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THE NEEDS OF MIDDLE CLASS FATHERS PARENTING CHILDREN WITH CHRONIC CONDITIONS IN TWO PARENT FAMILIES

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Judith Kay Hovey

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THE NEEDS OF MIDDLE CLASS FATHERS PARENTING CHILDREN WITH CHRONIC CONDITIONS IN TWO PARENT FAMILIES

By

Judith Kay Hovey

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ABSTRACT

THE NEEDS OF MIDDLE CLASS FATHERS PARENTING CHILDREN WITH CHRONIC CONDITIONS IN TWO PARENT FAMILIES

By

Judith Kay Hovey

Children with chronic conditions survive for longer periods of time than has been historically true, creating a need to promote optimal growth and development for them, their family members and the family as a unit. A review of the literature suggests that fathers of children with chronic conditions have parenting needs that may be different from fathers of well children. Little attention has been directed toward these differences and no comparative studies were found focusing on families of children with chronic conditions.

The purpose of this study was to identify and compare the concerns, beliefs, feelings, coping strategies, and perceptions of family care needs and spouse concerns of fathers of children with chronic conditions and fathers of well children. The sample consisted of 99 fathers of children in the service area of a large metropolitan medical center. The 48 fathers of children with chronic conditions and the 51 fathers of well children who participated each completed the Hymovich Family Perception Inventory (FPI) anonymously. The Hymovich instrument contains nine scales, eight that can be used independently or together as applicable

The results revealed significant differences in the parenting concerns of fathers of children with chronic conditions and fathers of well children. These concerns center

around their children's health and include the need for knowledge. Fathers of children with chronic conditions also reported significant differences in the parenting concerns of their wives but with strong correlations to their own concerns. There are indications that there is a place for professional anticipatory guidance, dissemination of information, and encouragement in the use of fathers' informal support systems to provide the kinds of support needed by fathers of children with chronic conditions.

DEDICATION

To my parents, Alvin and Lucille Hovey,

who taught me the

value and joy of knowledge

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To my sister, Ilene Hovey, who continually motivated me to keep going and never give up. Thank you for all you've done.

TABLE OF CONTENTS

TABLE OF CONTENTS (continued)

LIST OF TABLES

LIST OF TABLES

LIST OF FIGURES

CHAPTER I

INTRODUCTION

Jackson (1996) defines a chronic health condition as "one that is long term and is either not curable or has residual features that result in limitations in daily living requiring special assistance or adaptation in function" (p. 3). The National Center for Health Statistics conducted the National Health Interview Survey on Child Health (NHIS-CH) in 1988. They found that based on parent report an estimated 20 million children (31%) in the United States had one or more chronic conditions, excluding mental impairment (Jackson). Sixty six percent of the conditions were considered mild, 29% moderate, and 5% severe, impacting the child's function frequently or continuously. According to Perrin (1989), the incidence of the diseases classified as chronic has not increased but survival rates are longer.

Development in children is affected by their "physiological state, psychological competence, and external environment" (Vessey & Swanson, 1996, p. 16). As a result development can be delayed, deviant, or unaffected by a chronic condition. In children with marginal deficits, the disease process may be prolonged by denial of a problem by the parents resulting in a lack of recognition of symptoms needing intervention. This delay in recognition can cause developmental sequelae (Vessey & Swanson). Fatigue may also limit the children's ability to participate in classroom activities because of the time and effort needed to manage their chronic condition. This may further hinder development (Mearig, 1985). Children with debilitating conditions may achieve

milestones as expected only to lose them over time with progression of the disease. Children with uncertain futures may be deprived of goal formation, which limits their ability to learn since this longitudinal perspective is important in shaping cognitive processes (Vessey & Swanson). The treatment itself, side effects of drugs and radiation can add to temporary or long-term developmental interruptions.

The characteristics of the child also impact the child's development. The age of the child at the time a condition occurs will greatly influence the child's development. Many children develop the resilience to overcome their chronic conditions and excel in life (Vessey & Swanson, 1996). Sinnema (1991) states that "a strong self-concept, or a positive interpretation of one's own individualism, is developed through successfully mastering a variety of physical, intellectual, social, and emotional tasks" (p. 484). Hertzig (1992) reported that although a single condition does not appear to effect the child's psychological outcomes, multiple conditions do. He states that "factors known to place children at greater risk for psychological co-morbidity are 1) having a poor self-concept, 2) having a dysfunctional family, and 3) living in an isolated area and/or poverty" (p. 25).

Family resilience, cultural orientation, and social class all influence development in children with chronic conditions (Vessey & Swanson, 1996). A family crisis occurs at the time that a child is diagnosed with a disease process. This is especially true with a child who has a condition that is potentially chronic in nature. The family's reaction to the crisis is individual to the family and may be based on preconceived ideas of what the diagnosis means (Shepard & Mahon, 1996). Once the family accepts the condition as

chronic, normalization needs to occur. This places the emphasis back on the child instead of the condition (Shepard & Mahon).

Chronic conditions may be costly to the family in ways of medical care, special diets, transportation, babysitting for siblings, and time lost from work (Shepard & Mahon, 1996). Shepard and Mahon go on to state that "a primary need of most families is emotional support and practical help" (p. 49). But race, ethnicity, parental gender and age may influence the ways they utilize support (Williams, 1993, & Winkel, 1988). According to Shepard and Mahon, the work of parenting children with chronic conditions is qualitatively different than parenting children without chronic conditions. But, they go on to say that the needs of these parents are the same as the parents of children without chronic conditions. Knowledge about normal growth and development, care of minor childhood diseases, management of childhood behavior, diet, physical and fiscal ability to parent future children, and the child's future as a parent his or herself is sought by parents of children with and without chronic conditions.

According to Starn (1996) "the definitions of chronic conditions and disability have often been grounded in the dominant Euro-American values of socially and psychologically defined uniformity, normative behaviors, and responses to stress and illness" (p. 58). Starn goes on to state "varying cultural values affect decision making regarding the care of children with special health care needs" (p. 63). Family demographics, orientation, communication, family relationships, education, religion, nutrition, and beliefs about health may be different from the dominant Euro-American family.

Children with Cancer

Approximately 8,200 children are diagnosed with cancer annually in the United States (Dragone, 1996) with an incidence of 14:100,000 per year for children under 15 years of age. The treatments for the various childhood cancers include medications, radiation, and surgery, all of which may involve side effects that have long term consequences on growth and development. At the time of diagnosis the illness is generally considered life threatening and then becomes a chronic condition over time with varying degrees of developmental impact as cited above. Long term survival is a reality for the majority of children with childhood cancer. Growth and development, diet, safety, care for minor illnesses, and financial matters are all areas of concern to parents of children with cancer (Dragone).

Children with Cystic Fibrosis

Cystic fibrosis affects multiple systems of the body. Significant breakthroughs in the past 15 years have resulted in these children living into adulthood. The disease, however, demands intensive daily therapy that frequently causes fatigue and slows development. The disease itself impacts growth of the child causing further delays. The incidence of the disease is "approximately 1:2,000 to 2,500 live births" (McMullen, 1996, p. 327). Again, the areas of concern for parents are generally the same, i.e. growth and development, diet, safety, care for minor illnesses, and financial matters (McMullen).

Children with Juvenile Rheumatoid Arthritis

Juvenile Rheumatoid Arthritis (JRA) is one of the most common chronic childhood illnesses. Singsen (1990) reports an incidence of 9 to 25:100,000 with an "estimated 65,000 to 70,000 children in the United States affected with JRA"

(McIlvain-Simpson, 1996, p. 531). Many children go into permanent remission without significant complications while others must deal with residual problems. According to McIlvain-Simpson, the goal of early diagnosis and treatment is to maximize normal growth and development and minimize residual deformity. Physical and occupational therapy are critical to successful treatment of the condition along with medication and dietary counseling. JRA is a chronic, unpredictable condition that may progress despite treatment. Children with systemic manifestations are most at risk for life threatening sequelae. Seventy to ninety percent of children, however, will go into spontaneous permanent remission or suffer no serious disability. The concerns of the parents are the same as parents of children with other chronic conditions.

Parenting Children with Chronic Conditions

To promote optimal development in the child and maintain family development, the parents must first come to terms with the chronic condition. When they are able to focus on the child rather than the disease, the parents are able to parent more effectively (Mearig, 1985). Lamb (1997) reports a high incidence of marital discord and second order effects that may occur when parenting a child with a chronic condition.

In Hymovich's research (1976), she found parents needed information, trust in themselves, their children, and the health professionals caring for their children. They needed guidance from these professionals and access to other supportive resources. Hymovich delineates three parental tasks 1) understanding and managing the child's illness, 2) helping the child understand and deal with the condition, and 3) meeting the needs of all family members. Enscar, Carlsson, Golsater, Hamrin, and Kreuger (1997) stated that everyday life is overshadowed by the child's condition and parents feel

powerless watching their child suffer. Parents must also deal with the child's physical and psychological reaction to the disease and treatment. Parents must deal with their own strong emotions and reactions, which influence their feelings of self-esteem and impact their concerns about the child's future (Enscar et al.).

Fathering Children with Chronic Conditions

There is very little literature on the fathers of children with chronic conditions and it is conflicting. Lamb (1997) states that fathers who are minimally involved in the everyday care of their chronically ill children have longer periods of adjustment to the condition or may withdraw from the children altogether. May and Samuelson's 1989 study reported that fathers of children with disabilities received support and guidance from fathers' groups, neighbors, extended family, friends, and the health care team. The researchers also reported that fathers needed to know what development was possible, that the stages of grief they were experiencing were normal, and they needed the opportunity to deal with family stress in a positive way (Pierce, Sarason, & Sarason, 1996).

In a preliminary study, the author found that fathers of children with cancer had different needs than mothers (Hovey, 1991). Sterken (1996) found that for the most part fathers felt like the forgotten parent, not involved in the frequent trips to the doctor and the child's treatment. Slammon (1990) found that "as time since diagnosis increased family reframing and fathers' tendency to maintain social supports, self esteem, and psychological stability decreased" (p. 154).

Fathering Well Children

Although there is a paucity of literature on fathering children with chronic conditions, fathering of children in general has received much attention of late. Glennon (1995) defines the fathering role as protector, communicator, and breadwinner. The fathering role involvement is specific to the gender of the child and clearly influences the child's development (Snarey, 1993). Fathers' involvement with children in positive, affirming ways increases both sons' and daughters' intellectual competence but in different ways. Children whose fathers participate in their care have higher levels of social-emotional competence as children and are more successful in mid-life. Fathers who encourage girls' athletic pursuits and fathers who value their sons' academic development positively impact their children's success as well rounded, highly adaptive adults (Snarey).

Levine and Pittinsky (1997) view the father in the role of teacher. Involved fathers enhance intellectual and social development by open, honest communication between the child and father and by a good marital relationship between the father and mother. Children also profit from sharing their father's life experiences and the understanding, empathy, and support that he offers through coaching (Glennon, 1995). Fathers can help their children evaluate new situations to determine how much risk is reasonable and how to feel comfortable and unintimidated in foreign territory (Glennon).

STATEMENT OF PROBLEM

This study will compare the needs of fathers of children with chronic conditions (cancer, cystic fibrosis, or juvenile rheumatoid arthritis) to the needs of fathers of well children regarding concerns, family care needs, beliefs, feelings, coping behaviors and resources, and spouse concerns using Hymovich's Family Perception Inventory (FPI).

CONCEPTUAL AND OPERATIONAL DEFINITIONS

Within the context of this study the following definitions apply:

Concerns are conceptually defined as those thoughts emanating from a perceived present or potential family dysfunction. They are the worry about a family member's current situation and its impact upon the individual and family system.

Concerns are operationally defined as those things that engage a person's attention, interest, or care, or that affect a person's welfare or happiness; a worry as measured by the FPI, such as "extra demands on my time", "feeling worn out", "getting to do activities together as a family" and "I wonder how my children think about themselves."

Family care needs is conceptually defined as information necessary for a person to successfully provide family care. When a change in one family member occurs it stimulates change in the family as a whole and in each individual in the family.

Family care needs is operationally defined as the lack of information wanted or deemed necessary related to one's family care as measured by the FPI, including "physical care", "diet", and "development" of one's children.

Beliefs are conceptually defined as opinions or convictions, confidence in the truth or existence of something not immediately susceptible to rigorous proof.

Beliefs are operationally defined as truths about things that influence the way a person lives as measured by the FPI, for example, "sometimes getting away from something makes it easier to handle".

Feelings are conceptually defined as the emotions within an individual family member and elicited within a family system that are separate from and independent of rational thought.

Feelings are operationally defined as emotions or emotional perceptions or attitudes as measured by the FPI, such as "anger", "confidence", or "anxiety".

Coping is conceptually defined as those behaviors and attitudes one adopts to meet the challenges of predictable and unpredictable family events. It is the ability to function in a manner that strives to accomplish desired goals and activities within the environment. The optimal health of the family is reflected in the balance between the various members' goals and activities, and those of the group.

Coping is operationally defined as those things a person does in order to make circumstances better or try to make one feel better as measured by the FPI, including "talking with someone about my feelings", "crying", and "getting information".

Illness is conceptually defined as any physical or mental ailment that demands a change in family routine such that all family members are affected and role flexibility is needed to successfully adapt to the change.

Illness is operationally defined as any physical or mental ailment of a child that demands a change in parent routine and occurring in the child with a chronic condition in "the

father of a child with a chronic condition" group and occurring to any child in the home in the "father of well child(ren)" group.

Child is conceptually defined as a person between the ages of newborn to 18 years who lives at home with his/her parents.

A **child with a chronic condition** is operationally defined as a person between the ages of newborn and 18 years who has been diagnosed with cancer, cystic fibrosis, or juvenile rheumatoid arthritis for at least three months.

A **well child** is operationally defined as a person within the ages of newborn and 18 years who has not been diagnosed with an illness of more than six months duration with permanent physical or mental limitations.

RESEARCH OBJECTIVES

The overall purpose of this research is the identification of fathers' concerns, beliefs, feelings, and coping related to the parenting responses of fathers of children with chronic conditions and fathers of well children. In order to reach this goal, several more specific objectives were developed to guide the research. The objectives are:

- to compare the concerns of fathers of children with chronic conditions with the concerns of fathers of well children regarding themselves, their spouses, their children;
- to compare the beliefs and feelings of fathers of children with chronic conditions with the beliefs and feelings of fathers of well children regarding caring for their children;

- to compare the coping strategies of fathers of children with chronic conditions with the coping strategies of fathers of well children and how helpful these strategies are.

RESEARCH QUESTIONS AND HYPOTHESES

The research questions and hypotheses to be explored in the study are:

Research Question 1

1.1 What concerns does the father of a child with a chronic condition identify regarding his role in the family?

1.2 What concerns does the father of a well child identify regarding his role in the family?

1.3 Do fathers of well children differ from fathers of children with chronic conditions in their role concerns?

Hypothesis: Fathers of children with chronic conditions will have significantly greater concerns regarding their role than fathers of well children as measured on the FPI.

Research Question 2

2.1 What concerns does the father of a child with a chronic condition identify for his spouse?

2.2 What concerns does the father of a well child identify for his spouse?

2.3 Do fathers of well children differ from fathers of children with chronic conditions in the concerns they identify for their spouses?

Hypothesis: Fathers of children with chronic conditions will identify significantly greater concerns than fathers of well children for their spouses as measured on the FPI.

Research Question 3

3.1 What family care needs does the father of a child with a chronic condition identify?

3.2 What family care needs does the father of a well child identify?

3.3 Do fathers of well children differ from fathers of children with chronic conditions in their identification of family care needs?

Hypothesis: Fathers of well children will identify significantly fewer family care needs than fathers of children with chronic conditions as measured on the FPI.

Research Question 4

4.1 What beliefs regarding childrearing does the father of a child with a chronic condition identify?

4.2 What beliefs regarding childrearing does the father of a well child identify?

4.3 Do fathers of well children differ from fathers of children with chronic conditions in their beliefs regarding childrearing?

Hypothesis: Fathers of children with chronic conditions will have significantly less positive beliefs than fathers of well children regarding child rearing as measured on the FPI.

Research Question 5

5.1 What feelings regarding childrearing does the father of a child with a chronic condition identify?

5.2 What feelings regarding childrearing does the father of a well child identify?

5.3 Do fathers of well children differ from fathers of children with chronic conditions in their feelings regarding childrearing?

Hypothesis: Fathers of children with chronic conditions will have significantly less positive feelings than fathers of well children regarding child rearing as measured on the FPI.

Research Question 6

6.1 What coping strategies does the father of a child with a chronic condition use?

6.2 How helpful does the father of a child with a chronic condition report these coping strategies to be?

6.3 What coping strategies does the father of a well child use?

6.4 How helpful does the father of a well child report these coping strategies to be?

6.5 Do fathers of well children differ from fathers of children with chronic conditions in the use of various coping strategies?

6.6 Do fathers of well children differ from fathers of children with chronic conditions in the helpfulness of various coping strategies?

Hypothesis: Fathers of children with chronic conditions will use coping strategies significantly more often, than fathers of well children as measured on the FPI.

Hypothesis: Fathers of children with chronic conditions will find their coping strategies significantly less helpful when they have problems than fathers with well children.

ASSUMPTIONS

Assumption 1: It is assumed that the father's functioning within the family is important to the function of the family as a unit.

According to Bronfenbrenner (1979), "...it appears that if one member of the pair undergoes a process of development, the other does also. . . . In addition, a systems model of the immediate situations extends beyond the dyad and accords equal developmental importance to what are called N + 2 systems – triads, tetrads, and larger interpersonal structures." (p. 5). Roy (1999) defines a system as "a set of parts connected to function as a whole for some purpose and that does so by virtue of the interdependence of the parts." (p. 32). Therefore, in viewing the family as a system it is assumed that the father's functioning within the family is important to the function of the family as a unit.

Assumption 2: Humans are capable of adaptive behavior in attempts to meet their needs.

Roy (1999) "views human adaptive systems as functioning with interdependent parts acting in unity for some purpose. Living systems, however, are regarded as nonlinear, multifaceted, and complex phenomena. The process is never viewed as a single stimulus initiating a given response. Rather living systems, particularly human adaptive systems, involve complex processes of interaction." (p. 33).

Assumption 3: The parenting needs of absent fathers may be different from those of resident fathers.

For the purposes of this study, a father is a male, living in the home with the child and who has assumed the role of father. It is also assumed that the father reads and understands English. For the purposes of this study a family is considered a father, mother, and at least one child.

THEORETICAL BASE

Life consists of a series of developmental changes, both anticipated and unexpected. In an attempt to deal with these changes adaptation, effective or ineffective, takes place. The diagnosis of a long term illness within a family is disruptive of the family process of orderly change and development. When that illness becomes a chronic condition, the impact on the family and each of its members is immense. To study the subject of children with chronic conditions and their impact on fathering, a theoretical framework is needed.

The framework for this study evolved from two theoretical models. The two models are the human ecological model of Urie Bronfenbrenner and the nursing model developed by Sister Callista Roy. The nursing model fits within the human ecology model.

CONCEPTUAL MODEL

Development and Adaptation

The emphasis of the Bronfenbrenner model is human development across the life span, while Roy looks at the world of human change and human environmental interaction as a process of adaptation. Both models include the active involvement of the human during change (Bronfenbrenner, 1979, 1993, 1995, 1995a; Bronfenbrenner & Ceci, 1994; Roy & Roberts, 1981; Roy, 1984; Roy & Andrews, 1999). In Bronfenbrenner's model, the setting most conducive to development for an individual is

one that fosters the growth of mutual trust, positive orientation, goal consensus, and an evolving balance of power in the direction of the developing person. These characteristics of reciprocity, trust, and evolving balance of power, termed *proximal processes,* lead to increasingly complex behaviors that endure over time and into new situations, *molar activities* (Bronfenbrenner, 1995). Bronfenbrenner's concepts of resilience, transforming incidents, turning points, and *molar activities* fit well with Roy's concept of adaptation.

Roy (1981) defines adaptation as patterns of behaviors that occur at the times of expected and unexpected change in the environment. She looks at patterns of behaviors that endure over time and place and defines an *adaptive response* as one that promotes integrity. This integrity is demonstrated in terms of the goals of survival, growth, reproduction, and mastery. Roy's theory describes the process by which input into the system creates changes in behavior patterns. These *internal* and *external stimuli* are processed by the *regulator* and *cognator* subsystems resulting in the responses by which adaptation occurs. Both models are based on systems theory in which input comes into the system, is regulated by some form of control mechanism and produces output, which in turn is utilized as input via a feedback loop.

Person-Context-Process-Time Model

Person. The developing person and the adaptive system are basically the same. Roy (1984) states that the individual is always viewed in interaction with others. Bronfenbrenner (1979) uses the dyad as his basic unit of analysis and examines the impact of the environment on the development of the individual. There is strong reciprocal effect of both the environment and the developing person. Both models clearly

include the environment. The differences lie in the nesting of the dyad within the environment that is the hallmark of the Bronfenbrenner model and the stimuli

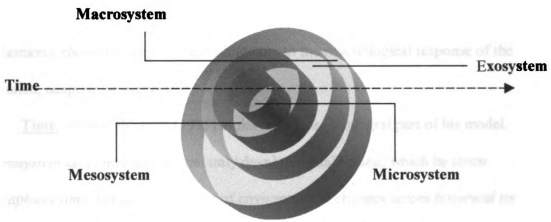

Figure 1. Bronfenbrenner Nested Ecological Model

Roy looks at within the environment and the immediacy of their impact on the person. Bronfenbrenner uses the terms micro-, meso-, exo-, and macrosystems to delineate the sources of stimuli (see Figure 1).

Context. Both Bronfenbrenner and Roy recognize the impact of nature and nurture on the ability of people to grow in positive ways. Roy's (1984) *focal*, *contextual*, and *residual stimuli* are delineated by the responses demanded by their presence in the environment. This input triggers coping mechanisms that cause effector responses and produce output.

Process. The process-time portion of the Bronfenbrenner Ecological Model demonstrates the similarity between the focal stimuli and the proximal processes as input that evoke adaptive or developmental responses. Bronfenbrenner (1979) focuses upon the links in the process through which transitions occur. The regulator subsystem processes stimuli resulting in physiologic responses.

The *cognator subsystem* delineates the psychological responses to internal and external stimuli. These processes activate four areas of response; perceptual/information processing, learning, judgment, and emotion. All of these processes lead to a psychomotor choice of response and ultimately to the psychological response of the individual, adaptive or ineffective.

Time. Bronfenbrenner (1995) looks at *time* as an integral part of his model. His *chronosystem* takes into account not only developmental timing, which he terms *biographical time*, but also the impact of environmental changes across *historical time* (see Figure 2). Bronfenbrenner maintains that the timing of events is more important to

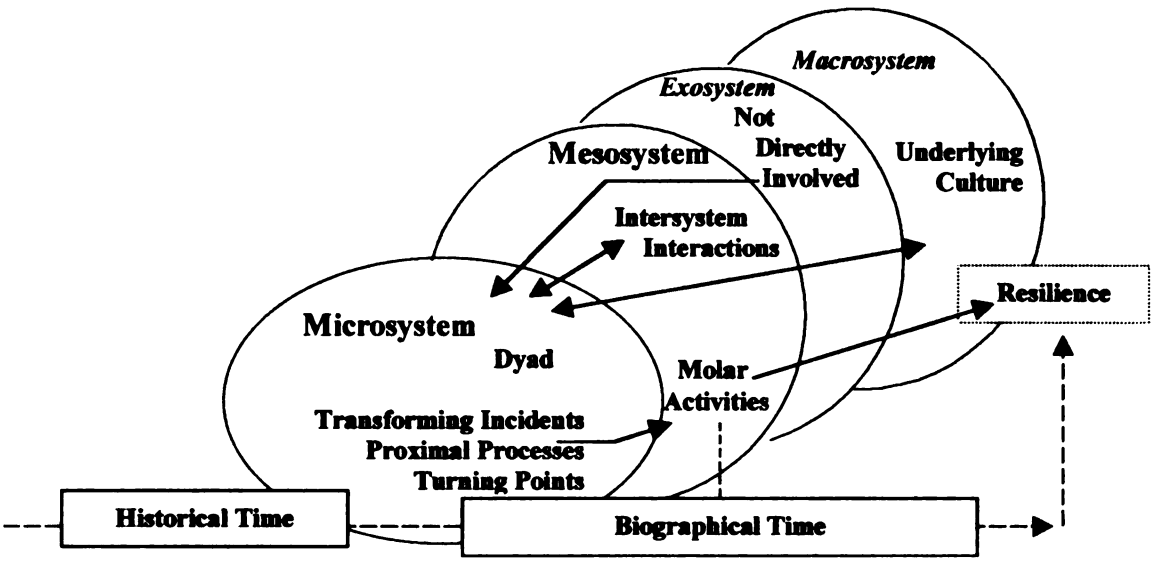

Figure 2: Bronfenbrenner's Process Model

the development of the individual than the actual occurrence of the event itself. Roy (1984), on the other hand, mentions time when discussing the long and short-term goals of *instrumental* and *expressive* behaviors and the effects of interactions.

Combined Models

In examining the two models, I found that the Roy model belonged primarily in the microsystem, between the proximal processes, transforming incidents and turning points (the inputs to the system), and the mesosystem activities (the outputs). Anticipatory guidance was a natural outcome related to the acceptance of the father role (see Figure 3). The other factors, the school in the exosystem and the father's belief in the community and in the future within the macrosystem support and broaden the model. The time element increases the breadth of the concepts and assists in clearly delineating the context in which the changes are occurring. The long-term adaptive/developmental responses are the same as in the separate models with future fathering behaviors as the ultimate goal.

The Roy model elucidates an area in the larger Bronfenbrenner model. This is the area of human behaviors within the microsystem that explains the processes by which adaptation occurs. The Bronfenbrenner model expands the Roy model into the broader ecological perspective.

Figure 3. Combined Models

SIGNIFICANCE OF PROBLEM

Because the illness of one family member impacts the function of the entire family system, it would be helpful to understand not only the needs of the mothers and siblings of children with chronic conditions, but also the needs of the fathers of these children. The microsystem is composed of all of these family members and the functioning of the microsystem reflects the interaction of the various dyads within the system. Therefore, the interdependent relationships within the system as well as the functioning of each member are important.

Holaday (1984) looked at the coping strategies of parents of children with chronic conditions. She identified three primary positive coping strategies, 1) assigning meaning to the illness, 2) normalization, and 3) social support. She noted that parents who assigned meaning to the illness were informed about the child's illness, confident in their ability to care for the child appropriately and maintained active life styles. Normalization is needed to decrease the ill child's vulnerability to stress and by doing so "minimizes the impact of chronic illness by maximizing the child's ability" (p. 366). Through social support "the family accumulates successful ways of problem solving over time and tends to view the environment as masterable" (p. 367).

Research has found that the adaptation of the child with cancer is favorably related to parental distress levels and the social support available to them (Koocher, 1986). Results from the Cohen, Friedrich, Jaworski, Copeland, and Pendergrass (1994) study on sibling adjustment stress the need to examine the child in a variety of ecological contexts including parental and family functioning. Cox's (1990) study, on coping with

pediatric cancer treatment, draws attention to the importance of the role of the parent-child relationship in stressful situations. None of these studies, however, discusses fathers or addresses their needs specifically.

Winkel (1988) noted that younger parents of children with juvenile rheumatoid arthritis appeared to need more support and information about the disease than older parents did. Newacheck, McManus, and Fox (1991) report that adolescents with chronic conditions, including arthritis, experienced 35% more behavioral problems than adolescents without chronic conditions.

Newacheck and Taylor (1992) report a "sevenfold increase in survival to age 21 among children with cystic fibrosis" (p. 364). Venters' (1981) findings supported two areas of particularly stressful events for parents of children with cystic fibrosis. The first stress was the time during which symptoms first appeared and were recognized and the time during which the actual diagnosis was made. The second was the inability of the family to anticipate the severity of the child's illness after the diagnosis was made. Over time, differing degrees of family tension occurred dependent upon remissions and exacerbations of the disease process.

CHAPTER II

REVIEW OF LITERATURE

Copious literature is available on the impact of parenting on children and their development. There is also a body of literature on the impact of children on the marital dyad. Literature was reviewed that examined the impact of various factors on families and parenting in general, on parenting of children with chronic conditions; its impact on mothers and siblings of these children, and on fathering and fathering of children with chronic conditions.

Many factors influence parents' approaches to parenting; "it stands to reason that our understanding of parenting behavior will be enhanced if we consider the combined influence of several factors rather than thinking about each factor singly" (Luster and Okagaki, 1993, p. 227). In order to understand parental behavior, it is important to understand the relationship between the characteristics of both the parent and the context over time (Luster and Okagaki). Belsky (1984) discusses the various factors that influence how individuals parent. These factors are delineated in his determinants of parenting model, and include the parent's developmental history, personality, work, marital relationship, and social network as well as the child's characteristics and development. A major macrolevel influence on human development is socioeconomic status (SES).

Influence of Socioeconomic Status on Parenting

Socioeconomic status indicates not only how much money or education someone has, but also the types of experiences and opportunities to which the individual has access (Okagaki and Johnson Divecha, 1993). Kohn (as cited in Okagaki and Johnson Divecha) found that parents from different social classes differ in their parenting practices because they hold different values for their children, and these values resulted from social class differences.

Work shapes parents' conceptualizations of how their environment operates and the qualities required to be successful in that environment (Ogbu as cited in Okagaki and Johnson Divecha, 1993). This in turn shapes parents' values about the characteristics that are important to the success of their young (Crouter and McHale, 1993). Opportunities in the work place vary in their support of positive parenting behaviors. This may be through skill acquisition, informal support or formal benefits and programs that enable parents to carry out their parenting roles more effectively.

Kohn (as cited in Okagaki & Johnson Divecha, 1993) argues that men see the world differently depending on their position in the occupational hierarchy. The characteristics important to attaining success in their jobs influence the qualities they value and want for their children. This in turn influences the characteristics they will support or discourage in their children. Social networks also influence parenting behaviors.

Glennon (1995) views the role of the father as protector, communicator, and breadwinner. He views the influences on the fathering role as the father's own growth and development, his desire to find his own father, and the timing of his fatherhood.

Belsky (1984) writes of multiple influences on a father's fathering style. These include the child's individual characteristics, the father's personality and psychological well being, and the contextual sources of support and stress he experiences. He goes on to state that a father's social system will enhance his fathering behavior when it provides emotional support, instrumental assistance, and guidelines for social expectations.

Social Networks for Parents

Personal networks influence the family and individual by bringing the values of society into the home (Cochran, 1993). In this way, a parent's network reflects his or her standing in society. Therefore, it is important to understand that the influence of the parents' networks on their parenting attitudes and behaviors reflects their positions in the social structure and its impact. Unlike social support, network relations can be both supportive and stressful and their influence is very broad. Because personal networks are influenced by the larger society, sociologists believe that family income, the educational level of parents, and the status and complexity of their occupations, to a large extent determine the family's social class standing. Cochran states "of these factors, Fischer found that educational level had the most consistent effect upon the personal networks" (p. 155). The preferred explanation is that with more *education* and greater income, individuals obtain social skills and material resources that can be used to build and maintain network ties. Culture and class also influence the size of social networks (Cochran). There has been some specific attention given to fathering.

Fathering

In an article in The New York Times (August 11, 1998), Elizabeth McGuire writes about the search by women in their twenties for men who are willing to balance

careers and family involvement. She states that there is a long way to go within corporate America to structure workplaces that are family friendly. She continues that "instead of the traditional corporate ladder, which emphasizes stamina, we must seek a model of career progress that resembles mountain climbing, which requires flexibility, lateral moves and lengthy rest at base camp" (p. A20).

In a 1996 Gallup Poll conducted by the National Center for Fathering, 61.1% of the fathers interviewed reported that they would be more productive at work if their employers implemented more family-friendly policies. The poll also showed that 90.3% of the men and women interviewed agreed that "fathers make unique contributions to their children's lives." However, they needed to increase their knowledge and skills.

Snarey (1993) studied fathers and found that they have a clear influence on their children's development. This was evident in the areas of intellectual competence, social-emotional competence, and nontraditional continuities. Coltrane (1996) states that the division of housework in a family reflects family values and that responsibility for childcare and housework go hand in hand. Social, friendship, occupational, and kin networks all influence the division of paid and family labor.

Nelms (1997) stated that fathers encourage exploration, provide safe places to make mistakes, and expect good work in school. All of these factors "foster better problem-solving abilities and cognitive development" (p. 154). Fathers are also important as role models for both their sons and daughters and help form their children's gender identities.

Belsky, Gilstrap, and Rovine (1984) found that while through the first nine months of life mothers and fathers treat their *male* and *female* offspring alike, there was a

much greater difference in the behaviors of fathers in respect to the child's *birth order*, than the behaviors of mothers. "Although fathers are as capable as mothers of being highly involved with and sensitive to their infants...under naturalistic, everyday conditions, the behavior of mothers and fathers is strikingly different" (p. 701). Fathers are much less involved. In Volling and Belsky's work (1992) they cited MacDonald and Parke's finding that "whereas mothers' verbal stimulation is correlated with sons' peer popularity, fathers' physically playful, affectionate, and socially engaging interaction is predictive of boys' popularity with peers" (p. 1210). They also stated that facilitative and affectionate fathering behaviors appear to promote a prosocial and friendly relationship among siblings.

Age of Child

Easterbrooks and Goldberg (1984) studied the associations between characteristics of fathering and toddler development. In looking at 75 toddlers and their parents they found that high father involvement related to optimal toddler development. Father involvement contributed uniquely to child development and also was seen in mother child interactions as well. They found that the father's involvement was associated with children's problem-solving behavior more strongly than attachment and that the amount of time they spent with the child was more influential in the child's development than taking on caregiving responsibilities. For fathers, behavioral sensitivity, and a relaxed manner were most consistently related to optimal toddler development. They confirmed in the child-father relationship that children who were securely attached to their fathers also exhibited more positive affect and orientation in problem solving. There was a trend for "...fathers to spend more time with their toddler

sons than daughters. Both qualitative and quantitative aspects of fathering were more strongly related to toddler development for boys than for girls" (p. 751).

Sex of Child

Biddulph (1998) also declares differences between raising boys and raising girls. He states that boys need a great deal of affection during the years from birth to six. However, from six to 14 they become very interested in "maleness," and the father becomes the dominant parent. Most boys love to be physically active, hug and play wrestle with their fathers. They enjoy stories about his life. They like to meet his friends and see what he does for a living. They love to have him teach them things. By copying their fathers, boys learn how to show their emotions and attitudes in a healthy way. Rough and tumble games teach boys "self control by stopping and setting some rules when the game gets too rough" (p. 95). Fathers also need to teach their sons to respect their mothers and to respect themselves.

In Cherishing our Daughters (Bassoff, 1998) the author discusses the impact of fathers on their daughters' development. She states "It is from her mother that a girl learns to be a woman; it is from her father that she learns what to expect from men in the way of love and respect" (p. 30). The differences in mothers' and fathers' care are most evident in physical contact, play, discipline, and communication. From her father she also learns "focus, determination, direction, assertiveness, ambition, and adventurousness" (p. 31). This combination of characteristics moves a girl toward a mature, balanced, and flexible personality. Fathers, however, frequently see themselves as outsiders. The son will develop in ways that are familiar, whereas the daughter is growing in unfamiliar ways. This can cause feelings of insecurity in the father. The role

of the father today is trailblazer and protector. During her teenage years, he is also the affirmer of his daughter's femininity in a non-sexual way by taking her seriously as a person (Bassoff).

When daughters become adolescents, their relationships with their fathers change. According to Adams (1999), fathers often feel alienated from their teenage daughters. She states that fathers need to offer acceptance and encouragement to their daughters. She encourages fathers to connect with their daughters on a "one-on-one" basis, tuning in to not only what their daughters are saying but to the emotions behind the words.

Families of Children with Chronic Conditions

Few children are not vulnerable to risk of psychological injury at one time or another. According to research most children can cope with one or two risk factors. But the accumulation of risk factors jeopardizes development; especially when there are no compensatory forces at work. By preventing the further accumulation of risk we can endeavor to prevent the precipitation of developmental damage (Garbarino and Abramowitz, 1992).

Often times, a family of a child with a chronic condition faces situations that have no ready-made solutions. This can be so disruptive to family routines that the family may be at a loss as to where to begin and, dependent on the parents' sense of competence, they may feel incapable of improving the situation (Patterson and McCubbin, 1983).

Parents of Children with Juvenile Rheumatoid Arthritis

Winkel (1988) studied 118 parents of children with juvenile rheumatoid arthritis (JRA) to determine their needs. Out of these parents, 37% indicated a desire to join a support group. Travel time, distance, the child's state of remission, and finances were

considerations in making the decision. Younger parents and mothers of children with JRA were more likely to express a desire to participate in a support group. No literature was found that addressed the issues of fathers relative to other family members or the child with JRA exclusively.

Mothers of Children with Chronic Conditions

While the family unit is typically acknowledged, much of the early literature on parents' responses to their children's illnesses has studied mothers. McCollum and Gibson (1970) studied 56 families of children with cystic fibrosis. Mothers reported many negative feelings toward themselves and their infants before diagnosis related to feeding problems and failure of the infant to thrive. Among other negative feelings post diagnosis, intense grief, guilt, resentment, anger, anxiety and helplessness were also reported. Chodoff, Friedman, and Hamburg (1964) reported that mothers of children with malignant disease searched for meaning, blamed themselves or others for the child's illness, or found religious significance in the event. Binger, Ablin, Feuerstein, Kushner, Zoger, and Melkelson (1969) reported mothers feeling physical distress, depression, inability to function, anger, hostility, and self blame gradually subsiding to acceptance and resolution in meeting the special needs of the child with cancer.

Siblings of Children with Cancer

Numerous studies have been done on the effects of childhood cancer on the siblings of the ill child. High levels of family cohesion and adaptability were associated with better adaptation for siblings (Cohen, Friedrich, Jaworski, Copeland, and Pendergrass, 1994). Eight major sources of anxiety and isolation were identified by Bendor (1990) related to the siblings of children with cancer. McKeon (1987) looked at

the tension between the conflict and harmony that exists between siblings. She stated that parental influence provided the support and influence that facilitated sibling interaction. Variables influencing the dynamics of the relationship included sibling contextual variables, parental contextual variables, family contextual variables, and sociocultural variables. Bush (1987) studied the factors that contribute to good versus poor adaptation in healthy siblings of pediatric cancer patients. Significant relationships were found between anxiety and perceived siblings' similarity, family cohesion, and family expression. A study of the specific factors in the individual personality, family environment, and external family support system, which may influence the healthy sibling's adaptation in relationship to the child with cancer, revealed some important trends. These included the sibling's perceptions of self worth, family cohesion, family communication and the parents' perception of the sibling's activity level as possible indicators of positive or negative adaptive sibling responses (Asada, 1987).

Fathering Children with Chronic Conditions

In a study of fathers of children born with congenital anomalies, Baumann and Braddick (1999) found that fathering, for the participants in the study, was "a desire to grasp the situation, mingled with disturbing feelings, while facing one's own limits" (p. 373). The fathers reported that their major feelings were worry and a sense of responsibility. They perceived their importance to their wives and children increased; as the need for income and medical benefits increased they became more internally and family focused. The fathers felt their children were vulnerable and that they needed to be more circumspect about their situation. In some instances, having a child with special needs had strengthened their marriages. The fathers also reported that they were more

present oriented than they had previously been. "They wondered what challenge each day would bring or if their child would survive" (p. 276). Many of the fathers in the study reported the importance of receiving information from health professionals and self-help groups.

In Sabbeth's (1984) study of parents with chronically ill children, fathers had special difficulty in dealing with the lack of control imposed by the illness resulting in feelings of helplessness. She found that men, accustomed to actively working to achieve, tended to hide their feelings and vulnerabilities. This contributed to a sense of isolation. McCubbin, McCubbin, Patterson, Cauble, Wilson, and Warwick's (1983) study of families of children with cystic fibrosis, cerebral palsy, and myelomeningocele compared mothers' and fathers' responses. This study showed those fathers' use of coping patterns was different and complimentary to the mothers' in supporting the system-maintenance dimensions of family life. These findings support that fathers have unique needs within the family system that may not be addressed by current support systems. Moyer (1989) interviewed 160 parents of children with diabetes. Although the parents felt they were dealing with the care of the child related to the disease process, many had "immediate and ongoing needs for information, support, and help with several aspects of their child's care and development regardless of the age of the child or the duration of the condition" (p. 543).

Fathering Children with Cystic Fibrosis

In another study, McCubbin (1984) indicated positive correlations between family income and "the father's effort to maintain family integration, cooperation, and an optimistic definition of the situation" and between family income and the age of the child

related to "the father's attempts to understand the health care situation through communication with other parents and consultation with the health care team" (p. 413). Venters (1981) reported a need to reorganize home routines around the needs of the child with cystic fibrosis. These families also incurred unexpected expenses for medical care and equipment that was needed in the home to care for the child. She found that both "endowing the illness with meaning" and "sharing the burdens of the illness" were significantly related to long term positive family adaptation (p. 292). I found no other literature specific to fathers of children with cystic fibrosis.

Fathering Children with Cancer

Only three studies were found that specifically addressed the needs and concerns of fathers of children with cancer. The author (1991) found that there were significant differences in the satisfaction with employment status for mothers and fathers while satisfaction with the spousal relationship was significantly related to mothers' responses but not to fathers'. Cayse (1994) studied 23 fathers of children with cancer and found their most common concern was their "child's future". The most common and most helpful coping strategy for these fathers was "praying". Sterken's study (1996) of fathers of children with cancer identified several issues. These include feelings of exclusion by the medical team as active participants in the child's care, lack of first hand information on the child's treatment, and follow-up care. They also expressed the need for restructuring of socialized masculine ideals, roles, and thought patterns, the need to regularly voice their concerns, and the need to feel that their opinions and questions were valued.

Coping of Families of Children with Chronic Conditions

The National Commission on Children reported that important characteristics of many strong families include "the ability to adapt to and cope with stressful and potentially damaging events, as well as predictable life cycle changes" (as cited in Garbarino, 1992, p. 80). Part of this adaptability comes from the family's social network including friends, extended family, neighbors, and community organizations.

Help can come from professionals or lay people (Garbarino, 1983). Garbarino goes on to state that

> rather than looking to the individual, those working within this framework look to the collective – to the social network, to the extended family, to the group. Proponents of this approach see that social resources can compensate for individual inadequacies and provide buoyancy so that individuals need not sink even if they do not know how to swim. What is more, those who emphasize social resources argue that no one can master the heaviest seas of life alone and that even those with normally adequate levels of personal resources may need to be thrown a lifeline or even a life raft in time of extraordinary stress (p. 20).

The result is a joint product containing both personal and social resources. This help consists of the resources the individual brings to the situation and the resources available in the social environment. The goal of professionals is to promote successful coping and assist individuals in converting these stresses into growth-inducing challenges (Garbarino).

Coping competencies are a mixture of learning (experience) and innate capacity (temperament) and must be translated into specific behaviors appropriate to each situation. Individuals bring their effective or ineffective coping behaviors with them to each new situation, and these experiences have a cumulative effect. These cumulative experiences are important in differentiating among individuals and between groups, and

they are important in determining the level of social resources available from a group to its members (Garbarino, 1983).

"This brief summary of findings regarding parental coping emphasizes that parents employ active efforts to manage the stress and hardships associated with having a chronically ill child, while at the same time coping with other normative life changes and sources of stress in the family" (Patterson and McCubbin, 1983, p. 34). Both negative and positive consequences are possible for overall family functioning. Through effective adaptation, physical, emotional, and social growth and development of all family members, including the chronically ill child, can occur. Because of the physical and emotional demands placed on parents of children with chronic conditions, it is important for parents to balance this childcare with care for themselves as individuals and for the family as a whole. The father's role and his coping efforts in maintaining family organization, reducing conflict, and promoting the child's health are important. Patterson and McCubbin further state "Being aware that certain predictable patterns emerge over time within families with a chronically ill child is the first step in lessening the stressful consequences" (Patterson and McCubbin, p. 34).

CHAPTER III

METHOD

Their physical and psychological status and the surrounding environment affect development in children. Development can be delayed, altered, or unchanged by a chronic condition or its treatment. Parents are critical components in a child's development. Culture, social status, and family resilience must also be considered.

Many studies have been published utilizing mothers of children with chronic conditions as subjects when examining parenting needs. There are very few studies available that examine fathers' needs related to parenting children with chronic conditions. Since the interactions between members of the entire family are important, it is of interest to investigate the needs of fathers parenting children with chronic conditions and to compare them to the needs of fathers parenting well children.

Fathers of 48 children with chronic conditions; cancer, cystic fibrosis, and juvenile rheumatoid arthritis, were compared with 51 fathers of children without chronic conditions in respect to their 1) concerns about themselves, their spouses or partners, their children; 2) beliefs and feelings regarding caring for their children, and 3) coping strategies and their helpfulness. An exploratory, cross sectional, non-experimental research design was used. Fathers responded to questionnaires in their homes.

The sample was taken from parent lists of children seen in the immunology, oncology, and pulmonary clinics and by private pediatricians in the general medical

clinic at Children's Hospital of Michigan. There were 48 fathers parenting children with chronic conditions and 51 fathers parenting well children. This number was chosen to provide an analytical power of .8 and medium effect size.

Sampling Procedures

The names of these fathers were taken from lists provided by the social workers in the Hematology/Oncology Clinic who indicated which families had fathers living in the homes of the oncology patients they were covering. This included all the families meeting the criteria and currently seen in the clinic. Forty-four fathers were identified and of these, 17 responded and 16 were included in the sample (see Table 1).

Table 1. Group Frequencies

Group	Frequency
Chronic Conditions	
Cystic Fibrosis	16 (33.3%)
Cancer	18 (37.5%)
Juvenile Rheumatoid Arthritis	14 (29.2%)
Total	48
Well	51

The fathers of children with cystic fibrosis also comprised the convenience sample chosen from the pediatric population of the Pulmonary Clinic. The fathers were identified by chart audit and 36 were sent letters of information and questionnaires. Of these, 20 questionnaires were completed and returned and 18 were appropriate for use in the study.

The fathers of the children with juvenile rheumatoid arthritis were chosen from the Immunology Clinic population of the same urban medical center. Thirty packets containing informational letters and questionnaires were given to the senior attending

physician responsible for the clinic. She then distributed them to the families she determined met the study criteria. Of these thirty, 14 responded and were included in the study.

A convenience sample of the fathers of the well children was selected from the General Pediatric Clinic's private practice population of the same urban medical center by chart audit. Forty packets were sent out to fathers with a return of six completed questionnaires. Because of the low response rate in this group, fathers in the community were also solicited by the researcher and packets distributed. Of the total number of 102 fathers of well children receiving packets, 52 completed questionnaires were returned and 51 were included in the study.

The fathers of children with chronic conditions ranged in age from 20 to 69 and the fathers of well children ranged in age from 20 to 59 (see Table 2). The mean ages in both groups were 30 to 39 years. The family incomes in the chronic condition group ranged from $14,000 to greater than $50,000 with a mean of $40,000 to $49,000 and a standard deviation of 1.13. In the well group the range was from $30,000 to greater than $50,000 with a mean of $40,000 to $49,000 and a standard deviation of .48.

The educational range for the fathers in the fathers of children with chronic conditions group was from less than seventh grade to graduate school with a mean of 2.73 years of college. In the fathers of well children group the fathers' education ranged from tenth grade to graduate level with a mean of 3.02 years of college.

Table 2. Sample Demographics

Demographic	Families of Children with Chronic Conditions		Families of Well Children	
Income M	$40,000 - $49,000		$40,000 - $49,000	
SD	1.13		.48	
Range	$14,000 - $50,000		$30,000 - $50,000	
	Fathers	Mothers	Fathers	Mothers
Age: 20 – 29 years	2 (4.2%)	2 (4.2%)	3 (5.9%)	8 (15.7%)
30 – 39 years	15 (31.2%)	20 (41.7%)	22 (43.1%)	21 (41.2%)
40 – 49 years	23 (47.9%)	22 (45.8%)	18 (35.3%)	20 (39.2%)
50 – 59 years	6 (12.5%)	3 (6.3%)	8 (15.7%)	2 (3.9%)
60 – 69 years	2 (4.2%)	1 (2.1%)		
Family Income:				
$14,000-$19,999	1 (2.1%)			
$20,000-$29,999	3 (6.2%)			
$30,000-$39,999	9 (18.8%)		2 (3.9%)	
$40,000-$49,999	6 (12.5%)		5 (9.8%)	
$50,000 or more	24 (50.0%)		43 (84.3%)	
Education:				
7th Grade or <	1 (2.1%)	1 (2.1%)		
10th or 11th Grade		2 (4.2%)	1 (2.0%)	
12th Grade	1 (2.1%)	13 (27.1%)	8 (15.7%)	4 (8.0%)
College	28 (58.3%)	25 (52.1%)	31 (60.8%)	32 (64%)
Graduate School	12 (25.0%)	7 (14.6%)	13 (25.5%)	14 (28.0%)
Ethnic Background				
Asian		1 (2.1%)	1 (2.0%)	2 (4.0%)
Black	4 (8.5%)	4 (8.5%)	6 (12.0%)	6 (12.1%)
White	41 (87.2%)	40 (85.1%)	42 (84.0%)	39 (78%)
Hispanic				1 (2.0%)
Native American	1 (2.1%)			1 (2.0%)
Other	1 (2.1%)	2 (4.2%)	1 (2.0%)	1 (2.0%)

Information was also gathered concerning the fathers' spouses. The majority of wives were between the ages of 30 and 49 years. The age span for the wives of fathers of children with chronic conditions ranged from 20 to 69 years while the age range for wives of fathers of well children was slightly lower, 20 to 59 years. Three (6.3%) of the wives of fathers of children with chronic conditions had less than a high school education, while the majority, (52.1%) had a year or more of college education (M 2.37, SD 1.16) and seven (14.6 %) attended graduate school.

Fathers reported the health status of themselves and their spouses, as well as that of their children (see Table 3). Two fathers in each group rated their own health as poor to fair and five (10.4%) fathers of children with chronic conditions rated their wives' health as poor to fair also. The majority of fathers in both groups rated their health and their wives' health as good to very good. Excellent health was reported by 6 (12.5%) fathers of children with chronic conditions and by 10 (19.6%) fathers of well children. They also reported their wives' health as excellent (10.4% and 27.5%).

In the fathers of well children group, 32 (64%) of the wives had at least one year of college (M 3.02, SD 1.26) and twice the number of wives (14, 28%) had attended graduate school as in the fathers of children with chronic conditions group. The ethnicity of the two groups was very similar for both parents.

Although only two percent of the children in the chronic conditions group were considered to be in excellent health, 19 (41.3%) were thought to be in very good health, and another 17 (37%) in good health. Only eight (17.4%) were labeled as having poor health in this group. In the well group, 24 children (48%) were considered to be in excellent health, while 22 (44%) were thought to be in very good health, and 4 (8%) in

Table 3. Family Health

Health Status Past Three Months	Fathers of Children with Chronic Conditions	Fathers of Well Children
Fathers: Poor/Fair	2 (4.2%)	2 (3.9%)
Good	21 (43.8%)	16 (31.4%)
Very Good	19 (39.6%)	23 (45.1%)
Excellent	6 (12.5%)	10 (19.6%)
Mothers: Poor/Fair	5 (10.4%)	
Good	25 (52.1%)	16 (31.4%)
Very Good	13 (27.1%)	21 (41.2%)
Excellent	5 (10.4%)	14 (27.5%)
Children: Poor/Fair	8 (17.4%)	
Good	17 (37.0%)	4 (8.0%)
Very Good	19 (41.3%)	22 (44.0%)
Excellent	2 (4.3%)	24 (48.0%)
Child Care		
Someone to take care:		
For a day	37 (78.7%)	43 (84.3%)
For a week	21 (44.7%)	40 (78.4%)

good health. None of the children in the well group were labeled as having poor health.

Instrumentation

The Hymovich Family Perception Inventory (FPI) was employed for data collection for this study. The Hymovich instrument contains nine scales, eight that can be used independently or together as applicable (see Appendix A). For the purposes of this study all nine scales were used. There was a total of 165 items on the questionnaire and an additional 36 questions concerning subject, child, and spouse demographics. Likert scales were used in each scale to rate the fathers' answers. The average reading level of all scales in the FPI is grade 6.4. The highest reading level is grade 7.1 for the scale on beliefs and feelings; the lowest reading level is grade 5.8 for the coping scale.

Testing of its content validity, reliability, and comprehensibility has been ongoing since development of the original instrument, The Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI: PQ). The current instrument, the FPI, is a revision of this original questionnaire. The most recent internal consistency figures of the FPI are generally high with the majority of the alpha reliabilities ranging from .95 to .73. However, the belief scale reliability alpha, which is .59, is low and Dr. Hymovich states that "this scale has always been low and should be used with caution" (see Appendix B).

The original questionnaire consisted of 500 closed-ended questions developed from analyses of interviews of families with osteogenesis imperfecta, cystic fibrosis, and juvenile diabetes mellitus. The pilot study was then run with a sample consisting of 29 parents attending a variety of clinics in a university hospital (Hymovich, 1981). The second pilot study with a sample of 33 parents with demographics similar to the first group utilized the revised CICI: PQ. The reliability coefficients ranged from .76 to .92. The third pilot study utilized the new version of the CICI: PQ. This was a sample of 44 parents, visiting the university clinics previously utilized. The reliabilities for this study ranged from .79 to.94 with an overall reliability of .95 (Hymovich, 1984). Three revisions were made to reduce redundancy and eliminate questions specific to certain conditions and age groups.

The content validity was established through review by a clinical psychologist, three master's prepared registered nurses working with families of children with chronic conditions and one doctorally prepared nurse faculty member working with chronically ill adults. Internal consistency, using Hoyt's coefficient demonstrated reliabilities in the mid nineties. (Hymovich, 1983). A British study by Moyer (1989) utilized the revised

CICI: PQ in which 160 parents of 10- to 18-year olds with diabetes were interviewed. She reported only the reliability of the parents' concerns scale, which was coefficient alpha .87. The author (1991) utilized the third revision of the CICI: PQ, renamed the Parent Perception Inventory (PPI), in a study of 22 parents of children with cancer. The reliability of the scales ranged from an alpha of .94 for the feelings scale to .62 for the beliefs scale. Utilizing all but the siblings and spouse concerns and coping scales, Cayse (1994) found the internal consistency reliability of the PPI to range from .33 to .92 and the test-retest reliability coefficient to range form .74 to .92. "The internal consistency reliability for each section used was 'concerns,' .88; 'coping,' .62; and 'helpfulness of coping,' .80. For this study, the internal consistency estimate for each section was 'concerns,' .91; 'coping,' .82; and 'helpfulness of coping,' .64" (p. 104).

Fathers' concerns regarding themselves in relation to other family members were measured by asking them to indicate on a five point Likert scale how much concern they have had in the last three months in certain defined areas. Questions were coded so that higher feelings of concern are reflected in a higher score. See Appendix A, Table 21 for sample questions.

Family care needs as perceived by the fathers were measured by a five point Likert scale that includes health, growth and development, and physical needs. Fathers' beliefs regarding factors influencing their way of living were measured by asking the fathers to indicate on a five point Likert scale their beliefs about things that influence their way of living in certain areas. Fathers' feelings regarding their families were measured by asking the fathers to indicate on a four point Likert scale certain defined

feelings that they have experienced in the past three months. Questions were coded so more positive beliefs and feelings are reflected in higher scores.

Fathers' coping strategies were measured by asking them to indicate on a four point Likert scale the coping strategies they have used in the past three months. On a companion four point Likert scale fathers were asked to indicate how helpful these coping strategies are for them. Questions were coded so that more positive and more helpful coping strategies are reflected in higher scores.

Fathers' concerns regarding their child(ren) were measured by asking them to indicate on a six point Likert scale how their child(ren) has/have been coping in certain defined areas in the past three months. Their perceptions regarding their spouses' concerns were measured by asking them to indicate on a four point Likert scale how much concern they think their spouses have had in certain defined areas in the last three months.

Fathers' perceptions of their spouses' coping related to family needs were measured by asking the fathers to indicate on a four point Likert scale their perceptions of their spouses' coping related to family needs. Questions were coded so that more positive coping strategies and greater concerns are reflected in higher scores.

To promote optimal development in the child and maintain family development, the parents must first come to terms with the chronic condition. When they are able to focus on the child rather than the disease, the parents are able to parent more effectively (Mearig, 1985). Parents must deal not only with the child's psychological and physical reaction to the disease and treatment, but with their own emotions and reactions as well. By using Hymovich's Family Perception Inventory it is possible to study the various

factors involved in this process and to describe them in detail. The current version of Dr. Hymovich's instrument allows exploration of parenting concerns, needs, beliefs, feelings, and coping for all fathers, those with well children and those with children with chronic conditions and for comparison of those needs. There is little information on the parenting needs of fathers of children with chronic conditions and it would be helpful to have a clearer idea of what those needs are and if they differ from those of fathers of well children. The FPI facilitates collection of this data for analysis.

Conceptual And Operational Definitions

Within the context of this study the following definitions will apply:

Control Variable.

Fathers is conceptually defined as the adult male in the home with the child who provides nurturance and paternal care.

Fathers is operationally defined as any adult male living in the home with the child who has taken on the fathering role.

Independent Variables.

Child is conceptually defined as a person between the ages of newborn to 18 years who lives at home with his/her parents.

Child with a Chronic Condition is operationally defined as a person between the ages of newborn and 18 years who has been diagnosed with cancer, cystic fibrosis, or juvenile rheumatoid arthritis for at least 3 months.

Well Child is operationally defined as a person within the ages of newborn and 18 years who has not been diagnosed with an illness of more than six months duration with permanent physical or mental limitations.

Dependent Variables.

Family Care Behaviors is conceptually defined as those behaviors that strive to accomplish desired goals within the family environment, as reflected in the balance between the various members' goals and activities, and those of the group and those behaviors necessary for successful coping within the family structure.

Family Care Behaviors is operationally defined as those behaviors identified in the **Family Care Needs, Father Coping**, and **Spouse Coping** scales of the Hymovich Family Perception Inventory (FPI).

Family care needs are conceptually defined as information necessary for a person to successfully provide family care. When a change in one family member occurs it stimulates change in the family as a whole and in each individual in the family.

Family care needs is operationally defined as the lack of information wanted or deemed necessary related to one's family care as measured by the FPI, including "physical care," "diet," and "development" of one's children.

Coping is conceptually defined as those behaviors and attitudes one adopts to meet the challenges of predictable and unpredictable family events. It is the ability to function in a manner that strives to accomplish desired goals and activities within the environment. The optimal health of the family is reflected in the balance between the various members' goals and activities, and those of the group.

Coping is operationally defined as those things a person does in order to make circumstances better or try to make one feel better as measured by the FPI, including "talking with someone about my feelings," "crying," and "busying myself".

Increased Energy Needs are conceptually defined as the physical energy increase that occurs when one is dealing with increased physical, emotional, and mental tasks.

Increased Energy Needs are operationally defined as those needs identified in the Father's and Spouse's **Concerns Scales** and the **Children Scale** of Hymovich's Family Perception Inventory (FPI).

Concerns are conceptually defined as those thoughts emanating from a perceived present or potential family dysfunction. They are the worry about a family member's current situation and its impact upon the individual and family system.

Concerns are operationally defined as those things that engage a person's attention, interest, or care, or that affect a person's welfare or happiness; a worry as measured by the FPI, such as "extra demands on my time," "feeling worn out," or "getting to do activities together as a family".

Bonding/Adoption of the Fathering Role is conceptually defined as the behaviors and perceptions the father has toward his children and their behavior, including his feelings and beliefs related to family functioning and the fathering role.

Bonding/Adoption of the Fathering Role is operationally defined as the attitudes, feelings and beliefs the father holds regarding his family as measured by the **Children**, **Feelings**, and **Beliefs Scales** of Hymovich's Family Perception Inventory (FPI).

Feelings are conceptually defined as the emotions within an individual family member and elicited within a family system that are separate from and independent of rational thought.

Feelings are operationally defined as emotions or emotional perceptions or attitudes as measured by the FPI, such as "anger," "confidence," or "anxiety".

Beliefs are conceptually defined as opinions or convictions, confidence in the truth or existence of something not immediately susceptible to rigorous proof.

Beliefs are operationally defined as truths about things that influence the way a person lives as measured by the FPI, for example, "sometimes getting away from something makes it easier to handle".

Feelings of Increased Social Support Needs is conceptually defined as those needs for emotional support, tangible assistance, cognitive information, and directive guidance that a father experiences within the family and childrearing context.

Feelings of Increased Social Support Needs is operationally defined as those needs measured by the **Family Resources Scale** of Hymovich's Family Perception Inventory.

Family Resources is conceptually defined as those supports available to the father in relationship to his fathering needs.

Family Resources is operationally defined as those measured by the **Family Resources Scale** on Hymovich's Family Perception Inventory (FPI), such as "clergy," "doctor," and "relative or spouse."

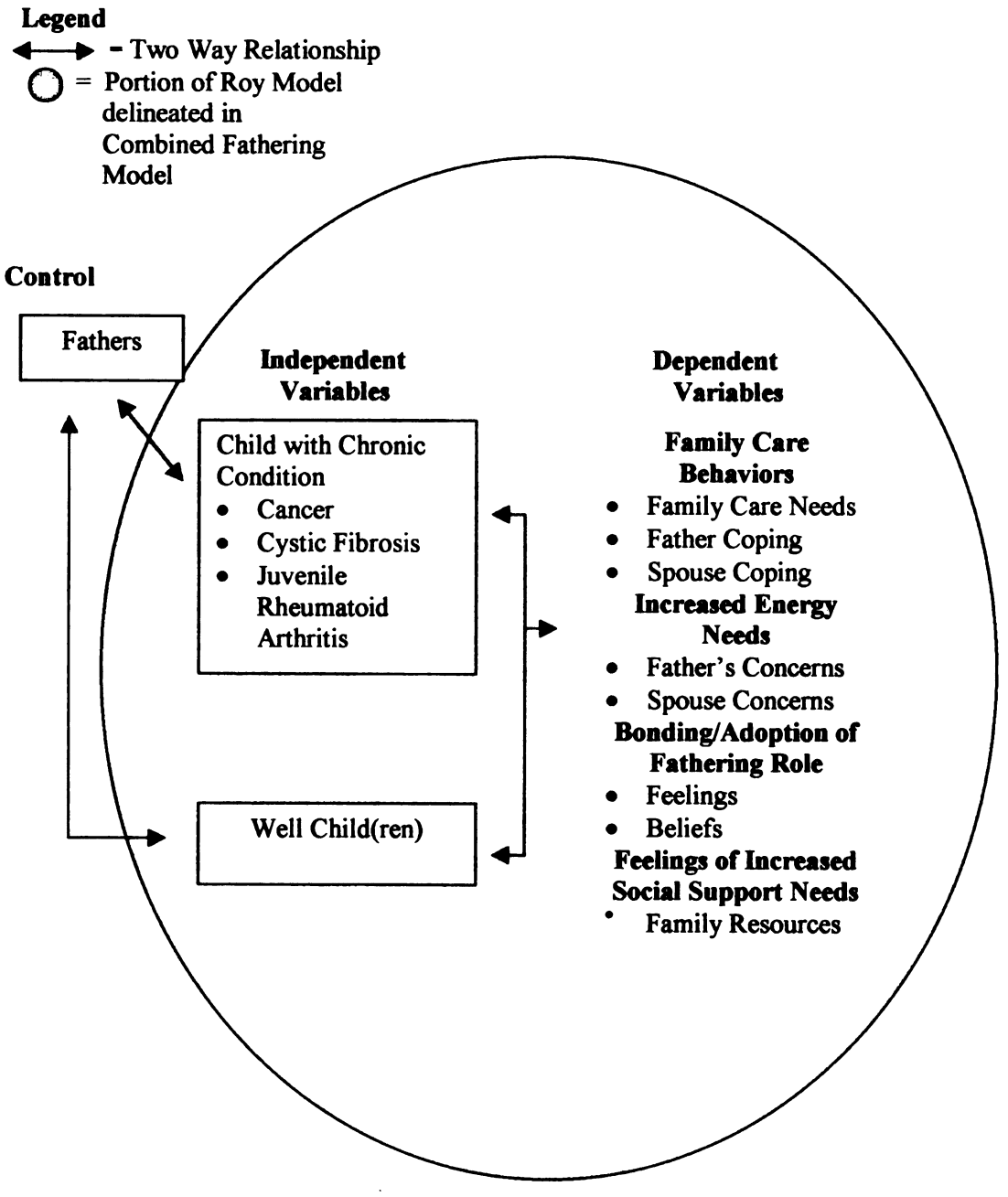

Figure 4: Operational Map

Data Collection Procedures

Permission to carry out the research was received from the Michigan State University Committee on Research Involving Human Subjects and the Wayne State University Human Investigation Committee. Liaison was established with the Nursing Researcher at Children's Hospital of Michigan and letters of permission were obtained from primary physicians in each of the clinics selected for data collection. These included the Hematology/Oncology Clinic, the Pulmonary Clinic, the Immunology Clinic, and the General Medical Clinic (see Appendix C).

The fathers of the oncology and cystic fibrosis patients, and the well children from the pediatric clinic were contacted by mail at their home addresses. Letters of explanation (see Appendix D) and questionnaires were sent in the fall of 1999. The fathers of the juvenile rheumatoid arthritis patients also received letters and questionnaires through their attending physician at this time. The fathers were instructed that the questionnaires would take about 30 minutes to complete and that it would be helpful if they could fill them out and return them within the next week. The subjects were also informed in the letters that the needs of fathers and the ways they view their needs are frequently different from others and that there were no wrong answers. The fathers were requested not to put their names anywhere on the questionnaires so that confidentiality could be maintained.

The questionnaires were assigned numbers according to the condition of the respondents' children, whether they were well, or had cancer, cystic fibrosis, or rheumatoid arthritis. Subjects were requested to return the questionnaires in the self-addressed, stamped envelopes provided after they had completed them. Follow-up

telephone calls were made to inquire about the status of the questionnaires. If the subject was still willing to participate, a new questionnaire was sent. A total of two follow-up calls at two-week intervals was made.

Thirty informational letters and questionnaires were given to the senior attending physician responsible for the Immunology Clinic. She then distributed them to the families she determined met the study criteria. Of these thirty, 14 responded and were included in the study.

Data were collected until 99 subjects meeting the criteria had responded, 48 from the fathers of chronic conditions group and 51 from the fathers of well children group. Data collection took approximately seven months.

Data Analysis

Descriptive statistics were used to provide information on the ages, incomes, ethnic backgrounds, and educational levels of the subjects and their spouses. The fathers' perceptions of their family members' health was also obtained including the time fathers spent caring for family health care needs and if resources were available to them for child care. Means, standard deviations, frequencies, and percentages were calculated for each scale and scale item related to fathers' concerns, perceptions of family care needs and spouses' needs, his childrearing beliefs and feelings, and his coping behaviors. Comparative analyses of the responses of the fathers with children with chronic conditions and fathers of well children were conducted using one tailed t tests. This method was used because of the anticipated directionality of the results. Although, strictly speaking, this method is used with a random sample, it was used here with a convenience sample because of the size of the available population. Data was analyzed

using the SPSS Base 10.0 data analysis program. There were 48 fathers of children with chronic conditions and 51 fathers of well children included in the study.

According to Cohen (1988) "The power of a statistical test depends upon three parameters: the significance criterion, the reliability of the sample results, and the 'effect size', that is, the degree to which the phenomenon exists" (p. 5). This sample size allows a power of .8 with an alpha of .05, a beta of .2 and a medium effect size (Cohen).

Limitations of Research

The generalizability of these research findings is limited to the Midwestern United States because the heterogeneity of the sample is limited. The majority of participants were white. The sample is racially skewed related to the choice of chronic conditions that include cystic fibrosis, a disease occurring in only populations of European descent. This, of course, limits the generalizability of the results. The majority of participants were individuals with higher levels of education. Again, the heterogeneity of the sample was limited and the ability to generalize the results is limited.

CHAPTER IV

RESULTS

This study sought to address 6 research questions. Data related to the first two questions under each research question was analyzed by use of descriptive statistics including frequencies and percentages. These tests were used to describe the frequency of the responses for the collective 99 fathers as well as separately for the 48 fathers of children with chronic conditions and the 51 fathers of well children. This was also done for the first four questions under research question six. For the remaining question(s) in each research question section, which sought to compare the two groups, one tail t tests were used because of the directionality of the hypotheses. The following are findings related to each of these questions.

Research Question 1

1.1 What concerns does the father of a child with a chronic condition identify regarding his role in the family?

Over 90% of the fathers of children with chronic conditions were concerned about "talking with or understanding my family", "making my family comfortable or happy", "doing family activities together", and "my children's health." Fathers of children with chronic conditions were more likely to be concerned in the areas of "talking with or understanding my family", "sexual relationship with my spouse", "making my family comfortable or happy", "wondering what my family's future is likely to be", "having enough money to meet my family's needs", and "my children's health." More than 50%

Table 4: Concerns Scale Items
Affirmative Responses
Including "Little bit", "Quite a bit", & "Great deal"

Concerns	% of Total (n = 99)	% of Fathers of Children with Chronic Conditions (n = 48)	% of Fathers of Well Children (n = 51)
Extra demands on time	89.9	87.5	92.1
Feeling worn out	81.9	73.0	90.2
Enough fun & relaxation	88.8	85.4	92.0
Enough time alone with family	80.8	83.4	78.4
Talking with/understanding family	81.9	91.6	72.5
Sexual relationship with spouse	81.6	87.2	76.5
Making family comfortable/happy	93.0	93.8	92.1
Enough attention from family	74.5	78.7	70.6
Getting out with spouse alone	86.9	83.4	90.1
Getting out by myself	68.7	66.7	70.5
Doing family activities together	90.8	95.8	86.3
Enough support from family	60.2	63.8	56.8
Whether taking care of family best	77.7	79.1	76.5
Traveling too far for health care	30.3	45.9	15.7
Enough health insurance for family	42.4	60.5	25.4
Right agencies in community	38.4	56.2	21.6
Wondering about family's future	78.8	83.4	74.5
Responsibility of caring for family	78.7	81.3	76.4
Enough money to meet family needs	76.8	79.2	74.6
Enough money for extra pleasures	77.8	77.2	78.5
Someone to talk to about worries	62.7	60.5	64.6
Someone to stay with family member	41.9	50.1	34.0
How family members feel about themselves	75.8	77.1	74.5
Getting enough sleep	77.8	83.4	72.5
Talking to children about their health	65.4	70.2	60.8
Talking to neighbors/friends about family	29.6	35.5	24.0
Cost of family's health care	47.5	66.7	29.4
Recognizing important changes in health of any family member	65.7	81.3	51.1
Enough family health information	51.5	64.6	39.2
Family members helping with chores	72.7	70.8	74.5
My spouse's health	82.8	81.2	84.3
My health	74.7	68.8	80.3
My children's health	90.9	97.9	84.4

of the respondents indicated "quite a bit" or a "great deal" of concern in each of these areas (see Table 4).

The Children Scale was also used to examine fathers' concerns (See Table 5). Fathers, as a whole, reported moderate concern about parenting issues, with over 50% in agreement with "don't have much time to do things with child(ren)", it is "hard to punish my children", "hard to manage jealousy/fighting", "hard to set limits", "hard to get child(ren) to help with chores", and "wondering how children think about themselves".

In addition to the above, over 50% of fathers of children with chronic conditions reported that it is "hard to talk to children about health", "hard to know how much to tell about health", and "hard to find someone to stay with children."

Table 5: Children Scale Items
Affirmative Responses

Concerns about Children	% of Total (n = 99)	% of Fathers of Children with Chronic Conditions (n = 48)	% of Fathers of Well Children (n = 51)
Hard to punish my child(ren)	79.8	79.2	80.4
Hard to talk to children about health	38.4	52.1	25.6
Hard to manage jealousy/fighting	53.5	56.3	50.9
Hard to know how much to tell about health	50.0	56.3	44.0
Try not to talk about health to child(ren)	19.5	25.1	14.0
Don't have much time to do things with child(ren)	61.7	66.7	56.9
Hard to set limits for child(ren)	60.6	62.5	58.9
Family talks about problems easily	83.9	87.5	80.4
Hard to get child(ren) to help with chores	73.5	79.2	68.0
Hard to find someone to stay with child(ren)	41.4	56.2	27.5
Wonder how children think of selves	77.8	77.1	78.5
Hard to get out without children	64.3	64.6	64.0

1.2 What concerns does the father of a well child identify regarding his role in the family?

Over 90% of the fathers in the fathers of well children group identified "extra demands on time", "Feeling worn out", "enough fun and relaxation", "making my family comfortable or happy", and "getting out alone with my spouse" as concerns. The only area of "quite a bit" or a "great deal" of concern to more than 50% of the fathers of well children was "making my family comfortable or happy."

There were no areas on the Children Scale in which 50% of the fathers of well children reported concerns not reported by fathers of children with chronic conditions.

1.3 Do fathers of well children differ from fathers of children with chronic conditions in their role concerns?

The fathers of children with chronic conditions group and the fathers of well children group reported significantly different mean scores in the areas of "having to travel too far for health care," "having enough insurance to meet family health expenses," "having the right agencies in the community to provide the care my family needs", "wondering whether I will recognize important changes in the health of any of my family members", "the cost of my family's health care", and "my children's health" ($p < .001$); "getting enough information about my family's health", ($p < .01$); "talking with or understanding my family," "finding someone to stay with any of my family members", "talking to my children about their health", "talking with neighbors or friends about my family", ($p < .05$); (see Table 6).

There were no significant differences in the childrearing concerns of the two groups of fathers or in the individual items on the Children Scale. Trends were noted in

Table 6: Concerns Scale Items
Differences in Means

Affirmative Responses Concerns	Total (n = 99)		Fathers of Children with Chronic Conditions (n = 48)		Fathers of Well Children (n = 51)	
	T	*p*	*M*	*SD*	*M*	*SD*
Talking with/understanding family	2.116	<.05	2.46	.97	2.00	1.18
Enough attention from family	1.840	<.1	2.21	1.20	1.78	1.10
Traveling too far for health care	4.109	<.001	1.33	1.45	.37	.75
Enough health insurance for family	4.180	<.001	1.75	1.45	.65	1.15
Right agencies in community	3.775	<.001	1.54	1.46	.57	1.06
Wondering about family's future	1.801	<.1	2.02	1.21	1.88	.99
Someone to stay with family member	2.083	<.05	1.33	1.29	.82	1.14
Getting enough sleep	1.673	<.1	2.27	1.21	1.88	.99
Talking to children about their health	2.440	<.05	1.98	1.33	1.37	1.11
Talking to neighbors/friends about family	2.176	<.05	1.06	1.21	.60	.86
Cost of family's health care	5.035	<.001	2.10	1.49	.75	1.16
Recognizing important changes in health of any family member	3.794	<.001	2.21	1.20	1.31	1.14
Enough family health information	3.340	<.01	1.81	1.25	1.00	1.17
My children's health	4.919	<.001	3.29	.80	2.31	1.16

the areas of "having enough attention from my family", "wondering what my family's future is likely to be", and "getting enough sleep for myself", ($p < .1$).

Research Question 2

2.1 What concerns does the father of a child with a chronic condition identify for his spouse?

The majority of fathers, overall, reported that they thought their wives had some concerns, with 74% reporting at least a little concern. About 90% of the fathers of children with chronic conditions reported that their spouses had at least a "little bit" of

Table 7: Spouse Concerns Scale Items
Affirmative Responses

Spouse Concerns	% of Total (n = 99)	% of Fathers of Children with Chronic Conditions (n = 48)	% of Fathers of Well Children (n = 51)
Extra demands on time	92.8	89.3	96.1
Feeling worn out	97.0	97.9	96.1
Enough fun & relaxation	81.6	76.7	86.3
Enough time alone with you	87.8	85.1	90.2
Talking with/understanding you	82.7	83.0	82.4
Sexual relationship with you	69.4	72.3	66.7
Making family comfortable/happy	88.8	85.1	92.1
Enough attention from you	82.6	78.7	86.3
Getting out with you alone	78.6	76.6	80.5
Getting out alone	72.4	72.3	72.6
Doing family activities together	85.7	87.3	84.2
Whether taking care of family best	78.6	78.7	78.5
Traveling too far for health care	35.4	54.2	17.7
Enough health insurance for family	44.4	60.5	29.4
Right agencies in community	33.4	45.8	21.6
Wondering about family's future	81.8	83.3	80.4
Responsibility of caring for family	86.0	89.6	82.4
Enough money to meet family needs	78.8	79.3	78.4
Enough money for extra pleasures	73.7	72.9	74.5
Someone to talk to about worries	69.7	72.9	66.6
Cost of family's health care	52.6	68.8	37.3
Her own health	70.7	70.9	70.6
Your health	67.3	71.8	63.2
Children's health	89.0	95.9	82.3
How family members feel about selves	67.7	70.9	64.7

concern about "extra demands on time", "feeling worn out", "the responsibility of caring for the family", and "children's health." Over 50% reported their wives having "quite a bit" to a "great deal" of concern about "feeling worn out", "making the family comfortable or happy", and their "children's health" (see Table 7).

2.2 What concerns does the father of a well child identify for his spouse?

Ninety percent of the fathers of well children identified "extra demands on time", "feeling worn out", "enough time alone with you", and "making family comfortable or happy" as concerns for their wives. Over 50% reported their wives had "quite a bit" to a "great deal" of concern about "extra demands on time", "feeling worn out", "having enough fun and relaxation", "making the family comfortable or happy", and "whether taking care of family in best way."

2.3 Do fathers of well children differ from fathers of children with chronic conditions in the concerns they identify for their spouses?

Table 8: Spouse Concerns Scale Items Differences in Means

Spouse Concerns	Total (n = 99)		Fathers of Children with Chronic Conditions (n = 48)		Fathers of Well Children (n = 51)	
	T	*p*	*M*	*SD*	*M*	*SD*
Traveling too far for health care	4.49	<.001	1.42	1.25	.45	.83
Enough health insurance for family	3.54	≤.01	1.52	1.20	.71	1.08
Right agencies in community	3.53	≤.01	1.23	1.08	.53	.88
Cost of family's health care	3.91	<.001	1.92	1.29	.96	1.13
Her own health	1.67	<.1	2.10	1.15	1.75	.98

Examination of the individual items, as seen in Table 8, revealed significantly different levels of perceived spouse concerns by the fathers of children with chronic conditions and the fathers of well children. Fathers of children with chronic conditions perceived their spouses to have greater concerns regarding "having to travel too far for health care", "cost of family's health care" ($p < .001$); "having enough insurance to meet health care", and "having the right agencies in the community to provide the care my family needs", ($\leq > 01$).

There is a trend toward significance between the means of the fathers of children with chronic conditions respondents perceived concern of their wives over their "own health" ($p < .1$) in comparison to the fathers of well children.

Research Question 3

3.1 What family care needs does the father of a child with a chronic condition identify?

Overall, fathers indicated a low level of need about family care issues with 28.4% indicating "needed a little bit" and an additional 6% indicating "needed a lot". Thirty-one percent of fathers of children with chronic conditions reported a little bit of need with another six percent indicating a lot. Table 9 reports the individual items on the family care needs scale. The items of greatest need were "dental needs" with 52.5% of the fathers responding affirmatively.

Fifty percent of the fathers of children with chronic conditions cited "dental needs." Greater than 50% reported "health", as another family care need.

3.2 What family care needs does the father of well a child identify?

Fifty-five percent of the fathers in the fathers of well children group also reported "dental needs" as a family need. Twenty seven percent of fathers of well children responded that they had a little bit of need and six percent, a lot of need.

Table 9: Family Care Needs Scale Items
Affirmative Responses

Family Care Needs	% of Total (n = 99)	% of Fathers of Children with Chronic Conditions (n = 48)	% of Fathers of Well Children (n = 51)
Physical care	36.4	39.6	33.4
Diet or nutrition	39.4	43.8	35.3
Sleep habits	25.2	29.2	21.6
Care of minor illnesses	42.9	40.5	45.1
Dental needs	52.5	50.0	54.9
Play or recreation activities	31.3	33.4	29.4
Managing behavior	39.4	33.3	45.1
School or learning experiences	44.9	45.9	44.0
Physical development	26.5	31.3	22.0
Social development	29.3	33.4	25.5
Emotional development	33.6	31.2	36.0
Intellectual development	36.4	33.4	39.2
Health	41.4	52.1	31.4
Knowing when to see the doctor	36.7	41.7	32.0
Money	36.3	37.5	35.3
Food	16.5	19.6	13.7
Housing	17.1	20.8	13.7

3.3 Do fathers of well children differ from fathers of children with chronic conditions in their identification of family care needs?

Means of 1.7603 and 1.6989 were compared using an independent samples t test to determine if there were significant differences at the .05 level. Overall there was no significant difference in the means of the two groups. In examining the individual items on the scale, no significant differences were found.

Research Question 4

4.1 What beliefs regarding child raising does the father of a child with a chronic condition identify?

In looking at the individual items, shown in Table 10, 41% of the fathers' of children with chronic conditions responses fell within the "agree" category with ten percent falling within the "strongly agree" area.

Table 10: Beliefs Scale Items
Affirmative Responses

Beliefs	% of Total (n = 99)	% of Fathers of Children with Chronic Conditions (n = 48)	% of Fathers of Well Children (n = 51)
Family usually has control over things that happen	76.8	66.7	86.3
Parents need to take care of own needs first	24.2	22.9	25.5
Parents need to get out to relieve strain of child care	87.9	85.4	90.2
Usually better to talk about one's feelings with others	74.5	81.3	68.0
Trying to forget makes things easier	61.7	58.4	64.7
One day at a time is usually better than long term planning	38.8	47.9	30.0
Getting away makes things easier	31.3	33.4	29.5
People should try to handle problems themselves	25.2	20.9	29.4
Not much family can do about health	85.8	83.4	88.2
Sometimes family is a nuisance	4.0	4.2	3.9
Parents need someone to talk to about raising children	72.7	62.5	82.4

4.2 What beliefs regarding child raising does the father of a well child identify?

Of the fathers of well children, 43% responded in the "agree" category, and 11% strongly agreed.

4.2 Do fathers of well children differ from fathers of children with chronic conditions in their beliefs?

Means of 3.0758 and 3.0483 were compared using a one tailed t test to determine if there were significant differences at the .05 level. There was one significant difference in the means of the two groups; "my family usually has control over things that happen to it" ($p < .02$). There were some other interesting differences between the two groups of fathers. Trends were apparent in the means of the affirmative responses of the fathers of children with chronic conditions and the fathers of well children to "it is usually better to talk about one's feelings with others", ($p < .094$); and "taking one day at a time is usually better than long term plans" ($p = .057$).

Table 11: Beliefs Scale Items Differences in Means

Beliefs	Total (n = 99)		Fathers of Children with Chronic Conditions (n = 48)		Fathers of Well Children (n = 51)	
	T	*P*	*M*	*SD*	*M*	*SD*
Family usually has control over things that happen	2.379	<.020	2.46	.92	2.06	.73
Usually better to talk about one's feelings with others	-1.692	<.094	2.00	.83	2.32	1.04
One day at a time is usually better than long term planning	-1.928	<.057	2.85	1.17	3.28	1.01

Research Question 5

5.1 What feelings regarding child raising does the father of a child with a chronic condition identify?

Overall, on the feelings scale, fathers reported their feelings, positive and negative. In looking at the groups separately, there was no significant difference in their

mean scores, fathers of children with chronic conditions and fathers of well children. This was also true of the individual items as seen in Table 12. Eighty percent or more of the fathers reported that they "often" to "very often" felt "confident", "good", "guilty", "happy", "helpless", "hopeful", "in control", "resentful", "sad", and "satisfied." They denied feeling "defeated" and "depressed."

Over 50% of the fathers in the fathers of children with chronic conditions group reported "often" to "very often" feeling "confident", "content", "good", "happy", "hopeful", "in control", "pleased", and "satisfied".

5.2 What feelings regarding child raising does the father of a well child identify?

Over 50% of the fathers of well children reported "often" to "very often" feeling "confident", "content", "good", "happy", "hopeful", "in control", "lucky", "pleased", and "satisfied."

Table 12: Feelings Scale Items
Affirmative Responses

Feelings	% of Total (n = 99)	% of Fathers of Children with Chronic Conditions (n = 48)	% of Fathers of Well Children (n = 51)
Angry	39.4	41.7	37.2
Anxious	44.5	43.7	45.1
Confident	80.9	83.3	78.4
Content	67.7	60.9	74.0
Defeated	7.1	10.4	4.0
Depressed	12.1	14.6	9.8
Disappointed	26.3	29.2	23.5
Frustrated	44.4	45.9	43.2
Good	87.9	85.5	90.2
Guilty	90.9	93.8	88.3
Happy	88.9	83.3	94.1
Helpless	86.9	87.6	86.2
Hopeful	88.9	89.6	88.2
In Control	82.9	79.2	86.3
Lucky	48.5	41.6	54.9
Overwhelmed	55.1	57.4	52.9
Pleased	76.8	66.7	86.3
Resentful	91.9	95.9	88.2
Sad	85.8	87.5	84.3
Satisfied	81.8	79.2	84.3
Uneasy	69.7	72.9	66.6

5.3 Do fathers of well children differ from fathers of children with chronic conditions in their feelings?

Means of 1.7553 and 1.7663 were compared using a one tailed t test to determine if there were significant differences at the .05 level. Overall, there was no significant difference in the feelings of the respondents of the two groups. Of interest, however, is the difference in the means of the fathers' responses to feeling "lucky" ($p < .075$) (see Table 13).

Table 13: Feelings Scale Items Differences in Means

Feelings	Total (n = 99)		Fathers of Children with Chronic Conditions (n = 48)		Fathers of Well Children (n = 51)	
	T	*P*	*M*	*SD*	*M*	*SD*
Lucky	-1.801	<.075	1.15	1.01	1.47	.76

Research Question 6

6.1 What coping strategies does the father of a child with a chronic condition use?

Fathers, in general, reported use of many of the coping behaviors and the vast majority (81%) found most of them helpful. Table 14 indicates the responses to the individual items in the coping scale. Among the coping behaviors used most frequently, over 80% of respondents reported "looking at options", "asking questions", "trying to figure out what to do", "trying to relax", "weighing choices", "getting information", and "trying to change things." Over 50% of the fathers of children with chronic conditions indicated positive behaviors.

Table 14: Coping Scale Items
Affirmative Responses

Coping	% of Total (n = 99)		% of Fathers of Children with Chronic Conditions (n = 48)		% of Fathers of Well Children (n = 51)	
	How often	How helpful	How often	How helpful	How often	How helpful
Cry	14	88	22	82	8	100
Busy myself	63	91	63	92	63	90
Talk with someone	64	99	59	97	69	100
Ignore/try to forget	34	57	22	48	45	64
Look at options	94	100	93	100	94	100
Get away for awhile	36	90	28	94	43	87
Hide feelings	57	59	59	58	55	59
Change expectations	53	88	46	85	60	91
Blame someone	25	33	15	44	34	26
Yell/scream/slam doors	39	46	44	44	34	49
Exercise	61	99	56	100	66	98
Ask for help	54	99	56	97	51	100
Take alcohol/drugs	18	60	13	50	22	67
Pray	70	97	77	94	63	100
Blame myself	37	46	32	41	42	50
Ask questions	82	100	81	100	82	100
Get advise	68	99	68	100	69	98
Try to figure out	95	99	94	100	96	98
Sleep	52	87	53	86	50	88
Find help	56	97	60	97	53	97
Smoke	12	59	13	50	12	67
Laugh/joke about it	79	93	73	97	84	90
Eat	40	53	50	58	31	46
Try to relax	80	96	80	95	80	98
Read about problem	61	95	62	97	59	93
Wish problem away	52	26	56	21	47	30
Weigh choices	90	100	85	100	94	100
Get information	80	100	87	100	73	100
Try to change things	84	95	81	95	86	96

Another area that was examined was what informational resources they used related to family problems or needs. Over 50% of the fathers of children with chronic conditions reported using doctors, friends, nurses, relatives or spouses, and newspapers/magazines as sources of information (see Table 15).

Table 15: Information Resources Scale Items Affirmative Responses

Information Resources	% of Total (n = 99)	% of Fathers of Children with Chronic Conditions (n = 48)	% of Fathers of Well Children (n = 51)
Clergy	36.4	45.8	27.5
Doctor	81.8	87.5	76.5
Friend	80.8	79.2	82.4
Nurse	37.4	54.2	21.6
Teacher	32.3	31.3	33.3
Relatives or spouse	80.8	79.2	82.4
Pharmacist	18.2	25.0	11.8
Other parent	38.4	27.1	49.0
Social worker	16.2	29.2	3.9
Nutritionist	13.1	22.9	3.9
Therapist	19.2	25.0	13.7
Library	22.2	22.9	21.6
Newspaper/magazines	44.4	52.1	37.3
Support group	10.1	18.8	2.0
Community agency	6.1	8.3	3.9
Internet	10.1	12.5	7.8

6.2 How helpful does the father of a child with a chronic condition report these coping strategies to be?

All of these behaviors were reported by high proportions of the respondents as helpful as well as "crying", "busying myself with other things", "talking with someone about feelings ", "getting away for a while", "changing my expectations", "exercise", "asking for help", "praying", "getting advise of others", "sleeping", "finding help",

"trying to laugh or joke about it", and "reading about the problem" although used by fewer respondents. In examining the fathers' of children with chronic conditions, over 50% indicated they found the positive behaviors they used helpful.

6.3 What coping strategies does the father of a well child use?

Greater than 50% of the fathers of well children reported using "busying myself", "talking to someone", "looking at options", "hiding feelings", "changing expectations", "exercise", "asking for help", "prayer", "asking questions", "getting advise", "trying to figure out what to do", "finding help", "laughing or joking about it", "trying to relax", "reading about the problem", "weighing choices", "getting information", and "trying to change things."

Over 50% of fathers of well children utilized doctors, friends, and relatives or spouses when in need of information. Another 49% relied on other parents as resources.

6.4 How helpful does the father of a well child report these coping strategies to be?

Fifty-nine to one hundred percent of the fathers in the fathers of well children group found these coping strategies helpful.

6.5 Do fathers of well children differ from fathers of children with chronic conditions in the use of various coping strategies?

Fathers of children with chronic conditions were significantly more likely to use "crying" ($p = .007$), than fathers of well children, while fathers of well children were more likely to "ignore or try to forget" ($p = .023$) and "blame someone" ($p = .004$) than fathers of children with chronic conditions. Trends toward increased use of "praying" ($p = .083$) was evident in the fathers of children with chronic conditions group over the fathers of well children group. However, "trying to figure out what to do" ($p = .07$) and

"changing my expectations" (p =.059) was utilized more by the fathers of well children than the fathers of children with chronic conditions (see Table 16)..

Table 16: Coping Scale Items
Differences in Means

Coping	Total (n = 99)		Fathers of Children with Chronic Conditions (n = 48)		Fathers of Well Children (n = 51)	
	T	*p*	*M*	*SD*	*M*	*SD*
Cry	2.788	.007	.76	.79	.35	.63
Ignore/try to forget	-2.319	.023	.85	.82	1.25	.91
Change expectations	-1.916	.059	1.52	.76	1.20	.88
Blame someone	-2.995	.004	.61	.80	1.16	1.00
Pray	1.752	.083	1.96	1.02	1.56	1.14
Try to figure out	-1.832	.070	2.44	.74	2.68	.55

Means of .39 and .30 were compared using a one tailed t test to determine if there were significant differences at the .05 level. There was a significant difference in means overall with the mean of fathers of children with chronic conditions greater than the mean of fathers of well children. In examining the individual sources, the fathers in the fathers

Table 17: Information Resources
Differences in Means

Information Resources	Total (n = 99)		Fathers of Children with Chronic Conditions (n = 48)		Fathers of Well Children (n = 51)	
	t	*P*	*M*	*SD*	*M*	*SD*
Nurse	3.502	<.002	.54	.50	.22	.42
Support group	2.788	<.010	.19	.39	1.96E-02	.14
Other parent	-2.287	<.050	.27	.45	.49	.50
Social worker	3.518	<.002	.29	.46	3.92E-02	.20
Nutritionist	2.828	<.010	.23	.42	3.92E-02	.20

of children with chronic conditions included the nurse (p <.002), social worker (p <.002); nutritionist and support group (p <.01); and other parent (p <.05) (see Table 17).

6.6 Do fathers of well children differ from fathers of children with chronic conditions in the helpfulness of various coping strategies?

Fathers of children with chronic conditions were more likely to find "trying to laugh or joke about it" (p =.09) more helpful than fathers of well children. However, fathers of well children found "crying" (p =.058) more helpful . A third or less of the respondents found "blaming someone" and "wishing problem would go away" helpful.

Table 18: Coping Helpfulness Scale Items Differences in Means

Coping	Total (n = 99)		Fathers of Children with Chronic Conditions (n = 48)		Fathers of Well Children (n = 51)	
	T	*P*	*M*	*SD*	*M*	*SD*
Cry	-1.997	.058	1.11	.74	1.62	.77
Laugh/joke about it	1.715	.090	1.69	.77	1.40	.84

Because the fathers' coping behaviors impact the coping abilities of the entire family, the subjects were also asked to answer questions about how their families were managing problems, feelings, and stress (see Table 19). In the fathers of children with chronic conditions group, 20 (41.7%) of the fathers felt that the family was not handling problems well, with another 22 (45.8%) feeling that the family was managing problems fairly well. No fathers in this group rated problem management in the "very well" category. In the fathers of well children group, the majority of fathers rated their family

Table 19. Family Coping

Family Management of Problems	% of Fathers of Children with Chronic Conditions	% of Fathers of Well Children
Not Well	41.7	5.9
Fairly Well	45.8	27.5
Well	12.5	45.1
Very Well		21.6
Ability to Change Things when there are Problems		
Not very often	43.8	16.0
Almost always	52.1	74.0
Always	4.2	10.0
Family Management of Feelings and Concerns		
Not Well	2.1	5.9
Fairly Well	50.0	37.3
Well	41.7	41.2
Very Well	6.3	15.7
Satisfaction with Family Management of Stresses		
Dissatisfied	18.8	19.6
Satisfied	79.2	74.5
Very Satisfied	2.1	5.9

problem management as "fairly well" (14, 27.5%) to "well" (23, 45.1%) with an additional 11 (21.6%) stating that management was indeed, very good.

Twenty-one fathers of children with chronic conditions (43.8%) expressed that they were able to change things infrequently when there were problems. However, another 25 (52.1%) stated that they almost always were able to change things when problems arose. Thirty-seven (74%) fathers of well children rated their ability to change things when there were problems at "almost always".

Of the fathers of children with chronic conditions, 91.7% (44) rated their families' management of feelings and concerns as "fairly well" (24, 50%) to "well" (20, 41.7%). In the fathers of well children group the responses were very similar with 19 (37.3%) "fairly well" and 21 (41.2%) "well". The majority of fathers of children with chronic conditions (38, 79.2%) and fathers of well children (38, 74.5%) were satisfied with their families' management of stress.

Means of 1.60 and 1.94 were compared using a one tailed t test to determine if there were significant differences at the .05 level. There was only one significant difference with the fathers in the fathers of children with chronic conditions feeling their family could less often change things when there was a problem ($p = .003$), than fathers in the fathers of well children group.

This study shows significant findings in the areas of fathers' concerns of their own and perceptions of their wives concerns. Other significant findings included one individual childrearing belief, "family usually has control over things that happen" and individual coping strategies including the use of various informational resources.

Chapter V

DISCUSSION

This discussion will begin with a review of the analysis of the demographic data. In addition, six research questions and seven hypotheses were brought forward and will be discussed in relationship to the analytical findings. The findings will be further discussed in conjunction with the theoretical framework used and the implications for practice in the clinical area. Limitations, implications for further study, and conclusions will be included.

Findings of Demographic Data

The demographics for the two groups of fathers were similar. Both groups had mean ages of 30 to 39 years and annual family incomes between $40,000 and $49,000. The mean income of the group of fathers of children with chronic conditions was closer to $40,000 and significantly less than the group of fathers of well children with an income mean close to $49,000. Both groups of fathers were college educated, although many did not complete their degrees. The ethnic backgrounds of the groups were also very similar with 80% white, and nearly 10% black. While the fathers in both groups rated their own health as good, the fathers of children with chronic conditions reported their wives' health to be significantly poorer than the health of the wives of the fathers of well children. As expected, this was also true of the reported health of the children. There were significant differences in the demographics of the wives. The mothers of the well children had more formal education, worked outside the home, and had better health.

They were very similar in age and ethnic origin. There was a significant difference in family resources including the availability of someone to care for a family member for a week, and the ability of the family to change things when there were problems. Fathers of well children reported greater family resources than those reported by fathers of children with chronic conditions.

Findings of the Research Instrument

Reliability analysis revealed study alphas comparable to the author's alphas on most scales (see Table 21). The reliability was generally high with the exception of the beliefs scale (author's $\alpha = .59$, study $\alpha = .35$). Dr. Hymovich noted in a personal communication (1999) that this scale should be used with caution because of its lower reliability. There was a large discrepancy in the reliability of the feelings scale between the author's analysis and this study's analysis (author's $\alpha = .85$, study $\alpha = .40$). The alpha increased to .84 ($\underline{M} = 31.40$, $S.D. = 6.80$, $n = 5$, and n of variables = 25) with the exclusion of the item "smoking". The author's guidelines for recoding of the beliefs and feelings scales were followed with more positive responses indicating more positive beliefs and feelings overall. Two additional scales were compiled from the existing questions. These were the Health Needs Scale with an alpha of .87 and the Information Resources Scale, alpha .69. These scales were compiled to look at possible differences in the health concerns and acceptable resources between the two groups of fathers.

Table 20. Means, Standard Deviations & Reliability

SCALE	No. of Study Items	Author's Mean*(n)	Study Mean (n)	Author's S.D.	Study S.D.	Author's Alpha*	Study Alpha
Concerns	33	59.62 (45)	63.12 (94)	24.88	22.61	.95	.93
Family Needs	17	26.06 (47)	28.78 (92)	10.28	12.35	.89	.91
Beliefs	11	33.33 (48)	30.80 (97)	2.93	3.75	.59	.35
Feelings (unrecoded)	21	31.82 (44)	36.26 (95)	4.88	4.78	.75	.61
Coping	29	50.07 (42)	43.44 (82)	9.36	9.86	80	.79
Coping-Help	29	36.60 (5)	13.33 (3)	10.16	2.89	.85	.40
Children	12		28.96 (95)	12.21	11.65	.80	.83
Spouse Concerns	25	45.19 (47)	50.86 (94)	17.81	15.05	.93	.91
Information Resources	17	-	5.82 (99)	-	2.54	-	.69

Hymovich (personal communication, 1999)

Purpose of Study

The purpose of this study was to identify and compare the concerns, beliefs, feelings, coping strategies, concerns about children, perceptions of spouse concerns and spouse coping behaviors of fathers of children with chronic conditions and fathers of well children. The sample consisted of 99 fathers of children in the service area of a large metropolitan medical center. The 48 fathers of children with chronic conditions and the 51 fathers of well children who participated each completed the Hymovich Family Perception Inventory (FPI) anonymously.

Findings of Study Data

The primary finding of this study was that there were differences between fathers of children with chronic conditions and fathers of well children on selected aspects of perception measured by the FPI. The areas of significant difference between the fathers were that of concerns regarding function within the family including informational resources, perceived and spousal concerns. The majority of fathers (70%) reported they had concerns. However, over 50% of the fathers of children with chronic conditions expressed concern about talking with or understanding their families, sexual relations with their wives, making their families happy or comfortable, wondering about their families' futures, and concern for their children's health. The one concern reported by the majority of fathers of well children was about making their families comfortable or happy.

Fathers of children with chronic conditions were significantly more concerned than fathers of well children about health related matters. These included traveling too far for health care, having enough health insurance, having the right agencies in the

community to provide needed family care, talking about health to their children and about their families with neighbors and friends, recognizing important changes in the health of family members, getting enough information about their families' health, their children's health, and the cost of health care. In addition, these fathers were significantly more concerned about talking with or understanding their families and finding someone to stay with family members. There were no areas of concern for fathers of well children that were reported as significantly greater than those of the fathers of children with chronic conditions. This supports hypothesis one, which states that fathers of children with chronic conditions will have significantly greater concerns about their role than fathers of well children as measured on the FPI.

It is not unexpected that the areas of greater concern for fathers of children with chronic conditions involve family health, comfort, and happiness, since these are factors that would impact everyday life much more frequently and intensely than for families with well children. It also supports the literature, in the contention that the areas of concern for parents are the same with both children who are well and those with chronic conditions in items, but different in quantity.

Fifty-nine percent of the fathers, overall, had concerns regarding parenting their children and 36.4% had perceived family care needs. There were no significant differences in the concerns that fathers had about their children. However, there are some interesting parallels related to the individual items and their reporting. Over 60% of all the fathers reported finding it hard to punish their children, hard to set limits, hard to get their children to help with chores, and hard to get out of the house without their children. They also had concern about not having much time to do things with their children and

wondered what their children think about themselves. There was a general consensus among the fathers that their families talked easily about problems. Fathers of children with chronic conditions additionally found it hard to find someone to stay with the children. While 60% of the fathers of well children were concerned with difficulty punishing their children, wondering what the children think about themselves, and finding it hard to get out of the house without the children.

In looking at these results, it becomes clear that the difference in concerns is primarily related to health issues. Even though only the concerns and spouse concerns scale means were significantly different between the two groups of fathers, it is of interest to look at the individual items in the scales in relationship to the two groups. The fathers of children with chronic conditions expressed concern about not having time to spend with their children, having a hard time setting limits, having a hard time getting children to help with chores, and having a hard time finding someone to stay with their children. All of these items can relate to children both well and with chronic conditions. However, having difficulty finding someone to stay with a family member was significantly greater for fathers of children with chronic conditions than fathers of well children. This was also true demographically.

Over 60% of the fathers of children with chronic conditions expressed concerns about traveling too far for health care, the cost of health care, recognizing changes in family members' health, getting enough information about family's health, their children's health, having enough health insurance, and having the right agencies in the community. Because this was not a concern reported by the majority of fathers of well children, one is led to believe that these issues are related to the chronicity of the child's

condition. With the health related concerns removed the fathers' parenting needs were comparable in both groups.

Perceived spouse concerns were reported by nearly three-quarters of the fathers (74%). Over 50% of the fathers, overall, felt their wives were concerned "quite a bit" about feeling worn out and making the family happy or comfortable. The fathers of children with chronic conditions also reported their perceptions that their children's health was also an area of "quite a bit" to a "great deal" of concern for their wives. Fathers of well children reported their perceptions that their wives had concerns about the extra demands on their time and whether they were taking care of the family in the best way. The fathers of children with chronic conditions perceived their wives to be significantly more concerned about traveling too far for health care, having enough insurance, having the right agencies in the community to provide for family needs, and the cost of health care than was perceived by the fathers of well children. All of these concerns are health related and instrumental in nature. Fathers of children with chronic conditions perceived significantly greater spousal concerns than fathers of well children as measured on the FPI, which supports hypothesis two.

The majority of fathers of children with chronic conditions perceived their wives to have fewer concerns, than they themselves had. The mutual concerns were making their family happy or comfortable and their children's health. This was also true of the significantly greater concerns that fathers of children with chronic conditions had. Fathers in this group perceived that both they and their wives were concerned about traveling too far for health care, having enough health insurance, having the right agencies in the community to provide for the family's needs, and the cost of health care.

The fathers also perceived fewer significant differences in the concerns of mothers of children with chronic conditions and the mothers of well children. Whereas, fathers of well children perceived their wives to have more concerns than both themselves and the mothers of children with chronic conditions, fathers of children with chronic conditions perceived themselves having more concerns than their wives.

Mothers of well children, the vast majority of whom were working outside the home, might reasonably be concerned about the extra demands on their time that the extracurricular activities of their children and the balancing of family and work obligations creates. Also, mothers who work outside the home might worry about whether this infringes on their ability to take care of their families in the best way.

Not only did all the fathers have "quite a bit" to a "great deal" of concern about making their families happy, wondering about their families' futures, having enough money, and their children's health, but fathers of children with chronic conditions also were concerned about talking with their families about health and their sexual relationships with their wives. The majority of fathers of well children, on the other hand, were only concerned quite a bit to a great deal about making their families happy or comfortable.

The family care needs of concern to the fathers, overall and within each group, were dental needs. In addition, fathers of children with chronic conditions expressed informational needs regarding their family's health. These needs, however, were expressed by less than 40% of the fathers.

Childrearing beliefs were very similar in both groups with no significant difference in means, overall. Fifty-three percent of the fathers agreed with the

childrearing beliefs put forth in the questionnaire. Fathers of children with chronic conditions means were greater than fathers of well children in the areas of "it is usually better to talk about one's feelings with others" and "taking one day at a time is usually better than making long term plans." Fathers of well children reported that their family usually has control over things that happen to it to a greater extent than fathers of children with chronic conditions. The stress of diagnosis, treatment, and uncertain long-term prognosis are evident in the need to talk about one's feelings, along with the diminished feelings of control over events. The need to take one day at a time also coincides with the uncertainty of the child's condition day to day. However, due to the poor reliability of the scale, these results must be viewed with caution.

It is interesting to note that over 70% of the fathers, overall and in each group, reported that sometimes parents need to get out of the house to relieve the strain of child care and that there is not much their families could do about their health. With the emphasis on preventative health care and healthy living habits, the latter is a surprising finding. Because of the lack of significant differences in the means of the two groups for the overall scale and its poor reliability, hypothesis three, fathers of children with chronic conditions will have significantly less positive beliefs than fathers of well children regarding child rearing as measured on the FPI, was not supported.

Hypothesis four, fathers of children with chronic conditions will have significantly less positive feelings than fathers of well children as measured on the FPI, was not supported. There was no significant difference in the means of the overall scale and only one meaningful difference in means on one item. Fathers of well children reported a higher incidence of feeling "lucky" than fathers of children with chronic

conditions. Over 80% of all the fathers reported feeling confident, good, guilty, happy, helpless, hopeful, in control, resentful, sad, and satisfied within the last three months. Over 80% of fathers of children with chronic conditions shared these feelings with the exception of feeling in control or satisfied. Fathers in the fathers of well children group agreed except they felt pleased but not confident in over 80% of the cases.

Fathers reported utilizing 58% of the coping behaviors in the coping scale during the last three months. There was no significant difference in the means for the two groups. In looking at the individual items there was also very little difference in the behaviors employed and their helpfulness. Therefore, hypotheses five and six were not supported. These hypotheses stated that fathers of children with chronic conditions will use coping strategies significantly more often than fathers of well children as measured on the FPI and that fathers of children with chronic conditions will find their coping strategies significantly less helpful when they have problems than fathers with well children as measured on the FPI.

Although there were no significant differences in coping behaviors, there were significant differences in what sources the two groups used when accessing information. Again, health issues impacted resource uses. There were significant differences in the means of the two groups, the means of fathers of children with chronic conditions greater than the means of fathers of well children. Over 50% of fathers of children with chronic conditions utilized doctors, nurses, friends, relatives or spouses, and newspapers and magazines to access desired information. Fathers of well children utilized doctors, friends, relatives or spouses, and other parents. Although the means of fathers of children with chronic conditions were significantly higher in the use of the nurse, social worker,

nutritionist, and support group, only the nurse was used by greater than 50% of the fathers. Other parents were used significantly more by fathers of well children.

Conceptual Framework

The theoretical framework, the combined Bronfenbrenner/Roy model, works well as the grounding point for this study. The microsystem, of which the father and child are a dyad, is continuously changing and evolving. The child is born with certain parenting needs that he/she exhibits through his/her behavior patterns. These needs change as the child grows and develops, the father's comfort level grows with his increasing knowledge and ability to provide for the child's needs. However, when a child has a chronic condition there are environmental changes the fathers experience. These changes are health focused and they demand changes in the fathers' coping, physiologic, and psychological responses to these stimuli. This results in changes in the proximal processes within the family microsystem. Those concerns that are significantly different from fathers with well children include changes in family care behaviors (finding someone to stay with a family member, talking to the family about health, having the right agencies in the community to meet the family's needs, recognizing changes in family members' health, getting enough information about the family's health, and the children's health), increased energy and financial needs (traveling too far for health care, having enough health insurance, the cost of health care), bonding (talking with or understanding the family), and adopting the fathering role (talking to neighbors and friends about the family). These concerns, when acted upon will stimulate proximal processes that are adaptive or ineffective. Information gathering sources for over 50% of all the fathers include doctors, friends, and relatives or their spouses. For over 50% of

fathers of children with chronic conditions, this list of resources expands to include nurses, newspapers and magazines. With the anticipatory guidance of health care professionals, the input of their informal social support networks, and print media, molar activities will increase the effective adaptation of these fathers to their changing fathering role. With the anticipated increased feelings of control and pleasure in their role accomplishments, fathers may have increased feelings of self-esteem, competence, and accomplishment, leading to future positive fathering behaviors and fostering resilience. These results then might be extended to increasingly positive relationships in the exosystem and the macrosystem.

Review of the Literature

A bit higher in severity than was reported by Jackson (1996) as mild, moderate, and severe conditions, children's health was reported as poor to fair by 17% of the fathers of children with chronic conditions, good by 37%, and very good to excellent by 46%. The cost of health care in terms of travel distances, child caregivers for more than a day, having enough insurance, and out of pocket health care expenses are significantly greater concerns for parents of children with chronic conditions than those of well children. This agrees with the findings of Shepard and Mahon (1996).

Lamb (1997) found a high incidence of marital discord in his study of families with children with chronic conditions that did not appear to be present in the current study with about 90% of all the fathers (both fathers of children with chronic conditions and fathers of well children) rating their families as close and satisfied with their family relationships. Nor were Shepard and Mahon's (1996) findings supported in that fathers

did not report a significantly greater need for information about their children's growth and development, managing their behavior, diet, or care of minor illnesses.

There were significant differences between the two groups of responses with fathers reporting greater concern about feeling worn out, and having enough money, which is in agreement with Shepard and Mahon (1996). Wondering about their family's future is in agreement with both Shepard and Mahon's findings and Cayse's (1994) report.

The current study supported that fathers of children with chronic conditions work toward understanding and managing the condition (concern for their children's health, getting enough information about their families' health, and recognizing important changes in the health of family members), helping the child understand and deal with the condition (talking about health to their children, having the right agencies in the community), and working toward meeting the needs of other family members (talking with or understanding their families, finding someone to stay with family members) as reported by Hymovich (1976).

The powerlessness reported by Enscar, et al (1997) was demonstrated in this study by the significantly lesser feelings of control by the fathers of children with chronic conditions than the fathers of well children. This is also supportive of Sabbeth's (1984) findings that fathers had special difficulty dealing with a lack of control imposed by the illness leading to feelings of helplessness.

All the segments of the fathering role showed evidence of the impact of the child's chronic condition. These include the role as protector (feelings of events being out of family control), communicator (having enough information about my family's

health, what to tell friends and neighbors about my family, talking with or understanding my family), and breadwinner (having enough money for health care costs). This also supports Sterken (1996) in his report of fathers feeling a lack of first hand information regarding their child's treatment and follow-up care and the need to regularly voice their concerns and feel their opinions and questions are valued (better to talk about feelings, ask questions, and get help).

These findings support Belsky's (1984) contention that a father's social system enhances fathering behavior by providing emotional support, instrumental assistance, and guidelines for social expectations. That these needs are greater in fathers of children with chronic conditions is supported to greater and lesser extents in the current study.

Implications for Clinical Practice

Although it may seem intuitive it is encouraging to see that the fathers of children with chronic conditions remain, at base, fathers, with differences related only to adaptation necessitated by their child(ren)'s health. This probably indicates that opportunities for significant impact on their concerns and coping exists. Health care providers, particularly nurses and doctors, have a window of opportunity to intervene and facilitate positive adaptation at the time of diagnosis. Although this is a time of particular stress for the family, it is also a time when fathers are usually present. It is at this time, early in the process, that information can be made available, both verbally and in writing, to 1) put both parents in the knowledge loop,

2) identify and encourage use of all family members' informal social support systems,

3) correct any misconceptions and answer questions accurately to prevent misconceptions, and 4) provide whatever instrumental support is necessary. By

strengthening the role of the father, the mother-child dyad is strengthened and the entire family unit profits. When the groundwork is laid at the beginning of the professional relationship with both parents, work toward positive adaptation is optimized.

Limitations

Although fathers from a variety of ethnic and socioeconomic groups were invited to participate in the study, the sample was not as heterogeneous as desired. No data were collected that would differentiate fathering of children by sex. Fathering of boys and girls has been previously shown to be different. The parenting needs of fathers of children with chronic conditions who live separate from their children was not explored. Related to the low reliability alphas on the two scales, beliefs and helpfulness of coping, these data must be interpreted with caution. It is not possible to generalize from this information to chronic conditions other than those utilized in this study nor does the significant information obtained in this study permit generalization to a wider population.

Implications for Future Study

Because of the narrow socioeconomic range of these subjects, continued research needs to be done to replicate the findings of this study. Exploration using different chronic conditions and differentiating the sexes of the children would be of interest. Also, although correlations were found between the fathers' concerns and coping and their wives, a more extensive examination might be useful. Further study of interventions in the clinical area would be helpful to optimize adaptation.

Conclusions

Children with chronic conditions survive for longer periods of time than has been historically true, creating a need to promote optimal growth and development for them,

their family members and the family as a unit. A review of the literature suggests that fathers of children with chronic conditions have parenting needs that may be different from fathers of well children. Little attention has been directed toward these differences and no comparative studies were found focusing on families of children with chronic conditions. The purpose of this study was to identify and compare the concerns, beliefs, feelings, and coping strategies of fathers of children with chronic conditions and fathers of well children.

Ninety-nine fathers participated in the study, 48 fathers of children with chronic conditions and 51 fathers of well children. The Hymovich Family Perception Inventory (FPI) was completed by each father anonymously in the privacy of his own home.

The results revealed significant differences in the parenting concerns of fathers of children with chronic conditions and fathers of well children. These concerns center around their children's health and include the need for knowledge. Fathers of children with chronic conditions also reported significant differences in the parenting concerns of their wives but with strong correlations to their own concerns. There are indications that there is a place for anticipatory guidance, dissemination of information, and encouragement in the use of fathers' informal support systems to provide the kinds of support needed by fathers of children with chronic conditions.

APPENDICES

APPENDIX A

Table 21: Sample Items from FPI

Table 21. Sample Items from FPI

Scale 1: Concerns	No/Does Not Apply	Not Sure	Little Bit	Quite a Bit	Great Deal
Feeling worn out	0	1	2	3	4

Scale 2: Needs	Does Not Apply	Did Not Need	Not Sure	Needed a Little Bit	Needed a Lot
Sleep Habits	0	1	2	3	4

Scale 3: Beliefs	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
Parents need someone to talk to about raising their children	1	2	3	4	5

Scale 4: Feelings	Not at All	Not Often	Often	Very Often
Angry	0	1	2	3

Scale 5: Coping	How Often			
	Do Not Do This	Very Rarely	Sometimes	Very Often
Hide Feelings	0	1	2	3

Scale 6: Helpfulness	How Helpful			
	Never Help	Sometimes	Almost Always	Always Helps
Hide Feelings	0	1	2	3

Scale 7: Children	No/Does Not Apply	Not Sure	Little Bit	Quite a Bit	Great Deal	Strongly Disagree
It is hard to punish my child	0	1	2	3	4	5

Scale 8: Spouse Concerns	No/Does Not Apply	Not Sure	Little Bit	Quite a Bit	Great Deal
Feeling worn out	0	1	2	3	4

APPENDIX B

Table 22: Means, Standard Deviations, & Reliability

Table 22. Means, Standard Deviations & Reliability

(Coefficients of the PPI)

SCALE	No. of Study Items	Author's Mean*	Study Mean	Study S.D.	Author's Test-Retest*	Author's Alpha*	Study Alpha
Concerns	34	1.81	1.56	.51	.82	.88	.92
Childhelp	18	1.58	1.56	.45	.86	.92	.85
Beliefs	12	1.81	2.00	.31		.33	.62
Feelings	22	1.09	1.47	.56	.74	.88	.94
Coping	21	2.38	2.34	.36	.78	.62	.73
Coping-Help	21	1.84	1.96	.43	.84	.80	.90
Spousecope	21	2.82	2.31	.41	.82	.66	.77
Spouse Concerns	26	2.26	2.60	.60	.92	.88	.91
Siblinghelp	7	1.78	1.57	.59		.90	.88

*Hymovich (personal communication, 1989)

APPENDIX C

Permission Letters

MICHIGAN STATE
UNIVERSITY

September 17, 1999

TO: June Pierce Youatt
Unit #3, Paolucci Bldg.
Room 233

RE: IRB # 99300 CATEGORY: 1-C

TITLE: THE NEEDS OF FATHERS PARENTING CHILDREN WITH CHRONIC CONDITIONS

ANNUAL APPROVAL DATE: May 18, 1999
REVISION REQUESTED: September 13, 1999
REVISION APPROVAL DATE: September 17, 1999

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete and 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'S REVISION.

This letter approves the addition of Dr. Lichgenberg's name to the cosent form.

RENEWALS: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Projects continuing beyond one year must be renewed with the green renewal form. A maximum of four such expedited renewal are possible. Investigators wishing to continue a project beyond that time need to submit it again for a 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, 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 further assistance, please contact us at 517 355-2180 or via email: UCRIHS@pilot.msu.edu.

Sincerely,

David E. Wright

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bd
cc: Judith K. Hovey

OFFICE OF
RESEARCH
AND
GRADUATE
STUDIES

University Committee on
Research Involving
Human Subjects
(UCRIHS)

Michigan State University
246 Administration Building
East Lansing, Michigan
48824-1046

517/355-2180
FAX: 517/353-2976

Wayne State University
Human Investigation Committee

University Health Center, 6G
4201 St. Antoine Blvd.
Detroit, MI 48201
(313) 577-1628 Office
(313) 993-7122 Fax

NOTICE OF EXPEDITED APPROVAL

TO: Judith K. Hovey
(Nursing Research)
23161 Marine Ave.
Eastpointe, MI 48021

FROM: Peter A. Lichtenberg, Ph.D. Peter A. Lichtenberg
Chairman, Behavioral Institutional Review Board (B03)

DATE: August 17, 1999

RE: Protocol #07-66-99(B03)-ER; "The Needs of Fathers Parenting Children with Chronic Conditions." No funding requested

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The above Protocol and Information Sheet were APPROVED following Expedited Review (Category 7*) by the B03 Chairman, for the Wayne State University Institutional Review Board, for the period of August 17, 1999 through August 16, 2000.

EXPIRATION DATE: August 16, 2000

This approval does not replace any departmental or other approvals that may be required.

Federal regulations require that all research be reviewed at least annually. It is the Principal Investigator's responsibility to obtain review and continued approval before the expiration date. You may not continue any research activity beyond the expiration date without HIC approval.

- If you wish to have your protocol approved for continuation after the above approval period, please submit a completed Continuation Form at least six weeks before the expiration date. It may take up to six weeks from the time of submission to the time of approval to process your continuation request.
  Failure to receive approval for continuation before the expiration date will result in the automatic suspension of the approval of this protocol on the expiration date. Information collected following suspension is unapproved research and can never be reported or published as research data.

- If you do not wish continued approval, please submit a completed Closure Form when the study is terminated.

All changes or amendments to your protocol or consent form require review and approval by the Human Investigation Committee (HIC) BEFORE implementation.

You are also required to submit a written description of any adverse reactions or unexpected events on the appropriate form (Adverse Reaction and Unexpected Event Form) within the specified time frame.

*Based on the Expedited Review List, Revised November, 1998
c: Maureen Frey, Ph.D., Nursing Research (IM-53), CHM 1st Floor

Revised 1/99

The Detroit Medical Center

Wayne State University

DMC Children's Hospital of Michigan

Wayne State University
School of Medicine

Department of Pediatrics
Division of
Hematology/Oncology

June 28, 1999

I, Kanta Bhambhani, give my permission for Judith K. Hovey, to contact selected families of my patients to obtain data for the completion of her study, "The Needs of Fathers Parenting Children with Chronic Conditions".

Thank you,

Kanta Bhambhani, MD

Kanta Bhambhani, M.D.
Associate Professor of Pediatrics
Division of Hematology/Oncology

June 28, 1999
Date

KB/jan.win97

Children's Hospital of Michigan
3901 Beaubien Boulevard Detroit, Michigan 48201-2196 313.745.5515 Fax 313.745.5237

The Detroit Medical Center

Wayne State University
DMC Children's Hospital of Michigan

Wayne State University
School of Medicine

Department of Pediatrics

Division of Immunology, Allergy & Rheumatology

Ellen C. Moore, M.D.
Ricardo Vinuya, M.D.
Elizabeth Secord, M.D.
Kameswari Konduri, M.D.
Inocencio A. Cuesta, M.D.
P. Michael Long, Ph.D.
Michael R. Simon, M.D.
Alan Kwasslow, M.D.
Reka Mahajan, M.D.

June 8, 1999

I, Ellen C. Moore, M.D., agree to collaborate with Judith K. Hovey, if her study receives IRB approval, in soliciting fathers to participate in her study, "The Needs of Fathers Parenting Children with Chronic Conditions."

Ellen C. Moore MD.

Ellen C. Moore, M.D., Interim Chief
Immunology, Allergy & Rheumatology Division

Children's Hospital of Michigan
3901 Beaubien Boulevard Detroit, Michigan 48201-2196
Allergy/Immunology appointments 313.745.4450
Rheumatology/Immunology appointments 313.745.4450 Fax 313.993.3873

The Detroit Medical Center

Wayne State University
DMC Children's Hospital of Michigan

Wayne State University
School of Medicine

Department of Pediatrics
Division of Pulmonary Medicine and
Infant Apnea Identification Program

Ibrahim Abdulhamid, M.D.

Debbie Toder, M.D.

June 22, 1999

Judith Hovey
23161 Marine Avenue
Eastpointe, MI 48021

Dear Ms. Hovey:

This is to confirm that we will assist you in reaching fathers of children with Cystic Fibrosis for the purpose of your study on the needs of fathers parenting children with chronic conditions. Of course, this is dependent on approval of the Human Subjects Committee here at Wayne State University and appropriate privacy safeguards.

I wish you every success with this project.

Sincerely,

Debbie S. Toder, M.D.
Pediatric Pulmonologist
Director, Cystic Fibrosis Center
Office: (313) 745-5541
Fax: (313) 993-2948
email: dtoder @ med.wayne.edu

DT:WE:20
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The Detroit Medical Center

Wayne State University
DMC Children's Hospital of Michigan

Wayne State University
School of Medicine

Department of Pediatrics
Division of Primary Care

Mary Lu Angelilli, M.D.
Director, Division of Primary Care
313.745.2336

Adolescent Medicine
313.745.4045

Alcsea A. Backos, M.D.
Yvonne M. Friday, M.D.
Sharon P. Marshall, M.D.
Anju Sikand, M.D.
Kathryn L. Wright, D.O.

Ambulatory Pediatrics
313.745.4323

Ahdi Amer, M.D.
Mary Lu Angelilli, M.D.
James W. Collins, M.D.
Howard Fischer, M.D.
Teresa G. Holtrop, M.D.
Katherine Ling-McGeorge, M.D.
Dilli Ramesh, M.D.
Rosemary Shy, M.D.
Lynn Smitherman, M.D.

Internal Medicine - Pediatrics
313.745.4045

Eric Ayer, M.D.
John Hopper, M.D.
Howard Schubiner, M.D.

June 30, 1999

To Whom It May Concern:

I am writing in support of Judith K. Hovey and her proposal, "The Needs of Fathers Parenting Children with Chronic Conditions". This support includes the permission for Dr. Hovey, the Principle Investigator, to contact selected families of the patients of Dr. James Collins and myself to obtain data for the completion of her study.

Lynn C. Smitherman, M.D.
Assistant Professor of Pediatrics
Wayne State University
University Pediatrics Faculty Practice
Division of Ambulatory Pediatrics
Children's Hospital of Michigan

Children's Hospital of Michigan
3901 Beaubien Detroit, Michigan 48201-2196 Fax 313.993.7124

APPENDIX D

Informational Letter

Informational Letter

Dear Mr. _____,

Because you are a father, you are in the best position to provide information that will help health professionals improve the care that we give to families, both with well children and with children with chronic conditions. Therefore, as a father, I invite you to be a part of this study although there will be no direct benefit to you.

The investigator is a registered nurse currently enrolled in the Ph.D. Program in Family and Child Ecology at Michigan State University. She is working on a research study about families who have children with chronic conditions and about families with children who do not have chronic conditions. Because the well being of one family member affects every other family member, she is asking for information about your concerns, your beliefs and feelings about caring for your child(ren), your coping, some general information, your view of your spouse's concerns and coping, and about your children, both with and/or without chronic conditions. The study is entirely voluntary and your decision to participate or not participate will in no way affect or interfere with the care you receive or might receive in the future from your child's health care provider(s).

A questionnaire has been enclosed that will take about thirty minutes to complete. Please fill it out and return it within the next week if possible. There is also a stamped, self-addressed envelope in which to return your completed questionnaire and a two-dollar bill as a token of appreciation for your anticipated participation.

The needs of fathers and the ways they view their needs are frequently different from others. The answers of each father will not necessarily be the same. There are no wrong answers.

When you look at the questionnaire, you will notice that there is no place for your name. Please do not write your name anywhere on the questionnaire. This way the answers you give me will be totally confidential. The information you provide will be combined with the answers of other fathers to give an overall picture. Individual responses will not be singled out for use in any way. When you read the questionnaire, you may choose to answer any or all of the questions. Return of the completed questionnaire will indicate your voluntary consent to participate. If you do not wish to participate after all, please return the blank form in the enclosed envelope.

The University Committee on Research Involving Human Subjects (UCRIHS) chair: David E. Wright, can be reached at (517) 355-2180 if you have any questions regarding your rights as a research subject. The investigator, Judith Hovey who can be reached at (248) 370-4477 will answer any questions you have regarding the study. Dr. Peter Lichtenberg, Chairman of the Wayne State University Behavioral Investigation Committee can also be contacted if you have questions regarding your rights as a research subject at (313) 577-5174. Thank you for your consideration.

Sincerely,

Judith K. Hovey, PhDc MSN, RN, CPNP

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REFERENCES

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