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FREQUENCY OF LIFE EVENTS AS REPORTED BY CHRONICALLY ILL CHILDREN

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FREQUENCY OF LIFE EVENTS AS REPORTED BY CHRONICALLY ILL CHILDREN

By

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ABSTRACT

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The purpose of this study was to compare the frequency and perception of reported life events experienced by chronically ill children with the frequency and perception of life events reported by children without a chronic illness. A secondary data analysis was done on a data set obtained from research conducted by P. Peek, C. Barnes, and L. Spence, College of Nursing, Michigan State University. The sample in the primary research consisted of 28 families with a child between 8 and 12 years who had been diagnosed for at least one year with the chronic illnesses and 17 comparison families with healthy children that had no known physical abnormalities or developmental deficits. A life events survey listing specific life events, to whom the event had happened, and what it was like for the respondent was given to each of the participants. Chronically ill children reported a significantly greater number of life events than the comparison children. No significant difference was found in the number of negative life events reported between the two groups. However, the chronically ill children reported a significantly greater number of positive events than the comparison children.

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INTRODUCTION

What is the relationship between children having a chronic illness and the frequency of life events reported by these children? Chronic illness and disability among children in the United States from birth to 18 years is estimated to be about 30% or approximately 20 million children (Newacheck & Taylor, 1992; Patterson & Blum, 1996; Velsor-Friedrich & Frager, 1990). Chronic illness is defined as conditions with active pathology such as diabetes, sickle cell disease, asthma and heart disease, whereas disabilities or impairments are conditions with stable pathology such as musculoskeletal, deafness and hearing loss, blindness and visual impairments, speech defects and cerebral palsy.

Mortality rates from infectious diseases of children in the early 20th century have declined through improvements in infectious disease control, sanitation, housing and medical care. The prevalence of childhood chronic disease has not decreased with evidence suggesting an increase in the prevalence of non-life-threatening chronic conditions such as asthma (Newacheck & Taylor, 1992). Medical advances in the past decades have lengthened the survival rate of children with chronic illness. Added to coping with the health demands associated with a chronic illness for affected children are the stressors of life events that can be influenced by the stress caused from the challenges associated with chronic illness for families. Life events

are common situations such as the birth of a sibling, changing schools or the death of a family member that have been credited with affecting adjustment, adaptation and susceptibility to diseases.

Life events that are both positive and negative require a readjustment or change in life by an individual and result in stress (Coddington, 1972b). Stress from life events is manifested in children both physiologically and behaviorally. Heisel, Ream, Raitz, Rappaport, and Coddington (1973) concluded that "children in any patient population experience more significant life events preceding an illness than is to be expected in a healthy population" (p. 121). Several studies noted the relationship between psychological factors and changes in immune function thus increasing susceptibility to disease (Cohen, Tyrrell & Smith, 1991; Cohen & Williamson, 1991; Jemmott & Locke, 1984). Boyce, and colleagues (1995) conducted two studies in a pediatric population and found that an individual's psychobiologic reactivity influenced the incidence of disease in high stress settings. Children who are compromised with the presence of a chronic illness are susceptible to effects of stressful life events on their disease management as demonstrated in a study using school-age children with insulin-dependent diabetes mellitus (Goldston, Kovacs, Obrosky & Iyengar, 1995). Bedell, Giordani, Amour, Tavormina, and Boll (1977) studied chronically ill children attending a 3-week residential summer camp and correlated the frequency of acute symptoms

associated with chronic illness to experiencing high levels of stress. Compared to low stressed children who only had 19 episodes of illness, children who were highly stressed had 69 episodes of illness, which demonstrated that stressful life experiences were associated with the frequency of acute symptoms in chronic illness.

Behavioral manifestations from experiencing stressful life events have been studied in populations of healthy and chronically ill children (Brown & Cowen, 1989; Cowen, Corey, Keenan, Simmons, Arndt & Levison, 1985; Dubow & Tisak, 1989; Jensen, Richters, Ussery, Bloedau & Davis, 1991; Loss, Beck & Wallace, 1995; Sandler, Reynolds, Kliewer & Ramirez, 1992; Spirito, Stark, Gil & Tyc, 1995; Tavormina, Kastner, Slater & Watt, 1976). Chronic illness increases a child's vulnerability to the stresses of life due to the exposure to more anxiety producing situations that arise from exacerbations of their disease and result in the need for extensive medical treatment (Bedell et al., 1977).

Two factors influencing reactions to stress by healthy children and children with chronic illnesses are family functioning and social support systems. Social support can function in a protective role to lessen the impact of stressors. In some instances, children with chronic illnesses have been shown to cope better with stressors since these children and their families have had to adapt to and cope with the stressors involved with their particular disease (Brown & Cowen, 1989; Tavormina et al., 1976). Although major life events such as the death of a parent or

relative cause stress to children, a number of successive life events in a given time has been found to be more significant and cause greater stress (Brown & Cowen, 1988; Brown & Cowen, 1989; Coddington, 1972b). Studies have been done to ascertain if children perceive experiences as stressful and if their perceptions differ from the perceptions of adults (Banez & Compas, 1990; Brown & Cowen, 1988; Yamamoto, 1979). Children's self-reports and instruments developed to measure life events in terms of stress showed that children differed from parents in some of their choices for stress causing events and that events related to parents and family functioning problems had higher ratings.

The significance of the accumulation of life events adding up to greater stress, that may be manifested in children both physiologically and behaviorally, makes studying the frequency of life events reported by chronically ill children relevant to health care. Knowing the frequency and type of life events reported may give information about family functioning and insight into coping skills of the children (Brown & Cowen, 1989; McCubbin & Patterson, 1983; Tavormina et al., 1976). Family routines such as adhering to medical regimens are effected by stressful events and family functioning may either buffer the effects or intensify the disruptiveness of the events (Hamlett, Pelligrini & Katz, 1992). Chronic illness management depends on the quality of family relationships. The child's and family's perception of the stressors

associated with the illness and resulting coping response are influenced by the characteristics and strength of the family. Coping may be manifested in the children's reaction to life events in ways such as exacerbation of their illness, an increase in behavior problems, or difficulty in managing their illness as in maintaining metabolic control in diabetics (Goldston et al., 1995; Sandler et al., 1992). Children who report frequent life events can be targeted for early preventive interventions to understand what the children find stressful in order to avoid the build up of stress and exacerbation of their disease and to identify strategies used to cope with the stressors.

Purpose of the Study

The purpose of the study is to compare the frequency and perception of reported life events experienced by chronically ill children with the frequency and perception of life events reported by children without a chronic illness. A secondary analysis of data collected by P. Peek, C. Barnes, and L. Spence, College of Nursing, Michigan State University, will be used to obtain reported specific life events that were experienced by the families of the chronically ill children as well as the healthy comparison children.

Hypotheses

Chronically ill children will report a significantly higher number of life events than healthy children.

Chronically ill children will report significantly more negative than positive life events.

Theoretical Framework

The theoretical framework this study will be based on is the double ABCX model developed by McCubbin and Patterson (1983), that is an expansion of Hill's (1958) ABCX family-stress model. Hill's original ABCX model focused on the impact of a single stressful event on the family and the resulting outcome whereas the double ABCX incorporates the concept of stressor pile-up to explain the accumulation of stressors that a family can experience with the resulting post-crisis behavior (Day, Gilbert, Settles, & Burr, 1995). Interaction of multiple factors that result in crisis as well as post-crises factors influence family outcomes and behaviors. Figure 1 is a diagram of the double ABCX model.

Factor "a" represents the stressful event or stressor. Stressor is defined as a life event or transition that impacts the family to produce or potentially produce a change in the family social system (McCubbin & Patterson, 1983). Areas of the family life that can be affected by the change are the family's boundaries, goals, patterns of interaction, roles, or values. Demands that are specifically associated with the stressor event are called hardships. The family's need for additional money, rearrangement of work and recreational plans to accommodate increasing medical expenses and other demands associated with a chronic illness are examples of hardships.

Factor "b" represents the family's resources to meet the demands of a stressor with the associated hardships (McCubbin & Patterson, 1983). Resources, which are

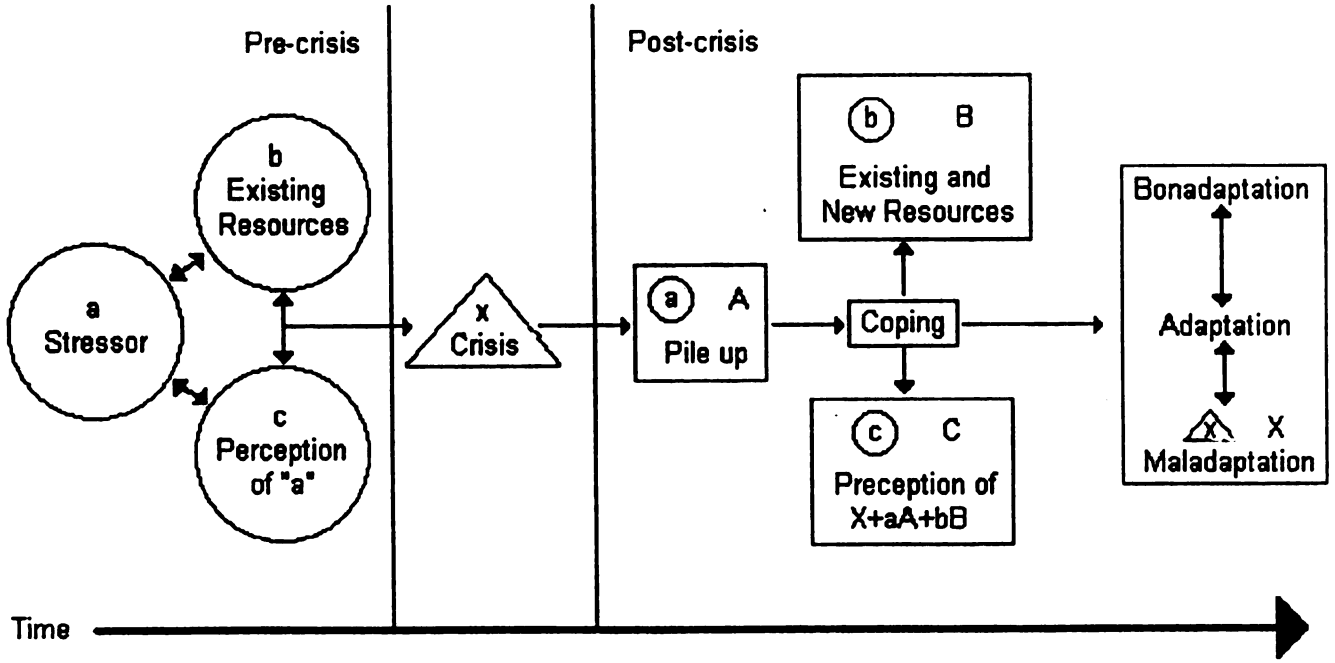

Figure 1. The double ABCX model (McCubbin, Patterson; 1983.)

comprised of economical and psychosocial components, are described as the family's ability to prevent an event from creating a crisis. Economic resources may include the family's income and material resources such as housing and transportation. Constituting family psychosocial resources are individual family members personality traits; the value of family integration, most prominent being common interests, affection, a sense of economic inter-dependence; the family's agreement about its role structure; placing family goals before personal ambitions; obtaining satisfaction within the family by successfully meeting the physical and emotional needs of its members; having collective family goals; and adaptation or the family's capacity to meet obstacles and shift its course of action.

Factor "c" is the family's subjective definition of the seriousness of the experienced stressor and associated hardships and resulting impact on the family (McCubbin & Patterson, 1983). Reflected in the meaning of the definition are the family's values and their previous experience dealing with change and meeting crises. The family can view the event as challenging or interpret the stressor as an uncontrollable prelude to the family's demise. Stress emerges when tension is produced by the stressor event and associated hardships. Family stress arises from a demand-capability imbalance in the family's functioning. It is characterized by a multidimensional demand for adjustment or adaptive behavior, and can vary depending on the nature of the situation, the

characteristics of the family, and the psychological and physical well-being of its members. Family distress is an unpleasant state of disorganization that arises from the actual or perceived imbalance in family functioning.

Factor "x" , the crisis, is the result of interactions between the stressor event and hardships, the family's resources, the meaning or definition of the situation to the family, and the resulting stress or distress (McCubbin & Patterson, 1983). These interactions influence the family's ability to prevent the stressor event from developing into a crisis. If the stress is such that the family is unable to restore stability and has continuous pressure to make changes in the family structure and patterns of interactions a crisis will result. However, if the family restores stability by using existing resources and defines the situation to resist systematic changes, the stress may never become a crisis.

Family crises evolve, are resolved over time, and may result in multiple strains and stressors or a pile-up of stressors referred to as the "aA" factor in the double ABCX model (McCubbin & Patterson, 1983). Contributing to the pile-up in a crisis situation are five general types of stressors and strains including: the initial stressor and associated hardships; normative transitions; prior strains; life events' consequences resulting from the family's efforts to cope and intra-family and social ambiguity. Individual member's and the family system's demands are in an ongoing state of change through the normal growth and

development processes. These transitions occur independently but simultaneously with the other stressors placing additional demands on the family unit. Residual strain from unresolved prior stressors' hardships and transitions may become exacerbated when a new stressor is experienced, adding to the pile-up of demands. Behaviors used by the family in an effort to cope with the crisis such as a member changing roles can contribute to the pile-up of stressors and strains. Social ambiguity occurs when society's guidelines for managing a particular type of stress during a family's crisis are lagging or absent offering no solutions for the family. An important factor in the successful adaptation to stress is the fit between the family and the community.

Additional demands that emerge during a crisis situation result in the development of new resources, represented by factor "bB" (McCubbin & Patterson, 1983). Individuals, the family and community are strengthened when combining existing resources with the new ones. Social support, one of the most important components of the "bB" factor, provides a sense that the family is cared for, loved, esteemed, valued and belongs to a network of mutual obligation and understanding. Social support strengthens the family's ability to resist crisis, recover from crisis and restore stability.

Factor "cC" combines the family's definition of the initial stressor and hardships with the pile-up of stressors to give meaning to the total situation (McCubbin &

Patterson, 1983). Utilizing existing and new resources the family estimates the necessary steps to bring balance back to the family system through redefining the situation. Redefining requires clarification of the issues, hardships and tasks that makes them more manageable and responsive to efforts of problem solving. When the family redefines the situation by viewing it as a challenge, an opportunity for growth, or endows it with special meaning such as "God's will", family coping and adaptation is facilitated.

Coping is the family's responses to the interaction of the pile-up, their resources and their definition of the situation (McCubbin & Patterson, 1983). Efforts to cope may be aimed at eliminating or avoiding stressors or strains; managing the hardships; maintaining integrity and morale; acquiring or developing new resources to meet additional demands; and/or restructuring the family system for demand accommodation. Coping entails simultaneous management of multiple stressors and strains or pile-up of stressors that requires compromising and acceptance of the best possible outcome.

Factor "xX" is the outcome of the family's response to the situation or the level of adaptation to the situation (McCubbin & Patterson, 1983). The goal is to eliminate disruption in the family system and restore stability. Accomplishing homeostasis provides new opportunities for growth and development within the family. Elements to be considered for the outcome of family adaptation are: individual family members maintaining balance within the

family system; the family maintaining balance within the community by balancing work and home commitments; and the family maintaining coherence by minimizing the discrepancy between resources and demands.

Family adaptation is the central concept that describes the family's post-crisis adjustment and efforts to return balance and stability of family functioning. There is a continuum of outcomes, with bonadaptation at the positive end of the continuum and maladaptation at the negative end of the continuum. Family bonadaption is characterized by the family maintaining or strengthening its integrity, maintaining independence and control over the environment and continuing promotion of development of individual members as well as the family unit. Maladaptation is at the opposite end and is characterized by family integrity deterioration, loss of family autonomy, and deterioration or curtailment of individual member and family development.

The double ABCX model was developed to study family stress. Family stressors and hardships related to the ongoing chronic illness of a child impact family functioning and also influence the chronically ill child's functioning. Variables that impact the functioning of a family with a chronically ill child are illustrated using each factor of the double ABCX model. Figure 2 is a modified diagram of the double ABCX model with the above variables applied.

Diagnosis of a chronic illness can be viewed as the initial stressful event, factor "a". Chronic illness has demands associated with it that are ongoing and changing.

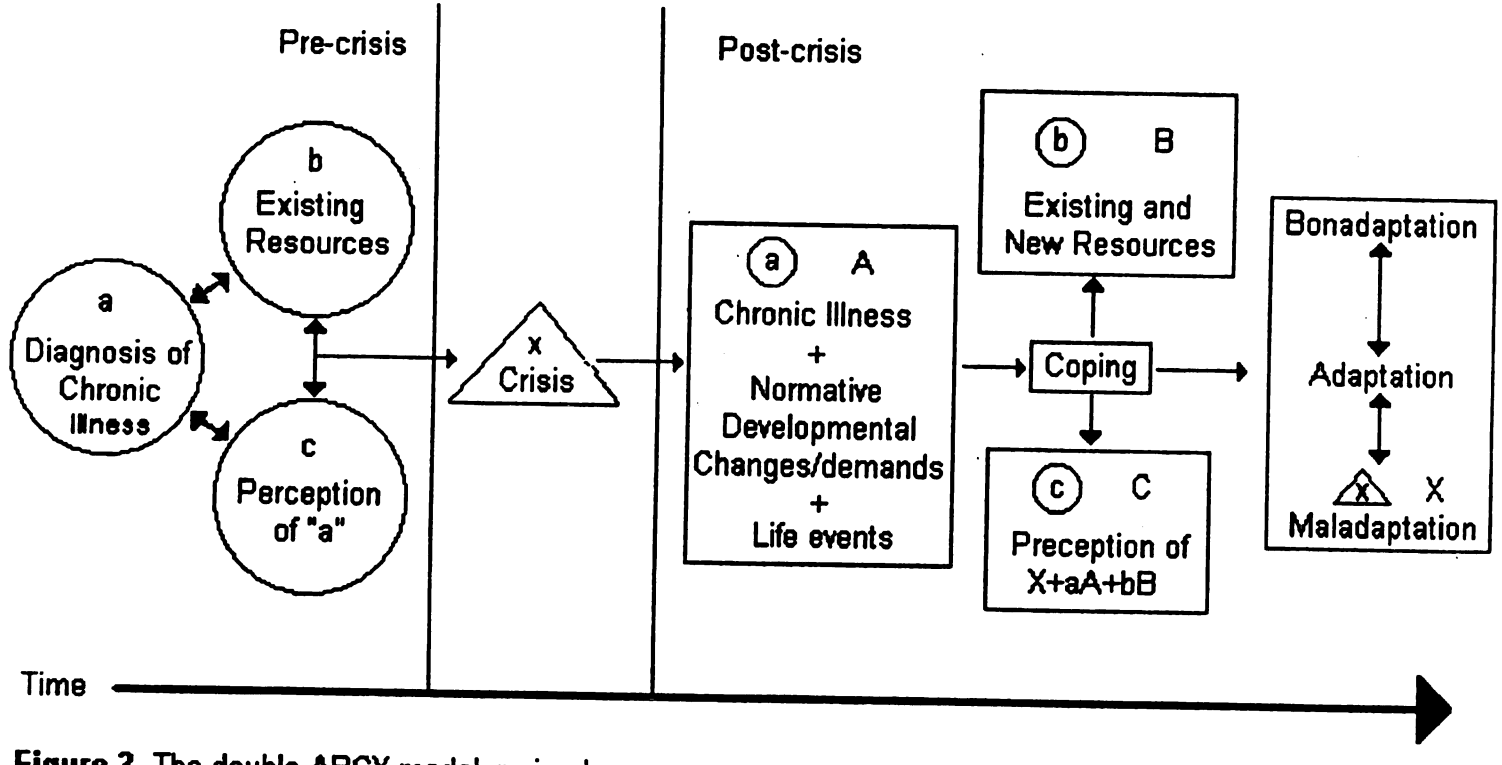

Figure 2 The double ABCX model, revised.

For example, some of the ongoing demands would include treatment requirements, symptom management and functional limitations. Exacerbation of the illness can occur if the child becomes ill after exposure to infection such as an upper or lower respiratory illness, thus resulting in changes of treatment regimens, symptom management and further functional limitations. Time requirements for treatment may interrupt the child's social life as well as that of other members in the family.

Resources of the family, factor "b", are influenced by the demands of chronic illness and affect each member of the family. Economic demands increase from cost of medications, treatments and other medical expenses such as equipment, physician visits, therapy and hospitalizations (Patterson & McCubbin, 1983). Changes in the family's usual lifestyle, such as affordability of recreational activities and time spent with members by the parent earning the income, can result. The working parent may have to take an additional job or work longer hours to meet the financial demands while the other parent may have to assume the role of caretaker. The caretaker can become over protective reducing the child's development of independence which can impact the child's self esteem (Patterson & McCubbin, 1983). Siblings may become competitive for the parent's time and blame the chronically ill child (Patterson & McCubbin, 1983). Emotional support impacts the chronically ill child's own resources such as self esteem.

The meaning of the chronic illness diagnosis to the family and the affected child is factor "c". One perception that occurs is the parents and child feel they could have done something to prevent the disease (Silverstein & Johnson, 1994). Parents as well as some children may experience grief and sadness over the loss of health and carefree lifestyle. The seriousness of the disease's impact on the child's daily activities or functioning influences the family's and child's definition of the event of being diagnosed with a chronic illness.

Interactions between factor "a", the stressors associated with the initial diagnosis and the period immediately following; factor "b", existing resources of the family and the child with a chronic illness; and factor "c", the family's and child's perception of the seriousness of the disease and impact on the child's lifestyle can result in a crisis, factor "x". Behavioral or emotional problems can occur with the child using the chronic illness as a manipulative tool (Silverstein & Johnson, 1994). There may be displays of anger caused by the disruptiveness of treatment demands. Anxiety about disease management can be manifested in behavior and can impede knowledge acquirement. Self image of being different can lead to non-adherence to regimens. Return to normal functioning usually occurs within 9 months of the diagnosis (Rubin & Peyote, 1992).

The present study will focus on the second half of the model, ongoing adaptation after the diagnostic period (figure 3). Chronic illness with the associated strains and

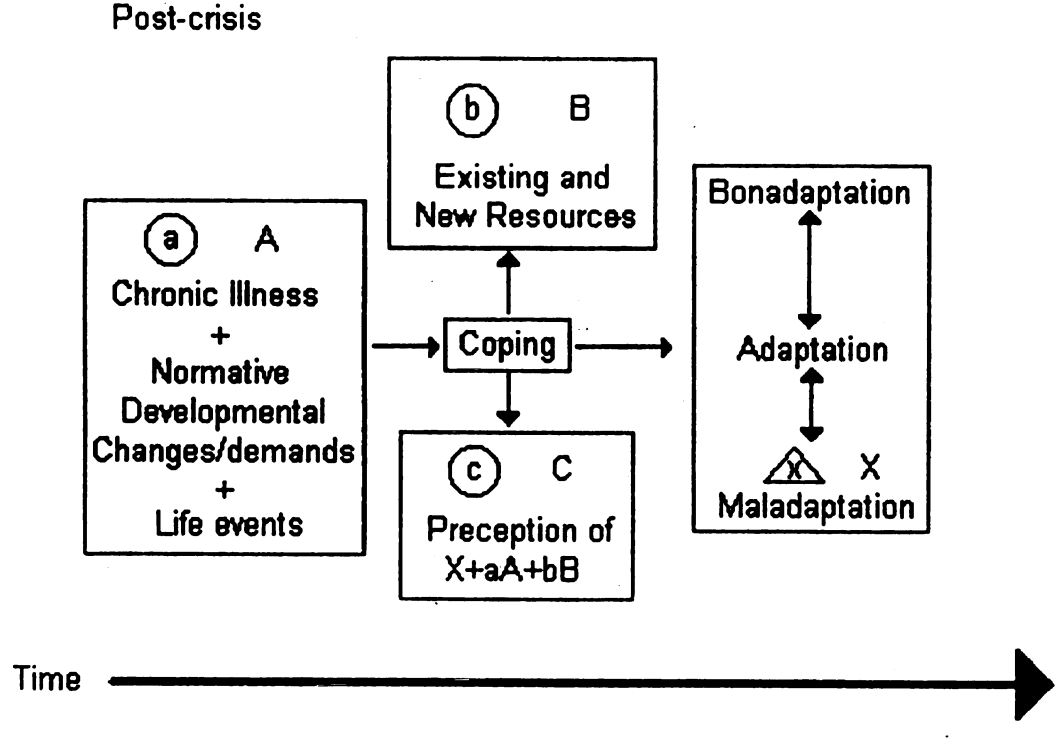

Figure 3 The revised double ABCX model, after diagnostic period.

hardships of disease management added to the normative developmental transitions and life events experienced by the family can cause a pile-up of demands, factor "aA". Treatment and symptom management are daily, ongoing factors which influence intra-family relationships, time management, financial responsibilities and other stressors mentioned in the "a" factor. Normal developmental changes, such as starting a new school, or new grade in school, developing peer relationships, physical and cognitive development as the child ages can be a source of stress that adds to the demands of the chronic illness (Patterson & McCubbin, 1983).

New resources must be developed and acquired to meet the demands associated with the chronic illness and the normative changes, factor "bB". Ongoing education of the child about the chronic illness and associated treatment required will increase his/her self esteem and help to develop a sense of mastery over the illness (McCubbin & Patterson, 1983; Patterson & Blum, 1996; Rubin & Peyrot, 1992; Silverstein & Johnson, 1994). Finding community resources and medical specialists is required for the child's management and adjustment to the disease. Social support of friends and relatives outside the immediate family are important resources for maintaining the child's sense of well-being.

Factor "cC" combines the definition of the chronic illness with the stressors associated with normative, developmental changes, and those associated with life events. The family and child may initially see the illness

as hopeless, shameful, overwhelming and beyond his/her ability to manage. Family support contributes to the definition given and dealing with the stressors of life events. Time helps the family and child to redefine the event of a chronic illness and to utilize existing and new resources to restore stability to his/her life.

Coping strategies are used by the family and child to bridge the interaction between the "aA" pile-up of stressors with "bB" existing and new resources and "cC" the perception or definition of the situation. Adaptation is the outcome of the family's ability to cope. An example of inadequate coping efforts is overprotection by the care giving parent that then limits the child's ability for independence and results in competition among the other siblings and spouse for attention. Reactions of the child can include withdrawal from social involvement out of shame or embarrassment and denial of the reality of the chronic illness thereby ignoring special physical needs (Patterson & McCubbin, 1983; Rubin & Peyrot, 1992). An example of positive coping behavior is an attempt by the family to normalize their life through understanding the illness. Family emotional support as well as social support from the community for the child and family is instrumental in achieving bonadaptation.

Conceptual Definitions

Chronic illness is characterized by the need for specialized medical care, management of daily treatment regimens or activities of daily living which may require

extra skill and time, frequently shortened life expectancy, and no known cure or uncertain prognosis (Patterson & McCubbin, 1983; Patterson & Blum, 1996; Stein, 1983). Chronic illness is a life long condition during which a child may become better or worse at times but is never a healthy child (Patterson & McCubbin, 1983). Cystic fibrosis is a lethal genetically caused example of a chronic illness that profoundly affects the daily lives of children and their families. Although the disease is fatal, medical advances have prolonged the life span to a mean age of 29 years (Ievers & Drotar, 1996). Asthma and diabetes are examples of chronic illnesses that also impact the daily life of children but are associated with a relatively normal life span. Chronic illness differs from acute illness in that during the course of a chronic illness there are periods of acute exacerbations that require intensive medical treatment but the child with a chronic illness lives at home and depends on the family for doing treatment and care. Responsibility for treatment of an individual with an acute illness resides with the physician and hospital staff since acute illness usually requires hospitalization.

Life events have been credited with affecting the adjustment, adaptation and susceptibility to diseases. Life events are common situations that require a change or readjustment in an individual's ongoing lifestyle (Coddington, 1972b; Kale & Stenmark, 1983). These events can be undesirable, positive or ambiguous yet seen as stress producing since change is involved that interferes with

normal activities. Stress is an individual's pattern of physiological and psychological reaction in response to stressful conditions or stressors (Rabkin & Struening, 1976). Although stress has been credited with causing illness, a person's perception or appraisal of the significance of a stressful event as potentially harmful, challenging or threatening influences the resulting outcome.

LITERATURE REVIEW

This review of literature will include studies correlating perception of stressors and life events to symptomatology of illness. It will also review research examining stressors and life events in chronically ill children with particular focus on cystic fibrosis, asthma and insulin dependent diabetes mellitus in children.

Major Life Events in Children

Numerous studies have looked at children's perception or appraisal of the stressfulness of life events and sought to determine if their appraisal differs from adults. Many of the studies make reference to the two classic studies conducted by Coddington (1972a; 1972b). In the first study (1972a), using the Holmes and Rahe method modified to children, teachers, pediatricians and mental health workers were utilized to determine the significance of life events for children from four age groups: preschool, elementary, junior and senior years of high school, and to establish the relative value and rank order of the events. Items to be rated for importance were chosen from literature and previous experience with children. There were no

significant differences among the respondents in the assignment of rank order to the items resulting in relative agreement about the importance of all items. Attaching value to items in regard to the effect or the requirement for readjustment from a given life event differed statistically between the teachers and health care professionals. Significance attached to life events differed within the three groups depending on the length of experience the individuals had in working with children and values attached to the items for each age group. Values attached to the items or events are called Life Change Units and can be summed to determine the amount of social-psychological readjustment a child has undergone during a specific time period. Since the difference between the teachers and two health care professional groups was small, this instrument is viewed as a good measurement device of environmental factors that impact children, can be completed in a few moments, and can be done without interviewer bias and subject bias if the time period is carefully designated to minimize recall inaccuracies. Coddington reported two psychiatric clinical cases using the instrument and in each case the client had undergone life changes amounting to greater than 300 Life Change Units. Limitations of this study include the discrepancy in number of years of experience in working with children of the participants and that the values attached to life events were obtained from the opinion of adults and not the children themselves for whom the instrument was intended.

In the second study Coddington (1972b) used a life event record with the Life Change Units to gain understanding of the amount of social readjustment from the environment that is required for healthy children. The same four age groups in the above study were used. Forms for preschool and elementary school children were completed by the parents while forms for junior high and senior high students were completed by the subjects themselves. Older children were found to have a greater number of life events. At age 12-14, with the advent of puberty and adolescence, children risk the occurrence of more life events that require more social readjustment. Adjusting to external environmental changes is a complex combination of biological, immunological and emotional components that impinge on health depending on one's ability to adjust. Coddington cited a case involving an event for an adolescent girl that by most would have been viewed as good but was stressful enough for her to attempt suicide, demonstrating that both bad and good events can be stress provoking. Children who had been hospitalized within the past year accumulated a higher score in Life Change Units indicating that a large readjustment requirement may be significant in the case of physical illness. Over 3500 healthy children were surveyed in this study for the number of events requiring social readjustment that had occurred in the preceding year. Based on the large number of participants, this method and the Life Event Record with Life Change Units would be applicable in the study of all children, both

healthy and ill, for understanding the impact of life events on health status. It should be noted that responses of preschool and elementary school age children are from parents and not the children themselves. Although the occurrence of life events was reported, the number of times an event occurred to a given subject within the year was not evaluated. This author also questions the accuracy of recall over a year's time by the children.

Yamamoto (1979) studied 367 children in the fourth, fifth and sixth grades for perception of upsettingness of and previous experience with 20 life events from review of literature and teacher's suggestions that were considered potentially unpleasant for children. Classroom teachers presented the events to the children who then rated the events on a Likert scale for upsettingness and indicated whether an event had been personally experienced. Some experiences such as loss of sight and pants wetting, although infrequently experienced, were rated as very upsetting. Common events such as parental fights were seen as more stressful than the birth of a sibling, contradicting the belief of professionals. Experiences that coincided with evaluation by professionals as upsetting were the loss of a parent and academic retainment. Yamamoto concluded from this study that constructing a meaningful life event scale for children is feasible and subcultural variations need to be studied. This study is limited to children in the age ranges found in those three grades and can not be applied to other age groups.

Another study by Brown and Cowen (1988) also focused on children in fourth to sixth grades to judge upsettingness of events and frequency of event occurrence in the children's lifetimes. Responses were obtained from the children themselves. Events judged to be highly upsetting by children, like adults, were serious injury to or death of a parent and parental divorce. Birth of a sibling was found to be the least upsetting in this study as in Yamamoto's (1979) suggesting that children's perception of stressfulness differs from adults. Frequency of events varied according to severity of the event. For example, events such as being unable to watch a favorite show on TV or receiving a bad mark on a test occurred more often than death of a parent or school suspension. The average number of stressful events reported occurring in a lifetime was seven. Conclusions of this study are limited to children in the age ranges studied and some events were omitted because of their powerful effect on children. Insight into the meaning of stressful life events to children is gained from the study since the children rated the upsettingness of an event on a Likert scale. Comparing the children's reports of event occurrence with those of knowledgeable observers such as parents and teachers would be more reliable in determining accuracy for recall of the children's reactions at the time of occurrence.

Brown and Cowen (1989) found in their study of children in fourth to sixth grade that cumulative stressful life events correlated with less competency and more serious

school adjustment problems. The children who had experienced many stressful events, by self-report and teacher's report, identified behaviors that were different from children who had experienced few stressful events. Another purpose of this study was to assess the nature and breadth of children's support network using a 6-item questionnaire. Children rated their self-adjustment using a 35-item Child Rating Scale and indicated the extent that each item applied to him/her. Through the children's self-reports, support was perceived to contribute positively to adjustment. Teachers used a two-part Child Rating Scale to describe children's school adjustment problems and assess school competencies. When teacher ratings for adjustment criteria were used, an inconsistency compared to the children's self-reports was found in the relationship between the support and adjustment. More important than support network size for correlation between support and adjustment may be the support available during the occurrence of a stressful event and satisfaction with that support, not measured in this study. However, there were significant statistical interactions found between the number of events experienced and level of support when the teacher ratings of child adjustment criteria were used. In the low support groups the total number of events experienced had a positive correlation with problem behaviors and a negative correlation with competencies.

Banez and Compas (1990) studied students in the fourth and fifth grades in two elementary schools to correlate

self-reported daily stressors with reported daily stressors of their parents. Internalizing emotional/behavioral symptoms of anxiety and depression associated with the stressful events were assessed as reported by the children themselves and compared with reports by their parents. Children's self-reported daily stressors were significantly related to self-reported problems of depression indicating that daily stressors are related to emotional distress in young children. Father's reports of the problems coincided with the children's but the mother's reports did not. Parents' daily stressors were related to children's self-reported symptoms of anxiety. Conclusions of this study are limited to children in the age groups studied and findings can not be generalized to other populations because of the small sample size. Note that it also raises question about using parental report for children's life events and their stressfulness. A longitudinal study rather than cross-sectional study may be more useful. Assessing stress related externalization problems would also be useful. This study revealed the value of the father's observations when conducting studies of children.

Perception of stressful life events has been associated with symptomatology of illness in healthy as well as chronically ill individuals. A correlation between the increase of disease symptoms and stress was noted in DeLongis, Folkman and Lazarus (1988) study of healthy adults. In Coddington's (1972b) study of healthy children, children who had accumulated a high score of Life Change

Units from experiencing stressful events had also been hospitalized. Loss, Beck and Wallace (1995) studied third and sixth grade children using the Coddington Life Event Record to measure the accumulation of Life Change Units over the past year. The instrument was administered to the mothers and a modified understandable version that measured the positive and negative impact of life events was administered to the children. An evaluation of depressive symptoms was also done using the Children's Depression Inventory (CDI). Children with high scores on the CDI reported significantly more life events during the past year and the findings were corroborated with the mother's reports. Children in the third grade were less accurate in recalling events that occurred within the 12 month period. Generalization to other populations can not be done because the sample consisted of mostly Caucasian children in two age groups. These studies are examples of the impact that stress from the occurrence of frequent life events has on the health and well-being of healthy individuals.

Life Events in Chronically Ill Children

Chronic illness and the associated burdens increase an individual's vulnerability to stress from life events. A study by Heisel et al. (1973) mentioned above was done on an inpatient pediatric population and revealed a considerably higher incidence in the frequency and/or severity of life events prior to the onset of illness than found in a population of healthy children. This was accomplished by surveying the parents using Coddington's Life Event Record

(Coddington 1972a, 1972b) for events that had occurred in the year preceding the onset of illness or admission to the hospital. Results from the parental reports were compared to scores of Life Change Units obtained from the survey of healthy children in Coddington's study (1972b) and were found to be statistically significant in the frequency and number of events experienced by the hospitalized children. The participants were limited to five distinct patient populations and selection of the participants was not randomized.

Bedell et al. (1977) also found an increase in episodic events of illness in chronically ill children who had experienced high levels of stress indicating that the frequency of acute symptoms related to chronic illness was associated with life experiences. Determining stress levels was achieved by surveying the children using Coddington's Life Event Record to assess the number of Life Change Units accumulated during the year preceding their camp experience. When the results of life stress scores were compared with normative data, the high stress group had experienced above average levels of stress. As previously mentioned above, the impact of stress was noted in the incidence of episodic events during the camp experience. Children in the high stress group perceived themselves as having more behavior problems and less ability in schoolwork. Although the results were significant, the sample size was small and the accuracy of recall by the children is questionable.

A longitudinal study by Goldston et al. (1995) of new onset insulin dependent diabetes mellitus in school-age children surveyed the children and at least one parent separately about their lives, psychiatric symptoms and diabetes care. Utilizing Coddington's Life Events Record (Coddington 1972a, 1972b) parents were asked to list events that had occurred over a specific time interval to determine if metabolic control over time was affected by the number of undesirable life events or the readjustment required by the occurrence of life events. Findings from the parents' responses suggested that the overall stress of life events, both positive and negative, that require a life change was relevant in the patients' attempts to maintain metabolic control. Greater life stress was associated with a lack of adherence to the medical regimen thus affecting metabolic control. These findings of the relationship between metabolic control and life stress can be generalized to children during the initial years of diabetes mellitus but further research is needed for generalization to other populations with insulin dependent diabetes mellitus.

Childhood chronic illness within the family context and the relationship of stressful life events, family functioning and social support were examined in a study by Hamlett, Pellegrini and Katz (1992). Children ages 6 to 14 with asthma and diabetes and their mothers as well as children of the same ages without significant illness and their mothers participated in the study. Chronically ill children experienced more stressful events over a 12 month

period than children in the control group as reported by their mothers, not the children themselves. Family functioning did not differ in the families of chronically ill children compared to the families of healthy children indicating that the families function well while coping with the demands of illness. Mothers of children with asthma reported less adequate social support and greater incidence of internalizing, anxious behaviors of the children suggesting the importance of social support for families with chronically ill children and the impact the mother's perspective has on the child. This study is limited by the small sample size.

In summary, research has found that the occurrence of a life event, whether it is perceived as good or bad, has been associated with stress and the onset of illness or the exacerbation of chronic illness. It has been found that children with a chronic illness report more frequent occurrences of life events. Perception of the stressfulness of life events has been found to differ between adults and children. Researchers have found the validity in children's self-report of life events. However, most of the research on life events has been conducted using instruments in which the value of a life event has been rated by adults. Parents or the children have rarely been asked to rate the stressfulness of events themselves.

METHODS

Research Design

A secondary analysis was done on a data set obtained from research conducted by P. Peek, C. Barnes, and L. Spence, College of Nursing, Michigan State University for a study examining family adaptation to chronic childhood illness. The primary research is a descriptive, cross-sectional, quasi-experimental design comparing families that have a child with a chronic illness with families that do not have a child with a chronic illness.

Sample

The sample consisted 28 families with a child between 8 and 12 years who had been diagnosed for at least one year with the chronic illnesses of asthma (8 families), congenital heart disease (6 families), cystic fibrosis (8 families) and insulin dependent diabetes mellitus (6 families), and 17 comparison families with healthy children who had no known physical abnormalities or developmental deficits. Four families were randomly selected from each of the four chronic illness categories for purposes of matching. Thirteen of these families were matched with 13 of the comparison families. Criteria used for matching consisted of: age, sex and birth order of the target child; number of parents in the home; approximate family size and income. Four non-randomly selected chronic illness families that were evenly distributed across the diagnostic categories were matched with the other four comparison families with the final sample consisting of 160 subjects

including parents, siblings and target children. Recruitment of the families with a chronically ill child was done through the pediatric subspecialty clinics in the Department of Pediatrics and Human Development, Michigan State University. The study was limited to these clinics in an effort to control the philosophical approach to the medical management of chronic childhood disease by encouraging patient and family participation in disease management.

All families meeting the criteria who came to the clinic successively were asked to participate since the number of chronically ill children in each diagnostic category was limited, making this a convenience sample. University, neighborhood and community agency announcements were used to recruit the comparison families. No significant differences between chronic illness and comparison families in characteristics of the target children, family characteristics, or father characteristics were revealed in Chi square analysis. Mothers in the chronic illness families had less education and were less likely to work outside the home than the mothers in the comparison families (Spence, 1992).

Procedure

Chronically ill families and comparison families meeting the criteria were sent letters explaining the research and inviting participation. Enclosed in the letters was a return postcard indicating willingness to participate and requesting available times for participation

and information about the composition of the family. A follow-up phone call was made to all respondents by the investigator to answer questions and schedule home visits at a time when the entire family was available. During the home visit the study was explained to all of the family members, questions were answered, informed consent was obtained, sociodemographic information from each family was obtained and illness demographic information from the chronically ill families was obtained. The investigator gave each family member the appropriate instruments to complete, answered questions and assisted the younger children in completing the instruments.

Protection of Human Subjects

The present project was approved by UCRIHS (# 98-277). The original study was approved by UCRIHS. All participants in the original research gave informed consent and participated willingly. The investigator for this study received the data on a computer disk with no identifying information.

Operational Definitions

Demands was operationally defined as the frequency of life events that occurred in the family as reported by the child on the Life Experiences Questionnaire.

Perception of life events was operationally defined as the interpretation by the child, as measured by the child's responses on the Life Experiences Questionnaire, of events as either positive or negative on a Likert scale indicating what the event meant to the child.

Instrument

The instrument used for the data base that this author analyzed was the Life Experiences Questionnaire (LEQ) that combined the Life Experiences Survey (LES) from Sarason, Johnson and Siegel (1978) with questions from the Children's Life Event Record (Coddington, 1972a, 1972b), both of which are established and frequently used instruments. Questions on the instruments requested information about family life events that had occurred within the past 6 months, to whom the event happened and what the event was like for the respondent. The impact of the event was rated on a 5 point scale from Very Bad to Very Good. The children's form had larger print and the wording was adapted for easier reading.

The LES is comparable with other life events questionnaires in reliability and validity (Sarason et al., 1978). Although life events items collectively provide a quantitative measure of major stressors, individually the life events are not necessarily stable or highly inter-related (Spence, 1992). Therefore, internal consistency is a less meaningful measure of reliability with life event measures than test-retest reliability done over time to examine event consistency. Sarason et al. (1978) reported test-retest reliabilities at 5- and 6- week intervals to be .19 and .53 for the positive change scores; .56 and .88 for the negative change scores; and .63 and .64 for the total change scores. A number of outcome measures have demonstrated the validity of the LES.

Coddington's (1972a; 1972b) Children's Life Event Record was the first instrument designed for children's assessment of life events and is used most often. Content validity is demonstrated by use of an expert panel to establish relative values and rank order of events to be used in the instrument that occur in the lives of children and were chosen from the literature and work with children. The children were able to understand and answer the questions when administered the instrument.

Data Analysis

Raw data from the primary research was analyzed using descriptive statistics and a t-test. Descriptive statistics were used to examine the frequency of life events reported, and whether the life events were perceived to be positive or negative. The t-test was used to determine if there was a significant difference between children with a chronic illness and healthy children in the frequency and perception of life events reported.

LIMITATIONS

Limitations of the study included the use of a small sample size and limiting the age to children 8 to 12 years. This limits the ability for generalization to younger and older populations and populations with different demographics. Control of the medical management style used warrants further research for the effect the style has on family adaptation to chronic childhood illness. A longitudinal study would provide more accurate information

about family adaptation as an on-going process and facilitate prediction of family functioning at a later time.

RESULTS

Demographic Data

There were 28 chronically ill children and 17 comparison children ranging in age from 8 to 12 years with a mean of 9.93 years for the chronically ill children and 10.45 years for the comparison children (Spence, 1992). Thirteen of the chronically ill children were female and 15 were male. Eight of the comparison children were female and 9 were male.

Hypotheses Results

Results in this section were obtained from the chronically ill children's and the comparison children's self-reported answers to a questionnaire about the frequency of life events experienced and the meaning of the event for the respondent. In the first analysis, the number of yes responses to the occurrence of each a life event were counted, totaled, and analyzed using a t-test (Table 1 and 2). Chronically ill children reported a significantly greater number of life events than healthy children. A mean of 9.00 events was reported by the chronically ill children and a mean of 5.35 events was reported by the healthy children ($p \leq .05$) supporting the first hypothesis, that chronically ill children would report a significantly greater number of life events that healthy children.

No significant difference was found in the number of negative life events reported between the chronically ill

Table 1.

Frequency of Reported Life Events Group Statistics

	N	Mean	Std. Deviation
Chronically Ill	28	9.00	4.93
Healthy	17	5.35	4.42

Table 2.

T-test for Equality of Means of Frequency of Reported Life Events

t-test for Equality of Means		
t	df	Sig. (2-tailed)
2.500	43	0.016*

*p ≤ 0.05

children and healthy children. Chronically ill children reported a significantly greater number of positive events than healthy children. Therefore, the second hypothesis was rejected.

The children's perception of life events was further examined using two methods. First, the number of responses to each rating of the Likert scale were counted, totaled, and analyzed using a t test (Tables 3 and 4). There were no

Table 3.

Frequency of Responses on Likert Scale Group Statistics.

Likert Scale Ratings		N	Mean	Std. Deviation
Very Bad (1)	Chronically Ill	28	3.18	3.09
	Healthy	17	2.24	1.82
Bad (2)	Chronically Ill	28	1.12	1.17
	Healthy	17	0.76	1.09
OK (3)	Chronically Ill	28	2.68	2.82
	Healthy	17	2.59	3.47
Good (4)	Chronically Ill	28	0.61	0.79
	Healthy	17	1.12	1.22
Very Good (5)	Chronically Ill	28	3.86	3.70
	Healthy	17	1.53	1.74

Table 4.

T-test for Frequency of Responses on Likert Scale

t-test for Equality of Means			
Likert Scale	t	df	Sig.
Very Bad (1)	1.140	43	0.260
Bad (2)	1.284	43	0.206
OK (3)	0.096	43	0.924
Good (4)	-1.712	43	0.094
Very Good (5)	2.429	43	0.019*

*$p \leq 0.05$

significant differences found in the number of responses for the "very bad" to "good" ratings. However, "very good" had a significantly greater number of responses by the chronically ill children (mean of 3.86) than the comparison children (mean of 1.53, $p \leq .05$).

Measuring the intensity of the reported Likert scale ratings provided a measure of the subjects perception of the demands associated with positive and negative life events. This was the second analysis done (Tables 5 and 6). A sum of the value of the positive responses "good" and "very good" was done and then analyzed with a t-test. The same process was repeated for the negative responses "very bad" and "bad". Chronically ill children responded positively 27 times with a mean of 4.8162 while comparison children responded positively 13 times with a mean of 4.5466 ($p \leq .05$). Chronically ill children responded negatively 26 times with a mean of 1.3780 and comparison children responded negatively 16 times with a mean of 1.3393 ($p \geq .05$). Chronically ill children rated positive life events significantly more positively than the healthy children and there was no significant difference between the groups in perception of negative life events.

DISCUSSION

Theoretical Framework

This study focuses on the "aA" factor (demands) and "cC" factor (perception of demands) of the revised Double ABCX model (Figure 3). Both of these factors occur post-crisis and for the chronically ill children, one year after the

Table 5.

Intensity of Positive and Negative Responses Group Statistics

Life Events		N	Mean	Std. Deviation
PLEI	Chronically Ill	27	4.8162	0.2945
	Healthy	13	4.5466	0.3274
NLEI	Chronically Ill	26	1.3780	0.3829
	Healthy	16	1.3393	0.4353

Table 6.

T-test for Intensity of Positive and Negative Responses

t-test for Equality of Means			
Life Event	t	df	Sig.
PLEI	2.616	38	0.013*
NLEI	0.302	40	0.764

*p ≤ 0.05

diagnosis of a chronic illness. Factor "aA" is concerned with a pile-up of stressors from the demands associated with a chronic illness, normative developmental changes with associated demands, and the occurrence of life events. It is not surprising to note the greater frequency of life events reported by chronically ill children since the added demands associated with a chronic illness increase the demands on the family as a whole.

Factor "cC" is the family's perception of the situation after defining the initial stressor and hardships with the pile-up of stressors. The expected outcome would be that chronically ill children would perceive the greater frequency in the occurrence of life events as well as the individual events more negatively given the stressors associated with having a chronic illness. Perhaps perceiving that the occurrence of the life event is directly related to the chronic illness would also be thought to result in a tendency toward more negative perceptions of events. The positive intensity of life events was significantly greater for chronically ill children than healthy children. That children with the added burdens associated with a chronic illness have more overall positive perceptions of life events may be associated with the resiliency of children. Since the occurrence of any life event is associated with stress, it was unexpected that the chronically ill children would report a significantly greater number of "very good" ratings on the Likert scale. Higher intensity of positive events is somewhat related to the greater number of positive events reported by the chronically ill children but may also be interpreted as a result of the children's coping abilities and developmental level or maintaining homeostasis within the family. Events such as hospitalization or exacerbation of a disease may be perceived negatively by adults. The child may perceive hospitalization as a means to relieve symptoms while providing more individual attention from the parents.

Parents perception of a situation, especially the mother's, influence the child's perception. Adaptation by children has been associated with family functioning, support, and redefining of events by the family in a positive manner.

Methods

Characteristics of the original study that may influence data interpretation will be discussed in the section. First, the sample size is small consisting of 45 subjects with 28 chronically ill children and only 17 comparison children. For the purpose of comparing characteristics of the two groups, homogeneity in the demographics of income, amount of work outside the home, and characteristics of the target child and family is beneficial. However, using a homogenous sample limits generalizing the results to other groups. Education level and a greater number of outside employment in professional positions by mothers in the comparison group may influence the results regarding the mothers' coping skills although the literature does not indicate that coping is related to education level.

Cross-sectional data collection of retrospective information may influence the results. Timing and sequence of the events may influence the child's perception of the event since children are fairly resilient but the literature does make reference to problems associated with an accumulation of stress from a pile-up of demands. Developmental level of the child and recall of the emotions

associated with events at the time of occurrence may be influenced by the time of data collection.

Current Literature

The first hypothesis was supported in this study. Chronically ill children reported significantly more life events than healthy children. This is also supported by the literature (Goldston et al., 1995; Hamlet, Pelligrini & Katz, 1992). There is little research that utilizes children themselves to rate the stressfulness of a life event. Many researchers have used professionals and parents to determine the perception by children of a life event. Research has revealed that perception of events differs between adults and children. This study recognized the validity in children's self-reports of the occurrence of life events and their perception of the events. Finding more positive numbers of events reported and more positive perception of reported events was not the expected outcome stated in the second hypothesis. The literature suggests that child's perception is influenced by the parent's perception, especially the mother's (Hamlett, Pellegrini & Katz, 1992). Results of this study, the reporting of more positive events and perceptions, may be due to the family's development of more effective coping behaviors as suggested by Folkman et al. (1986).

IMPLICATIONS

The Advanced Practice Nurse

The results of this study found that chronically ill children report a significantly greater number of life

events and more events were reported and perceived positively. Implications for the Advanced Practice Nurse (APN) in a primary care setting related to the results will be discussed in this section. Knowing that life event occurrence, whether it is perceived as good or bad, is a source of stress, is important for the APN when assessing a child with a chronic illness. Asking the family and child about the occurrence of life events should be included in the assessment at each visit. The added burden of demands associated with the disease and the tendency to experience more life events can lead to a crisis situation. Preventing a crisis can be facilitated by the APN through the identification of health care and education needs and coordinating care utilizing community resources. Educating the child and his/her family about the disease can help them gain a sense of control and mastery of the situation. Ongoing education about the disease process as well as developmental changes is important to help the family and child maintain control. Advocating for the client by providing information about the disease process and management and by establishing mutually agreed upon goals will also promote an assumption of responsibility by the child and family for self-care activities thus enhancing the feeling of control and mastery over the disease. Counseling the family and child will help the APN to identify concerns about the disease as well as provide information about the family's perception of the situation, social support, coping strategies, family functioning and stress producing deficits

such as financial burdens. Information given to the family by the APN about coping related behaviors can give them insight about coping skills and facilitate bonadaptation by teaching problem solving and coping skills. Knowledge of community resources available to assist the family in relieving burdens is essential for the APN.

Assessing the family's and child's perception of each life event that has occurred should also be done. It is important for the APN to realize that chronically ill children have an overall more positive perception of life events. Perception is individualized according to the meaning of the situation to the person. Establishing a rapport and mutual trust between the APN and child is facilitated by the APN acknowledging, inquiring about the rationale for the perception, and accepting the child's perception of the event rather than stating an opinion from having a preconceived idea of the appropriate perception. For example, a family member going to jail may be viewed as a positive event because having that person in the environment may have been stressful to the other members. Positive perception is also an indication of bonadaptation to the demands associated with the disease. Family functioning and support are important factors in achieving adaptation. Characteristics and strength of the family influence coping responses to the added demands of the disease.

Nursing Education

Nurses in all levels of education would benefit from the knowledge that families with chronically ill children experience more life events than families with healthy children. Children's perception of life events differs from adults but is influenced by the parent's reaction to an event. Chronically ill children have a tendency toward perceiving life events more positively, an indication of bonadaptation to the illness' associated demands. Education about the illness facilitates mastery in disease management by the family and child. Assessment of the chronically ill child should include questions about the occurrence of life events and the child's perception of the events. Ongoing education about the disease is important.

Future Research

A larger, more diverse sample with a more equitable number of chronically ill and comparison subjects in the groups would provide more conclusive results. Conducting longitudinal research over a designated period of time would provide more accuracy in recall by children and provide information about developmental levels related to changes in perception of demands. Knowing the timing and sequence of events would provide information about accumulation of stress and resulting perception. Other studies should be conducted similar to this one utilizing children's self-reports of life events and allow the children to rate their perception of the events. Assessing coping strategies used by the children for achieving bonadaptation would be

beneficial. Studying the impact on children of ongoing education would also be useful.

SUMMARY

The results of this study indicate that chronically ill children and their families experience more life events than comparison families and chronically ill children tend to have a more positive perception of the events. Advance Practice Nurses in primary care settings can assist families and children in the adaptation and management of chronic illness through education and the development of problem solving skills and coping strategies by helping the family to redefine the situation positively in order to avoid a crisis. Awareness by the APN of community resources and support is important to facilitate bonadaptation and decrease the additional burdens associated with having a chronic illness. Understanding that each family is unique in their approach to stress management, problem solving, and coping skills and knowing when the family is ready to receive assistance and counseling is also important for the APN.

LIST OF REFERENCES

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Banez, G. A., & Compas, B. E. (1990). Children's and parents' daily stressful events and psychological symptoms. Journal of Abnormal Child Psychology, 18(6), 591-605.

Bedell, J. R., Giordani, B., Amour, J. L., Tavormina, J., & Boll, T. (1977). Life stress and the psychological and medical adjustment of chronically ill children. Journal of Psychosomatic Research, 21, 237-242.

Boyce, T. W., Chesney, M., Alkon, A., Tschann, J. M., Adams, S., Chesterman, B., Cohen, R., Kaiser, P., Folkman, S. & Wara, D. (1995). Psychobiologic reactivity to stress and childhood respiratory illnesses: Results of two prospective studies. Psychosomatic Medicine, 57, 411-422.

Brown, L. P., & Cowen, E. L. (1988). Children's judgments of event upsettingness and personal experiencing of stressful events. American Journal of Community Psychology, 16(1), 123-135.

Brown, L. P., & Cowen, E. L. (1989). Stressful life events, support, and children's school adjustment. Journal of Clinical Child Psychology, 18(3), 214-220.

Coddington, R. D. (1972a). The significance of live events as etiologic factors in the diseases of children-I: A survey of professional workers. Journal of Psychosomatic Research, 16, 7-18.

Coddington, D. R. (1972b). The significance of life events as etiologic factors in the diseases of children-II: a study of a normal population. Journal of Psychosomatic Research, 16, 205-213.

Cohen, S., & Williamson, G. M. (1991). Stress and infectious disease in humans. Psychology Bulletin, 109, 5-24.

Cohen, S., Tyrrell, D. A., & Smith, A. P. (1991). Psychological stress and susceptibility to the common cold. New England Journal of Medicine, 325, 606-612.

Cowen, L., Corey, M., Keenan, N., Simmons, R. Arndt, E. & Levison, H. (1985). Family adaptation and psychosocial adjustment to cystic fibrosis in the preschool child. Social Science Medicine, 20(6), 553-560.

Day, D., Gilbert, K., Settles, B., & Burr, W. (1995). The ABCX family-stress model. Research and theory in family science. Pacific Grove, Ca.: Brooks/Cole publishing Co.

DeLongis, A., Folkman, S., & Lazarus, R. S. (1988). The impact of daily stress on health and mood: Psychological and social resources as mediators. Journal of Personality and Social Psychology, 54(3), 486-495.

Dubow, E. F., & Tisak, J. (1989). The relation between stressful life events and adjustment in elementary school children: The role of social support and social problem-solving skills. Child Development, 60, 1412-1423.

Folkman, S., Lazarus, R. S., Gruen, R. J., & DeLongis, A. (1986). Appraisal, coping, health status and psychological symptoms. Journal of Personality and Social Psychology, 50(3), 571-579.

Goldston, D. B., Kovacs, M., Obrosky, D. S., & Iyengar, S. (1995). A Longitudinal study of life events and metabolic control among youths with insulin-dependent diabetes mellitus. Health Psychology, 14(5), 409-414.

Hamlett, K. W., Pellegrini, D. S., & Katz, K. S. (1992). Childhood chronic illness as a family stressor. Journal of Pediatric Psychology, 17(1), 33-47.

Hammen, C. (1992). Life events and depression: The plot thickens. American Journal of Community Psychology, 20(2), 179-193.

Heisel, J. S., Ream, S. Raitz, R., Rappaport, M. & Coddington, R. D. (1973). The significance of life events as contributing factors in the diseases of children. Behavioral Pediatrics, 83(1), 119-123.

Hill, R. (1958). Generic features of families under stress. Social Casework, 39, 32-52.

Ievers, C. E., & Drotar, D. (1996). Family and parental functioning in cystic fibrosis. Journal of Developmental and Behavioral Pediatrics, 17(1), 48-55.

Jemmott, J. B., & Locke, S. E. (1984). Psychosocial factors, immunologic mediation, and human susceptibility to infectious diseases: How much do we know? Psychology Bulletin, 78, 78-108.

Jensen, P. S., Richters, J., Ussery, T., Bloedau, L. & Davis, H. (1991). Child Psychopathology and environmental influences: Discreet life events versus ongoing adversity. Journal of American Academy Child and Adolescent Psychiatry, 30(2), 303-309.

Kale, W. L., & Stenmark, D. E. (1983). A comparison of four life event scales. American Journal of Community Psychology, 2(4), 441-458.

Loss, N., Beck, S. J., & Wallace, A. (1995). Distressed and nondistressed third- and sixth- grade children's self-reports of life events impact and concordance with mothers. Journal of Abnormal Child Psychology, 23(3), 397-409.

McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: The double ABCX model of adjustment and adaptation.. In H.I. McCubbin, M. A. Sussman, & J. M. Patterson (Eds.), Social stress and the family: Advances in family stress theory and research (pp. 7-37). New York: The Haworth Press.

Newacheck, P. W., & Taylor, W. R. (1992). Childhood chronic illness: Prevalence, severity, and impact. American Journal of Public Health, 82, 364-371.

Patterson, J. & Blum, R. W. (1996). Risk and resilience among children and youth with disabilities. Archives Pediatric and Adolescent Medicine, 150, 692-698.

Patterson, J. M., & McCubbin, H. I. (1983). Chronic illness: Family stress and coping. In C. R. Figley, & H. I. McCubbin (Eds.), Stress and the family, Vol. II.: Coping with catastrophe. (pp. 21-36). New York: Brunner/Mazel.

Rabkin, J. G. & Struening, E. L. (1976). Life, stress, and illness. Science, 194, 1013-1020.

Rubin, R. R., & Peyrot, M. (1992). Psychosocial problems and interventions in diabetes. Diabetes Care, 15(11), 1640-1657.

Sandler, I. N., Reynolds, K. D., Kliwer, W., & Ramirez, R. (1992). Specificity of the relation between life events and psychological symptomatology. Journal of Clinical Child Psychology, 21(3), 240-248.

Sarason, I. G., Johnson, J. H., & Siegel, J. M. (1993). Assessing the impact of life changes: Development of the life experiences survey. Journal of Consulting and Clinical Psychology, 46, 932-946.

Silverstein, J. H., & Johnson, S. (1994). Psychosocial challenge of diabetes and the development of a continuum of care. Pediatric Annals, 23(6), 300-305.

Spence, L. J. (1992). Family adaptation to chronic childhood illness. Unpublished doctoral dissertation, Michigan State University, East Lansing, MI.

Spirito, A., Stark, L. J., Gil, K. M., & Tyc, V. L. (1995). Coping with everyday and disease-related stressors by chronically ill children and adolescents. Journal of American Academy Child and Adolescent Psychiatry, 34(3), 283-290.

Stein, R. (1983). Growing up with a physical difference. Children's Health Care, 12, 53-61.

Tavormina, J. B., Kastner, L. S., Slater, P. M. & Watt, S. L. (1976). Chronically ill children: A psychologically and emotionally deviant population. Journal of Abnormal Child Psychology(2), 99-110.

Velsor-Friedrich, B. & Frager, B. F. (1990). The federal government: Child Health. Journal of Pediatric Nursing, 5, 56-58.

Yamamoto, K. (1979). Children's ratings of the stressfulness of experiences. Developmental Psychology(5), 581-582.

APPENDIX A

Life Experiences Questionnaire

Life Experiences Questionnaire

This is a list of things that can happen to families. Each thing that can happen is underlined. Please put an X in the box next to the things that have happened to your family in the last 6 months.

For the things that have happened to your family be sure to answer the questions underneath what happened by putting an X in the boxes for your answers.

EXAMPLE

[X] A family member had the flu.

Who had the flu?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
[X] Me	[X]	[ ]	[ ]	[ ]	[ ]
[X] My Mother	[ ]	[X]	[ ]	[ ]	[ ]
[ ] My Father	[ ]	[ ]	[ ]	[ ]	[ ]
[ ] My Brother	[ ]	[ ]	[ ]	[ ]	[ ]
[ ] My Sister	[ ]	[ ]	[ ]	[ ]	[ ]

[ ] 1. A family member got married.

Who got married?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
[ ] My Mother	[ ]	[ ]	[ ]	[ ]	[ ]
[ ] My Father	[ ]	[ ]	[ ]	[ ]	[ ]
[ ] My Brother	[ ]	[ ]	[ ]	[ ]	[ ]
[ ] My Sister	[ ]	[ ]	[ ]	[ ]	[ ]

☐ 2. A family member was put in jail.

Who was put in jail?

What was it like for you?

	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 3. A parent died.

Which one of your parents died?

What was it like for you?

	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐

☐ 4. A family member has been sleeping a lot more or a lot less.

Who has been sleeping a lot more or less?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 5. A close family member died.

Who died?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐
☐ My Grandmother	☐	☐	☐	☐	☐
☐ My Grandfather	☐	☐	☐	☐	☐
☐ Someone else? Who? _____	☐	☐	☐	☐	☐

☐ 6. A family member has been eating a lot more or a lot less.

Who has been eating more or less?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 7. A close friend of a family member died.

Whose close friend was it?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Mine	☐	☐	☐	☐	☐
☐ My Mother's	☐	☐	☐	☐	☐
☐ My Father's	☐	☐	☐	☐	☐
☐ My Brother's	☐	☐	☐	☐	☐
☐ My Sister's	☐	☐	☐	☐	☐

☐ 8. A family member got a police ticket.

Who got a ticket?

What was it like for you?

	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 9. Your Brother's girlfriend got pregnant.

What was it like for you?

Very bad	Sort of bad	Ok	Sort of good	Very good
☐	☐	☐	☐	☐

☐ 10. Your Mother got pregnant.

What was it like for you?

Very bad	Sort of bad	Ok	Sort of good	Very good
☐	☐	☐	☐	☐

☐ 11. Your Sister got pregnant.

What was it like for You?

Very bad	Sort of bad	Ok	Sort of good	Very good
☐	☐	☐	☐	☐

☐ 12. Things at work changed a lot for Your:

	What was it like for You?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Father	☐	☐	☐	☐	☐
☐ Mother	☐	☐	☐	☐	☐
☐ Brother	☐	☐	☐	☐	☐
☐ Sister	☐	☐	☐	☐	☐

☐ 13. A family member got a new job.

Who got a new job?	What was it like for You?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ My Father	☐	☐	☐	☐	☐
☐ My Mother	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 14. A member of the family got very sick or badly hurt.

Who was sick or hurt?	What was it like for You?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐
☐ My Grandfather	☐	☐	☐	☐	☐
☐ My Grandmother	☐	☐	☐	☐	☐
☐ Someone else? Who? _____	☐	☐	☐	☐	☐

☐ 15. A family member had trouble with their boss.

Who had trouble with their boss?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 16. A family member had trouble getting along with relatives, like grandparents, aunts, uncles, and/or cousins.

Who had trouble getting along with relatives?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 17. We have a lot more or a lot less money than we used to.

What is that like for you?

Very bad	Sort of bad	Ok	Sort of good	Very good
☐	☐	☐	☐	☐

☐ 18A. Our family is closer than it used to be.

What is that like for you?

Very bad	Sort of bad	Ok	Sort of good	Very good
☐	☐	☐	☐	☐

☐ 188. Our family is not as close as it used to be.

What is that like for you?

Very bad	Sort of bad	Ok	Sort of good	Very good
☐	☐	☐	☐	☐

☐ 19. We have a new family member (like a baby or a relative moved in).

What is that like for you?

Very bad	Sort of bad	Ok	Sort of good	Very good
☐	☐	☐	☐	☐

☐ 20. We moved to a different house (or apartment).

What is that like for you?

Very bad	Sort of bad	Ok	Sort of good	Very good
☐	☐	☐	☐	☐

☐ 21. My parents separated because they were fighting.

What is that like for you?

Very bad	Sort of bad	Ok	Sort of good	Very good
☐	☐	☐	☐	☐

☐ 22. We attend church activities a lot more often or a lot less often than we used to.

What is that like for you?

Very bad	Sort of bad	Ok	Sort of good	Very good
☐	☐	☐	☐	☐

☐ 23. My parents got back together again after they were separated.

What is that like for you?

Very bad	Sort of bad	Ok	Sort of good	Very good
☐	☐	☐	☐	☐

☐ 24. There are a lot more or a lot less arguments than before.

Who is arguing more or less?	What is that like for you? Very bad	Sort of bad	Ok	Sort of good	Very good
☐ My parents	☐	☐	☐	☐	☐
☐ My brothers, sisters, and/or me	☐	☐	☐	☐	☐
☐ My parents with my brothers, sisters, and/or me	☐	☐	☐	☐	☐

☐ 25. My Mother either started or stopped working.

What is that like for you?

Very bad	Sort of bad	Ok	Sort of good	Very good
☐	☐	☐	☐	☐

☐ 26. My Father either started or stopped working.

What is that like for you?

Very bad	Sort of bad	Ok	Sort of good	Very good
☐	☐	☐	☐	☐

☐ 27. Doing fun things more or less often than before.

What is that like for you?

	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My mother	☐	☐	☐	☐	☐
☐ My father	☐	☐	☐	☐	☐
☐ My brother	☐	☐	☐	☐	☐
☐ My sister	☐	☐	☐	☐	☐
☐ My whole family	☐	☐	☐	☐	☐

☐ 28. A family member got fired from a job.

Who got fired from their job? What was it like for you?

	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 29. Went to parties, movies, visiting a lot less often or a lot more often than before.

Who has been to parties, movies and visiting more or less often?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐
☐ My entire family	☐	☐	☐	☐	☐

☐ 30A. My family built or bought a new house.

What is that like for you?

Very bad	Sort of bad	Ok	Sort of good	Very good
☐	☐	☐	☐	☐

☐ 30B. Our house needs a lot of repairs.

What is that like for you?

Very bad	Sort of bad	Ok	Sort of good	Very good
☐	☐	☐	☐	☐

☐ 31. A family member got divorced.

Who got divorced?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ My Parents	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 32. A close friend of someone in the family got badly hurt or was very sick.

Whose friend was it?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Mine	☐	☐	☐	☐	☐
☐ My Mother's	☐	☐	☐	☐	☐
☐ My Father's	☐	☐	☐	☐	☐
☐ My Brother's	☐	☐	☐	☐	☐
☐ My Sister's	☐	☐	☐	☐	☐
☐ My entire family's	☐	☐	☐	☐	☐

☐ 33. Brother or sister moved out of the house.

Who moved out of the house?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 34. A family member finished school.

Who finished school?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 35. Mother or Father is away from home a lot because of work or travel.

Who is away from home?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐

☐ 36. A family member got engaged to be married.

Who got engaged?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 37. A family member broke up with a girlfriend or boyfriend.

Who broke up with their girlfriend or boyfriend?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 38. A family member left home for the first time - like going away to school or camp.

Who left home for the first time?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 39. A family member made up with a girlfriend or boyfriend.

Who made up with their girlfriend or boyfriend?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 40. Someone began a new school, middle school, junior high school, or high school.

Who began a different school?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 41. Discovery of being an adopted child.

Who discovered they were adopted?	What was it like for you? Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 42. Someone in your family has a deformity others can see.

Who has a deformity?	What was it like for you? Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 43. Failure of a grade in school.

Who failed a grade in school?	What was it like for you? Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 44. Suspension from school.

Who got suspended from school?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 45. Got involved with drugs or alcohol.

Who got involved with drugs or alcohol?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 46. Beginning to date

Who began to date?	What was it like for you?				
	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

☐ 47. Family member hospitalized Who was in the hospital? What was it like for you?

	Very bad	Sort of bad	Ok	Sort of good	Very good
☐ Me	☐	☐	☐	☐	☐
☐ My Mother	☐	☐	☐	☐	☐
☐ My Father	☐	☐	☐	☐	☐
☐ My Brother	☐	☐	☐	☐	☐
☐ My Sister	☐	☐	☐	☐	☐

APPENDIX B

UCRIHS Approval Letter

MICHIGAN STATE
UNIVERSITY

April 27, 1998

TO: Linda Spence
A230 Life Sciences

RE: IRB#: 98-277
TITLE: FREQUENCY OF LIFE EVENTS AS REPORTED BY CHRONICALLY ILL CHILDREN
REVISION REQUESTED: N/A
CATEGORY: 1-E
APPROVAL DATE: 04/23/98

The University Committee on Research Involving Human Subjects (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project and any revisions listed above.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/ CHANGES: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171.

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Sherrie L. Roth

OFFICE OF
RESEARCH
AND
GRADUATE
STUDIES

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Research Involving
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