

THE IMPACT OF CHRONIC CHILDHOOD ILLNESS ON THE FAMILY  
AS PERCEIVED BY THE MOTHER

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## DEDICATION

This study is dedicated to:

Norma and the Conejo family, who taught me the meaning of living and dying with a chronic illness, and

My family in appreciation for all their help and support throughout graduate school.

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## CHAPTER 1

### INTRODUCTION

Because of the technological advances related to the treatment of previously life threatening conditions, there is a growing population of chronically-ill children in this country. As a result, children who previously would have died soon after being diagnosed with diseases like renal failure, cystic fibrosis, leukemia, or asthma are now surviving and living longer. The chronicity of such childhood illnesses places exceptional financial, psychosocial, and physical stresses on the families of these children.

The ongoing health needs of such children require that nurses working with these children either in the community or hospital setting provide quality care. Nurses must systematically assess the special needs of the chronically-ill child and his family. Through systematic assessment, nurses will be able to identify families at risk for developing interactional and developmental problems and then plan appropriate nursing interventions.

Thus, this study proposed to provide data on the impact of chronic childhood illnesses on families. Data

from this study and other similar studies should serve as guidelines for developing nursing diagnoses and nursing interventions for the chronically-ill child and the family.

#### Problem of Study

The focus of this study was to determine if there is a difference in the mother's perceptions of (a) family stress, (b) family coping patterns, and (c) family health among mothers who have children with either asthma, cystic fibrosis, leukemia, or renal disease.

#### Justification of Problem

The incidence of chronic childhood disorders has been estimated by Pless and Pinkerton (1975) to be between 5% and 10% of the population under 16 years of age. Pediatric nurses, therefore, come in frequent contact with families who have chronically-ill children. Nurses are expected to plan their interventions in accordance with the special needs of these children and their families. In order to plan effective nursing interventions, the nurse must have a strong knowledge base. The building blocks of this knowledge base include an awareness of the various affects that chronic illness has on families. This study met a need in nursing by contributing to the



growing body of knowledge on chronic illness and its impact on the family.

Previously, the majority of the research done on the impact of chronic childhood illness on the family has examined the impact of one specific disease. For example, Friedman, Chodoff, Hamburg, and Mason (1963) did a landmark study on the impact of the diagnosis of leukemia or other life threatening blood disorders in children on a group of 46 parents. The Friedman et al. study provided valuable information on the similarities among the 46 parents of how they reacted to the diagnosis, coped with the diagnosis, and coped with the management problems of a chronically-ill child. Other researchers have followed the example of Friedman et al. and have analyzed the impact of chronic illness on the family by examining the impact of a specific disease on the family. Kramer (1981) and Pearse (1977) examined the impact of leukemia on the parents and siblings. Harder and Bowditch (1982), Hymovich (1981), and Krueger, Shawyer, and Jones (1980) examined the impact of cystic fibrosis on the family.

All of the above research provided nursing with valuable data on the impact of chronic childhood illness

on the family. Such research has shown that the families of leukemic and cystic fibrosis children are at risk for developing psychosocial and management problems. The nursing issue that arises from these findings is whether or not the data from research on the impact of a specific disease on the family have implications for nurses who are working with children who have other chronic diseases. Based on their own and previous research, Krulik (1980), Lawson (1977), and Mattsson (1977) suggested that there are similarities among families with children who have different chronic illnesses. The primary similarities identified by these researchers are the initial response to the diagnosis and successful coping strategies utilized by the parents in the management of problems that commonly arise when caring for a chronically-ill child.

Hymovich (1981) suggested that nurses can play a major role in minimizing the potential problems of families with chronically-ill children by providing comprehensive care for the family. This care should focus on the normal aspects of development of the family as a unit and the development of each of its members, as well as on the illness of the child.

Hymovich (1981) and Lawson (1977) are among the few researchers who have studied the impact of chronic illness on the family in relation to the family's psychosocial growth and development. From her studies, Hymovich (1981) suggested that nurses cannot appropriately intervene with families of chronically-ill children until they adequately and systematically assess the needs of the family and identify specific areas in which these families are at risk. Systematic assessments should allow the nurse to generate specific nursing diagnoses so that etiologic-specific nursing interventions can be planned, implemented, and evaluated (Zeigler, Vaughan-Wrobel, & Erlén, in press).

In 1981, Hymovich developed a tool designed to assess the impact of chronic childhood illness on the family in relation to its developmental tasks and coping patterns. This tool has been utilized primarily in the assessment of the impact of cystic fibrosis on the family. This study contributes to the body of nursing knowledge on the impact of chronic childhood illness on the families. The data from the present study increases the nurse's awareness of the commonalities among families with chronically-ill children and of the different possible needs and concerns

of individual families. Ultimately, the data from this study should help nurses increase the effectiveness of their assessment and intervention skills when working with the families of chronically-ill children. Knowledge gained from such studies needs to be incorporated into nursing curricula and continuing education programs for nurses.

The health care literature is lacking, particularly in the form of documented nursing research, on the development of instruments which concretely measure the impact of chronic childhood illness on the family. Nursing is in need of assessment tools which can direct nursing intervention in dealing with the families of chronically-ill children. Nursing is in further need of research which documents the reliability and validity of assessment tools which do exist.

#### Conceptual Framework

Minuchin's (1974) family systems theory and Duvall's (1977) family developmental theory provide the conceptual framework for this study. Hymovich's (1981) developmental approach to families supplemented the conceptual framework.

According to Minuchin (1974), the family is a system composed of numerous interrelated subsystems. Each member of the family belongs to different subsystems where he possesses different levels of power and where he learns different interpersonal skills. Who and how individual members participate in the subsystems are defined by the subsystem's boundaries.

Minuchin (1974) developed a schema for analyzing the family system and its subsystems. The schema contains three components:

1. The structure of the family is that of an open sociocultural system in transformation.
2. The family undergoes development, moving through a number of stages that require restructuring.
3. The family adapts to changed circumstances so as to maintain continuity and enhance the psychosocial growth of each member.

Family structure is the invisible set of functional demands which organizes the ways family members interact. A family is a system that operates through transactional patterns. Repeated transactions establish patterns of how, when, and to whom to relate, and these patterns underpin the family system (Minuchin, 1974).

A crucial point emphasized in family systems theory is that change affecting one member affects the whole system. Therefore, continued existence of the family system is dependent on the entire family's ability to adapt to change. Successful adaptation is dependent on the family's range of transactional patterns, availability of alternative patterns, and the flexibility to mobilize alternative patterns when faced with stress or change (Minuchin, 1974).

From the viewpoint of family systems theory, illness in the family is a source of stress which mandates that change occurs within the family system. The change that occurs affects each of the family's subsystems differently. Chronic childhood illness in the family system necessitates that the family system and each of its members develop a wide range of transactional patterns in order to adapt to the ongoing needs of the chronically-ill child. Because of each family's unique structure and set of transactional patterns, the impact of chronic illness on one family may be quite different from the impact on another family (Minuchin, 1974).

The impact of chronic childhood illness may also vary among different families because of the differences in

developmental stages. The second component in Minuchin's (1974) schema for evaluating the family is the developmental stage of the family. A family normally develops by going through a number of stages that require restructuring. Restructuring of the family system demands a constant transformation of the "position of family members in relation to one another" (Minuchin, 1974, p. 60). The pressure for family transformation stems from the developmental changes occurring in each individual family member and subsystem and from societal demands for continual growth and development within the family. Chronic childhood illness in a family may inhibit family members from responding appropriately to the demands for transformation within the family structure.

Minuchin's (1974) third component suggests that successful adaptation to change allows the family to maintain continuity and enhances the psychosocial growth of each of its members. Illness in the family can be considered an idiosyncratic problem which often demands redistribution of functions and power in the family system. Chronic illness, therefore, continually demands that the family adapt to changes in distribution of functions and power as

family members attempt to meet the needs of the ill child.

Duvall's (1977) family developmental cycle theory further clarifies the concepts of family development, transformation, and adaptation. The developmental stage of the family is the focus of Duvall's theory. Duvall's theory is based on eight developmental tasks that are considered common to all American families, regardless of social class or subculture. The eight tasks are (a) physical maintenance; (b) the allocation of physical resources; (c) the allocation of psychosocial resources within the family; (d) socialization of family members; (e) placing family members in the larger society; (f) division of labor; (g) maintenance of order, motivation, and morale; and (h) the reproduction, recruitment, and release of family members.

In addition to the eight developmental tasks common to all families, Duvall (1977) developed eight critical stages which occur in the life cycle. These stages in the life cycle of the family are (a) married couple, (b) childbearing, (c) preschool, (d) school age, (e) teenage, (f) launching center, (g) middle-aged, and (h) aging



family members. These stages in the life cycle of the family are determined by four factors: (a) plurality patterns, (b) age of the oldest child, (c) school placement of the oldest child, and (d) functions of the family.

Viewed from the developmental approach, illness is a situational crisis which superimposes itself on the family's normal developmental tasks. Thus, chronic childhood illness in a family can be viewed as an ongoing crisis which may inhibit the family from accomplishing its normal developmental tasks.

Hymovich (1981), supplementing the developmental approach, suggested that family functioning may be affected by chronic illness. Hymovich proposed that the experience of having a chronically-ill child may be positive or negative, depending on the family's perceptions, resources, and coping abilities. According to Hymovich, the family's response to the child's chronic illness strongly influences the child's ability to adapt to his condition. Therefore, nurses and other health care workers should view the chronically-ill child and assess his needs within the context of his unique family.

Minuchin's (1974) family systems theory, Duvall's (1977) family developmental theory, and Hymovich's (1981) conceptual framework provided the direction for this study. Based on the stated theories and concepts, one can hypothesize that the stress of chronic childhood illness within a family can cause disruption in the family system and, therefore, may impede the family's psychosocial development. One can further hypothesize that the impact of chronic childhood illness may be dependent upon the family's unique patterns of coping, family stress, and the family's health.

#### Assumptions

The assumptions based on Minuchin's (1974) and Duvall's (1977) theory and Hymovich's (1981) conceptual framework for the study were:

1. Chronic illness in a family mandates continuous change within the family. This change affects the family as a whole as well as each of its members.
2. Development is sequential; each new aspect of a family's development is based on previously established structure and skills.

3. Individual family members will be able to describe, from their own perspective, the impact of chronic illness on the family.

### Hypotheses

The study tested the following three null hypotheses:

1. There is no significant difference in the perceptions of family stress among mothers having children with either asthma, cystic fibrosis, leukemia, or renal disease.

2. There is no significant difference in the perceptions of family copy patterns in caring for a chronically-ill child among mothers having children with either asthma, cystic fibrosis, leukemia, or renal disease.

3. There is no significant difference in the perceptions of family health among mothers having children with either asthma, cystic fibrosis, leukemia, or renal disease.

### Definition of Terms

For the purpose of this study, the following terms were defined:

1. Family stress--theoretically, family stress is any force or forces which produces tension within the family system and subsystems. Operationally, family stress was measured by calculating the total stress or scores of each group of mothers having children with either asthma, cystic fibrosis, leukemia, or renal disease using the Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ).

2. Coping patterns--theoretically, coping patterns are all psychological, social, and physical techniques used by family members to master a perceived psychological threat (Mattsson, 1971). Operationally, coping patterns were measured by adding the self-cope and the spouse-cope scores together of each group of mothers having children with either asthma, cystic fibrosis, leukemia, or renal disease using the CICI:PQ.

3. Family health--theoretically, beliefs, attitudes, and values toward family health are those ideals and principals that guide a family in working toward optimum health. Operationally, family health was measured by calculating the family health scores of each group of mothers having children with either asthma, cystic fibrosis, leukemia, or renal disease using the CICI:PQ.

4. Chronic illness--theoretically, chronic illness is any illness or disorder which is protracted and lasts longer than 3 months. The illness is considered fatal or life threatening during exacerbations. Operationally, chronic illness was defined as asthma, renal disease, cystic fibrosis, and leukemia existing in the school age population. The disease process must have been diagnosed over 3 months ago.

5. Mothers--theoretically, mothers are the adult female biological parent of the children. Operationally, mothers are the adult females in families in the study who were perceived by other family members as fulfilling the role of mother.

#### Limitations

The study was conducted with regard to the following limitations:

1. There was no control for the economic, social, or educational level of the subjects.
2. There was no control over the stage, length, or severity of the disease occurring in each child.
3. The study used a convenience sample.

4. The instrument's reliability is based primarily on a population of children with cystic fibrosis living on the East Coast.

5. Content validity is the only type of validity that has been established for the instrument.

6. There was no control over the developmental level of the family.

#### Summary

This study assessed the impact of chronic childhood illness of four different groups of families. The results of this study will help determine the usefulness of the CICI:PQ in assessing the impact of chronic childhood illness on various families. It is believed that the data from this study will assist nurses in updating their assessment skills. Furthermore, data from this study may give nurses more knowledge on which they can base their interventions, thereby, helping them to be more effective in meeting the needs of the family with a chronically-ill child. This study is important because it evaluated the whole family's response from the perception of mother to chronic illness, not just a particular member of the family. Based on Minuchin's (1974) theory, it may be assumed that successful adaptation to a stress such as

chronic illness is dependent on the family's ability to change as a unified system. The evaluation of the families' response to chronic childhood illness may allow the nurse to promote unified adaptation or coping within the family.

## CHAPTER 2

### REVIEW OF LITERATURE

Studies on the impact of chronic illness on families in regards to family functioning, family stress, and family's coping ability have been primarily descriptive and retrospective. It is generally hypothesized throughout the literature on chronic illness that chronic childhood illness appears to precipitate stress and disruption within the family (Hymovich, 1980; Mattsson, 1977). Themes consistently seen in the literature related to chronic childhood illness include family disintegration, disrupted marriages, sibling resentment, sibling rivalry, loss of family communication, and financial stress. More recently the literature has begun to focus on the relationship among the concepts of chronicity, family stress, and successful coping strategies.

The purpose of this literature review was (a) to further define the concept of chronicity, (b) to determine from current research how families of chronically-ill children perceive the impact of chronic illness, and (c) to determine how families of chronically-ill children cope



with various problems they encounter in caring for the child.

### Chronic Illness

Pless and Pinkerton (1975) defined a chronic illness as a health condition that lasts 3 months or more or a condition which requires hospitalization for at least 1 month. Mattsson (1977) comprehensively defined chronic illness as follows: "A disorder with a protracted course which can be progressive and fatal, or associated with a relatively normal life span despite impaired physical or mental functioning. Such a disease frequently shows periods of acute exacerbations requiring intensive medical attention" (p. 183). Hymovich (1981) derived her definition of chronic illness from Pless and Douglas (1971). Hymovich referred to a chronic illness as an illness which lasts longer than 3 months or requires hospitalization for at least 1 month.

It has been estimated that 10-20% of the nation's children have a physical health problem that is considered chronic (Pless & Pinkerton, 1975). The focus of health care literature on chronic childhood illness has been centered on individual diseases and their medical

implications . Studies on the impact of chronic childhood illness on the family are scarce and have been primarily descriptive in nature. Virtually absent from the health care literature are studies on the impact of renal disease or asthma on the family. The majority of the research which has assessed the impact of chronic illness on the family has been focused on children with leukemia, cystic fibrosis, or neurological disorders.

#### Impact of Chronically-Ill Child on Family Functioning

Friedman et al. (1963) and Mattsson (1977) examined the impact of chronic childhood illness of the family in relation to how families chose to cope with the continuous stress of chronic illness. The coping strategies that Friedman et al. (1963) identified as being utilized by parents of children with leukemia or bleeding disorders during the 3-month period after diagnosis of their child, were similar to the long-term coping strategies that Mattsson (1977) documented in his study of chronically-ill children.

Friedman et al. (1963) concluded that all parents in their study initially responded to the diagnosis with some

degree of guilt. Parents blamed themselves for not paying closer attention to early nonspecific manifestations of the disease. For the majority of the parents in the study, the guilt-ridden stage was transient. Parents who remained guilt ridden for an extensive period of time adapted poorly to ongoing hospitalization and illness. These parents characteristically became "over indulgent and over protective" (p. 613) and had a great deal of difficulty controlling their child's behavior in and out of the hospital.

Pless and Pinkerton (1975) studied a large number of chronically-ill children with various diagnoses. One of the conclusions of this study was that chronically-ill children and their families face similar problems regardless of their individual diagnosis. Pless and Pinkerton concluded that many chronic illnesses have similar consequences on the children and their families in terms of development and their means of coping.

Mattsson (1977) suggested that the adolescent who copes poorly with the chronicity of his disease is reflective of a family who has coped poorly with the disease and its chronicity. Poorly adjusted adolescents

with chronic illness are traditionally characterized by one of the three following behavioral patterns. The first group, the early passive dependent group, is described as fearful, inactive, and have lack of outside interests. This type of adolescent is markedly dependent on his family, especially his anxious and overprotective member. The second group includes the overly independent, daring, and risk-taking adolescent. These adolescents commonly partake in prohibited activities. The adolescent and his family characteristically adapt to the youth's illness by denying the seriousness of the illness. The third group of adolescents portray a more severe form of maladjustment. These adolescents are shy, lonely, withdrawn, and often harbor feelings of resentment toward their normal peers. Frequently, these adolescents come from families who have a great deal of difficulty accepting the child's illness. As a family, they see themselves being different from other families. The lack of adaptation by the family causes the youth to develop "a self image of a defective outsider" (pp. 191-192).

Hymovich (1981) concluded from her study of 13 families with children with cystic fibrosis that chronic

illness disrupted both the child's and family's development. Hymovich found that families of chronically-ill children have difficulty accomplishing developmental tasks due to the stress of coping with the child's illness. Parents in the study described the impact of the illness in terms of communication problems, decreased time spent with their spouses, and loss of time and energy.

Kramer (1981), in her observations of siblings of children with chronic illness, determined two factors that positively influence the sibling's adaptation to the chronicity of their sibling's illness. Those factors were open communication among the family members and parental promotion of sibling involvement in the child's care.

Kramer (1981) took a developmental approach in examining the effects of chronic illness on the sibling. She stated that the disruption caused in the family system related to the ill child impairs the sibling's ability to resolve developmental crisis. Lack of resolution of a developmental crisis often results in the healthy sibling having behavioral problems. Sources of stress for the healthy sibling with a chronically-ill child included perceived neglect from the parents, increased responsibility for maintaining family functioning, and witnessing

the physical decline of their sibling. Some of the documented manifestations of the siblings' stress included an increase in psychosomatic complaints, nightmares, preoccupation with the ill sibling's disease, fear of catching the disease, increased anxiety, and a multitude of angry feelings directed at the parents.

Unlike other authors, Kramer (1981) noted some of the positive effects of being a sibling of a chronically-ill child. Some of the effects listed by Kramer include siblings who matured faster and were perceived to be more independent than their peers. This increased maturity and independence allowed them to accept greater responsibility in other areas of their lives which promoted a greater sense of self-esteem. These siblings were also noted to possess a greater sense of empathy toward all people with whom they came in contact.

Stein and Jessop (1982) interviewed 209 children and their families. They concluded that the diagnostic labels were essential in managing the medical problems of the children; however, these labels did not begin to describe to health care practitioners any concerns in the lives of chronically-ill children and their families.

From their studies, Stein and Jessop (1982) concluded that the consequences of uncertainty involved in many chronic illness has a great psychological impact on many families. Unpredictability led to insecurity in the lives of many chronic children and their families.

The impact of chronic illness on the family found by Stein and Jessop (1982) was similar to the impact found by other researchers. Many parents described the impact as a sense of personal failure, constant fatigue, realignment of family members, lack of opportunity to advance in one's career, increased intrafamilial tension, withdrawal from neighbors and friends, and lack of social network. Stein and Jessop found that the siblings of chronically-ill children were often called to be the intermediaries between the outside world and the ill child.

#### Coping Behaviors of Families with A

##### Chronically-Ill Child

The coping behavior seen most frequently by Friedman et al. (1963) after the initial response to the diagnosis was a process of intellectualization. Rather than becoming emotionally overwhelmed by the situation or crisis at hand, the parents created a distance between themselves and the stressor. This behavior was typified by parents

daily seeing detailed information about blood counts, bone marrow results, and side effects of medication. The parents developed a set daily routine of how and when to receive such information and were greatly angered when this routine was disturbed. Divergent information from various medical staff caused parents to intensify their pessimism and anger toward the staff. This anger was considered by Friedman et al. to be displaced anger stemming from the parents' feeling of helplessness.

The second defense mechanism utilized by parents was denial of the seriousness of the illness. Friedman et al. (1963) concluded that denial was manifested in the parents' refusal to understand the value or importance of various therapeutic procedures and plans. Other coping behaviors seen at the time of acute crisis were an increase in parental motor activity, i.e., pacing the halls or knitting furiously while at the child's bedside and an increase in active parental participation in the child's care.

Parents developed two successful long-term coping mechanisms, a determination of the meaning of the illness and hope for an altered outcome. An explanation of why this illness occurred in this family was usually drawn



from a synthesis of scientific fact, fantasy, and religious beliefs. Finding meaning behind the illness allowed parents to cope daily with the fear of the unknown future (Friedman et al., 1963).

Emphasized by Friedman et al. (1963) as a particularly vital coping mechanism was the element of hope. In the study, parents universally emphasized hope as the tool which helped them cope and adapt to a life with a great deal of uncertainty in it. Friedman et al. suggested that hope differs from massive denial in that hopeful parents intellectually accepted the reality of the disease while desiring a more favorable outcome of the treatment for the disease. Massive denial distorts reality and interferes with effective behavior which prohibited intellectual acceptance of the disease and its prognosis. As the disease process progressed, the curtailment of hope occurred coincidingly with a rise in anticipatory grief. Anticipatory grief occurred when parents expressed doubts that the child would survive. It is interesting to note that the parents expressed these doubts to other parents of ill children and not to their "hopeful" relatives and friends. In the terminal phases of the disease, parents coped with the impending death with the use of bargaining.

They bargained with God for 1 more day or week. Parents coping with the intensified stress of a death of their child were noted to have a dramatic increase in their own somatic complaints. These complaints were often similar to their child's symptoms.

The sources of stress and characteristic coping behaviors that were found by Friedman et al. (1963) have been further documented in many other research studies. Labels for the various stages change frequently, but the principal ideas behind the labels remain unchanged. The stages of adjustment to a chronic illness include shock-disbelief, guilt and anger-denial, intellectualizing, acceptance or normalacy, hope, anticipatory grief, and bargaining (Pearse, 1977).

Krulik (1980) interviewed 20 parents of chronically-ill children in order to determine how the parents best adapted to the chronicity of the disease and what coping mechanisms their families used to maintain a sense of normalcy. Krulik focused on tactics used by the parents to reduce their child's feeling of being different from his peers. From interviews with the 20 parents, Krulik found several principles which underlined successful normalizing tactics. These principles were summarized by

Krulik as follows: (a) preparation--children adapt better if prepared by parents for changes in appearance, function, and routine; (b) participation--the child's active participation in decision making and management; (c) sharing--the sharing of the illness and its management among all members of the family and sharing the experience with those in the child's social environment; and (d) control and security--parents taking control where control is needed.

Hymovich (1981) formulated that the strategy which parents choose for coping is influenced strongly by the family's past experiences, its personality structure, and its developmental level. Hymovich concluded that regardless of how successful the coping strategy of the family is, the family to some degree was deterred from accomplishing their developmental tasks.

Green (1982) concluded from a study of families with chronic illness, that families "develop characteristic group behaviors in responding to stressful situations" (p. 11). Green stated that these group behaviors are reflective of the family developmental level.

Both Green (1981) and Hymovich (1981) concluded from their studies that the developmental stage of the family,

whether it be focused on establishing their identity or focused on establishing one of its members in society, determines how the family will deal with a stress. Green (1981) and Hymovich (1981) both suggested that health care workers should assess family stress related to an illness according to a data base which includes the following categories: family structure, family interaction, family developmental level, family and community interplay, and family health behavior.

#### Summary

In conclusion, the review of the health care literature on chronic childhood illness has demonstrated that the concepts of chronicity and coping have been adequately defined. The research literature has been successful in identifying the stages and strategies of coping with chronic illness.

The concepts seen throughout the health care literature on chronic illness are well-summarized by Waechter (1979) as follows:

Long term illness is usually accompanied by remissions and exacerbations. Because of this, the family must adjust and readjust constantly the disease progresses, and as the family grows and changes, the home situation may also be constantly changing. The needs of family members and the interactions between them

change, as siblings mature and develop and as parental needs vary. Therefore, the family must always learn to cope anew. (p. 205)

Only through research which provides specific data on family stress, needs of families with chronically-ill children, and coping strategies will nurses be able to meet the needs of families with chronically-ill children. Further research will help develop more concepts, theories, and hypotheses on the relationship between chronic illness and the variables of the impact of stress, coping strategies, family developmental level, family developmental tasks, and family health.

## CHAPTER 3

### PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

This study was a comparative descriptive study using an ex-post facto design. The purpose of a descriptive study is to observe, describe, and classify phenomena (Polit & Hungler, 1978). There was no manipulation of the variables of family stress, coping patterns, or family health beliefs. The purpose of this study was to describe and compare the impact of chronic childhood illness on the family. The study described the relationship between the independent variable of chronic childhood illness and the dependent variables of family stress, family coping patterns, and family health.

The study utilized the CICI:PQ developed by Hymovich in 1981. The questionnaire is designed as a self-report instrument. The questions were developed in order for the parents to describe from their experiences the impact of chronic childhood illness on their family.

### Setting

The study was conducted in the asthma, renal, pulmonary, and hematology outpatient clinics in a 150-bed nonprofit pediatric medical center. This facility is

located in a metropolitan area of over 1 million persons in the southwestern portion of the United States.

#### Population and Sample

The target population of this study was the total population of all mothers with chronically-ill school age children and their families. The accessible population was the population of mothers with chronically-ill children who routinely visited one of the four clinics in the medical center.

The total number of subjects in the study was 40. The mothers of 10 children from each clinic were selected by the convenience sample method. Clinic charts from each of the four clinics were reviewed in January, February, and March of 1984 to find school age children who met the following delimitations:

1. All children must have come from intact families where two adults fulfilled the roles of mother and father. Additionally, there must have been at least one sibling in the family. This delimitation was necessary so that all sections of the CICI:PQ questionnaire could be completed.

2. Group A, 10 mothers of school age children (6 years, 0 months to 12 years, 11 months) who had been diagnosed with asthma for a period of at least 3 months.

3. Group B, 10 mothers of school age children (6 years, 0 months to 12 years, 11 months) who had been diagnosed with renal disease for a period of at least 3 months.

4. Group C, 10 mothers of school age children (6 years, 0 months to 12 years, 11 months) who had been diagnosed with cystic fibrosis for a period of at least 3 months.

5. Group D, 10 mothers of school age children (6 years, 0 months to 12 years, 11 months) who had been diagnosed with leukemia for a period of at least 3 months.

6. Children in the study had only one chronic illness.

7. Mothers had to be able to read and write English.

Mothers were selected to be the subjects of this study as opposed to fathers because mothers usually come to the clinic. Fathers only come to the clinic infrequently. The first 10 mothers out of each group who agreed to participate in the study were considered the subjects.



### Protection of Human Subjects

The human rights of the children and mothers involved in the study were protected in the following manner. Permission was obtained to conduct the study from the Graduate School of Texas Woman's University (Appendix A) and the selected medical center (Appendix B).

The mothers of the children from each clinic were contacted by the researcher and asked to participate in the study. If they refused to participate, no further contact was made. If they agreed to participate in the study, they were given a brief verbal explanation of the study (Appendix C). Mothers were then given the CICI:PQ to complete. Their consent to participate in the study was in the form of the completed questionnaire. Mothers were reassured that they could withdraw from the study at any time while completing the questionnaire and their child's care would not have been affected.

There were no harmful effects seen related to participation in the study. However, the researcher was available in the clinics during the study to answer any questions or to alleviate any doubts. The researcher was also available by telephone to answer any questions of mothers after they had completed the questionnaire.

To assure anonymity and confidentiality of the respondents, all questionnaires were coded by the researcher according to the various disease groups. Individual participants were not identified in any way. The data were reported as group data. Copies of the raw data will be sent to Hymovich per her request.

#### Instrument

The instrument chosen for this study was the Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ). Permission to use the copyrighted instrument was obtained in writing from Hymovich (Appendix D).

The instrument is a parental questionnaire composed of several sections. The sections included in the questionnaire are general information, management concerns related to general care of an ill child, concerns about the child's condition and future, issues related to hospitalization, and issues related to general beliefs, attitudes, and values of family health. The general information section actually has several parts and is dispersed throughout the questionnaire. This was done to facilitate ease in completing the questionnaire. The general information deals with the age of the subject, age

of the child's mother and spouse, marital status, sex of the family members, severity of the child's illness, and length of the child's illness. The demographic data were needed to further establish the reliability of the instrument. The questionnaire took approximately 20-30 minutes to complete and, therefore, was completed by the mothers during one clinic visit. In order to have completed the questionnaire, mothers had to be able to read and write English.

The instrument was chosen because it assesses the impact of chronic childhood illness on the whole family. The differences or similarities in the perceived impact of chronic illness on the family among the four groups of mothers were seen in the comparison of group scores.

Content validity of the instrument was established by Hymovich (1981) with the initial instrument being reviewed by seven professional nurses and psychologists who had previously done a great deal of work with chronically-ill patients and their families. The content validity has been further established by researchers who have subsequently used the tool in their attempts to assess the impact of chronic illness on the family.

Hymovich (1981) established the reliability of the instrument by pilot testing the instrument with a group of 29 parents of children with cystic fibrosis. The internal reliability of the instrument was determined to be .84 and .88. The tool is currently being used by other researchers on the East Coast, primarily with similar populations of cystic fibrosis children. Because the instrument has been used so extensively with the cystic fibrosis population, the demographic data obtained from this study will be important in determining if the instrument can be used to assess the impact of chronic childhood illness in other populations.

The CICI:PQ is a 198-closed-item questionnaire. The instrument is scored by adding the items that pertain to seven individual categories. The even scores obtained are help score, family health score, self-concern score, spouse concern score, stressor score, self-cope score, and spouse cope score. The total stressor score is obtained by adding together the help score, family health score, self-concern score, and spouse concern score. The total coping scores is obtained by adding together the self-cope score and the spouse cope score.

To test the hypotheses in this study, the total stressor scores, total cope scores, and family health scores were calculated and compared. The range of scores for the individual mothers' stressor score was 48-231. The range of the scores for the individual mothers' total cope score was 40-150. The range of scores for the individual mothers' family health scores was 1-4. In this study, the individual mothers' scores were added together for each group of mothers having children with either asthma, cystic fibrosis, leukemia, or renal disease and the mean rank score for each group was calculated.

#### Data Collection

Data were collected following this procedure:

1. Clinic charts were reviewed in each of the four clinics to find children who met the delimitations of the study.
2. Permission to contact the mothers of the children was obtained from the medical chairman of the clinic areas.
3. Parents of the children were contacted in the clinic areas and given a brief oral explanation of the study (Appendix C). The first 10 mothers from each of the clinics who agreed to participate in the study were asked

to complete the questionnaire. The researcher was available during clinic visits to answer any questions.

4. Consent to participate in the study was in the form of the completed questionnaire. The mothers had the right to withdraw from the study any time prior to returning the completed questionnaire to the researcher.

5. The completed questionnaires were coded according to the specific delimitations of the study.

#### Treatment of Data

The three null hypotheses were tested using the Kruskal-Wallis nonparametric analysis of variance (Siegel, 1956). The level of significance was .05. Hypothesis 1 was tested by comparing the mean rank of the total stressor scores of each group of mothers. Hypothesis 2 was tested by comparing the mean rank of the total cope scores of each group of mothers. Hypothesis 3 was tested by comparing the mean rank of the family health score of each group of mothers. Demographic data were analyzed in terms of appropriate descriptive statistics. Frequency distribution techniques were applied to analyze data concerning the age of the mother, mother's level of education, race, degree of severity of the child's illness, and length of child's illness.

## CHAPTER 4

### ANALYSIS OF DATA

This chapter presents the results of the nonparametric statistics performed on the data collected testing three null hypotheses that there would be no difference in the total stressor scores, total cope scores, and family health scores among four groups of mothers. The sample is described, and the findings discussed.

#### Description of Sample

A total of 40 mothers of intact families of chronically-ill children responded to the CICI:PQ. The mothers were divided into four groups of 10, according to the disease of the child. Group A consisted of 10 mothers of school age children (6 years, 0 months to 12 years, 11 months) who had been diagnosed with asthma for a period of at least 3 months. Group B consisted of 10 mothers of school age children (6 years, 0 months to 12 years, 11 months) who had been diagnosed with renal disease for a period of at least 3 months. Group C consisted of 10 mothers of school age children (6 years, 0 months to 12 years, 11 months) who had been diagnosed with cystic fibrosis for a period of at least 3 months. Group D

consisted of 10 mothers of school age children (6 years, 0 months to 12 years, 11 months) who had been diagnosed with leukemia for a period of at least 3 months.

As shown in Table 1, 78% of the mothers were between 30 and 39 years of age. Fifty-eight percent of the mothers had at least some college education (Table 2). Seventy-five percent of the mothers were Caucasian, as shown in Table 3.

Table 1

Age of Mothers

Age (Years)	Frequency	Percentage
No response	1	2.5
25-29	2	5.0
30-34	18	45.0
35-39	13	32.5
40-45	5	12.5
45-49	1	2.5



Table 2

Level of Education of Mothers

School Grade Completed	Frequency	Percentage
No response	1	2.5
9th grade	1	2.5
10th grade	3	7.5
11th grade	1	2.5
12th grade	11	27.5
Some college	16	40.0
College graduate	6	15.0
Master's degree	1	2.5

Table 3

Race of Mothers

Race	Frequency	Percentage
No response	1	2.5
Caucasian	30	75.0
Black	3	7.5
Spanish-American	3	7.5
Native American	2	5.0
Other	1	2.5

Fifty percent of the mothers considered their children's illness moderately severe. Forty percent of the mothers considered their child's illness very severe (Table 4).

Table 4

Degree of Severity

Degree of Severity	Frequency	Percentage
Not severe (slight)	4	10.0
Moderately severe	20	50.0
Very severe	16	40.0

The median age of the children with the chronic illness was 9 years. The majority of the children was male (53%). As shown in Table 5, over 74% of the children had been diagnosed for over a year.

### Findings

The mean total stressor score for the individual mothers was 127.7. The mean total cope score for individual mothers was 107.1. The mean family health score for the individual mothers was 3.181 (Table 6).

Table 5

Length of Child's Illness

Length of Illness	Frequency	Percentage
Less than 3 months	0	0.0
3-6 months	8	20.0
7-11 months	2	5.0
12-23 months	5	12.5
2-4 years	12	30.0
Over 4 years	13	32.5

Table 6

Mean Individual Stress, Coping, and Family Health Scores

Variable	Mean	Standard Deviation	Minimum	Maximum
Total stressor	127.681	38.46	59.0	190.75
Total cope	107.10	19.647	66.0	150.00
Family health	3.181	.707	1.750	4.750

All scores in this study were tested using the Kruskal-Wallis nonparametric analysis of variance. The level of significance was set at the 0.05 level. The

first null hypothesis of the study was there would be no significant difference among the perceptions of family stress of mothers having children with asthma, renal disease, leukemia, and cystic fibrosis. Hypothesis 1 was tested by comparing the total stressor score of each group of mothers.

Using the Kruskal-Wallis one-way analysis of variance, no difference among the groups was found ( $\chi^2 = 2.4$ ,  $p = .49$ ). Thus, null hypothesis 1 was not rejected. The mean rank scores are given in Table 7.

Table 7

Total Stressor Scores

Disease of Child	Mean Rank
Asthma	22.75
Cystic fibrosis	19.35
Leukemia	23.55
Renal disease	16.35

The second null hypothesis stated that there would be no significant difference among the perceptions of mothers having children with asthma, renal disease, leukemia, and cystic fibrosis regarding coping patterns in caring for

chronically-ill children. Hypothesis 2 was tested by comparing the total cope score of each group of mothers. Using the Kruskal-Wallis one-way analysis of variance, no difference among the groups was found ( $\chi^2 = 3.05$ ,  $p = .38$ ). Thus, null hypothesis 2 was not rejected. The mean rank scores are given in Table 8.

Table 8

Total Cope Scores

Disease of Child	Mean Rank
Asthma	17.55
Cystic fibrosis	23.65
Leukemia	23.80
Renal disease	17.00

The third null hypothesis stated that there would be no significant difference among mothers having children with asthma, renal disease, leukemia, and cystic fibrosis in their described beliefs about family health. Using the Kruskal-Wallis one-way analysis of variance, a significant difference was found among the groups ( $\chi^2 = 10.8$ ,  $p = .012$ ). Thus, null hypothesis 3 was rejected. The mean rank scores are given in Table 9. Further

Table 9

Family Health Scores

Disease of Child	Mean Rank
Asthma	26.35
Cystic fibrosis	26.65
Leukemia	13.33
Renal disease	15.70

analysis revealed that those with renal disease or leukemia scored lower than those with asthma or cystic fibrosis.

## Other Findings

Frequencies and percentages were obtained to determine the mothers' reaction to the instrument itself. The majority (68%) of the mothers thought that all or most of the questions of the CICI:PQ applied to them and their families (Table 10). Sixty-three percent of the mothers believed that the questions of the CICI:PQ covered somewhat well the issues about parenting a chronically-ill child (Table 11).

Table 10

Application of Questions

Number of Questions Which Apply	Frequency	Percentage
All	7	17.5
Most	20	50.0
Some	10	25.0
Few	3	7.5
None	0	0.0

Table 11

Content Value of Questions

Number of Questions Covering Important Content	Frequency	Percentage
No response	1	2.5
Very well	11	27.5
Somewhat well	25	62.5
Not well	3	7.5

## Summary of Findings

A total of 40 mothers of chronically-ill children were surveyed regarding their perceptions of the impact of

stress, means of coping, and their beliefs about family health. The perceptions of the 40 mothers as tested by the CICI:PQ demonstrated that children with chronic illnesses such as asthma, renal disease, cystic fibrosis, and leukemia, and their families have similar stresses and similar means of coping with the stress of chronic illness.

Hypothesis 1 stated that there is no significant difference in the perceptions of family stress among mothers having children with either asthma, cystic fibrosis, leukemia, or renal disease. Hypothesis 1 was supported. The group of mothers with asthmatic and leukemic children had very similar total stressor scores. Their mean rank scores were 22.75 and 23.55, respectively. The two above group scores were slightly higher than the other two groups of mothers. The mean rank score of the cystic fibrosis group of mothers was 19.35, and the mean rank score of the renal disease group of mothers was 16.35.

Hypothesis 2 stated that there is no significant difference in the perceptions of family coping patterns in caring for a chronically-ill child among mothers having children with asthma, cystic fibrosis, leukemia, or renal



disease. Hypothesis 2 was supported. The total cope scores of these four groups of mothers were not significantly different. The cystic fibrosis and leukemic groups were quite similar in their mean rank scores of 23.65 and 23.80, respectively. In comparison, the mean rank scores of the asthmatic and renal disease group of mothers were similar (17.55 and 17.00, respectively).

Hypothesis 3 stated that there is no significant difference in the perceptions of family health among mothers having children with either asthma, cystic fibrosis, leukemia, or renal disease. Hypothesis 3 was not supported. Based on the data collected and analyzed, the findings of the study indicated that the four groups of mothers had significantly different perceptions in their described beliefs about family health. Statistical differences were found among the groups for their family health scores. The most significant difference was found between cystic fibrosis mothers with a group mean rank score of 26.65 and the group of leukemic mothers with a mean rank score of 13.33. Although interpretation of these scores needs refinement by the author of the instrument, it is worth noting that the asthmatic group of mothers with a mean rank score of 26.35 and the cystic

fibrosis group of mothers viewed their family's health to be worse or at greater risk than did the leukemic or renal group of mothers.

Finally, based on the frequencies and percentages obtained concerning mothers' responses to the questionnaire, a majority of the mothers, 63%, believed the questions of the CICI:PQ covered somewhat well the issues about parenting a chronically-ill child.

## CHAPTER 5

### SUMMARY OF THE STUDY

The problem of this comparative, descriptive study was to determine if there is a significant difference in mothers' perceptions of (a) family stress, (b) family coping patterns, and (c) family health among mothers who have children with either asthma, cystic fibrosis, leukemia, or renal disease. This chapter presents the summary of this study, findings of the data, conclusions and implications, and recommendations for further study are also given.

#### Summary

Chronic childhood illness affects a growing number of children each year. There have been tremendous advances in medical and nursing knowledge and treatment of such chronic illnesses as asthma, cystic fibrosis, leukemia, and renal disease. Despite this tremendous growth in knowledge, there has been little research on the impact of chronic childhood illness of the family and how these families choose to cope with the stress of chronic illness.

The focus of this study was on the perceptions of 40 mothers of chronically-ill children on the impact of chronic illness on family stress, their family coping patterns, and their described family health. This study utilized the comparative descriptive survey method. Minuchin's (1974) family systems theory and Duvall's (1977) family developmental theory provided the conceptual framework for this study. Hymovich's (1981) developmental approach to families supplemented the conceptual framework.

Minuchin (1974) suggested that illness in the family is a source of stress mandating change in the family system. Therefore, the family system must develop a wide range of transactional patterns in order to adapt to the ongoing needs of the chronically-ill child. Viewed from Duvall's (1977) developmental approach, illness is a situational crisis superimposing itself on the family's normal developmental tasks. Thus, chronic childhood illness may inhibit the family from accomplishing their normal developmental tasks.

Hymovich (1981), supplementing the developmental approach, suggested that the family functioning may be affected by chronic illness. Hymovich proposed that the

experience of having a chronically-ill child may be positive or negative, depending on the family's perceptions, resources, and coping abilities.

Based on the stated theories and concepts, it was hypothesized that the stress of chronic childhood illness within a family can cause disruption in the family system and thus impede the family health. Furthermore, it was hypothesized, based on Minuchin's (1974) family system theory, Duvall's (1977) developmental theory, and Hymovich's (1981) developmental concepts, that the impact of chronic childhood illness is dependent upon the family's stress, ability to cope, and health.

This study tested the following null hypotheses:

1. There is no significant difference in the perceptions of family stress among mothers having children with either asthma, cystic fibrosis, leukemia, or renal disease.
2. There is no significant difference in the perceptions of family copy patterns in caring for a chronically-ill child among mothers having children with either asthma, cystic fibrosis, leukemia, or renal disease.
3. There is no significant difference in the perceptions of family health among mothers having children with

either asthma, cystic fibrosis, leukemia, or renal disease.

The setting for the study was the asthma, renal, pulmonary, and hematology outpatient clinics in a 150-bed pediatric center. The total number of subjects in the study was 40 mothers of chronically-ill children. The mothers of 10 children from each of the four clinics were selected by the convenience sample method. The chronically-ill children had to be diagnosed for at least 3 months and be between the ages of 6 and 12 years.

The instrument used in the study was the CICI:PQ, which was developed by Hymovich in 1981. The CICI:PQ was piloted in 1979 and refined in 1981 and 1982. The instrument is expected to be further refined after data from this study and others are received by Hymovich. The CICI:PQ is intended to assess the impact of chronic childhood illness on the whole family. The areas covered on the questionnaire include demographic information, family stressors, parental coping patterns, and family health.

Total group scores were obtained for each group of 10 mothers. The scores obtained for this study included the total stressor score, total coping score, and family health score. The total group scores were compared using

the Kruskal-Wallis nonparametric analysis of variance. Descriptive statistics were used to summarize the demographic data. Demographic data included the age, race, and level of education of the mother; the degree of severity of the child's illness; and length of the child's illness.

#### Discussion of Findings

Based on the data collected, some concepts of Minuchin (1974), Duvall (1977), and Hymovich (1981) were supported. The conceptual framework suggested that there is a relationship between increasing levels of family stress and chronic childhood illness. Chronic childhood illness in the family can be viewed as a stress which may impede normal family functioning and coping. The individual mothers' total stressor scores demonstrated that families of chronically-ill children do have a considerable amount of stress in their lives related to the child's chronic illness. The total stressors scores on the CICI:PQ ranged from 48 to 231. The mean individual mothers' scores was 127.7, and the maximum individual score was 190.8.

Based on the conceptual framework, it was suggested that how families of chronically-ill children cope with the stress of the impact of a chronic illness is dependent

upon the family's unique patterns of coping and ability to adapt to changes in family structure. The mean individual mothers' total cope score was 107.1, and the maximum score was 150.0. The range of the total cope score was 40-150, the score of 150 signifying that the mothers use more frequently several different coping mechanisms such as crying, praying, or taking more alcohol. The cope scores do not tell the specific mechanisms used but they do demonstrate that each family has a set of family patterns which they rely on in terms of stress.

The mean family health score among the 40 mothers was 3.181. The range was 1-4, 4 signifying poor family health. The data from this study support the concepts of Minuchin (1974), Duvall (1977), and Hymovich (1981) that the whole family is affected by the child's chronic illness. Based on the concepts of these researchers, it is suggested that poor family health may be related to the disruption seen in the family structure caused by the impact of the stress of chronic illness.

Based on the total group scores, hypotheses 1 and 2 were not rejected. However, null hypothesis 3 was rejected at the 0.05 level of significance. Therefore, there was a significant difference in the 40 mothers'



perceptions of their described beliefs about family health but no significant difference in the mothers' perceptions of the impact of stress of chronic childhood illness or their perception of how the family chooses to cope with such stress.

A possible explanation for the similar total stressor scores and total cope scores among the groups is that families with chronically-ill children, regardless of the uniqueness of a particular illness, suffer similar amounts and types of stress. Furthermore, regardless of the particular illness, families choose similar coping strategies based on their individual family developmental patterns and level.

The significantly different family health scores among the groups may possibly be explained by the fact that the family health score is dependent upon every family member's individual health score. In several of the families, the chronically-ill child's health may have been currently good while another family member's health was bad. This may cause the total family health score to be higher. The relationship between the family members' health and the chronically-ill child's health needs to be more clearly defined.

Scoring of the data obtained from the instrument, especially the group scores, needs further refinement by Hymovich before the scores from this study can be adequately interpreted. These scores in the future may possibly be interpreted in such a manner as to support Hymovich's (1981) concept that having a chronically-ill child may be viewed by the family as a positive or negative experience.

Based on the frequencies and percentages obtained concerning the mothers' responses to the questionnaire, it is suggested that the CICI:PQ needs refinement before it can be universally used in the nursing assessment of families who have chronically-ill children. Most importantly, the interpretation of the total stressor scores, total cope scores, and family health scores need to be clearly analyzed and defined. Analysis of these scores needs to be done in such a manner that nurses may plan care and counsel individual families based on these scores.

#### Conclusions and Implications

Based on the findings of this study, the following conclusions and implications are made:

1. The findings of this study support the concept suggested by Hymovich (1981), Krulik (1980), and Lawson (1977) that there are similarities among families with children who have different chronic illnesses. Specifically, similarities in study were seen in the mothers' perceptions of the impact of a chronic illness on family stress and in family coping patterns in caring for a chronically-ill child.

2. The findings of this study also support the Hymovich (1981) concept that families must be individually assessed for their developmental growth and beliefs about family health. It is suggested that there are significant differences in how families perceive their family health. Additionally, the findings of the study suggest the need for nurses to assess families individually with a standard tool. In the future, the value of the CICI:PQ for the nurse is that it can provide data on the family structure of the chronically-ill child, the family's current stress status, the family's coping status, sibling involvement, family developmental needs, and the family's health beliefs. Once such data are obtained and analyzed, nurses should have a sufficient knowledge base from which they can develop nursing diagnoses for each family. Based on

these specific diagnoses, nurses can plan and implement etiologic-specific nursing interventions.

3. The CICI:PQ is an assessment tool designed to assess the stress impact and coping status of families with chronically-ill children. The CICI:PQ is a legitimate attempt to standardize nursing assessment; however, it is only in its infant stages. Based on the data from this study and other studies, the instrument needs to be refined and repiloted before it can be universally used in the nursing assessment of families who have chronically-ill children.

#### Recommendations for Further Study

Based on the findings of this study and the deficits seen in the research literature, the recommendations for further study are:

1. A further validation and reliability study be conducted of the CICI:PQ.
2. A replication of the study be conducted using different disease groups, such as diabetes, muscular dystrophy, heart disease, or neurological disorders.
3. A study be conducted further refining the scoring and interpretation of scores of the instrument.

4. A study be conducted to identify specific stressors and formulate appropriate nursing interventions.

5. Establish test-retest reliability of the CICI:PQ to help determine the stability of the instrument.

6. Further refinement be made of the interpretation of the scores obtained.

## APPENDIX A

PROSPECTUS FOR THESIS  
APPROVAL FORM

This proposal for a thesis by Kathleen M. McHugh  
\_\_\_\_\_ and entitled The Impact of Chronic Childhood  
Illness on the Family as Perceived by the Mother  
\_\_\_\_\_

has been successfully defended and approved by the members  
of the Thesis Committee.

This research is x is not \_\_\_\_\_ exempt from  
approval by the Human Subjects Review Committee. If the  
research is exempt, the reason for its exemption is \_\_\_\_\_  
The study is a descriptive study using a parental questionnaire.  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Thesis Committee: Judith A. Erlen, Chairperson

Marion A. ..., Member

Rose M. ..., Member

Date: 5/2/83

\_\_\_\_\_, Dean, College of Nursing

Date: \_\_\_\_\_

## APPENDIX B



TEXAS WOMAN'S UNIVERSITY  
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY\*

THE Children's Medical Center of Dallas

GRANTS TO Kathleen M. McHugh  
a student enrolled in a program of nursing leading to a  
Master's Degree at Texas Woman's University, the privilege  
of its facilities in order to study the following  
problem.

The Impact of Chronic Childhood Illness on the Family as Perceived by  
the Mother.

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the  
final report.
2. The names of consultative or administrative  
personnel in the agency (may) (may not) be  
identified in the final report.
3. The agency (wants) (does not want) a conference  
with the student when the report is completed.
4. The agency is (willing) (unwilling) to allow the  
completed report to be circulated through  
interlibrary loan.
5. Other \_\_\_\_\_

11-2-83  
Date  
Kathleen M. McHugh  
Signature of Student

\_\_\_\_\_  
Signature of Agency Personnel  
Judith A. Erlen  
Signature of Faculty Advisor

\*Fill out & sign 3 copies to be distributed: Original-  
student; 1st copy-Agency; 2nd copy-TWU School of Nursing

## APPENDIX C

## ORAL EXPLANATION TO SUBJECTS

My name is Kathleen McHugh, and I am a nurse working toward my Master's degree in nursing science at Texas Woman's University. I am currently involved in studying the impact of chronic childhood illness on the family from the perspective of mothers.

You are 1 of 40 mothers of chronically-ill children who are being asked to participate in this study. Participation in this study will involve your completing the Chronicity Impact and Coping Instrument: Parent Questionnaire. The questions ask you to describe your concerns as a parent of a chronically-ill child, possible concerns of your husband and other children, your means of coping with the many problems that arise in caring for a chronically-ill child, and your beliefs, values, and attitudes toward family health care. The questionnaire is expected to take approximately 30 minutes to complete. Since this is not a test, there are no right or wrong answers.

It is possible that some of the questions on the questionnaire might cause you some anxiety or doubt. If this is the case, you are invited to discuss your feelings

or questions about the questionnaire at any time with me during your clinic visit or by phone.

You are under no obligation to participate in this study, and you can withdraw from the study at any time prior to the completion of the questionnaire without your child's care being affected. Return of the completed questionnaire will be construed as your consent to act as a participant in this study. All information obtained will be considered confidential. You are requested not to put your name on the questionnaire as they are coded and all data will be reported as group data. A copy of the abstract of the study will be available in the asthma, renal, pulmonary, and hematology clinics in December, 1984, if you wish to review the study results.

It is believed that the data from this study might provide nursing with valuable information that could help nurses and other health care workers meet the special health care needs of the chronically-ill child and his family.

## APPENDIX D

*UNIVERSITY of PENNSYLVANIA*

PHILADELPHIA 19104

*School of Nursing*

Nursing Education Building/S2  
(215) 898-8281

March 15, 1983

Katie McHugh  
5223 Parry  
Dallas, Texas 75223

Dear Katie:

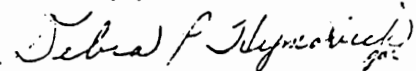
Enclosed is a copy of the CICI:PQ that you requested for your research. The guidelines for scoring are being revised and will be sent to you when they are completed.

As I mentioned to you on the telephone, there is currently no charge for the questionnaire so I am returning your check. I wrote "void" on it because the blank check could easily be used by someone else. I hope you don't mind. I also requested that you share your raw data with me for use in my reliability and validity studies when your data collection is completed.

Please continue to address your correspondence to me at 929 Longview Road, Gulph Mills, PA 19406.

Thank you for your interest in the questionnaire. Good luck with your thesis.

Sincerely yours,



Debra P. Hymovich, RN, PhD, FAAN  
Visiting Professor  
Program Director  
Nursing of Children

DPH:gdr

encl.

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