Key Issues in Chronic Illness Research: Lessons From the Study of Children With Diabetes

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Issues and controversies in chronic illness research are discussed, with data and examples from a program of research dealing with children and adolescents with diabetes. The key differences that demand consideration include prevalence, developmental issues, measurement, cultural issues, the lack of viable models, use of controls, the importance of the family, and ethical concerns.

CHRONIC ILLNESS AMONG both adults and children has become more prevalent in recent years. Among adults, by the age of 65, some 60% of the population has at least one chronic illness, and almost 40% are limited in their activities because of chronic illness (National Center for Health Statistics, 1993). Children, however, are thought to be generally healthy. Nonetheless, it is estimated that up to 31% of our nation's children less than 18 years of age suffer from some type of chronic illness (Adams & Marano, 1994), and up to 6.5% have disabling chronic illnesses (Newacheck & Halfon, 1998). The level of seriousness and associated medical and developmental problems vary from individual to individual. Nevertheless, this special population and their families have a variety of medical, developmental, social, emotional, and environmental needs and issues that require comprehensive case management and long-term monitoring.

Empirical studies that focus on the human responses and needs of those with chronic illnesses assist the professional nurse to determine the best management and treatment approach. Research on the impact of chronic illness on children began in the 1970s and continues to the present. The purposes of this article are to discuss the differences in child and adult chronic illness research, identify key issues in chronic illness research, and explore implications for developing nursing science in the care of children with chronic illness using examples from one program of research with children with diabetes.

The definition of chronic illness that will be used in this article is "any anatomical or physiological impairment that interferes with the individual's ability to function fully in the environment. Chronic illnesses are characterized by relatively stable periods that may be interrupted by acute episodes requiring hospitalization or medical attention. The individual's prognosis varies between a normal life span and unpredictable early death" (Rose & Thomas, 1987, p. 5). Clearly, type 1 diabetes, which is most commonly diagnosed in childhood or early adolescence, meets these criteria for classification as a chronic illness. Type 1 diabetes is characterized by alterations in glucose, protein, and fat metabolism because of absolute lack of insulin. Treatment is complex and demanding, requiring insulin replacement by injection, usually three or more injections per day, to achieve near normal glucose metabolism once total insulin replacement is necessary. Determination of the appropriate insulin regimen is accomplished through routine

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self–blood glucose monitoring and careful regulation of dietary intake and physical activity. Regular visits to health care providers allow for assessment of metabolic control and monitoring to attempt to decrease the potential for long-term complications and early death (Grey & Boland, 1996).

DIFFERENCES BETWEEN CHRONIC ILLNESS IN ADULTS AND CHILDREN

There are major differences between children and adults with chronic illness that apply to clinical research. The key differences that demand consideration include prevalence, developmental issues, measurement, lack of viable models, use of controls, importance of the family, and ethical concerns.

Prevalence

The most common chronic illnesses found in children ranked in order of cases per 1,000 are respiratory diseases (allergies, otitis media, asthma) and mental impairments (Newacheck & Halfon, 1998). In contrast, with adults, heart disease is the most prevalent (cases per 1,000), followed by hypertension, orthopedic problems, asthma, and diabetes (National Center for Health Statistics, 1991). A disease such as diabetes, for example, that is very common in adults, is much less common in children, with 8 cases of diabetes per 1,000 children compared with approximately 23 cases per 1,000 adults (National Institute of Diabetes, Digestive, and Kidney Diseases [NIDDK], 1995). These differences in prevalence create difficulties for accumulating necessary samples for studies of children with chronic illness. At any one academic site, there may be only small numbers with a particular diagnosis from which to draw a sample, and as few as one to two patients may be found in any one primary care site. For example, if a researcher is interested in studying children with newly diagnosed diabetes in a particular age range, there may only be 10 to 20 in a site in 1 year, even though the site may follow a large number of children who were previously diagnosed (Grey, Cameron, Lipman, & Thurber, 1995). To deal with this limitation, the researcher needs to choose between a multisite disease-specific approach or a noncategorical approach (Stein, 1982).

Multisite Disease-Specific Studies

A multisite disease-specific approach may be warranted when there are a limited number of subjects from any one site. Such studies involve using several sites from which to access subjects, all of whom have the same illness or condition. The advantage of this approach is that it has the potential to minimize the variance in variables related to the disease.

There are several disadvantages to this approach, however. Although this approach would increase external validity within the illness category, generalizability of the findings is limited to similar settings and only to the disease studied. Variations in research sites can also lead to increased variance associated with subtle differences in setting, samples, treatment, management, and data collection. In our study of the natural history of the development of psychosocial adjustment in young people with diabetes, for example, it was important to assure that variations such as differing philosophies about the intensity of management desired or demographic composition in the different clinical sites were not related to the psychosocial variables of interest. Thus, metabolic control data were collected and controlled in our analyses (Grey, Cameron, Lipman & Thurber, 1997; Grey, Cameron & Thurber, 1991).

Using more than one site can also be very costly. Increased costs can be attributed to the use of multiple investigators, data collectors, coordinators, equipment, and supplies for each of the data collection sites. Other issues that make multisite research complex include obstacles in accessing samples and lack of familiarity with various organizational structures and personnel. Having personnel in multiple sites can lead to poor communication, lack of motivation, or difficulties with adhering to a consistent research protocol. All of these issues need to be considered as potential limitations when using the multisite approach. Nonetheless, when researchers are interested in studying aspects of one disease for which samples are necessary that exceed the availability of subjects in one clinical site, the multisite approach can be helpful.

Noncategorical Approach

An alternative choice for studying children with chronic illnesses is to use a noncategorical approach. With this type of research, one assumes that the "experience" of chronic illness is more important than the specific illness per se (Stein, 1982). The methodological challenge in this approach is to identify and control descriptive information and relevant dimensions that are similar across illnesses.

Several important areas have been identified that may vary from illness to illness and may affect noncategorical studies. First, illness burden may

vary enough to affect potential outcomes. Illness burden is the degree to which the management of the illness and the impact of the illness are perceived by the family as "burdensome" (Stein, 1982). For instance, a child who is ventilator-dependent because of a progressive neuromuscular disease will probably not have the same illness burden as a child that has a nonprogressive condition such as a C2 fracture. The differences in illness burden associated with these two similar conditions may affect their management and treatment as well as the family's perception of the illness. These differences should be considered when planning this type of methodological approach.

Variation in functional status among the selected sample of patients may significantly affect the outcome results and deserves attention. There is tremendous variation in levels of functional status, such as cognitive functioning, bowel and bladder control, and nutrition, between children who have cerebral palsy and those with spina bifida (as well as variation within the specific diagnoses). The researchers should attempt to equalize these variations as much as possible, otherwise differences in outcomes may be attributable to differences in functional status rather than to the study variables.

There are several advantages for using a noncategorical methodological approach. First, there are more subjects available for potential study participation in any one clinical site. The researcher is not limited to only one diagnosis. Tied into this advantage is the potential for a less costly study because children with a variety of diagnoses can be recruited at one location. Findings from these studies can be generalized to a broader range of individuals because people with a variety of diagnoses were studied rather than those with a single diagnosis. This approach also allows examination of other variables across diagnoses for comparisons such as development and maturation, economics, and family management. In addition, because the subjects are drawn from a larger population, the findings of the study may contribute to broader support for the conceptual or theoretical framework that undergirded the study. There have been a number of noncategorical studies of adaptation to chronic illness in childhood that have included children with diabetes.

Developmental Issues

Another major difference between adults and children with chronic illness that researchers must consider is the issue of development. Although some studies of children with chronic illness may focus on short-term gains, long-term developmental outcomes are most valuable for treatment, management, and parent/child educational purposes. The difficulty with dealing with these issues in childhood is that normal developmental maturation may be confounded with outcomes in research studies.

Disease duration has an effect on the child's adjustment to a chronic illness (Kovacs, Brent, Feinberg, Paulauskas, & Reid, 1986). The effect can be partially related to the developmental stage of the child. It is important to examine initial adjustment as well as longer-term adjustment over time. Disease duration also has an effect on the disease state itself because some diseases have periods of remission and exacerbation. An example of these relationships is shown in our previous study of coping and adaptation in children who have type 1 diabetes over time (Grey et al., 1991). Previous researchers had suggested that diabetes in childhood was associated with either no increase in psychosocial problems or a significant increase. By examining children's depression at 6, 12, 18, and 24 months after diagnosis and comparing depression in children with and without diabetes, we were able to show that there are critical periods in adjustment to chronic illness that vary with time since diagnosis (Grey et al., 1995). It is important to quantify such information to understand what these children experience and to provide the appropriate interventions or guidance for them and their parents.

Developmental stage and life transitions may also affect outcomes. It is only recently that the issues related to the transitions from pediatric care to adult care have been considered (Rosen, 1995). Bussing and Aro (1996) surveyed adolescents in a school at age 16 and at age 22 and compared those with chronic illness to those without chronic illness to determine the effect of the illness on a variety of functional outcomes. They found that adolescents with chronic illness attained levels of well-being, education, and marriage or dating as young adults similar to their peers without chronic illness. Their findings also suggest, however, that males with a chronic illness may be at higher risk for depression than females or those without chronic illness. Wysocki and colleagues studied 81 young adults with diabetes and found higher rates of psychopathology compared with others and that poorer metabolic control and poorer adjustment to diabetes in adolescence is associated with poorer status in early adulthood (Wysocki, Hough, Ward, & Green, 1992).

Another area associated with developmental concerns for children with chronic illness is quality of life. Quality of life is increasingly being considered an important outcome of treatment, and it has been defined as the subjects' perceptions of impact of illness and treatment on general satisfaction with life and on concerns over social and vocational issues (Diabetes Control and Complications Trial (DCCT) Research Group, 1996; Ingersoll & Marrero, 1991). Measurement of quality of life is dependent on who defines it: the affected child, the parent, or the provider (Nassau & Drotar, 1995). There have been discrepancies in quality of life findings among these three sources. For instance, in our study of coping and adaptation of children with diabetes, parents' ratings were lower than their children's on perceived health status (Grey, Cameron, Lipman, & Nicholson, 1993). Thus, even though children with diabetes perceive their overall health status as "very good to excellent," their parents may perceive their health status as lower simply because the child has a chronic illness. Unfortunately, no studies could be found in which other raters, such as teachers or other adults, rated children with diabetes, so no conclusions can be drawn about different assessments by other raters.

Measurement Issues

Children are constantly developing, and this development may affect how measures can be used. It is extremely important that measures used are developmentally appropriate for the subjects studied. For example, a researcher could not ask a toddler to complete a paper-and-pencil test. However, occasionally, instruments that are appropriate for adults are used with adolescents and younger children, and such use may cause difficulty in the interpretation of findings.

The DCCT was a landmark study conducted to investigate whether intensive insulin therapy aimed at normalizing the blood sugar could slow the onset and progression of the microvascular and neurological complications of diabetes (DCCT Research Group, 1993). The study found that improved control was associated with a 50% to 75% reduction in complications; metabolic control was linearly associated with complications; and there were no adverse effects on cognitive function, psychological symptoms, or quality of life. There were 195 adolescents in the DCCT, who have been characterized as a highly selected and motivated sample. They also required most of the time of the clinical team, and they took longer to reach metabolic nadir as compared with the 1,200 adults in the study. In addition, the measures used to assess quality of life were not developmentally specific for the adolescent patients (DCCT Research Group, 1994). Indeed, Ingersoll and Marrero (1991) have criticized the instrument for containing limited items that pertained to adolescents' issues with school, peers, and work. Thus, studies involving the translation of the DCCT into treatment recommendations for adolescents need to carefully assess adolescent-specific quality-of-life outcomes (Grey, Boland, Yu, Sullivan-Bolyai, & Tamborlane, 1998).

Similarly, it is difficult to determine what is measurement effect and what is true change over time in children without extensive psychometric analyses. For example, in the cross-sectional study of coping and adaptation in children with diabetes, we found that depression was twice as common in adolescents as in younger school-aged children (Grey & Thurber, 1991). It is impossible, however, to determine if the rate of depression detected by this measurement tool is real or is an artifact of the interpretation of the instrument by children at different ages. We assume that there is an increase in depression over time because of other data supporting that hypothesis (Bennett, 1994). Another issue is that many researchers have combined children across multiple age groups into one, presumably homogeneous, cross-sectional sample, but the developmental differences in psychosocial phenomena may make such groupings difficult to interpret.

Cultural Issues

Another issue that may also be influenced by development and needs to be considered when doing research with children who have chronic illness is cultural influences. Much has been written pertaining to the ambiguous definition of race and culture in research studies across disciplines (Nelson, 1994). Even when the researcher has followed the usual recommendations for translating, back translating, and validating new translations of measures, it may be unclear whether the findings actually reflect cultural differences or cultural interpretations and responses to the instrument (Lipton & Fivecote, 1995; Sterling, Peterson, & Weekes, 1997). In our longitudinal study, we examined the depression scores using the Children's Depression Inventory (CDI) (Kovacs, 1985) among white and Hispanic or African American children with diabetes, and found consistently more depression in the nonwhite group (Figure 1). Unfortunately, it is not possible to determine, without clinically validating the findings, that such differences exist. Certainly,

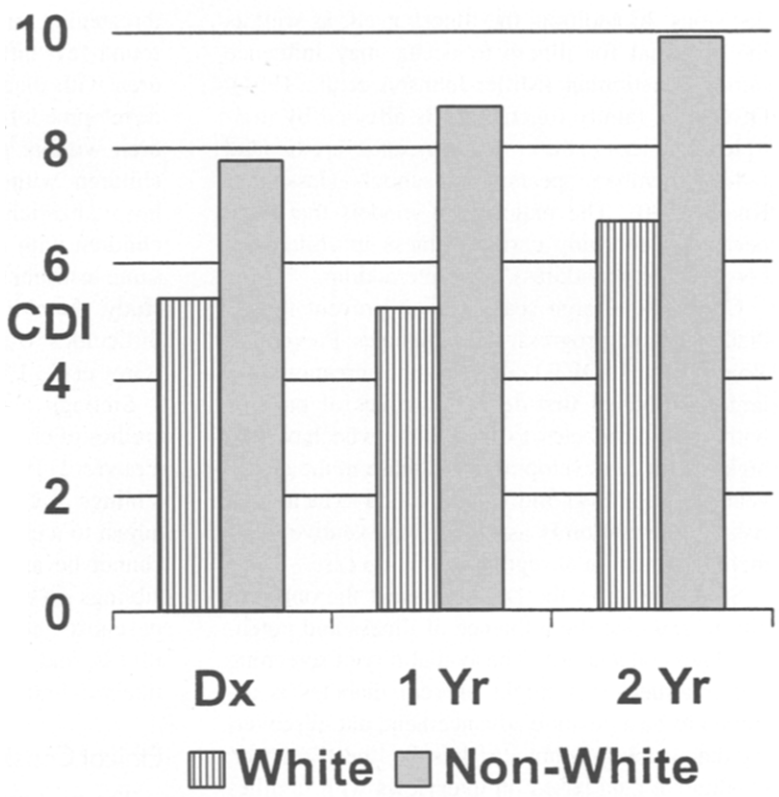

Figure 1. Depression in white and non-white (Hispanic and African American) children with diabetes (n = 89).

previous studies have not led to the conclusion that this finding is true (Bennett, 1994).

Lack of Appropriate Models

The fifth key research issue that differentiates children from adults with chronic illness is the lack of theoretical models that apply specifically to children. Much research using a model has developed from models in other fields, such as risk and resistance, stress and coping, compliance/adherence, and the Health Belief model. Several nursing models have been developed to study adults with chronic illness as well. Mishel's (1988) model of uncertainty in illness and Pollack's adaptation (1993) of the Roy model (1984) are a few of the models that have been used to guide research with adults who have a chronic illness. Unfortunately, all of these models cannot be adapted directly for the study of children because they do not account for developmental and family issues. For example, Ryan-Wenger (1989) has shown that only portions of the stress and coping models developed for adults adequately explain how school-aged children cope with stress.

Grey and Thurber (1991) developed a Stress-Adaptation Model for Childhood Chronic Illness to guide our studies of children with diabetes. In the model, the developmental level of the child and the contribution of the family to coping and adaptation in chronic illness in childhood are explicitly defined and potential relationships are elucidated based on prior research. Thus, the model assists us in understanding the process of adaptation for children with a chronic illness. The model can also be used to examine biological outcomes as well as psychosocial outcomes.

There are few such integrated models in chronic illness research in children. Knafl and Deatrick (1986) have defined a model of family adaptation to chronic childhood illness they called normalization. This model is helpful in understanding family adaptation, and it was developed in studies including families with a child with diabetes, but it does not assist our understanding of individual adaptation or biological outcomes. Given nursing's emphasis on the understanding of relationships between the psychological, the social, and the physiological aspects of an individual, it is important that models that can assist us in understanding these relationships in children be developed and tested.

Importance of the Family

The preceding discussion points out the important role of the family in understanding chronic illness in childhood. As Knafl and Deatrick (1986) have noted, the family may influence management

decisions. In addition, the illness itself, as well as the potential for illness to occur, may influence family functioning (Miller-Johnson et al., 1994). Of course, family functioning is affected by multiple influences in the community, such as extended family members, peers, and schools (Jassak & Knafl, 1990). The majority of models that have been used to study chronic illness in childhood, however, do not address these interactions.

Currently, a large scale trial to prevent type 1 diabetes is in progress. The Diabetes Prevention Trial—Type 1 (DPT-1) involves the screening of a large number of first-degree relatives of patients with type 1 diabetes to find those who have the highest risk of developing the disease in the next 7 years (Ingle, 1994). Individuals found to be at high risk will be randomly assigned to preventive treatment with insulin or regular follow-up care.

Studies such as the DPT-1 present the opportunity to examine the influence of illness and potential illness on a family. The availability of screening and treatment that might prevent diabetes is assumed to be a positive advancement, and discovering that a sibling is not at risk is the "best" answer. Qualitative data based on interviews with families of children undergoing screening suggest that it is not as straightforward as might be assumed. For example, we found that not all families want to have the siblings of the child with diabetes screened; they would rather wait and see what happens naturally. Finding out that no other child in a family is at risk often means that families need to come to terms with the idea that one child was "selected" by diabetes. For some families, finding out that a sibling may be at risk may lead to feelings of relief, but may also lead to grief over the potential diagnosis. Further, parents with children who have been determined to be at risk often adopt behaviors and management associated with a child who has already been diagnosed with diabetes, even though these children do not have diabetes yet.

Use of Controls

The next key research issue when studying children with chronic illnesses is the use of controls. In their attempts to understand what effects are caused by chronic illness, researchers have compared children with chronic illness with their siblings, with children who have experienced an acute illness, and with children without a chronic illness. Jacobson et al. (1990) compared adjustment over time in children having diabetes with children who had been hospitalized, but had non–life-threatening and nonchronic illnesses, and they found few differences. They concluded that children with diabetes were at no higher risk for the development of psychosocial difficulties than children without diabetes. On the other hand, when children without chronic illness and no recent hospitalization were compared over 2 years with children with newly diagnosed diabetes using the same instruments, differences may be found. In our study, the children with chronic illness had more difficulties with adjustment than their age-mates (Grey et al., 1995).

Siblings have also been used as controls in studies of children with chronic illness. Drotar and Crawford (1985) have clearly shown, however, that siblings of children with chronic illness also must adjust to a chronic illness in a family member and cannot be assumed to be control subjects. Thus, siblings do not represent a group at lower risk for psychosocial problems than those with chronic illness, and studies using siblings as controls are likely to find few differences in overall adjustment.

Ethical Considerations

The final research issue that differentiates children from adults with chronic illness is ethical considerations. Although there are specific guidelines that govern the inclusion of children as research subjects, in practice, interpretation and understanding vary (Thurber, Deatrick, & Grey, 1992). Parents must provide fully informed consent for all children under the age of 16, and children are required to provide assent to participate in treatment or research. In practice, however, many researchers seek fully informed consent from youth younger than 16 years old. It is also important to remember that children have the right to refuse to participate in research, even when their parents have consented, and researchers need to acquiesce to the child's wishes. In our study of intensive management of adolescents with diabetes, the protocol requires significant effort on the part of the adolescent. Therefore, regardless of age, we have insisted that they and their parents provide fully informed consent to participate in the study. In some cases, parents have consented, but the adolescent has refused, and these adolescents were not enrolled in the study. It is also important to remember that the legal mandate is the minimum, but children younger than the age of majority are developmentally capable of understanding the risks and benefits of research, and therefore should be actively involved in the process.

CONCLUSIONS

There are many lessons to be learned from a critique of past research studies and findings dealing with children with chronic illness and their families. These lessons are summarized below.

Sampling is Important

Sampling in chronic illness research with children offers two options: a noncategorical and a disease-specific approach. With children there is a need for more multisite studies and noncategorical studies to avoid the problem of low statistical power. There is also a need for more studies with adequate samples to examine differences by subgroups, such as different functional status, or age and developmental status, or gender.

Outcomes

As is true with this program of research, the majority of studies of children with chronic illness are cross-sectional and do not involve the testing of interventions (Deatrick, 1998). It is very important to develop studies of interventions and to carefully describe both the long-term and short-term outcomes of the natural history of the disease and adaptation process as well as the impact of nursing care. Further, the assessment of the effects of nursing interventions on functional status and quality of life needs to be a focus of research.

Measurements

It has been said that the state of a discipline can be judged by the state of its measurements. Measurement in nursing has developed rapidly in the past decade, but the development of appropriate measures for the study of children with chronic illness is in its infancy. Much more work needs to be done to develop methods for studying children's own perceptions of illness and the adaptation process in addition to the perspective of the parent or provider. Nurse researchers need to be careful to attend to the developmental and cultural issues inherent in the measurement of key variables in chronic illness research.

Models

The lack of models dealing with the biopsychosocial dimensions of chronic illness in childhood needs to be remedied. Models need to be developed and tested that incorporate the personal with the social aspects of the child's life. Further, nursing models need to focus on the physical aspects of disease management equally with the psychosocial.

Lack of Intervention

The program of research described here has focused on assessment and planning aspects of care for children with diabetes. As Deatrick (1998) has described, there are remarkably few carefully controlled studies of interventions with children who have a chronic illness. Most researchers who have conducted intervention studies have taken the approach that a given intervention will work for all subjects. Clinically, we know that this is not true. Certain patients and their families respond to certain interventions. Therefore, intervention studies need to be developed that can test which interventions are most effective for which constellation of personal and social characteristics of patients.

Summary

Clearly, children with chronic illnesses are not small adults. The illnesses children have are different than those faced by adults; thus, the methods used to study these problems and work with these children and families cannot be merely downsized from the large literature on adults with chronic illnesses. Care of children with chronic illnesses such as diabetes needs to be based on empirical findings from solidly constructed studies that address the developmental and social issues engendered by chronic illness in childhood.

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