*, 11(3), 379-391.

- Coupey, S.M., & Cohen, M. (1984). Special considerations for the health care of adolescents with chronic illnesses. *Pediatric Clinics of North America*, 31, 211-219.
- Drotar, D. (1981). Psychological perspectives in childhood chronic illness. *Journal of Pediatric Psychology*, 6, 211-228.
- Erikson, E. (1950). *Childhood and society*. New York: Norton.
- Gadow, K.D. (1982). School involvement in the treatment of seizure disorders. *Epilepsia*, 23, 215-224.
- Gortmaker, S.L., & Sappenfield, W. (1984). Chronic childhood disorders: Prevalence and impact. *Pediatric Clinics of North America*, 31, 3-18.
- Hagen, J., Anderson, B.J., Barclay, C., Goldstein, G., Kandt, R., Genther, C., Segal, S., Feeman D., & Bacon, G. (1985, April). *Academic, cognitive, and family functioning in diabetic children*. Paper presented at the meeting of the Society for Research in Child Development, Toronto.
- Haggerty, R.J., (1984). Forward-chronic disease in children. *Pediatric Clinics of North America*, 31, 1-2.
- Hobbs, N., & Perrin, J. (Eds.). (in press). *The constant shadow: Serving chronically ill children and their families*. San Francisco: Jossey-Bass.
- Leaverton, D.R. (1979). The child with diabetes mellitus. In J.D. Call, J.D. Noshpitz, R.L. Cohen, & I. Berlin (Eds.), *Basic handbook of child psychiatry* (Vol. 1, pp. 452-458). New York: Basic Books.
- McCollum, A. (1981). *The chronically ill child*. New Haven: Yale University Press.
- McKeever, P. (1983). Siblings of chronically ill children: A literature review with implications for research and practice. *American Journal of Orthopsychiatry*, 53, 209-218.
- Perrin, E.C., & Gerrity, P.S. (1984). Development of children with a chronic illness. *Pediatric Clinics of North America*, 31, 19-31.
- Perrin, J.M., & Ireys, H. (1984). The organization of services for chronically ill children and their families. *Pediatric Clinics of North America*, 31, 235-257.
- Pless, I., & Pinkerton, P. (1975). *Chronic childhood disorder: Promoting patterns of adjustment*. London: Henry Kimpton.
- Ponte, P. (1985). *A survey of pediatricians on the school-related problems of chronically-ill children*. Unpublished manuscript, University of Michigan, Ann Arbor.
- Stein, R. (1983). Growing up with a physical difference. *Children's Health Care*, 12, 53-61.
- Stein, R.E., & Jessop, D.J. (1984). General issues in the care of children with chronic physical conditions. *Pediatric Clinics of North America*, 31, 189-198.
- Walker, D.K. (1984). Care of chronically ill children in schools. *Pediatric Clinics of North America*, 31, 221-233.
- Walker, D.K., & Jacobs, F.H. (in press). Chronically-ill children in schools. In N. Hobbs & J. Perrin (Eds.), *The constant shadow: Serving chronically-ill children and their families*. San Francisco: Jossey-Bass.
- Weitzman, M. (1984). School and peer relations. *Pediatric Clinics of North America*, 31, 59-69.