FAMILIES OF CHRONICALLY ILL CHILDREN: THE RELATIONSHIP BETWEEN MOTHERS' REPORTS OF NORMALIZATION AND SOCIAL SUPPORT

by

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Thesis submitted to the
School of Graduate Studies and Research
in partial fulfilment of the requirements for the degree
of Master of Science in Nursing.

University of Ottawa

July, 1996.

ISBN 0-612-16437-3

Canada

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ABSTRACT

The purpose of this study was to explore mothers' reports of the use of normalization in families of chronically ill children. This study tested the hypotheses that mothers of chronically ill children who reported high use of normalization by their families had higher levels of perceived social support. Additionally, the internal reliability of the Normalization Scale (Murphy, 1992) was determined. A non-probability purposive sample of thirty-three mothers of chronically ill school-aged children was recruited from a medical day unit of a regional pediatric tertiary health setting. Employing the Family Management Style Model (Knafl & Deatrick, 1990) as a conceptual framework, the study used a descriptive correlational design. Data were collected from mothers using the Normalization Scale (Murphy, 1994), the Personal Resource Questionnaire, (Weinert, 1987) and a demographic questionnaire. Data analysis was completed using descriptive and correlational analyses. Mothers' reported use of normalization by their families was found to be associated with perceived social support ($r=.36$; $p<.03$), and their satisfaction with help received from their social support network ($r_S=.34$; $p=.05$). The relationship between mothers' reported use of normalization and the size of the social support network was not significant. The study demonstrated that family and friends are the sources of support that mothers most frequently cite as helpful. This investigation also confirmed the importance of health care professionals in the family's process of normalizing their child's illness and their family life. Support groups were not perceived as helpful by these

mothers.

The findings of this study have the potential to increase nurses' awareness of normalization as a prevalent family management style and, to guide nurses in both the assessment and selection of supportive intervention strategies. Additionally, the results may be helpful to current concept development regarding normalization as a specific management style in families of chronically ill children.

ACKNOWLEDGMENTS

I would like to acknowledge the many individuals who have contributed to this project coming to fruition.

To the members of my research committee, Dr. Elizabeth Cragg for her patient guidance and direction, Professor Jean Dunning for her expert knowledge and insightful feedback, and Pat McCarthy for her generous contributions of time and expertise to this work.

I would like to express my gratitude to the mothers in this study who have willingly shared their experiences of life with their chronically ill child.

I would like to recognize the financial contributions from the Canadian Nurses Foundation and the Hospital for Sick Children School of Nursing Alumnae.

I wish to express my appreciation to my graduate student colleagues, Judy Rashotte, Jill Stevenson-Gale, Leslie Newell, and Riek VanDenBerg. I have been honored to learn in the supportive milieu created by these truly remarkable women.

I would like to acknowledge the unfaltering support provided to me by my cherished husband Orland and my children Amanda and Christian. Their love and assistance have sustained me throughout this process.

And finally, I would like express gratitude to my parents Margaret and Norris Mara and to my family of origin. It is in this environment that I have learned the importance of a supportive family network and the habit of perseverance towards a desired goal.

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CHAPTER ONE

PROBLEM, PURPOSE AND RESEARCH QUESTIONS

Problem

Chronic physical illness in Canadian children is a significant concern. Estimates of the incidence of chronic physical illness range from 7% to 15% (Austin, 1991; Oderkirk, 1993). The Ontario Child Health Study (1987) reported the prevalence of chronic illness in children 4 to 16 years was 177/1,000 (Cadman, Boyle, Szatmari & Offord, 1987).

According to the 1991 Canadian Health and Activity Limitation Survey (HAL) 389,400 Canadian children -- 7% of all children in Canada -- had at least one long term condition (Oderkirk, 1993). These conditions included asthma, bronchitis and other lung conditions, heart and kidney conditions or diseases, cancer, diabetes, epilepsy, cerebral palsy, spina bifida, cystic fibrosis, muscular dystrophy, paralysis, arthritis behavioral or emotional conditions, mental handicaps, learning disabilities, missing or malformed limbs and hypertension (Oderkirk, 1993).

As a result of decreased childhood mortality rates, improved neonatal care, and mass immunization programs, long term conditions and chronic illness have replaced infectious diseases as the most challenging health problems faced by children (Oderkirk, p. 1993). By 1986, more than 99% of Canadian children with a long term condition or

chronic illness were living within the family unit rather than in institutions or specialized centers (Oderkirk, p. 23). Thus, the day-to-day management of these children is an issue of concern for families as well as the communities and services supporting these families.

Knafl & Deatrick (1990) have conceptualized how families adjust to chronic illness over time and have developed the term "Family Management Style" to depict a family's response to chronic illness in their children. The Family Management Style Model (FMS) describes three interactive components within these families: the family's definition of the situation, family member's management behaviors and the sociocultural context. The FMS model guided this study.

Definition of the Situation. Research to date suggests that one of the common ways that families with a chronically ill child attempt to manage their daily family life is to engage in normalization behaviors or living life as normally as possible (Darling, & Darling, 1982; Davis, 1963; Deatrick, Knafl, & Walsh, 1988; Krulik, 1980). Normalization, as a specific management style, is defined as "the constant process of actively accommodating the changing physical and emotional needs of the chronically ill child" (Knafl et al., 1988). Families who use normalization as a management style, acknowledge the existence of the chronic illness yet define their family and the social consequences of the child's illness as normal. Additionally, these families engage in behaviors designed to demonstrate the essential normalcy of their family

to others (Knafl & Deatrick, 1986). The purpose of normalization is to promote the chronically ill child's development as a member of the family and society (Holaday, 1978).

Normalization Behaviors. Normalization strategies used by parents are thought to alleviate the child's sense of being different and contribute to the family's ability to lead what they define as a "normal family life" (Knafl & Deatrick, 1987; Krulik, 1980). A positive outcome of the use of normalization is that it supports hope and focuses on the abilities of the chronically ill child rather than on the child's deficits (Robinson, 1993). Regardless of the diagnosis of their child's illness, normalization is the response preferred by families with chronically ill children (Davis, 1963; Krulik, 1980; Darling, & Darling, 1982; Deatrick, et al., 1988). Factors related to parents' use of normalization strategies include the child's age, the nature of the child's condition and the time since diagnosis (Knafl & Deatrick, 1986). Although the factors impacting families use of normalization have been described, for instance, child's age, age at onset and the nature of the child's illness (Knafl & Deatrick, 1986), little is known about the extent to which these factors impact normalization as a family management style.

The Sociocultural Component. This component of the Family Management Style model includes the social, political, and economic structures and processes that shape how family members define and manage the illness

experience (Knafl, & Deatrick, 1990). The specific factors associated with the definition of the sociocultural component of the model have been neither clearly described, nor investigated by research using the family management style model as a framework. However, external support has been identified as an important component of the sociocultural context of family management. For this investigation, social support is conceptualized as a dimension of the social structures and processes that shape how families of chronically ill children define and manage the illness experience. Social support has been found to contribute to the success of parents' normalization efforts (Roskies, 1972; Voysey, 1972; Darling & Darling, 1982). Specifically, social support provides validation to the family's definition of "life as normal" (Darling & Darling, 1982; Robinson, 1993; Roskies, 1972; Voysey, 1972). Health care professionals are viewed as part of the social support system available to families with a chronically ill child (Brandt, 1984b; Gallo, 1990; Gibson, 1988; Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994). Robinson (1993), has described health care professionals as potentially having both a positive and a negative effect on how families define the meaning of their child's illness and their use of normalization strategies.

The aim of this study was to describe the extent to which mothers of chronically ill children report normalization as a management style. Furthermore, the study explored the relationship of mothers' perceptions

of their family's use of normalization and social support variables including; size of social support network, mothers' satisfaction with the help provided by their social supports and a global measure of perceived social support.

Significance of the Problem

Given the pervasiveness with which research suggests that families use normalization as a strategy to manage daily living with children experiencing chronic illness (Darling, & Darling, 1982; Davis, 1963; Deatrick, Knafl, & Walsh, 1988; Krulik, 1980), it is essential that nurse researchers further explore this concept. Nurse researchers may examine the family as both a unit of care as well as a unit of analysis (Feetham, 1984, 1990). Inquiry in the area of families' response to childhood chronic illness is germane to the emergent specialty of family nursing. Robinson (1995) proposes a schema of four categories of family research depending on the focus of inquiry and analysis. These four categories include investigations that range from the individual as a family member to the family as an aggregate. Robinson's (1995) four categories of family research include: (1) individual/family member, (2) individual/family subgroup, (3) family group, and (4) individual/family system. This study considered the mother's perceptions of normalization and social support as foreground, with the family as context. That is to say, the mother's perceptions of her family's management and social

support are the phenomena of interest, yet her perceptions are conceptualized within the environment of the family unit. Within Robinson's schema, this study would be considered an example of the first category or level one family research.

In their work with families who have with a chronically ill child, nurses are in a key position to validate the meaning of the child's disability to the family unit and to support the family's normalization strategies (Bossert, Holaday, Harkins, & Turner-Henson, 1989). However, it has been found that nurses have misinterpreted normalization strategies as "denial" of the child's chronic condition (Bossert et al., 1989) and that family normalization strategies have been undermined by nurses' lack of awareness of this important management style (Robinson, 1984, 1985, 1993). The findings of this study have the potential to increase nurses' awareness of normalization as a management style common to families with a chronically ill child. This study has the capacity to contribute to the knowledge of normalization as an important management style in families with chronically ill children.

Nurses, as members of the professional health care team, are a component of the social support network for families of children with chronic illness. In addition to the identification of the extent to which the health care professional is a source of external support to the family, this study attempted to identify the extent to which other sources of support were important. Significant associations identified

between normalization and perceived social support will provide nurses with direction in the assessment of social support systems as an important factor in the family's definition of their situation as "normal." Furthermore, this knowledge lends strength to nurses' selection of social support interventions, such as support mobilization, to enhance normalization strategies in families with chronically ill children.

Through the exploration of factors thought to be associated with normalization strategies, this study enhances our understanding of the theoretical components of the Family Management Style Model. Although research has defined and described the components of the Family Management Style Model, these components have not been operationalized.

Only one instrument was found which attempted to quantify the use of normalization as a family management style. This study provides additional psychometric data on the normalization scale developed by Murphy (1994) using a population similar to the one on which the instrument was initially evaluated. By sharing this data, revisions can be made that will enhance the instrument's use in both the clinical assessment of normalization and further research efforts.

Study Purpose

The purposes of this descriptive, correlational study were to: (1) enhance understanding of normalization as a management style for families who have a child diagnosed with a chronic illness (2) examine the relationship between normalization and perceived social support in mothers of chronically ill children and (3) determine the internal reliability of the Normalization Scale (Murphy, 1994).

Research Questions

The specific questions for this study were:

1. To what extent do the mothers of chronically ill children report the use of normalization by their families?

2. Is there an association between the mothers' reports of their family's use of normalization and their level of perceived social support?

3. Is there an association between the extent to which mothers of chronically ill children report the use of normalization by their families and the size of their perceived social network?

4. Is there an association between the extent to which mothers of chronically ill children report the use of normalization by their families and how satisfied they are with their social support network?

Definition of Terms

For purposes of this study seven terms were defined as follows: Chronic illness (or condition) refers to a physical impairment that rarely is cured, is characterized by both acute episodes and stable periods, and interferes with the maximum functioning of the child (Thomas, 1984). For the purposes of this investigation the child's chronic condition must require daily care, for example, medication, treatments or monitoring.

Family is defined as "two or more persons who are joined together by bonds of sharing and emotional closeness and who identify themselves as being part of the family" (Friedman, 1992, p. 9). The Family Management Style Model "is not predicated on a particular definition of family" (Knafl & Deatrick, 1990, p. 8). Thus, the model is applicable to research grounded in varying definitions of what constitutes family. It is congruent with the self perception dimension of the components of the Family Management Style Model and includes the various family structures in contemporary society. For this study, the family unit must include a child with a chronic health problem.

The mother of a chronically ill child refers to the natural or adoptive mother or the legal guardian of the chronically ill child.

Family Management Style refers to how the family as a unit responds to a child's chronic condition of illness (Knafl & Deatrick, 1990).

Normalization, as a specific management style, is defined as "the constant process of actively accommodating the changing physical and emotional needs of the chronically ill child" (Knafl et al., 1988, p. 17). Defining criteria for normalization have been delineated and include (1) acknowledgement of the existence of the impairment, (2) defining their family life as essentially normal, (3) defining the social consequences of their situation as minimal, and (4) engaging in behaviors designed to demonstrate the essential normalcy of their family to others (Knafl & Deatrick, 1986, p. 219). The Normalization Scale (Murphy, 1994) will be used to measure normalization (see Appendix D).

Social Support is a multidimensional construct. The dimensions of social support include (a) provision for attachment/intimacy; (b) social integration - being a integral part of a group; (c) opportunity for nurturant behavior; (d) reassurance of worth as an individual and in role accomplishments; and (e) the availability of informational, emotional, and material help. These five dimensions of social support are potentially available from sources within the family system or external to it. Thus, social support can emanate from informal sources

such as spouse, family members, or friends. In addition, it can arise from more formal sources such as professionals, agencies, self-help groups or other social organizations (Weinert, 1984, 1988). Three dimensions of social support measured in this investigation were the size of the social support network, the satisfaction with help received from social support resources, and perceived social support .

Size of Social Support Network refers to the number of personal resources that a mother identifies in stressful life situations. The size of the social support network will be measured by the Personal Resource Questionnaire-Part 1 (Brandt & Weinert, 1981) (Appendix E).

Satisfaction with Help Received from Social Support Resources refers to the mothers' reports of satisfaction with her identified social support resources. Satisfaction with help will be measured by the Personal Resource Questionnaire-Part 1 (Brandt & Weinert, 1981) (see Appendix E).

Perceived Social Support is defined as consisting of the provision for attachment, intimacy and social integration. Perceived social support includes the opportunity for nurturant behavior and reassurance of worth as an individual. It includes the mothers' perception of the availability of informational, emotional and material assistance (Weinert & Tilden, 1990). For this investigation, perceived social

support as a global measure of social support, will be measured by the Personal Resource Questionnaire-Part 2 (Brandt & Weinert, 1981) (Appendix E).

CHAPTER TWO

REVIEW OF THE LITERATURE AND CONCEPTUAL FRAMEWORK

This chapter includes a review of relevant empirical and theoretical literature pertaining to normalization, the Family Management Style Model, and related social support concepts as they apply to families of chronically ill children. In addition, the conceptual framework, which outlines the key variables of this investigation is presented. The chapter concludes with the research hypotheses and study assumptions.

Review of Relevant Literature

Chronic Illness in Children

A chronic illness refers to a physical impairment that rarely is cured, and is characterized by both acute episodes and stable periods, and interferes with the maximum functioning of the child (Thomas, 1984). Chronic illness in children has been associated with increased physical and psychosocial problems in the affected child (Harkins, 1994; Cadman et al., 1987). Despite the increased health risks and vulnerability associated with chronic illness the population of children with chronic illness is increasing. The enhanced survival of children with chronic illness can be attributed mainly to improved health care and technological improvements (Harkins, 1994; Oderkirk, 1993).

Chronic illness affects not only the chronically ill child, but also

the entire family unit, and can be viewed as a stressful event (Anderson & Elfert, 1989; Austin, 1991; Canam, 1993). Impacted by the illness are many aspects of family life including financial, social, emotional, and coping processes (Harkins, 1994; Holaday, 1978). In addition, how the family views the child's illness and manages the treatment regime is critical to how the child adapts to the illness demands and meets age-related developmental requirements (Anderson, 1981; Harkins, 1994; Knafl & Deatrick, 1986). Normalization is cited as a common adaptive process in families with a chronically ill child, which has as it's goal the optimal functioning of the child and the family unit (Anderson, 1981; Bossert, Holaday, Harkins, & Turner-Henson, 1989; Knafl & Deatrick, 1986, 1988; Krulik, 1980).

Historical Perspective of Normalization

The origin of the concept of normalization has been traced to a 1959 Danish law governing services to the mentally disabled. The Danish law proposed letting the mentally retarded obtain an existence as close to the normal as possible (Wolfensberger, 1977a). Wolfensberger is responsible for the introduction of an expanded form of the concept to North America in the early 1970's (Olson, 1985). In it's North American form, Wolfensburger (1977b) viewed normalization as a "meta-theory" applicable not only to services for the mentally disabled, but to all types of human services. Wolfensberger (1977a) defined normalization as the utilization of means aimed at establishing, enabling or supporting behaviors, appearances, experiences and interpretations that are as

culturally normative as possible. The concept of normalization has been applied to individuals who are "devalued" because they are different from others and this difference is "negatively valued" (Wolfenberger, 1977a, p. 8).

Normalization, as a family response to chronically ill children in particular, was first described by Davis (1963) in his classic study of 14 families who had a child with poliomyelitis. Davis identified normalization and disassociation as interactional stratagems used by the families. Furthermore, Davis found normalization to be the parents' favored stratagem for adjusting to the experience of poliomyelitis in their children. Several authors during the 1970's further applied the concept of normalization to families of children with a variety of chronic physical conditions (Darling, 1979; Holaday, 1978; Roskies, 1972; Voysey, 1972). These early, descriptive, qualitative studies documented the pervasiveness of normalization, described behavioral strategies used by parents, and identified factors related to parents' adoption of normalization as a day-to-day management style.

Anderson (1981), in her ethnographic study of four families with a chronically ill child, attempted to describe the phenomenon of normalization. Anderson stated that "the emphasis was on deconstructing the disease label, and emphasizing the normality of the child" (p. 428). Anderson's work emphasized the significance of the meaning of the child's illness to the family and identified that the parent's perception of the illness influenced how the family managed their interactions with the affected child.

Through the process of concept analysis, Knafl & Deatrick (1986) identified four criteria for defining and recognizing normalization: (1) Acknowledgement of the existence of the impairment; (2) Defining their family life as essentially normal; (3) Defining the social consequences of their situation as minimal; and (4) Engaging in behavior designed to demonstrate the essential normalcy of their family to others (p.219).

As a specific management style for parents of chronically ill children, normalization has been defined as, "the constant process of actively accommodating the changing physical and emotional needs of the child" (Deatrick et al., 1988). The purpose of normalization for these families is to promote the chronically ill child's development as a member of the family and society (Holaday, 1984).

Knafl and Deatrick (1990) developed a model to describe family management style as a reflection of the day-to-day management of the child's illness within the context of the family unit and the broader social community. The Family Management Style Model is an over-riding model that designates how a family responds to a child's chronic illness. The term "management" captures the theorists' intent to focus on an "active behavioral" emphasis, and "style" denotes a consistent manner of response (Knafl & Deatrick, p. 17). Normalization in the model has been designated as a particular management style used by families of chronically ill children.

Normalization appears to be a significant family management style as it is cited as the most prevalent family response to children's chronic illness (Davis, 1963; Darling, 1979; Krulik, 1980; Knafl,

Deatrick et al., 1988). In examining family experiences in thirty five families with congenitally handicapped children, Darling & Darling (1982) stated that, ideally all families should achieve normalization. Thus, normalization has been viewed as a positive family management style.

Normalization Behavioral Strategies

Several authors have used a variety of terms thought to describe behavior that displays normalization strategies. Davis (1963) described three categories of parental interactional stratagems used to normalize: (1) minimizing abnormalities in the child's physical appearance, (2) participation of the child and family in usual activities, and (3) maintenance of ongoing social ties. Voysey (1972) interviewed twenty families with disabled children and found that families managed interaction with others outside the immediate family by using impression management in order to project a desirable image of their child and family. Strategies considered as impression management included (1) conveying the desired image, (2) breaking through interactional problems with others by communicating their (family's) definition of the situation, (3) controlling the amount of information that they reveal to others, and (4) obtaining information from significant others (physicians, friends) regarding their perceptions of their child.

Krulik (1980) identified "successful normalizing tactics" aimed at strengthening the resources and coping ability of the child and aimed at altering the family environment to compensate for and accept the child.

Krulik further identified five factors underlying the successful use of normalizing tactics, including (1) preparation of the child and his/her close environment, (2) child participation in decision-making and management of the regimens, (3) the illness regimen management as a shared experience by the whole family, (4) the illness regimen management as an experience shared with people in the child's social environment and (5) identification of areas where control can be included so that the feelings of uncertainty, passivity, and helplessness can be decreased.

Anderson (1981) found normalization strategies were evident in families who were coping well. Anderson referred to "lifestyle adjustment" to describe how the four families in her ethnographic study minimized the "deviant label" and reconstructed the disease label by emphasizing the "normality of the child" (p 428).

Deatrick's et al. (1988) study of 15 children with osteogenesis imperfecta found that the families of these children developed management behaviors in the following areas: the child's activities of daily living, disciplining and monitoring the child, and engaging in family activities. Parents identified these behavioral strategies as essential to a "normal" family life.

In a recent study of seventy-six mothers and their chronically physically disabled children, Murphy (1994) examined the relationship between the family's use of normalization and psychosocial adjustment in children diagnosed with diabetes, cystic fibrosis, arthritis, renal-urological, and gastrointestinal conditions. Murphy developed a

normalization scale for this study based on the conceptual domains of normalization identified by Knafl and Deatrick (1986). The scale included four subscales of the normalization dimensions including (1) the actual effect of the chronically physically disabled child on the family, (2) the perception by the family and others of the chronically physically disabled child and family, (3) comparison of the chronically physically disabled child and the family to other chronically physically disabled children and families, and (4) encouragement of normal activities. The children's psychosocial variables were measured by the Harter's Self-Perception Profile for Children (1985) and Stein and Jessop's Personal Adjustment and Role Skills Scale (1990). Murphy found that mothers' perceptions of their family and their disabled child as normal were strongly related to overall high personal adjustment, as well as better peer relationships and better psychosocial functioning in their physically disabled child. Normalization was not related to the disabled child's perception of self-competence in this study. The normalization scale provides a means to measure the extent to which a family uses normalization as a management style.

Robinson (1993), using the constant comparative methodology, analyzed the accounts of sixty-two families with a family member diagnosed with a chronic illness. Nine informants were parents of children with a variety of chronic illnesses. Robinson found that different families performed the "story of normalization" in different ways and described these performances as practices or management behaviors. These practices included covering up the illness, the use of

desensitization through interactions with others when visible differences could not be covered up, doing "normal" things, and giving something up to gain something else that was of value to the family's definition of normal. Limitations of Robinson's study were the large number of participants for the qualitative methodology used and the fact that the data were collected from individual family members rather than the whole family system.

Normalization behaviors may vary among family members and within the same family member over time. The variation in normalization behavior over time was well illustrated in case study research with one five member family conducted by McCarthy and Gallo (1992). In this case study, the parents shared the belief that their twelve year old diabetic son should assume increased responsibility for the daily management of his diabetes, but the affected child preferred shared responsibility with his parents. Additionally, McCarthy and Gallo found that the father's perception was that his son's diabetes had a major impact on his child's life, yet the son perceived the effect of his diabetes as minimal.

In summary, despite using different terminology, several authors have described similar behavioral strategies used by families to normalize the experience of life with a chronically ill child. Research appears to support normalization as a management style preferred by the families of chronically ill children (Davis, 1963; Darling, 1979; Deatrick et al., 1988; Krulik, 1980, Robinson, 1993). The work of Knafl and Deatrick (1986) has established the defining criteria for these

family normalization strategies as including the families' acknowledgement of the existence of the impairment, defining their family as essentially normal, defining the social consequences of their situation as minimal and engaging in behavior designed to demonstrate the essential normalcy of their family to others. Murphy's (1994) work seems particularly significant in operationalizing these behavioral strategies.

Normalization strategies have been shown to be influenced by two categories of factors: characteristics of the child, such as, the child's age and illness severity; and by external support (Knafl & Deatrick, 1986). External support contributed to successful normalization in families by providing validation, from persons outside of the immediate family, that their child and family was "essentially normal" (Knafl & Deatrick, p. 218).

Normalization and Social Support

Social support is a multidimensional concept and thus includes a number of related phenomena (Gottlieb, 1981; Weinert, 1984). Social support concepts and their operationalization have been described by several theorists, and can be classified into three broad categories: social embeddedness, perceived social support and enacted support (Barrera, 1986). According to Barrera, social embeddedness refers to connections individuals have to others in their social environments, including the concept of a social network. Perceived social support refers to an individual's cognitive appraisal of being "reliably

connected to others" (Barrera, p. 416). Enacted support is described as actions that individuals perform while providing support to others.

Critical to the conceptualization of social support constructs is the notion of reciprocity (Fugate-Woods, Yates, & Primomo, 1989). Reciprocity refers to the individual's need to return support to others in addition to being the recipient of support. In families with a chronically ill member, the ability to reciprocate support may be compromised by the burden of illness and this may place a strain on the social support network and may contribute to social isolation for the individual and the family (Tilden & Weinert, 1987; Woods, Yates & Primomo, 1989).

It has been hypothesized that social support acts to promote family well-being by buffering the effects of stress in families with a chronically ill family member (Barrera, 1986; Cooke, Rossmann, McCubbin, & Patterson, 1988). The stress buffering effects of social support in families with a chronically ill child have been investigated. Brandt (1984b), using self-administered questionnaires, examined the relationship between stress, social support, and maternal discipline in ninety-one mothers of children with a developmental handicap . She found that, in situations of stress, maternal discipline was reduced when the mother reported high levels of support. Social support was inversely related to to restrictive discipline for high stress mothers, but not for low stress mothers.

Similarly, in a prospective longitudinal study of parent-infant attachment in 36 mothers of infants with and without a handicap Capuzzi

(1989) reported that the presence of social support reduced the stress of having a handicapped child and facilitated maternal attachment. Affirmation support, as measured by the Norbeck Social Support Questionnaire, was significantly associated with maternal attachment behaviors in Capuzzi's study.

From the early conceptual beginnings, normalization strategies in a family have been considered within a broader social context. Several authors have identified the availability of appropriate educational and treatment resources as enhancing the parents' abilities to use normalization as a coping strategy (Davis, 1963; Darling & Darling, 1982; Voysey, 1972). Krulik's (1980) study of twenty school aged children with a variety of chronic illnesses emphasized the importance of a shared illness management regime between the family and the chronically ill child's school. In Gibson's (1988) study of 56 parents of children with cystic fibrosis, social support was the resource identified by the largest number of parents as influencing their ability to cope with their child's diagnosis. Supports for the parents in Gibson's study were (a) the spouse or family, (b) the multidisciplinary team in the cystic fibrosis clinic, and (c) the Cystic Fibrosis Foundation. Gallo's (1990) case study of a family with a child with Type 1 insulin dependent diabetes, further elucidates the concept of the support component of coping with a child with a chronic illness. Gallo identified two major types of support. The first type of support was personal resources which included employment, health benefits, marital harmony and absence of illness in other family members. The second type

of support was family system resources including relatives, friends, school personnel and health care professionals. These sources of support were consistent with earlier findings (Gibson, 1988). Venter's (1981) study of one hundred families with cystic fibrosis found families who reported "sharing the burdens of illness"--both among family members and with individuals outside the family--were associated with higher levels of family cohesion, positive communication, and satisfaction with the family unit. Family outcome measures in Venter's study were assessed by the self-administration of the Adequacy of Family Functioning Scale and semi-structured interview guides. In addition, Venter found that the two familial behavior patterns which elicit continuing support from contacts outside the family were (1) maintaining meaningful external contacts and (2) perceiving outside contacts as helpful. Similarly, McCarthy and Gallo (1992) identified personal resources and social network as dimensions of the sociocultural context of normalization.

According to Caplan, social support is thought to influence family coping in three ways: (1) by providing emotional support to the family, (2) by providing instrumental assistance of goods and services, and (3) by providing social expectations (as cited in Barrera, 1986).

In a case study analysis of a family with a school aged boy with diabetes, Gallo (1990) described how these social support influences related to the family's definition and management of the child's illness. This family's shared management style was influenced by the positive nature of the family's personal and family system resources (father's employment and health benefits), and a social network

(relatives, friends and health care professionals) that reciprocally influenced the family members' definitions and management. This is one example where the literature has described a clear relationship between the the concept of social support as it impacts the definition and management of life with a chronically ill child.

Correlational studies have examined the relationship of social support variables to positive family outcomes, such as family cohesion (Venters, 1981), parental coping (Gibson, 1988), maternal attachment (Capuzzi, 1989), and maternal discipline (Brandt, 1984). However, there is a paucity of research that correlates social support variables to normalization as a specific management style for families with a chronically ill child. Within the social support network of families of a chronically ill child, health professionals have the potential to influence how the family defines and manages their child's illness and their family life (Knafl & Deatrick, 1986).

The Influence of Health Care Professionals in Supporting Normalization Strategies

Several authors have identified health care professionals, including nurses, as significant to the family's normalization processes (Darling & Darling, 1982; Robinson, 1993; Roskies, 1972; Voysey, 1972). Knafl and Deatrick (1986) determined that for parents to maintain normalization they needed validation from persons outside the family and that health care professionals were very important in this regard.

Research has identified that health care providers may impede,

rather than support, parents' abilities to cope with their chronically ill children (Ray & Ritchie, 1993; Robinson, 1985, 1993; Thorne & Robinson, 1988; Stewart et al., 1994). Robinson (1993) found that health care professionals can have a negative influence on a family's use of normalization. For example, health care professionals may interpret normalization practices as evidence of denial. In addition, they may prescribe treatment regimes that interfere with the family's normal routine or provide information that puts an emphasis on problems or obstructs the family's decisions regarding "trade-offs". Trade-offs refer to decisions families make to give up something in favour of something else that is of greater value to their definition of the situation as normal. A cited example of a trade off is the decision to use a wheel chair in order to shop with a family member at a mall (Robinson, p. 19). Robinson (1985) found that, although parents of chronically ill children defined hospitalization as part of every day life, and incorporated hospitalization as part of the "ongoing trajectory" of the child's chronic illness, hospitalization was found to be a disruptive force to families' normalization efforts when health care professionals and routines "sabotaged" the child's normal routines. Parent's expert knowledge of their chronically ill child may be "systematically disregarded by professional health care providers" when the child is hospitalized (Robinson, 1985, p. 62). Anderson and Elfert (1989), in an ethnographic longitudinal study with 45 families caring for a child with a chronic health problem, found that interactions with health professionals were not supportive and often reinforced the notion

that mothers were to blame for their child's health problem.

Thus, it would appear that the literature supports health professionals as part of the external support network for families with a child with a chronic illness. Furthermore, the need for health care professionals to have a better understanding of the use of normalization as a family management style has been identified.

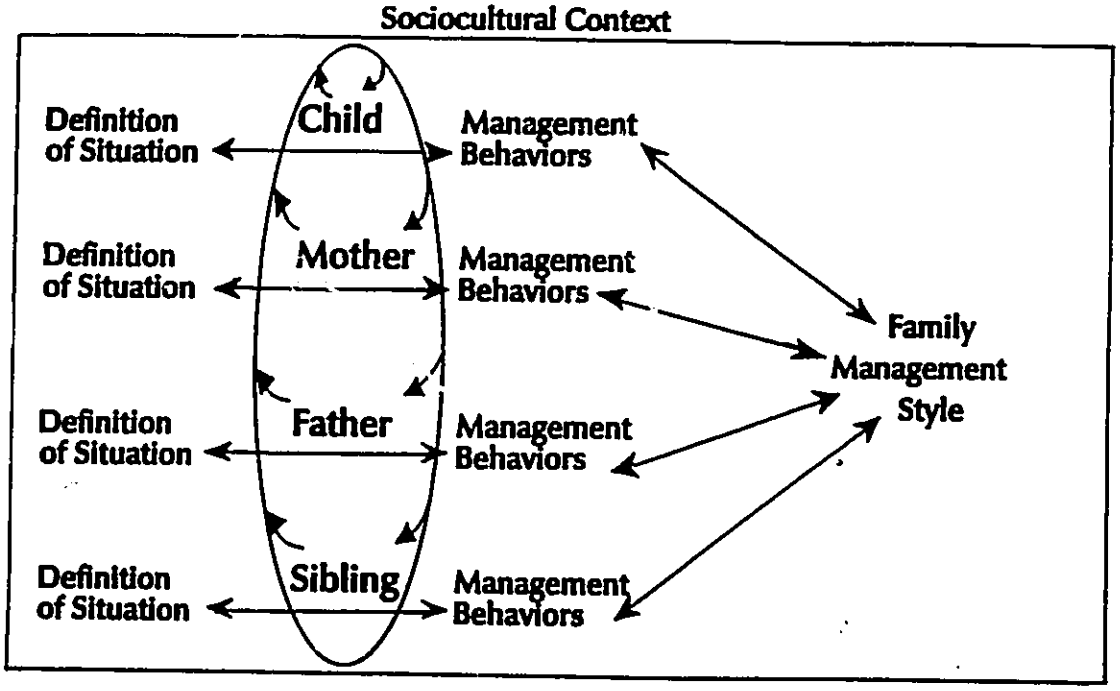

Figure 1. Family Management Style Model (Knafl & Deatrick, 1990, p.8)

Family Management Style Model

The conceptual model guiding this study is the Family Management Style Model as conceptualized by Knafl and Deatrick (1990) (Figure 1). Family Management Style refers to how the family, as a unit, responds to a child's chronic condition. Individuals are considered within the context of the family system. According to Knafl and Deatrick, the term management implies the active, behavioral component of the family's response to the child's illness and is defined as, "actions families and

their individual members engage in as a result of having a family member with a chronic illness and style connotes a somewhat consistent manner of response" (p. 9). The Family Management Style Model identifies three component concepts in reciprocal family relationships that apply to families with a chronically ill child: definition of the situation, management behaviors, and sociocultural context.

The first component of the model is the definition of the situation. The definition of the situation, is the individual family member's identification and interpretation of significant aspects of his or her setting. Definition of the situation includes both the defining process as well as the content of that definition (Knafl & Deatrick, 1990, p. 9). The resulting configuration of definitions that family members bring to bear in managing the child's chronic illness constitute the basis for action or behavior.

The second component of the model is management behaviors. Management behaviors are discrete behavioral accommodations that family members use to get along on a daily basis. Management behaviors include both individual accommodations and more general accommodations, as when family meals or vacation plans are altered to adapt to the special needs of the child with a chronic illness (Knafl & Deatrick, 1990). Management behaviors and definitions of the situation are inextricably interrelated. Family members' management behaviors are influenced by how they define the situation. Conversely, how they interpret the outcome of their management efforts influences the ongoing defining process. The goal of these management behaviors is to help the family unit, including

the chronically ill child, to accommodate the demands created by the illness.

Management behaviors have been further conceptualized in terms of five dimensions: goal, underlying conceptual dimension, implementer, foci, and target behaviors (p. 16). The goal refers to the result towards which the family's efforts are directed. Goals shape the nature of the target behaviors. However, goals themselves may not be obvious to the observers of the behavior. In fact, the same behavioral accommodation may derive from very different goals, both within a family and between families. The underlying conceptual dimension defines the descriptive or organizing framework characterizing the management behaviors. The identification of the underlying theoretical basis of the behavior extends the understanding of the significance of the day-to-day experiences of the family. Examples of underlying conceptual dimensions of management behaviors are family roles and relationships, decision making, and impression management. The implementer dimension of management behaviors describes who carries out the behaviors necessary to accommodate the needs generated by the child's illness or disability. The implementer may be the mother, father, siblings or other family member. Of particular interest is the evolving role of the affected child, as children usually become increasingly involved in the implementation of their own care. The foci refer to the points of concentration towards which the management behaviors are directed and may include the ill child, the family or the social system. Target behaviors are the actual observable, discreet behavioral accommodations

that family members use to manage on a daily basis and may also be directed towards the child, the family and the social system.

The third component of the Family Management Style Model is the sociocultural component. This component includes culturally, ethnically and religiously influenced values and beliefs as well as the social, political and economic structures and processes that shape how family members define and manage the illness experience. "An especially salient aspect of the sociocultural context is the culturally defined meaning of illness" (Knafl & Deatrick, 1990, p. 9). The effect of culture on parents' perceptions of their child's long term illness was well demonstrated in a comparison study between Chinese and Caucasian families. It was noted that Caucasian families emphasized the normality of their child while the Chinese families emphasized the comfort and contentment of the child (Anderson & Chung, 1982).

Summary

Together, the three components of the Family Management Style Model --definition of the situation, management behaviors and sociocultural context--provide a framework for conceptualizing how families and their individual members respond to chronic illnesses in their children (Knafl & Deatrick, 1990). Family management style is viewed as "an overarching construct that encompasses a variety of specific management styles" (Knafl & Deatrick). Normalization, as a specific management style in response to chronic illness in children, is conceptualized within this model, and is a key variable in this study.

The Family Management Style Model supports the reality that the

family unit is the key environment for the child with a chronic illness. The notion of a shared family perspective is inherent in the model and is congruent with recent theorizing regarding family nursing practice (Feetham, 1984, 1990, 1992) and the author's experience working with chronically ill children. Chronic illness in children is characterized by periods of change. Superimposed on the change caused by the chronic illness, are the adjustments inherent in the developmental process of both the child and the family unit. The reciprocity of the key concepts in the family management model, and the resultant dynamic nature of the model reflect the actual changing responses in a family with a child with a chronic illness. Although all management styles have not been clearly delineated, normalization as a specific style has been defined and described. This conceptualization of normalization as a specific management style in families with chronically ill children will enable the present study to examine the relationship of normalization strategies to the concept of social support (Figure One).

Other Management Styles in Families with a Chronically Ill Child

Several other management styles have been described in families with a chronically ill child including Denial, Disassociation, Thriving, Accommodating, Enduring, Struggling, and Floundering. Through concept analysis, Knafl and Deatrick (1986) have differentiated normalization from denial and disassociation as management styles.

Denial is distinguished from normalization mainly by the family's lack of acknowledgement of the child's disease. However, there are

dimensions of denial as a management style that may appear to be very similar to normalization: defining family life as normal, minimizing the social consequences of their situation and engaging in behaviors designed to demonstrate the normalcy of their family to others (Knafl & Deatrick, 1986).

Disassociation as a management style is viewed as the opposite to normalization (Knafl & Deatrick, 1986). The family that disassociates relinquishes the definition of their family as normal. These families identify significant negative social consequences to their situation and tend to be isolated from both normal society and other similarly situated families.

A recent study examined the response of sixty-three families to their child's chronic illness and found that the experience of chronic illness varied considerably across families (Knafl, Breitmayer, Gallo, Zoeller, in press). Five Family Management Styles were identified as follows: Thriving, Accommodating, Enduring, Struggling, and Floundering. Most families viewed their child as normal, viewed the illness as manageable, maintained an accommodative parenting philosophy and viewed the illness treatment regime as routine. Normalization was characteristic of both the Thriving and Accommodating Style. In contrast however, in three Family Management Styles (Enduring, Struggling, Floundering) normalization was not found to be a characteristic way of managing their child's chronic illness. Rather parents presented conflicting views on both their child's illness and their management to the illness. Although management styles other than normalization have

been described in the recent literature, research is in the early exploratory stages and conceptual relationships have not been clearly defined.

Chronic Illness in Children - Methodological Issues and Knowledge Gaps

In a review of fifty nursing research studies related to the care of chronically ill children, Ogden-Burke and Roberts (1990) commented that research-based knowledge for practice with handicapped and chronically ill children is only in its early stages. Their findings suggested that research was mainly exploratory or descriptive. Convenience sampling was most commonly used while some qualitative studies used purposive sampling.

Non-random sampling methods are apparent in a review of research on normalization and chronic illness in children. Studies of normalization have used mainly qualitative inductive approaches to identify and describe familial or parental management styles (Knafl & Deatrick, 1990). Thus, studies of normalization as a management style in families of children with chronic illness lack generalizability. Furthermore, an understanding of any potential relationships among the components of normalization as a management style is lacking. Recent studies of normalization, through quantitative methods and statistical analysis, are moving beyond inductive approaches to investigation of the phenomenon (Breitmayer, et al., 1992; Murphy, 1994).

The small sample sizes used in many of the studies poses another methodological concern. The small sample sizes may be related to the

emphasis on qualitative methods to describe management styles where sample size is determined by saturation and recurrent patterning (Forchuk & Roberts, 1993).

Further methodological issues are related to whether or not to choose samples for investigations according to the child's medical diagnosis. A categorical approach would group subjects based on a similar chronic illness diagnosis, whereas a non-categorical approach would include a variety of diagnoses within the same study sample. Ogden-Burke and Roberts (1990) identify an increased trend in research to use non-categorical approaches in families with chronically ill children. It has been argued that, regardless of the specific disease, children with diverse chronic medical problems have similar life experiences and that their needs are "shared among those with many types of chronic conditions" (Stein & Jessop, 1982, p. 361). Stein and Jessop (1989) reported that within each diagnostic illness category, variability of psychological and social parameters is as great or greater than variability between illness categories. It has been suggested (Stein & Jessop, 1982) that illnesses may be categorized according to a similarity in their psychosocial impact on families.

Both categorical and non-categorical approaches are reflected in research in the area of normalization. Categorical approaches were used by Davis (1963), Deatrick et al. (1988), and Gibson (1988), to study poliomyelitis, osteogenesis imperfecta and cystic fibrosis respectively. Non-categorical approaches were employed to study a wide range of chronic conditions by Holaday (1978), Krulik (1980), and Murphy (1994).

Although studies suggest that many chronic diseases appear to have similar impact on children and their families, there is a wide range of disease severity levels within the studies utilizing non-categorical approaches. Therefore, research related to the concept of normalization would be rendered more valid if the severity of the child's illness were better controlled in research design.

Concept analysis continues to be the focus of research on normalization and chronically ill children and their families (Murphy, 1994). Research needs to move beyond concept analysis to better understand the process by which families come to define their child and family circumstances as essentially normal (Knafl & Deatrick, 1986). Research also needs to identify the specific factors associated with the sociocultural context and to explore their impact on normalization. Research related to the concept of normalization needs to use quantitative methods. This is not to devalue the important conceptual work done through qualitative approaches, but rather to suggest that research needs to also examine the relationships among the emerging components in the Family Management Model and key child and family factors that mediate family response to chronic illness. This is the next logical step in order to work towards intervention studies to guide nursing practice in supporting normalization in children with chronic illness and in their families. The development of an instrument to measure normalization (Murphy, 1994) is an important advancement as it attempts to quantify family's use of normalization. As a new instrument, however, it will need further development, testing and revision.

Conceptual Framework of Present Study

The conceptual framework for this study is derived from the conceptual components of the family management model (Knafl & Deatrick, 1990). At an exploratory level, this study will examine the relationship between key child and maternal attributes and mothers' reports of normalization as a management style. Additionally, the study will examine the relationship between normalization and social support variables including the mothers' social support network, satisfaction with help received from social support resources and perceived social support. For this study, social support is conceptualized as a factor within the sociocultural component of the family management model (Figure 2).

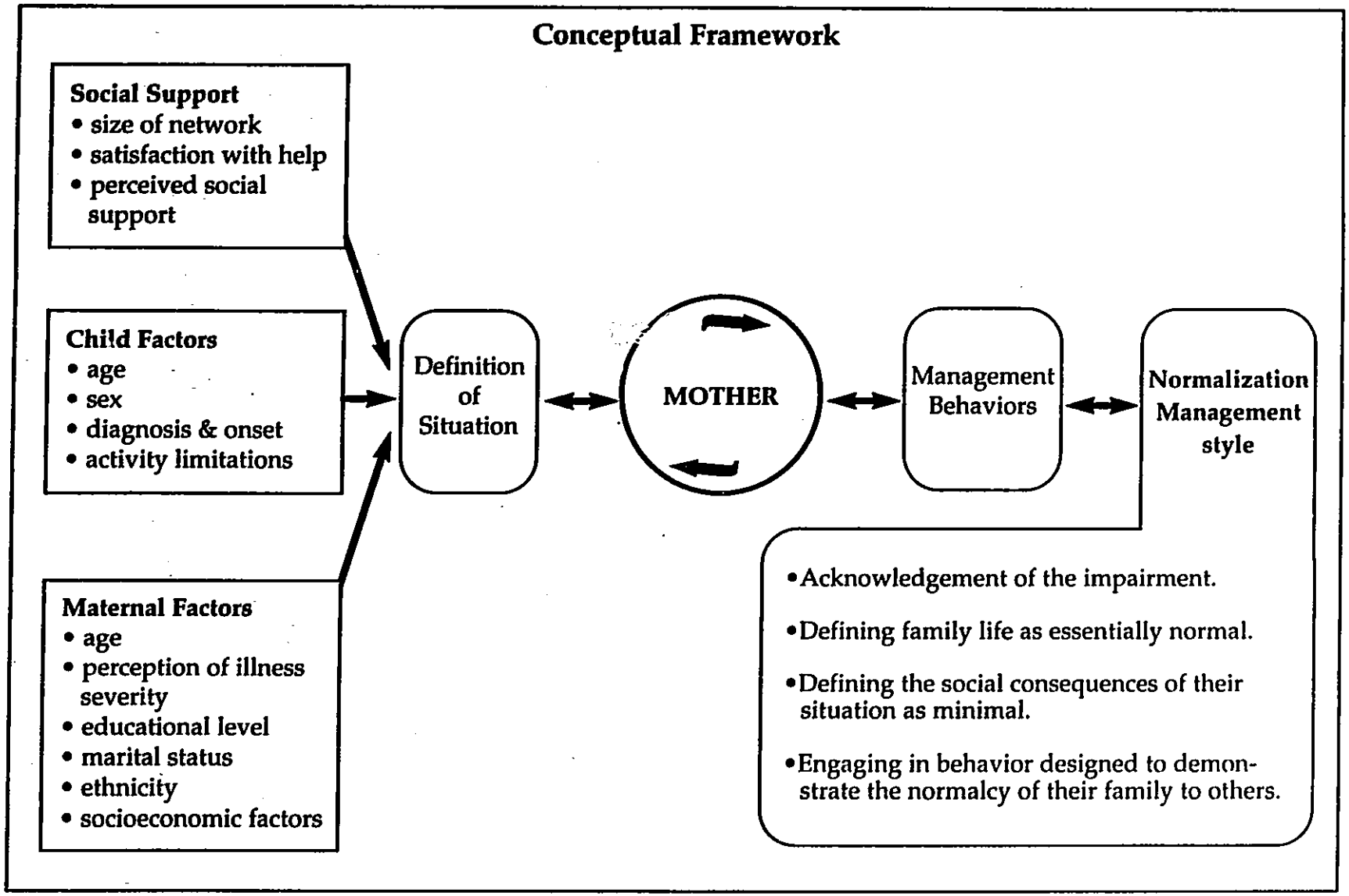
Conceptual Framework
Social Support
• size of network
• satisfaction with help
• perceived social support
Child Factors
• age
• sex
• diagnosis & onset
• activity limitations
Maternal Factors
• age
• perception of illness severity
• educational level
• marital status
• ethnicity
• socioeconomic factors
Definition of Situation
MOTHER
Management Behaviors
Normalization Management style
•Acknowledgement of the impairment.
•Defining family life as essentially normal.
•Defining the social consequences of their situation as minimal.
•Engaging in behavior designed to demonstrate the normalcy of their family to others.

Figure 2

Study Hypotheses

1. Mothers of chronically ill children who report high use of normalization by their families will have higher levels of perceived social support.

2. Higher reported use of normalization by mothers in families of chronically ill children will be associated with larger social support networks.

3. There will be a positive relationship between the mothers' reported use of normalization by their families and the mothers' satisfaction with their social support network.

Study Assumptions

This study is based on the following assumptions:

1. Chronic illness is a multidimensional experience with similar aspects despite varying disease processes.

2. The onset and progression of a chronic illness is viewed as a stressful life situation for the family system.

3. Families have the capacity to adapt.

4. The presence of chronic illness in a child requires adaptation by the family system.

5. The family both affects and is affected by chronic illness in a child family member.

6. The chronic illness of a child can exert positive and negative influences on the family system.

7. The family unit responds as a whole. The family response is different from the sum of the individual family member's responses; however, mothers are able to reflect a family perspective, and thus are valid sources of information concerning the family as a whole (Anderson & Elfert, 1989; Robinson, 1994).

8. There is a reciprocal relationship between the three elements of the Family Management Style Model. This reciprocity implies a dynamic or changing dimension to family management. Despite the 'moment in time' nature of the data collection process, mothers are able to reflect on the dynamic nature of their family management style.

9. Normalization, as a family management style, is desired and promotes optimal development of the ill child and the family as a whole (Holaday, 1978; Deatrick, Knafl, & Walsh, 1988; Bossert et al., 1989).

10. Nurses are factors within the external support environment for families with children with chronic illness.

CHAPTER THREE

METHODS AND PROCEDURES

Design

This exploratory study, utilizing a descriptive correlational design, describes mothers' reports of the use of normalization in families of chronically ill children and explores the relationship between the key variables, normalization and perceived social support.

Setting

The medical day unit of a regional pediatric institution was the setting for the data collection. The medical day unit is an ambulatory care setting where children receive assessment, diagnostic testing and medical intervention on a day-care basis. Typical medical diagnoses of the children who receive care at the medical day unit include cancer, diabetes, renal failure and blood dyscrasias. It is usual practice for a parent to accompany the child for treatments such as hemodialysis, blood transfusions or diagnostic procedures under sedation, which often extend over several hours. Data collection occurred during the course of the child's regularly scheduled visit to the medical day unit.

Sample

A non-probability purposive sample of thirty-three mothers of chronically ill children was recruited from a regional, tertiary level pediatric institution in eastern Ontario. Given the growing incidence of female lone-parent families and dual-earner families in our contemporary Canadian society, mothers remain responsible for the day-to-day management of children. Additionally, clinical practitioners report that mothers more than fathers accompany children to their medical day unit appointments and are therefore more accessible as study participants. School aged children were selected for this study as normalization as a management style was noted to be easier during the school aged period compared to either the preschool or adolescent years (Knafl & Deatrick, 1986). The sample consisted of mothers who consented to participate in the study and who met the following inclusion criteria:

1. the mother was the natural, adoptive or legal guardian of the chronically ill child.
2. the mother was able to read and comprehend English.
3. the mothers were included regardless of their marital status or family composition.
4. the chronically ill child was aged five through twelve.
5. the child's chronic health condition had been diagnosed for at least one year.
6. the chronically ill child did not have a mental disability.

7. the chronically ill child's school grade was appropriate within one year.

Sample Size

The review of the literature revealed no previous estimates of effect size for correlations between normalization and social support measures. When prior estimates of effect size are unavailable, one must select a conventional value. A large effect size was predicted because the descriptive literature had established that external support was an important factor influencing normalization. A conventional value for a large effect size in a bivariate correlation situation is .5 (Polit & Hungler, 1991, p. 486). Therefore, an *a priori* effect size of .50 was established for this study. Given an effect size of 0.5, at a .05 level of significance (two-tailed), and a desired power of .80, a sample size of 28 mothers was required to compute parametric measures of association (Cohen, 1977).

Data Collection Procedure

After ethical approval by the participating hospital's nursing research and ethics committees, potential study participants were screened for eligibility by the researcher who examined the appointment logs and consulted with staff of the medical day unit. An introductory letter signed by the nursing unit administrator on the medical day unit

was sent to each eligible mother introducing the study objectives and the nurse researcher (Appendix A). One week prior to the child's clinic visit, the researcher contacted potential participants by telephone to introduce herself, explain the study, answer questions or concerns (Appendix B). Any mothers who did not wish to participate were not approached further. An appointment was established on the planned clinic day with interested mothers. At that time, further questions were answered and an informed consent was obtained (Appendix C). Mothers were given the choice to complete the questionnaire in a nearby conference room or at their child's bedside. The questionnaires were completed by the mother during the clinic visit whenever possible. In some circumstances the child's needs prevented the mother from completing the questionnaire during the clinic visit and the mother returned the completed questionnaire to the researcher in a stamped self-addressed envelope. As a gesture of appreciation for participation in the study, the mother received a "crazy pencil" and a button for her child that read, "My mom participated in nursing research today." The researcher was available for debriefing following the completion of the questionnaire. Three mothers and one father of a chronically ill child offered constructive commentary to the researcher following the completion of the questionnaires. These comments will be elaborated in the discussion of the study. The duration of the data collection phase of the study was six weeks.

Ethical Considerations

Prior to the collection of data, the research proposal was reviewed and approved by the Nursing Research and the Ethics Committees of the participating hospital. The study was explained to the potential participants through an introductory letter (Appendix A). A hospital contact person was identified that the mother could call if she did not want the researcher to contact her. A follow-up phone call was made to the mother by the researcher to answer questions and to obtain informal consent (Appendix B). Informed written consent for participation in the study was given by the mother in the clinic at the time of the child's appointment. The researcher was present on the medical day unit to answer questions or provide clarification as necessary. Participation was completely voluntary and mothers were free to withdraw from the study at any time. Except for the investigator, no one knew who did or did not choose to participate in the study. Mothers were assured that whether they chose to participate or not, the services and care that they and their children received at the medical day unit would not be affected in any way. Confidentiality and anonymity of the participants' responses was maintained. Mothers were assured that all data would be presented as grouped data and identifying data would be coded and known only to the researcher and her thesis committee. Grouped data would be shared with Frances Murphy RN, MSc. and Dr. Weinert, S.C., R.N., Ph.D. to provide further reliability data on the Normalization and PRQ-85

scales. Only grouped data would be shared through presentations or publications resulting from this study.

Mothers who expressed an interest in receiving the findings of the study completed an address card that was stored separately from the study data to ensure anonymity. On completion of the study, a report of the findings of the study will be mailed to these mothers.

Measurement Instruments

The variables investigated in this study included (a) normalization, (b) size of social support network, (c) satisfaction with help received and (d) perceived social support. Data was collected using three instruments: the Normalization Scale (Murphy, 1994), the Personal Resource Questionnaire-85 (Weinert, 1987) and the Demographic Questionnaire.

Normalization Scale (Appendix D)

The Normalization Scale, (Murphy, 1994), is a tool developed using Knafl and Deatrick's (1986) conceptualization of normalization. The 31 item instrument measures a family's use of normalization as a way of managing their child's chronic illness on a day-to-day basis. Twenty five of the items are used to determine the total scale and subscale measurements. The scale uses a visual analogue format. The respondent is asked to consider the degree to which the statements apply to her

family, and place a mark on a 10 centimetre line representing a continuum from a lot to a little. The length from the line anchor to the respondent's mark is measured in centimetres and the measurement represents the item score. Items are summed to yield a total score ranging from 0 to 250. Twelve items are reverse scored. The higher the score, the more extensive the reported use of normalization as a management style.

The psychometric properties of this instrument initially were determined using a sample of 76 mothers with children with a chronic physical disability (CPD) (Murphy, 1994). Ten nurse experts reviewed items for clarity and exhaustiveness to establish face validity of the instrument. Clarity of items was also reviewed by a panel of ten mothers of children with a chronic physical disability (CPD). Construct validity was examined using principal components analysis with varimax rotation (Murphy, 1994). Four factors, accounting for 51% of variance corresponded to the four subscales of the measure. These factors named as subscales, were (1) Actual Effect of the CPD on the Family, (2) Perception by the Family and Others of the CPD Child and Family, (3) Comparison of CPD Child and Family to Other CPD Children and Families, and (4) Encouragement of Normal Activities. These statistically derived subscales were found to approximate closely Knafl and Deatrick's (1986) theoretically derived domains of normalization (Murphy, 1994). The theoretical domains of normalization distinguished between mothers' own

perceptions and mothers' perceptions of other peoples' validation of their child and family. By comparison, the statistically derived factors divided items by how mothers and others compared their family and child to normal children and families versus other chronically physically disabled children and their families. Cronbach's alpha was calculated for each subscale. With the exception of the "Comparison of CPD Child and Family to Other CPD Child and Families" subscale, the coefficient alphas ranged from .65 to .91, indicating an acceptable degree of internal consistency. The Comparison of CPD subscale had a coefficient alpha of .33. Murphy (1994) attributes the low internal consistency of the comparison of the CPD subscale to the low number of items (4) in this subscale.

Social Support (Appendix E)

Social support was measured using the Personal Resource Questionnaire (PRQ-85) (Weinert, 1987). This instrument was developed to measure support as a multidimensional construct. The PRQ-85 measures the following variables: number of personal resources or size of social network, satisfaction with help received from resources and dimensions of perceived social support. The PRQ-85 instrument contains two parts. PRQ-Part 1 consists of ten life situations in which one might be expected to need some assistance. The ten situations include the domains of (a) urgent need or crisis, (b) extended help with an ill family

member, (c) problems with spouse/partners, (d) problems regarding family/friend, (e) financial problems, (f) loneliness, (g) help in the event of short-term illness, (h) frustrations with the conditions of life, (i) problems with work, and (j) day-to-day personal concerns. The PRQ-Part 1 provides descriptive information concerning the network size, whether or not the respondent has experienced the situation in the past six months, and satisfaction with the help received from the resources. The "number of resources" variable is obtained by summing each resource across each life situation. Scores of 0-100 are possible. For satisfaction with the help received, respondents could choose a rating scale from 6 (very satisfied) to 1 (very dissatisfied). An average satisfaction score is determined by summing the responses for all life situations and then dividing the total satisfaction score by the number of life situations experienced, with a high score indicating a high satisfaction with help received in the life situations experienced.

The PRQ-Part 2 measures the "perceived support". PRQ-Part 2 is based on the social relationship dimensions described by Weis (1974) and consists of five dimensions of perceived social support including intimacy, social integration, nurturance, worth, and assistance. The PRQ-Part 2 includes five items for each of the social relationship dimensions. The respondents are asked to rate each of the twenty-five items on a 7-point Likert scale ranging from "strongly disagree" (1) to "strongly agree" (7). Scores theoretically range from 25 to 175 with a

high score representing a perception of being highly supported.

Internal consistency for the PRQ-Part 2 has been established in a number of studies with samples representing a broad age range including adolescents, young adults, middlescent and older adults. Chronbach's alphas ranged from .87 to .93 (Weinert, Personal Communication, June 5, 1995). Two studies in particular reported acceptable reliability coefficients in samples of mothers with young children. Brandt (1984b) utilized the PRQ-85 to assess social support in ninety-one mothers of young children with a developmental lag and found the alpha coefficient to be .91. In a sample of 77 young, low-income women with dependent children Murtaugh (1982) reported an alpha coefficient of .90 for the PRQ-Part 2. Further evidence of the psychometric properties has been reported by Weinert and Brandt (1987). Using a sample of 100 adults, aged 30-37, a test-retest reliability coefficient of r=.72 was obtained for the PRQ-Part 2, within a four to six week interval.

Predictive validity reported by Weinert (1984) was initially established using two outcome criteria: the first was a measure of family functioning developed by Pless and Satterwhite (1973); while the second employed two subscales (dyadic consensus and dyadic satisfaction) from the Marital Adjustment Scale (Spainer, 1976). The validity coefficients ranged from .21 to .23 for PRQ-Part 1 and .30 to .44 for PRQ-Part 2. In a study involving 100 men and women aged 25 to 65, Weinert & Gibson (1987) examined convergence across support measures by

comparing scores on the PRQ-85 to scores on five other measures of social support including the Interpersonal Support Evaluation List (Cohen, Mermelstein, Kamarck, & Hoberman, 1985), the Social Support Scales (Lin, Dean, & Ensel 1981), the Norbeck Social Support Questionnaire (Norbeck, Lindsey, & Carrieri, 1981), the Cost and Reciprocity Index (Tilden, 1986) and the Inventory of Socially Supportive Behaviors (Barrera, 1985). Correlations between the PRQ-85 and these other social support measures ranged from .25 to .74 (Weinert, personal communication, June 5, 1995). Thus, the construct validity or the Personal Resource Questionnaire as a measure of social support concepts has been established.

Murtaugh (1982) administered the PRQ-85 and the Marlowe-Crowne Social Desirability Scale (Strahan & Gerbasi, 1972). A high correlation between the two scales would have indicated that the participants answered the questions on the PRQ-85 in a socially desirable manner. A correlation of -0.06 was obtained, indicating that no social desirability response bias existed.

Demographic Questionnaire (Appendix F)

Maternal, child and family characteristics were collected through a demographic questionnaire developed by the researcher. Maternal characteristics included perceptions of the severity of her child's illness, ethnic background, and educational level. Characteristics of

the chronically ill child included the age and sex of the child, grade in school, limitations in activity level, medical diagnosis and onset of the chronic illness. Family characteristics included the ethno-cultural background of the family, the number and relationship of individuals living together in the family, the presence of other ill family members, and the perceived adequacy of the family income to meet the family's financial needs.

Controlling for Testing Threats to Internal Reliability of Study

The testing threat was controlled through the use of structured questionnaires. The standardized format of the questionnaire helped to assure that all study participants were exposed to uniform stimuli (Waltz, Strickland, & Lenz, 1991). The order of the items in a questionnaire may affect how the respondents self report. It is possible that the experience of responding to the items on normalization impacted the respondents' reports on the social support scale (Burns & Grove, 1993). In order to determine the extent of this threat, half of the questionnaires were prepared with the normalization items presented first and the remaining were prepared with the social support items presented first.

Respondents may have wished to please the researcher, thus influencing their self reports. It is possible that both normalization and social support concepts are vulnerable to socially desirable

responses that pose a threat to internal validity (Waltz, Strickland, & Lenz 1991). Therefore, the term 'normalization' was not used in the information provided to the mother, as this term might have provoked a socially desirable response. Rather the term "day-to-day management of your child's illness" was used on the parent information letter, phone information and the consent form.

Data Analysis

Data were analyzed using the Statistical Packages for the Social Sciences software (SPSS-6.1 Macintosh Version). Prior to entering the data into the computer, a code book was developed to document the location and value of all variables in the study. Following data entry, a two step data verification procedure was completed. First, the data file was printed and compared with the original responses to the questionnaires. Then, a computer analysis of frequencies for each value of each variable was examined for responses outside the range of measurement. Since the Normalization scale has 12 items that are reverse scored, and the PRQ-Part 2 has five, these items were transformed in the computer program prior to data analysis.

Descriptive statistics were computed for sample characteristics. Percentages, ranges, means and standard deviation were calculated where appropriate and frequencies and percentages were used for nominally scaled data.

Data was examined for the normality assumption prior to correlational analyses. Non-parametric statistics, specifically the Spearman Rank Correlation Coefficients and the Chi-Square test of independence were used for ordinal data. The eta coefficient was used for analyses where one variable was measured on the ordinal scale and the other on an interval scale. The Pearson Correlation Coefficients were used for correlational analyses involving interval scaled data.

CHAPTER FOUR

RESULTS

Study findings will be presented in this chapter. First, the characteristics of the mother-participants and their families is described. This is followed by a description of the characteristics of their chronically ill children. Finally, the findings for the research questions are presented.

Characteristics of Mothers and their Families

Forty-one mothers of chronically ill children consented to participate in the study. This represented a response rate of 63% of the total number of eligible mothers who were sent introductory letters. Of these forty-one mothers, twenty-five completed the questionnaires in the Medical Day Unit during their child's treatment, and sixteen completed the questionnaires at home and returned them to the researcher by mail or at a later clinic visit. The mothers of seven children reported that they had been told that their child was mentally disabled. Given that the child attribute of mental disability was not in the inclusion criteria for this study, these seven cases were excluded from further analyses. In addition, one mother reported that her child had been diagnosed with cancer for less than one year and this case was excluded from further analyses. Therefore, the final sample size was thirty-three mothers of chronically ill children (Table 1).

Mothers' ages ranged from 24 to 44 years with a mean age of 36.3 years. The majority of the mothers lived with their marital partners and their children. Eighty-five percent of mothers reported their

marital status as "married" and a further six percent reported "common-law" marital status. The majority of families (77%) reported having two or three children including the chronically ill child.

Mothers were asked to report their ethnic or cultural group and to note as many groups as applied to their family. Seventy-five percent of the respondents were born in Canada and reported their ethno-cultural background as English. Thirty-three percent reported French as their ethno-cultural background. These results reflected the primarily bilingual nature of the community where the data collection took place. All mothers were able to read and comprehend English. Other reported ethno-cultural backgrounds of the respondents included Scottish (32%), Irish (18%), German (12%), Italian (6%), and Arabic, Hungarian, Ukrainian and Native Indian (3% each).

Most mothers in the study were well educated with twenty-three (70%) reporting a university or college education. Two mothers (6%) reported graduate or professional education. Six mothers (18%) reported high school as their highest level of education attained and two mothers (6%) reported less than high school education. The majority of participants represented middle income families, with the median annual family income level reported at the $40,000 to $59,000 range. Most mothers (67%) were satisfied with their family income, however, 34% were not satisfied and two mothers (6%) reported that their income was totally inadequate to meet their families' needs. A greater proportion of mothers with income levels of $40,000 or more were satisfied that their income met their family's needs ($X^2=3.7, df=1, p=.05$). Of particular significance to these findings is the impact of their child's chronic illness in creating financial hardship for their family. Fifty-two percent of mothers reported that their child's chronic illness created some financial hardship for their family. A

further eighteen percent of mothers responded that their child's illness created a great deal of financial hardship for their families.

Sixteen percent (n=5) of the mothers reported belonging to a support group related to their child's condition. The mothers who reported participation in a support group described a range of participation from 0 (a little) to 10 (a lot) with a mean score of 5. Only two mothers reported "a lot" of participation in a support group related to their child's illness.

In addition to the presence of a chronically ill child in their family, twenty-four percent of mothers reported illness in another family member. The ill family member category included self, spouse and siblings of the chronically ill child (Table 1).

Table 1
Characteristics of Mothers and Families (N=33)

	n	%
marital status		
married	28	84.8%
common law	2	6.1%
single	1	3.0%
divorced	2	6.1%
living with spouse		
no	3	9.1%
yes	30	90.9%
number of children		
1 child	4	13.3%
2 children	15	50.0%
3 children	8	26.7%
4 children	2	6.7%
5 children	1	3.3%
mother's education level		
< grade 12	2	6.1%
high school graduate	6	18.2%
university and/or college	23	69.7%
post graduate or professional degree	2	6.1%
family income		
$19,000. or less	3	9.4%
$20,000.-$39,000.	5	15.6%
$40,000.-$59,000.	10	31.3%
$60,000.-$79,000.	9	28.1%
$80,000. or more	5	15.6%
satisfaction with income meeting family needs		
very well	3	9.1%
adequate	19	57.6%
not very well	9	27.3%
totally inadequate	2	6.1%
financial hardship created by child's illness		
not at all	10	30.3%
somewhat	17	51.5%
a great deal	6	18.2%
illness of other family member		
yes	8	24.2%
no	25	75.8%

Characteristics of the Chronically Ill Children

The thirty-three chronically ill children ranged in age from 5 to 12 years with a mean of 8.4 years (Table 2). Sixty-seven percent of the chronically ill children were males and thirty-three percent were females. The medical diagnostic categories of the children were varied in keeping with the non-categorical approach of the study and included cancer, hematological disorders, immune deficiencies, diabetes, renal disease, asthma and other chronic disorders. Eighteen percent of the children were identified as having more than one chronic illness (Table 3). The mean years since diagnosis of the child's chronic illness was 4.6 years. The school grade level of the children ranged from junior kindergarten to grade eight. All of the chronically ill children were at or within one year of age-appropriate grade level in school.

Seventy-three percent of the mothers felt that their child's activities were limited because of the chronic illness. When comparing their chronically ill child with other children with the same illness, 39% of mothers reported that the severity of their child's illness was about the same. Eighteen percent of mothers considered their child's condition as more severe than other children with the same illness, compared to 6% who reported that their child's condition was less severe. Thirty-six percent of the mothers in this study were unable to compare their child's condition to other children as they did not know another child with the same chronic illness. Responding to the question, "How much is your child like other children who have a similar condition?" twenty six (79%) mothers reported a mean score of 5 with a possible range from 0 (low) to 10(high).

Table 2
Characteristics of Chronically Ill Children (N=33)

	n	%
age of chronically ill child		
five years	4	12.1%
six years	3	9.1%
seven years	7	21.2%
eight years	3	9.1%
nine years	3	9.1%
ten years	5	15.2%
eleven years	3	9.1%
twelve years	5	15.2%
child's sex		
male	22	66.7%
female	11	33.3%
child's activities limited by chronic illness		
yes	24	72.7%
no	9	27.3%
severity compared to other CI children		
more severe	6	18.2%
less severe	2	6.1%
about the same	13	39.4%
don't know another child	12	36.4%

Table 3
Illness Categories of Chronically Ill Children (N=33)

Chronic Illness Category	N	%
Cancer	10	30.3%
leukemia	9	
rabdosarcoma	1	
Hematological Disorders	9	27.2%
idiopathic thrombocytopenia	2	
hemophilia	3	
anemia	2	
thalassemia	1	
Diamond Blackfan	1	
Immune Deficiencies	7	21.0%
Diabetes	2	6.1%
Renal Disorders	2	6.1%
Asthma	2	6.1%
Other	3	9.1%
(blindness, lymphedema, precocious puberty and ADD)		
Children with more than 1 chronic illness reported	6	18.2%

Research Question One: To what extent do mothers report the use of normalization by their families?

Generally mothers reported high levels of normalization on the total normalization scale. Study mothers scores ranged from 76 to 225 with a mean score of 160 and a standard deviation of 42.1 (theoretical range 0-250). The mean, range and standard deviation of each of the four normalization subscales were calculated and are presented in Table 4. The Actual Effect of the Illness on the Family Subscale scores ranged from 18-96 with a mean score of 59.1 (theoretical range 0-100). The Encourage Normal Activities sores ranged from 2-40 with a mean score of 32.9 (theoretical range 0-40). The Perception of the Child and Family as Normal Subscale ranged from 14-69 with a mean score of 52 (theoretical range 0-70). The Comparison of the Chronically Ill Child and Family to Other Children and Families Subscale ranged from 0-33 with a mean score of 16 (theoretical range 0-40).

The Chi square test for independence was used to explore for independence between total normalization scores and each of the potential intervening variables including, the age and sex of the chronically ill child, the age of the child's mother, and the location of the completion of the questionnaire. The total normalization score was recoded into a dichotomous variable using a median split technique (Norman & Streiner, 1986;. No statistically significant relationships were found between the normalization scores and the sex of the chronically ill child (X^2= 2.97, df=1, p >.05); the age of the child (X^2 = 2.4, df=1, p>.05); the age of the mother (X^2 =1.46, df=1, p>.05); or the location of the completion of the questionnaire

(X^2 = .73, df=1, p>.05).

The eta coefficient is a measure of association appropriately utilized to explore the association between a dependent variable measured in an interval scale and an independent variable measured on a nominal scale (Norusis,1995). To determine the effect on total normalization scores by the order of the presentation of the normalization and social support questionnaires, the eta coefficient was calculated. Less than one percent of variability in the total normalization scores was accounted for by the order of presentation of the questions in the booklet ($\eta 2$ = .01).

In addition, the association of each mother's perception of the severity of her child's disease with total normalization scores was explored using the eta coefficient. Fifteen percent of the variability in the reported normalization scores was accounted for by the mothers' reports of the severity of their child's illness (η^2= .15). Thus, the mother's perception of the severity of her child's illness is an important factor influencing normalization.

Table 4

Descriptive Statistics of the Normalization Scale

Subscale	# Items	Range	M	SD
Actual Effect of Illness on Family[a]	10	18-96	59.1	25.0
Encourages Normal Activities[b]	4	2-40	32.9	7.8
Perception of Child and Family as Normal[c]	7	14-69	52.0	16.3
Comparison of Child & Family to Other Children & Families[d]	4	0-33	16.0	8.1
Total Normalization[e]	25	76-225	160.1	42.1

Note.

[a] scores theoretically range from 0 (low) to 100 (high)

[b] scores theoretically range from 0 (low) to 40 (high)

[c] scores theoretically range from 0 (low) to 70 (high)

[d] scores theoretically range from 0 (low) to 40 (high)

[e] scores theoretically range from 0 (low) to 250 (high)

Research Question Two: Is there an association between normalization and perceived social support?

The multidimensional construct of "perceived social support" was measured by the PRQ-Part2. The possible range of scores for this instrument was 25-175 with higher scores representing higher levels of perceived social support. Mothers in the study reported a high level of perceived social support with mean scores of 133.6 (SD 26.9, range 66-170). The lowest score of 66 represented a mild outlier (Norusis, 1995). This measurement was examined for the impact on the overall score for the group and found to have minimal effect. Therefore, this lowest score was included in the analysis. Internal reliability for the PRQ-Part 2, measured by the alpha coefficient, was .94.

The Pearson Product Moment Correlation Coefficient was used to correlate the mothers' total normalization scores with their total score for perceived social support. A significant relationship was found between the two key variables ($r=.36$; $p<.03$). Consequently, hypothesis one was supported; that is, mothers of chronically ill children who reported high use of normalization by their families also reported higher levels of perceived social support.

Research Question Three: Is there an association between the extent to which mothers report the use of normalization and the size of their social support network?

The size of the mother's social support network was calculated by summing the number of sources of social support reported across the ten life situations in the PRQ-Part 1. The mean number of sources of support reported was 26.3 within an actual range of ten to fifty-one sources of support. The most frequent source of support reported by the mothers was their spouse or partner followed by parents, friends,

relative, professional, neighbour or co-worker. The least frequently reported sources of support included a self-help group, agency, spiritual advisor or children (Table 5).

The Spearman Correlation Coefficient was used to correlate the mothers' total normalization scores with the size of their reported social support network. The relationship between these variables was not significant (r_S=.17; p=.33). Thus, hypothesis two was not supported; higher reported use of normalization in families with chronically ill children was not associated with larger social support networks in this study.

Table 5

Mothers Reported Social Support Across 10 Life Situations (PRQ-Part 1)

Support Source	M[a]	SD	Range
spouse or partner	6.64	2.9	0-10
parent	4.27	3.75	0-10
friend	4.24	3.36	0-9
relative	4.06	3.75	0-10
professional (nurse, counsellor, social worker, etc)	2.33	2.78	0-10
neighbour or co-worker	1.42	2.15	0-9
children	.91	1.28	0-4
spiritual advisor	.82	1.83	0-7
no one (prefer to handle it alone)	.70	1.13	0-4
no one (no one available)	.58	1.77	0-9
agency	.24	.56	0-2
self-help group	.15	.57	0-3

Note. [a] the number represents the mean frequency of each source of social support across 10 life situations.

Research Question Four: Is there an association between the extent to which mothers report the use of normalization and how satisfied they are with their social support network?

Each of the 10 life situations likely to require help (PRQ-Part 1) were reported by at least one mother at least once. The mean number of life situations experienced, as reported by mothers, was 4.6. The frequency of the specific life situations reported by the mothers in the past six months ranged from 28 (needing someone to talk to about personal concern) to 5 (being sick for a week and needing help to carry out usual activities) (Figure 3). Sixteen mothers (48.5%) reported needing help for an extended period of time in caring for a family member who is sick or handicapped. More mothers reported personal concerns and feeling lonely and upset than any of the other life situations.

Satisfaction with help received for each life situation experienced was measured on a scale of 1 (very dissatisfied) to 6 (very satisfied). Total satisfaction with the social support network was calculated by totalling the mothers' reports of satisfaction from help received for each of the life situations experienced. Given that every mother reporting did not experience every problem situation proffered, an average satisfaction score was calculated by dividing each mother's total satisfaction score by the number of problem situations experienced. The mean satisfaction with help received for mothers was 4.3 (SD 1.5) with a possible range of 1 to 6.

A Spearman Correlation Coefficient was also used to correlate the mothers' total normalization score with the average satisfaction score reported across the ten life situations depicted by the Personal Resource Questionnaire-Part 1. The correlation was significant (r_s=.34; p=.05). Therefore, hypothesis three was supported; there was a positive

association between the mothers' reported use of normalization by their families and the mothers' satisfaction with their social support network.

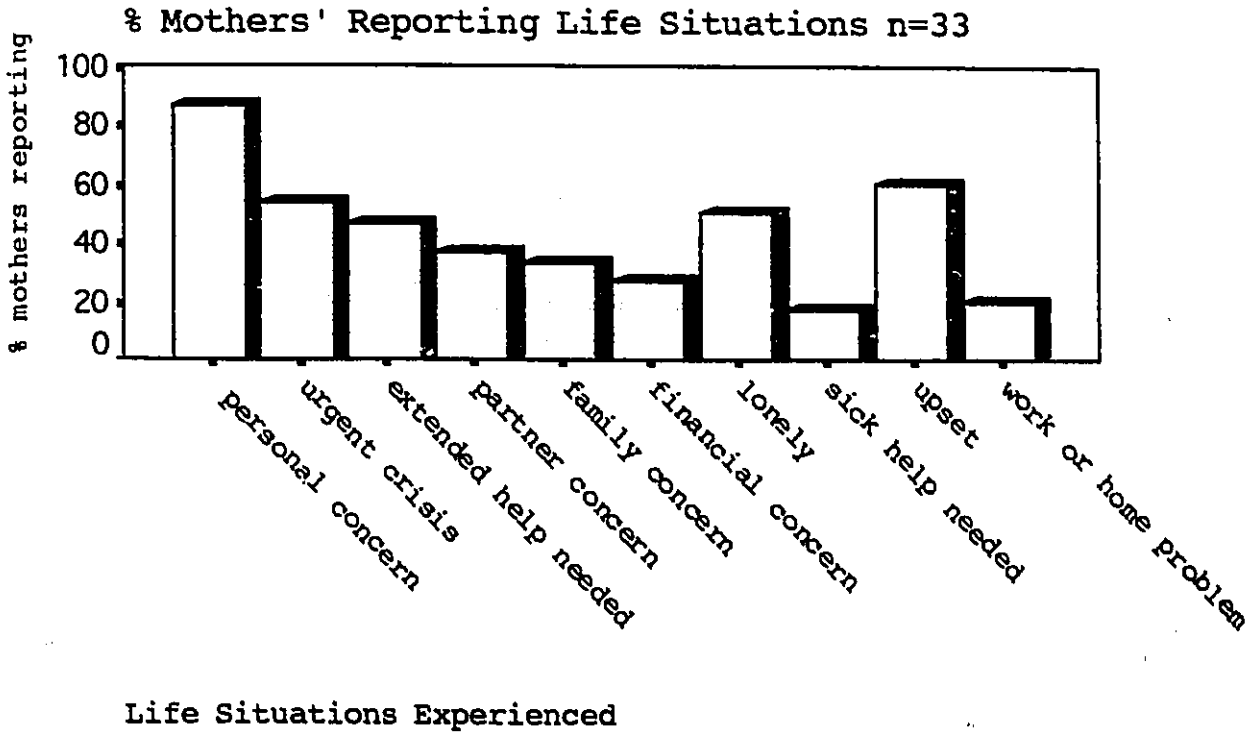

Figure 3. Percentage of Mothers Reporting Life Situations

Internal Reliability of Normalization Scale

Internal reliability measured by the alpha coefficient gauges the extent to which any one item in an instrument correlates with other measures of the same content domain (Waltz, Stickland, & Lenz, 1991). An alpha coefficient ranging from .8 to .9 indicates an instrument that reflects the fine discriminations in the levels of the construct measured by the instrument (Burns & Grove 1993). Reliability coefficients were calculated for the total normalization scale and each of the four normalization subscales (Table 6). Acceptable internal reliability was established for the total normalization scale (α.92) and three of the four subscales (.76 to .92). The "Comparison of Child and Family to Other Chronically Ill Children and Family Subscale" demonstrated a reliability coefficient of .19. The reliability coefficients for the Normalization Scale are comparable to those reported by Murphy (1994) (Table 6).

Table 6

Normalization: Comparison of Reliability Coefficients

Subscales	Mothers of Chronically Ill Children	
	Murphy (1994) N=76	Foster (1996) N=33
Actual Effect of Illness on Family	.84	.91
Encourage Normal Activities	.65	.75
Perception of Child and Family as Normal	.91	.92
Comparison of Child & Family to Other Children and Families	.33	.19
Total Normalization	-	.92

CHAPTER FIVE

DISCUSSION

The purpose of this study was to obtain a better understanding of normalization as a family management style for families that have a child diagnosed with a chronic illness. The study sought to examine relationships between family normalization as reported by the mother of chronically ill children and selected social support concepts.

Characteristics of Mothers, Children and their Families

The study families were unlike typical Canadian families on several family attributes. Most families in the study had one or two children and this typifies the size of the average Canadian family (Canadian Institute of Child Health, 1994). However, in the current study, mothers' reported their marital status as 85% married and a further 6% living common-law. This family composition contrasts sharply with family profiles that show married couples with children representing only 48% of Canadian families and common-law couples with children representing a further 4% of families (Vanier Institute of the Family, 1994). Only one single mother and two divorced mothers participated in this study. This is atypical of Canadian family profiles which describe 20% of Canadian families with children as lone parent families, and the majority of these families were female-headed. It is possible, that the associations between normalization and social support found in this study are not characteristic of single parented families. However, research has identified no significant differences in family stress and resources between single-parent and two-parent families (McCubbin, 1989). In fact, McCubbin identified that single-parents of children with cerebral palsy were more adaptable and flexible in their management of

their child's illness and family life when compared to two parented families.

The study families reported a median family income range from $40,000 to $59,000. This income level compares favourably with the national average income of two-parent families with children, however, it is much higher than the average family income of a female-headed lone parent family which is $22,186 (Health Canada, 1995). It is an important finding in the present study that most of the mothers, regardless of their income level, identified financial hardship associated with the care of their chronically ill child. The study did not identify the specific expenses that created financial hardship such as specialized equipment, medications, travelling expenses, additional child care costs, or lost income when child is accompanied to the medical facility for treatment. However, it is likely that these additional costs are of particular concern to families in the lower socioeconomic groups.

The mothers in the study had high educational attainment compared to Canadian women in the same age range. Twenty four percent of the mothers reported secondary school education or less, compared to 42% in Canadian women aged 25 to 44. Seventy-six percent of the study mothers reported post secondary education, compared to 49% of Canadian women of the same age. It is possible that mothers with higher educational attainment were more likely to volunteer to participate in the research project. This would limit the generalizability of the findings. It is also possible that the mothers who volunteered to participate were demonstrating a socially desirable response bias and wanting to please the health care professional. Another potential motivation for mothers participation may have been a desire to communicate a particular message about their life with their chronically ill child. Although the forced-

item response of the questionnaire limited the opportunity for individual participant input, three mothers and one father made an effort to speak to the researcher with particular concerns facing their families.

The majority (67%) of children in this study were males. This could be explained by the fact that compared to girls, a higher proportion of boys experience long term health conditions and limitations in normal activities (Canadian Institute of Child Health, 1994).

Most studies examining normalization in families with a child with chronic illness have relied on convenience samples of Caucasian, middle income, North American families (Anderson, 1981; Breitmayer et al., 1992; Gibson, 1988; Holaday, 1978; Knafl, Deatrick, & Walsh, 1988; Krulik, 1980; Murphy, 1994; Voysey, 1972). The findings of this study support normalization as a preferred management style in a similar sample of predominantly Caucasian, married, middle income mothers. Contrary to these findings, a comparative study examining how Chinese and Caucasian families manage the care of a chronically ill child found that striving towards normality was not a priority for the Chinese families compared to similarly situated Caucasian families (Anderton, Elfert, & Lai, 1989). Anderton et al. propose that ideologies underpinning western culture support normalization, and that these values may not apply to non-western immigrants in our communities. These findings suggest that there may be a cultural variation in the use of normalization that was not demonstrated in the present study due to the cultural homogeneity of the sample.

The Extent to Which Mothers Report Normalization as a Management Style

The mothers in the study reported high levels of normalization as a management style. The four subscales of the instrument reflect the conceptual dimensions of the normalization management style as conceptualized by Knafl and Deatrick (1986). The first subscale, "Actual effect of the chronically ill child on the family" measures the extent to which the mothers perceived their family life to be affected by their child's chronic illness. In the present study, mothers perceived their child's illness to minimally affect their family routines, activities and relationships with other people outside the family. This finding is consistent with other research that reports behavioral strategies of similar families are aimed at minimizing the impact of their child's illness (Anderson, 1981; Davis, 1963; Knafl & Deatrick, 1988; Krulik, 1980; Murphy, 1994). In a recent study, Knafl et al. (1992) found that most parents described the illness as a manageable condition which could be accommodated without becoming the focus of the family life.

The "Perception of the Child and Family as Normal Subscale" measured the extent to which the mothers perceived their chronically ill child and family to be like normal families, and the extent to which the mothers perceived that other people viewed their child and family as normal. When adopting normalization as a management style, families define their family life as essentially normal and define the social consequences of the illness as minimal (Knafl & Deatrick, 1986). In the present study, mothers perceived that their children and families were like other children and families. Additionally, the mothers perceived that other people treated their child and family like other families without a child with a chronic illness. These results are consistent with Murphy's finding (1994).

The encouragement of normal activities in the chronically ill child

is a critical component of the conceptualization of the Family Management Style. By encouraging the child's participation in usual family activities and outside activities, such as school and extracurricular endeavours, the family reinforces the notion that the child can participate in usual childhood activities regardless of the chronic illness. Robinson (1993) found that "doing normal things" was critical to the story of normalization in families with a chronically ill child. Knafl et al. (1992), describe this parenting behavior as an accommodative parenting philosophy.

The mean score for the "Encouraging Normal Activities Subscale" in the present study was 32.2 and comparable to the mean score of 36 found by Murphy (1994). This is an interesting finding, given the differences in the diagnoses of the children in the present study compared to Murphy. In Murphy's study, the children's diseases included diabetes, cystic fibrosis, renal-urological diseases, arthritis and gastrointestinal diseases. In the present study, there was a high proportion of children with cancer (30.3%) and immune deficiencies (21%) and the mothers reported an equally high level of encouragement of normal activities. For mothers to be concerned about infection they must be aware of the increased risk to their child. However, it is likely that the mothers in the present study were aware of the increased susceptibility of their children to infection. Particularly for the subset of mothers of children with cancer, regular monitoring of the child's blood for neutropenia and family teaching regarding increased susceptibility to infections are standards for nursing care for these children (McCarthy & MacDonald, 1993). It is more likely that the mothers' encouragement of normal activities in their children provides further evidence that the conceptual definition of normalization as described by Knafl and Deatrick (1986) is clinically significant when

describing the management of families with a chronically ill child.

In the present study, 36% of the mothers were unable to compare their child's condition to other similar children as they did not know another child with the same diagnosis. It has been identified that families of a chronically ill child who employ normalization as a management style tend to limit contact with similarly affected families (Birenbaum, 1970; Darling, 1979; Roskies, 1972). Contact with other chronically ill children and their families would most likely occur in a support group situation. The findings of the present investigation reflect similar patterns in the families studied. Eighty-two percent of the mothers' reported that they did not belong to a support group associated with their child's illness. Thus it would seem that families who use normalization strategies may actively avoid contact with other families of a chronically ill child. It is possible that association with other families with a chronically ill child would place an emphasis on the differences or deviations from normal and therefore serve to be counter productive to their normalizing strategies.

The Association Between Mothers' Reports of Normalization and Social Support

The study supported the nypothesis that use of normalization was positively associated with perceived social support. Perceived social support has been characterized as the cognitive appraisal of being reliably connected to others (Barrera, 1986). It would seem that families who adopt normalization as a management style feel more supported. This finding confirms Knafl and Deatrick's (1986) report that parents of chronically ill children are more likely to normalize when they receive external validation of their definition of the situation. Although the relational position of normalization and perceived social

support concepts has been confirmed by this study, the direction of the relationship is yet to be determined. Is it that the use of normalizing behaviors in these families puts them in contact with supportive relationships, or rather is it that social support provides enhancement to family normalization outcomes?

The study findings did not support the hypothesized association between mothers' reports of normalization and the size of the social support network. It would seem that the ability of the social support network to provide validation of the family's definition of their situation as normal is more critical to normalization as a management style than the number of resources available.

Support from family and friends was most frequently identified by the mothers as the source of support they would turn to when facing a life situation requiring assistance. These findings are consistent with other research which identifies informal support as being cited as significant to coping with a child with a chronic illness (Brandt, 1984; Copeland & Clement, 1993; Deatrick & Knafl, 1990; Gibson, 1988; Stewart et al., 1994; Thorne & Robinson, 1988; Venters, 1981).

The next most frequently cited source of social support for the mothers in the study was "professionals". Nurses were not discriminated from other professionals in this study, however, the chronically ill children whose mothers' participated in this study had frequent and regular contact with the nurses providing care in the medical day unit where their child received treatment. Health professionals, through the provision of informational and affirmational support to families, (Stewart et al., 1994) are in a key position to influence both how the family defines their situation, and the development of management strategies. Since most of the treatment management on the day medical unit was carried our by nurses, it would seem likely that nurses would

be considered by the mothers when identifying health professional as a resource.

The preference for informal sources of social support (spouse, friends and family) over formal support (professional or agency) may be based in the different nature of these social relationships. It has been noted that formal sources of support differ from informal sources of support in that they do not provide the opportunity for reciprocity (Fugate-Woods et al., 1989). Furthermore, research has identified that an inability to reciprocate may be an obstacle that discourages individuals from seeking help and limits the amount of assistance that they will accept (Tomlinson & Mitchell, 1992). It is possible that the study mothers' lack of an opportunity to reciprocate help towards the care providers contributes to the preference of informal rather than formal sources of support.

The study mothers' preference for informal sources of social support may have also been influenced by the regional nature of the hospital where the data collection took place. Many of the mothers who participated in the study lived at a significant distance from the specialized centre where their child received care. It is possible, that the professionals' help was less accessible to them in their day-to-day concerns compared to local family and friends and therefore, were more likely to provide day-to-day tangible assistance in the care of their chronically ill child.

Although this study confirms a positive relationship between mothers' perceptions of social support and the use of normalization, the exact nature of the relationship is unclear. The PRQ-85 instrument does not discriminate which dimension of social support is being provided by each of the contributing sources of social support. This information would be useful as it would assist the nurse in matching the type of

support needed by the family, with the most appropriate source of that particular dimension of support.

The study supported the hypothesis that mothers' satisfaction with help they received was positively associated with the use of normalization by their families. Although the mothers in the study were generally satisfied with the support that they received, including help from professionals, several researchers have reported that families are dissatisfied with the support that they received from health professionals (Stewart et al., 1994; Thorme & Robinson, 1988). In fact, it has been suggested that professionals may actively interfere with the family's process of normalizing (Robinson, 1985). Although this finding was not supported in the current study, it is possible that the PRQ-85 instrument was not specific enough to measure dissatisfaction with a particular source of support. It is conceivable that families who normalize are perceived by health professionals to be coping well with the management of their chronically ill child. The health professional may misinterpret the normalizing behaviors to mean that the family does not need support and thus not offer critical affirmational and informational support.

Psychometric Evaluation of the Normalization Scale

The Normalization questionnaire demonstrated reliability coefficients from .75 to .92 for the total scale and three of the four subscales. The reliability analysis results were consistent with those of Murphy (1994) (Table 6). These results support acceptable reliability for the second administration of this new instrument. The "Comparison of Child and Family to Other Chronically ill Child and Family Subscale" demonstrated low internal reliability (α.19). A possible explanation for the poor reliability of this subscale is the fact that many of the

mothers reported that they did not know another child with a similar chronic condition. Thus, only 21 cases of this 4 item subscale were entered into the reliability analysis. Further reliability analysis with larger samples is required.

Study Limitations

Limitations of this study include the sampling methods, as well as instrumentation and methodological weaknesses. Given the non-probability, purposive sample, it is possible that the participants selected for this study differed in some important ways from other parents of children with a chronic illness. The mothers in this study differed from average Canadian families on key socioeconomic attributes. Of particular importance is the lack of representativeness of the cultural influences of newly immigrated groups from Asia, Africa and South and Central America. This is a critical consideration as the meaning of illness in a family appears to be influenced by cultural values (Anderson, 1981; Anderton et al., 1989; Knafl & Deatrick, 1990).

This study did not highlight the special financial concerns of families with incomes in the lower ranges. As these families are more likely to be single parented, female headed families, studies comparing normalization in different family compositions would be useful. Therefore, the results of the present study are not generalizable beyond the participants.

Instrumentation concerns arose from limitations presented by the use of self-administered questionnaires in general, and by specific limitations of both the normalization and PRQ-85 instruments. The three instruments that were administered in this study were combined into one questionnaire booklet. One disadvantage to the use of a questionnaire in research is the inability to control the conditions of administration of

the instrument (Waltz, Strickland, & Lenz, 1991). Data was collected at a busy medical day unit in a regional pediatric tertiary level hospital. A pediatric medical day unit is a noisy, busy, active treatment environment. It was impossible to control the ongoing activities within this setting. Events varied daily during the data collection period. On occasion, unexpected medical emergencies occurred. Research participants may have been worried about the tests and treatments that their children were undergoing. It is possible that mothers' anxiety at the time of data collection was a threat to the validity of the study results, as it may not reflect the mothers' true day-to-day management of the child's illness. In order to reduce this testing threat, mothers were offered a private location to complete the questionnaire or permitted to complete the questionnaire at their child's bedside. Twelve mothers (36%) completed the questionnaire at home and returned it to the researcher by mail. A significant relationship between mothers' scores on normalization and the site of completion of the questionnaire was not found ($X^2 = .73$, df=1, $p>.05$). However, it is impossible to know if the questionnaires completed at home reflected input from additional family members.

As a newly developed tool, the normalization instrument lacks extensive reliability and validity data in varied populations of families with chronically ill children. The concepts of normalization and Family Management are in the process of update and revision (K. A. Knafl, personal communication, April 29, 1996). Although the normalization instrument demonstrates acceptable reliability on the total score and three of the four subscales analyses, it is possible that the instrument was developed prior to full exploration of the dimensions of normalization and the Family Management Style Model through inductive inquiry methods. Further construct validity analysis

is appropriate, particularly given the emergent nature of these important concepts.

The Personal Resource Questionnaire (PRQ-85) did not differentiate well between nurses and other health care professionals. It was not possible to discern from the findings mothers particular perceptions of nurses as sources of support. Instruments are needed that clearly differentiate nurses as sources of support to families who adopt normalization as a management style. This will guide intervention strategies that are within the scope of nursing practice. Additionally we need to identify the types of support that are perceived as helpful and then relate the types of support that are associated with specific sources of support.

Another limitation to the present study is the temporal nature of the data collection which may not be congruent with the phenomenon being observed. Normalization has been characterized as a dynamic process that evolves over time and which may be punctuated with periods of disease exacerbations or even hospitalizations. Several of the mothers in the study commented on the "ongoing" nature of their adjustment to their child's illness. One mother related that her family was managing well now, but there had been times when they felt they were unable to handle the demands of their child's illness. Given the attributes of the concept of normalization, the changes dictated by the evolving management of the child's illness, and the changing developmental needs of both the child and the family unit, longitudinal studies would be essential to understanding the process nature of the phenomenon.

Finally, *a priori* sample size calculations, based on predicted correlations of $r=.5$ between social support variables and normalization, determined the sample size requirement to be 28 (significance level $\leq .05$). The significant correlations found in this study were in the

weak to moderate range (r= .34 to .36, p≤.05). Hypothesis two, the relationship between normalization and the size of the social support network was not supported. It is possible that the study may have lacked enough power to detect a significant correlation between these two study variables.

Conceptual Issues

Nursing research concerning the family is strengthened when the unit of investigation, in this case the family unit, is dealt with as a consistent whole through each step of the research process. This would involve conceptualizing the family as a unit, using multiple family members as informants, as well as the selection of instruments, data scoring, and analysis which is consistent with the conceptualization of the family as an aggregate (Feetham, 1992; Larsen & Olson, 1990; Uphold & Strickland, 1989).

On a conceptual level, normalization as a family management style is meant to reflect on how the family, as a unit, responds to a child's illness (Knafl & Deatrick, 1990). Although mothers were reliable informants concerning the management of their families, it is possible that their perspective did not entirely reflect the perspective of each member of the family unit. Knafl, Gallo et al. (1992) found discrepant views between mothers and fathers in a study of 63 families with a school age child who had a chronic illness. Fourteen percent of parents disagreed on their view of their child, 26% had discrepant views of the child's illness, 32% differed in their parenting philosophy, and 42% disagreed concerning the ease of the child's treatment regime. An

incident of discrepant parental perspectives occurred during the data collection phase of the present study. A father of one of the chronically ill children called the nurse researcher and expressed concern that his view on the management of their child's illness was not being sought. From his perspective he was the one who most frequently accompanied his child to the medical day unit and made daily adjustments to accommodate his child's illness. This particular father stated that he felt his wife's views were likely to be "different" than his.

Although the conceptual base of this study is meant to reflect the family as a unit, the normalization instrument measures only the mother's perception of her family as a whole. The interpretation of the data as reflective of a family versus mother's management style is limited by the lack of shared perspective from the other family members including the views of the chronically ill child.

Implications for Practice, Theory and Research

The following section will propose implications of the study findings to nursing practice, theory development and research. In addition, implications for the subroles of the Clinical Nurse Specialist (CNS) described by Hamric and Spross (1989) as expert practitioner, educator, consultant and researcher will be highlighted. The CNS is in a central position to further the research and practice of nursing management of families and their chronically ill children.

Implications for Practice

Nurses working with families with chronically ill children, are in key positions to assess the management style used by families. Knowledge of the defining criteria for this important management style will allow nurses to identify the phenomenon in families within the practice setting. This is a particularly important implication, as research has identified that the health care professional can be non supportive and at times interfere with families' normalizing efforts (Breitmayer et al., 1992; Robinson & Thorne, 1988; Stewart et al., 1994). Families that seem to be managing well may not receive the important validation of their situation as "normal" yet this affirmational support has been identified as an important factor in the maintenance of normalization as a family management style.

This study confirms that social support is part of the sociocultural environment in which the family defines and manages their child's illness. Social support is positively associated with families' normalizing efforts. Through assessment of the social support network the nurse will identify resources and areas of concern, for instance, families with poorly developed informal social support networks (Brandt, 1984a). Together with families, the nurse will be able to use the social network assessment data to individualize social support interventions in order to increase the likelihood of acceptance and satisfaction with the help received. For example, this study has demonstrated clearly that for families who manage life with a chronically ill child through normalization, support groups are not identified as helpful.

The experience of a child's chronic illness within the family unit is both ongoing and evolving. The nurse working with a chronically ill child and the family will have repeated contact, whether it be in the hospital, clinic, community or school. The long-range view affords the nurse an excellent opportunity to see the family management behaviors develop over time, and to evaluate the success of interventions aimed at supporting the family's accommodation to the child's illness. The long term relationship with the family enhances the establishment of a trusting relationship between the nurse and family, which will make the validation provided by the nurse more meaningful. The nurse, through referral to other agencies or individuals, can enhance the instrumental support provided to the family. Informational support can be provided through the nurse's own expertise or referral to additional sources of information.

The nurse can serve as a role model for parents and children by demonstrating effective normalizing strategies, for example suggesting ways to normalize blood glucose monitoring for a diabetic child in a busy school day or demonstrating appropriate limit setting for a child with hemophelia. The care of the chronically ill child and family is usually a multidisciplinary endeavour. The nurse is often the best person to serve as the case manager for the team due to the holistic nature of nursing service, and the ongoing contact with the child and family. This role is critical, as the successful management of the child's illness is contingent upon collaborative efforts towards fulfilling common goals that have been mutually defined with the family.

As a client advocate, the nurse can promote family-centeredness by conveying to other health care service providers how a particular family defines their child illness and the impact of the illness on the family.

The nurse is in a vital position to identify salient problems involving chronically ill children and their families that would be amenable to investigation. In the practice of the nurse, frequent contact is made with families and other health professional working with chronically ill children. This recurring access provides the nurse the opportunity to thoughtfully consider issues of concern to children, families, and care providers; such as, financial matters, respite care or integration of the child's treatment regime into school activities.

Implications for the Role of the Clinical Nurse Specialist

Within the role of expert practitioner, the Clinical Nurse Specialist serves as a role model to other nurses who have access to her expertise working with families and their chronically ill children. In view of the advanced knowledge in family theoretical constructs in general, and in family management styles in particular, the Clinical Nurse Specialist is able to provide educational opportunities that will sensitize nurses to the defining criteria of normalization as a management style and foster their ability to differentiate normalization from other management styles such as denial. Target groups for educational strategies could include patients and family, staff nurses or other health team members.

The Clinical Nurse Specialist can serve as a change agent in improving the services to families of children with chronic illness.

Within the clinical environment, the clinical expert is able to demonstrate leadership in the revision of agency policy that would support the identification of family management styles and supportive interventions. A specific example would be the revision of agency documentation, such as nursing history forms, to reflect the identification of key family attributes that reveal how a family defines and manages their child's illness. Furthermore, improved assessment forms would enable nurses to identify specific sources of support, the type of support offered by the various sources and families' satisfaction with the help received.

The present study supports the use of normalization as a prevalent management style for families of chronically ill school aged children. For children at this developmental stage, school life is a critical component to "life as normal". As a consultant, the clinical nurse specialist can provide advice and support to families and school officials helping chronically ill children adapt their illness requirements to school life. An example of this consultant role is the School Reentry Program for children with childhood cancer. For children undergoing cancer treatment there are several stigmatizing effects of treatment including alopecia and decreased energy levels. Within the School Reentry Program, the CNS visits the child's school and together with the child's family provide educational sessions to the school staff and the child's classmates. These programs have been successful in sensitizing and accommodating the child's school environment and thus supporting normalization (personal communication, P. McCarthy, May,

1996).

Within a broader context, the Clinical Nurse Specialist, with expertise in the assessment and treatment of families managing childhood chronic illness, is in a key position to consult with governments developing public policy which impacts families. Chronic illness in children affects a significant number of Canadian children and their families; for those affected, living "life as normal" presents many challenges. Most mothers in this study reported financial hardship associated with their child's illness. Additionally, 24% of mothers reported illness in another member of the household. Financial hardship may be created by medication or treatment costs, expenses associated with travel to the treatment centres, additional child care costs, or income lost while accompanying children to treatment centres. It is likely that policy and program development around issues such as income security and respite services would be helpful to these families. The Clinical Nurse Specialist is in a key position to advocate on behalf of these families and influence policy development in areas that will be supportive to their efforts to normalize.

Through the Clinical Nurse Specialist's understanding of the research process, the CNS is able to develop research proposals which have high potential for providing clinically significant findings, as they are grounded in the day-to-day practice of nursing families with chronically ill children. An example of a clinically based problem is the urgent need for further investigation of the study finding that the majority of families that use normalization do not perceive support

groups to be helpful. Referral by nurses to a patient support group is a common intervention in chronic illness yet may not be perceived by these families as beneficial.

Through network contacts with other advanced practitioners working with families and chronically ill children in other jurisdictions, the CNS has the opportunity to participate in multi-site research projects. This is particularly vital to further research in family management styles and normalization. Multi-site studies would enable projects to have samples with increased numbers of participants and improved representativeness and thus improve the generalizability of study findings.

Implications for Theory Development

Walker and Avant (1988) proffer three sequential elements of theory building including (1) concept development, and (2) the development of relational or causality statements leading to (3) the development of theory. Walker and Avant describe the outcome of theory development as "an internally consistent group of relational statements that present a systematic view about a phenomena and that is useful for description, explanation, prediction, and control" (p. 22). The Family Management Style Model is at an emergent phase of the conceptual development stage of nursing theory development. Further concept development research is needed particularly concerning the model components of "sociocultural context" and the "definition of the situation". The description of the underlying dimensions or factors associated with these two key components will support the development of instruments that

operationalize the full theoretical structure of the Family Management Model. This development will allow the application of stronger research designs in the investigation of family management in families with a chronically ill child. Although the components of the Family Management Style are defined, the process of the model and the notion of reciprocity among components needs elaboration through further theory development. There is also a need to develop the themes of other management styles recently described as Thriving, Accommodating, Enduring, Struggling and Floundering by Knafl et al. (in press).

Recommendations for Further Research

There are several implications for further research concerning families with children with a chronic illness that arise from the findings of this investigation. These recommendations apply to the investigation of family management in general, and normalization as a specific management style.

Regarding investigations of family management of childhood illness, research needs to be grounded in the meaning of "family." From the initial conceptualiztion, through selection of methods and instruments and analysis, research needs to better explore the "shared" perspective of all members of the family, including the chronically ill child.

The need to examine the impact of sociccultural variables, such as, perceived financial hardship, varied family compositions, and cultural orientation, on the outcome of family management styles is particularly urgent. Additionally, further research is needed to delineate management styles that differ from normalization and to identify significant

correlates to all management styles including disease prognosis and predictability of symptoms, the child's developmental stage, and the child's ability to comprehend the effect of the condition on their life. Current research into normalization has been predominately qualitative in methodological approach. This crucial research has led to conceptualization and description of this prevalent management style in families of chronically ill children. Future research, building on these conceptual foundations will be enhanced through triangulated research methodologies. Methodological triangulation is particularly useful in examining complex concepts (Burns & Grove,1993) such as normalization. Although some components of the model are amenable to quantitative evaluation, for instance management behaviors; other concepts, such as "the shared definition of meaning of the illness, may best be illuminated through qualitative enquiry. Methodological triangulation would require the collaboration of researchers with expertise in both qualitative and quantitative methods, working together with families with chronically ill children.

The development of the Normalization instrument (Murphy, 1994) has operationalized the conceptual dimensions of normalization as a management style for families with a chronically ill child. Further psychometric evaluation is needed to establish the reliability and validity in similar and divergent populations. This is particularly important for the "Comparison of Chronically Ill Child to Other Chronically Ill Child and Family Subscale" due to poor reliability performance in this study. Further construct validity investigations of

the normalization scale are needed, particularly as the concepts are being revised.

Study Conclusions

In summary, the results of this study support previous findings that identify normalization as a management style that is prevalent in the families of school aged children with a chronic illness. Mothers' perception of their families' use of normalization was found to be statistically significant to both satisfaction with the social support network and perceived social support. The size of the mother's social support network was not significantly associated with normalization.

This study provides further evidence that social support is a factor within the sociocultural dimension of the family management model. Through interactions with sources of support within the social network, the family comes to define the meaning of illness to the family and develops management behaviors. This study confirms previous findings that identify social support as an important influence in the lives of families with a chronically ill child. The study confirms that the informal sources of support, specifically spouses, friends and family are most often cited as helpful. Furthermore, this research confirms the importance of the health care professional in the family's process of normalizing their child's illness and their family life.

Through the contributions of reliability analysis on the total normalization scale and related subscales, this investigation furthers the development of the first instrument designed to elucidate the

constructs underlying normalization as a family management style. Further development of this instrument has the potential to guide the assessment of normalization in the practice setting as well as further research.

Of particular clinical importance is the finding that mothers reported low participation levels in support groups associated with their child's illness. Referral to support groups is a common social support intervention recommended by health professionals; however, for families who have adopted normalization as a management style, this strategy may not be helpful.

The study provides further support to the clinical meaningfulness of the theoretical constructs of Normalization described by Knafl and Deatrick (1986): acknowledgement of the existence of the impairment, defining family life as essentially normal, defining the social consequences of their situation as minimal, and engaging in behavior designed to demonstrate the normalcy of their family to others.

It is apparent that programs of research are needed in order to develop concepts significant to nursing. Individual researchers working with concepts, such as normalization, must share their findings with the consortium of researchers in these research programs in order to further concept refinement and theory development. It is through such a concerted effort we will increase the knowledge of nursing science and advance nursing practice.

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Appendix A

Introductory Letter to Mothers

Children's Hospital of Eastern Ontario
Hôpital pour enfants de l'est de l'Ontario
401 SMYTH, OTTAWA, ONT. K1H 8L1 TELEPHONE (613) 737-7600

Dear

Ms. Christine Foster is a registered nurse and graduate student in Nursing at the University of Ottawa and is conducting a nursing research study on the Medical Day Unit at the Children's Hospital of Eastern Ontario. Ms. Foster works as a nurse educator at the Children's Hospital of Eastern Ontario.

The purpose of this study is to determine how families of children with chronic illness manage their day-to-day activities and to explore what types of support are perceived as helpful by the families. Mothers of school aged children, with a variety of health problems will be invited to participate. The information gained in this study will provide nurses with a better understanding of the experiences of families with children with chronic illness and help identify ways we can better support parenting efforts.

Your participation would involve meeting Ms. Foster and answering some questionnaires during your next visit with your child to the Medical Day Unit at the Children's Hospital of Eastern Ontario. The length of time required to answer the questionnaires will be 30-45 minutes. The meeting could occur in your home if it is more convenient for you.

Your participation is completely voluntary. Whether or not you agree to participate, your child's care at the Children's Hospital of Eastern Ontario will not be affected in any way.

Shortly Ms. Foster will be calling you to further explain the study and answer any questions you may have. If you do not wish to be contacted by Ms. Foster please phone Terri-Lynn Emmanuel on the Medical Day unit at 737-2470.

Sincerely,

Helene Thibault R.N., BScN., MHA
Nursing Unit Administrator, Medical Day Unit

20 Years of Caring
20 ans de soins

Appendix B

Telephone Contact

Telephone Contact with Parent

Hello Mr./Mrs./Ms. _____, my name is Christine Foster. I am a graduate nursing student at the University of Ottawa. Recently you received a letter from Helene Thibault, the nurse manager at the Medical Day Unit at the Children's Hospital of Eastern Ontario, introducing you to the nursing research study I am conducting on the unit. The reason I am calling you is to further explain the research study, and to answer any questions you may have.

The purpose of the study is to determine how families of children with chronic illness manage their day-to-day activities and to explore what types of support are perceived as helpful to the families. The information gained in this study will provide nurses with a better understanding of the experiences of families with children with chronic illnesses and help identify ways we can better support your parenting efforts. Mothers of children with a variety of health problems will be invited to participate in the study.

If you are interested in participating in the study I would meet with you at CHEO during your son's(daughter's) regularly scheduled clinic appointment.

The questionnaire takes approximately 30-45 minutes to complete and can be completed at your child's bedside or in a conference room nearby.

Your participation is completely voluntary. Whether or not you agree to participate, your child's care at the Children's Hospital of Eastern Ontario will not be affected in any way.

Do you have any questions? Would you like to participate in the study?

If no: That is fine. Thank you for your time.

If yes: What is the date and time of your next appointment at MDU? When would it be convenient for me to meet with you?

Date: _____

Time: _____

When I see you, if you decide not to participate, that is fine. If you have any further questions, please feel free to contact me at 726-1106. Thank you for your interest.

Appendix C

Consent

Children's Hospital of Eastern Ontario
Hôpital pour enfants de l'est de l'Ontario
401 SMYTH, OTTAWA, ONT K1H 8L1 TELEPHONE (613) 737-7600

Consent Form

1. Study Title: Mothers' Reports of the Day-to-Day Management in Families of Chronically Ill Children and the Relationship to Perceived Social Support

2. I, _____, agree to take part in a study which will examine how my family manages on a daily basis and what types of support I think may help. It is hoped, that the information gained in this study will help nurses gain a better understanding of the experiences of families with children having chronic illnesses and ways they can support these families.

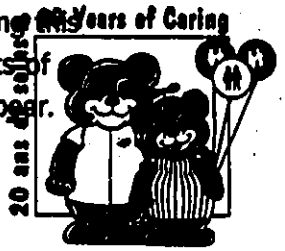
3. Christine C. Foster, RN., BScN., the principle investigator, has explained to me that my participation involves: (1) responding to a questionnaire concerning the management of my chronically ill child (2) responding to a questionnaire concerning types of support that I consider helpful and (3) completing a personal information sheet. My participation will take 30 to 45 minutes.

4. I understand that there will be no direct benefit to me or my child from participating in this study.

5. I understand that there are no risks involved in my participation.

6. I understand that I have the right to stop my participation in the study at any time. I understand that the care and services that my child and our family receive from the Children's Hospital of Eastern Ontario will not be affected in any way should I decide not to participate in this study at any time.

7. I understand that any information that is collected about me or my family during this study will remain confidential. No names will appear on any data. If the results of this study are reported or published, only information from the group will appear.



Children's Hospital of Eastern Ontario
Hôpital pour enfants de l'est de l'Ontario
401 SMYTH, OTTAWA, ONT K1H 8L1 TELEPHONE (613) 737-7600

8. I understand that all study data will be collected by Ms.Foster, stored in a secure place and shared only with her study advisor Dr. Elizabeth Cragg.

9. I understand that I am free to ask any questions about the study or my participation in the study by contacting the researcher or the research study advisor at the numbers listed below.

10.

_____	_____	_____
Mother's name (Print)	Signature	Date

11. I have explained the nature of the study to the parent and believe he/she has understood it.

Christine C. Foster	_____	_____
Researcher's name	Signature	Date

Researcher: Christine C. Foster RN. BScN. 726-1106
Study Advisor: Dr. Elizabeth Cragg RN. EdD. 562-5800 ext. 8394

Appendix D

Normalization Scale (Murphy 1994)

Management Style Questionnaire

Instructions: Please think about your child and your family over the last two months. For each question, you are asked to rate the frequency with which your child or family has believed something or done something by placing a slash (/) to cut the line somewhere between the two extremes labelled A LOT or A LITTLE- at the place that best corresponds to the answer that fits best for your child and family. For example, if you feel that the question describes your child/family a lot over the past two months, you should place the slash (/) at the A LOT end of the line. If you believe that the question sort of describes your child/family, you should place the slash (/) somewhere between the two extremes - closer to the A LITTLE end if it only partly describes your child/family and closer to the A LOT end if it pretty much describes your family. If the question hardly describes your child/family at all, you place your slash (/) at the A LITTLE end of the line.
Please remember -- there are no right or wrong (nor good nor bad) answers. You know what best describes your situation.

1. How much does your child's condition affect your family life?

a lot |----------| a little

2. How much do other people treat your family like they treat other families?

a lot |----------| a little

3. How much do you encourage your child to play with other children?

a lot |----------| a little

4. How routine does your child's home medical treatment feel?

a lot |----------| a little

5. How sure are you that your child has been correctly diagnosed?

a lot |----------| a little

6. How much does your child's condition affect how other children respond to your child?

a lot |----------| a little

7. How much do you encourage your child to attend school?

a lot |----------| a little

8. How much is your child like other children?

a lot |----------| a little

9. How much do other people find your family to be like other families?

a lot |----------| a little

10. How much does a child with a condition like your child's need to be treated differently because of the condition?

a lot |----------| a little

11. How much do you encourage your child to participate in extra curricular activities (eg., art, sports, drama, music)?

a lot |----------| a little

12. How reluctant are other people to include your family in an activity or event because of your child's condition ?

a lot |----------| a little

13. If your child did not have this chronic condition, how different would your family be compared to what it is like now?

a lot |----------| a little

14. How much should a child with a condition like your child's be treated like other children?

a lot |----------| a little

15. How much do other people find your child to be like other children?

a lot |----------| a little

16. How much of a hassle does your child's medical treatment create for your family's daily routine?

a lot |----------| a little

17. How much is your child like other children who have a similar condition?

a lot |----------| a little

18. How much does your child play with friends?

a lot |----------| a little

19.How much do you and your spouse/partner agree on how you see your child?
No spouse/partner ____

a lot |----------| a little

20. If your child did not have this chronic condition, how different would your child be compared to what she/he is like now?

a lot |----------| a little

21.How much of your family's daily activities have to be planned around your child's needs?

a lot |----------| a little

22. How much does your child participate in the same activities as his/her peers?

a lot |----------| a little

23. How much is your family like other families?

a lot |----------| a little

24. How much leeway in terms of your child's behaviour do you permit your child because of his/her condition?

a lot |----------| a little

25. IF YOU HAVE MORE THAN ONE CHILD : How much are your other children's activities affected by your child's condition?

not applicable___

a lot |----------| a little

26. How much is your family like other families who have a child with a similar condition?

a lot |----------| a little

27. How much do other people treat your child like they treat other children?

a lot |----------| a little

28. How much are your activities with your spouse/partner or other adults affected by your child's condition?

a lot |----------| a little

29. How much do you and your spouse/partner agree on how your child's condition and treatments should be managed?

No spouse/partner __

a lot |----------| a little

30. How much do other people find your family to be like other families who have a child with a chronic condition?

a lot |----------| a little

31. Do you belong to a support group or association related to your child's condition?

_____yes _____ no

IF YES: How active are you now in the support group or association related to your child's condition?

a lot |----------| a little

Appendix E

Personal Resource Questionnaire PRQ-85

(Weinert 1987)

PERSONAL RESOURCE QUESTIONNAIRE (PRQ-85)

© Brandt and Weinert

In our everyday lives there are personal and family situations or problems that we must deal with. Some of these are listed below. Please consider each statement in light of your own situation. **CIRCLE** the number before the person(s) that you could count on in each situation that is described. You may circle more than one number if there is more than one source of help that you count on. In addition, we would like to know if you have had this situation or a similar one in the past SIX MONTHS, and how satisfied you are with the help you received.

==========

Q-1a. If you were to experience urgent needs (crisis), who would you turn to for help? (Please **CIRCLE** all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you had urgent needs (crisis) in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-2a.)

c. If you have experienced urgent needs (crisis) in the past SIX MONTHS, to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-2a. If you needed help for an extended period of time in caring for a family member who is sick or handicapped, who would you turn to for help? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you needed help in caring for a sick or handicapped family member in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-3a.)

c. If you have needed help in caring for a sick or handicapped family member in the past SIX MONTHS, to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-3a. If you were concerned about your relationship with your spouse, partner, or intimate other, who would you turn to for help? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you had concerns about your relationship with your spouse, partner, or intimate other in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-4a.)

c. If you have had concerns about your relationship with your spouse, partner, or intimate other in the past SIX MONTHS, to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-4a. If you needed help or advice for a problem with a family member or friend who would you turn to for help? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you needed help or advice regarding a problem with a family member or friend in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-5a.)

c. If you have needed help or advice in the past SIX MONTHS regarding a problem with a member or friend, to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED

Q-5a. If you were having financial problems, who would you turn to for help? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you had financial problems in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-6a.)

c. If you have had financial problems in the past SIX MONTHS to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-6a. If you felt lonely, who would you turn to? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you felt lonely in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-7a.)

c. If you have felt lonely, in the past SIX MONTHS, to what extent do you feel satisfied with the help you have received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-7a. If you were sick and not able to carry out your usual activities for a week or so, who would you turn to for help?

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. During the past SIX MONTHS, have you been sick for a week and not able to carry out your usual activities?

1 YES
2 NO (If NO, skip to Q-8a.)

c. If you have been sick for a week during the past SIX MONTHS to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-8a. If you were upset and frustrated with the conditions of your life, who would you turn to for help?

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you been upset and frustrated with the conditions of your life in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-9a.)

c. If you have been upset and frustrated with the conditions of your life in the past SIX MONTHS, to what extent do you feel satisfied with help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-9a. If you were having problems with your work at home or at your place of employment, who would you turn to for help?

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you had problems related to your work in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-10a.)

c. If you have had problems with your work situation in the past SIX MONTHS, to what extent do you feel satisfied with help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-10a. If you needed someone to talk to about your day-to-day personal concerns, who would you turn to for help?

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you needed someone to talk to about day-to-day personal concerns in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-11)

c. If you have needed someone to talk to about day-to-day personal concerns in the past SIX MONTHS, to what extent do you feel satisfied with help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-11. Below are some statements with which some people agree and others disagree. Please read each statement and CIRCLE the response most appropriate for you. There is no right or wrong answer.

1 = STRONGLY DISAGREE
2 = DISAGREE
3 = SOMEWHAT DISAGREE
4 = NEUTRAL
5 = SOMEWHAT AGREE
6 = AGREE
7 = STRONGLY AGREE

STATEMENTS							
a. There is someone I feel close to who makes me feel secure	1	2	3	4	5	6	7
b. I belong to a group in which I feel important	1	2	3	4	5	6	7
c. People let me know that I do well at my work (job, homemaking)	1	2	3	4	5	6	7
d. I can't count on my relatives and friends to help me with problems	1	2	3	4	5	6	7
e. I have enough contact with the person who makes me feel special	1	2	3	4	5	6	7
f. I spend time with others who have the same interests that I do	1	2	3	4	5	6	7
g. There is little opportunity in my life to be giving and caring to another person	1	2	3	4	5	6	7
h. Others let me know that they enjoy working with me (job, committees, projects)	1	2	3	4	5	6	7
i. There are people who are available if I needed help over an extended period of time	1	2	3	4	5	6	7
j. There is no one to talk to about how I am feeling	1	2	3	4	5	6	7
k. Among my group of friends we do favors for each other	1	2	3	4	5	6	7

1 = STRONGLY DISAGREE
2 = DISAGREE
3 = SOMEWHAT DISAGREE
4 = NEUTRAL
5 = SOMEWHAT AGREE
6 = AGREE
7 = STRONGLY AGREE

STATEMENTS							
l. I have the opportunity to encourage others to develop their interests and skills	1	2	3	4	5	6	7
m. My family lets me know that I am important for keeping the family running	1	2	3	4	5	6	7
n. I have relatives or friends that will help me out even if I can't pay them back	1	2	3	4	5	6	7
o. When I am upset there is someone I can be with who lets me be myself	1	2	3	4	5	6	7
p. I feel no one has the same problems as I	1	2	3	4	5	6	7
q. I enjoy doing little "extra" things that make another person's life more pleasant	1	2	3	4	5	6	7
r. I know that others appreciate me as a person	1	2	3	4	5	6	7
s. There is someone who loves and cares about me	1	2	3	4	5	6	7
t. I have people to share social events and fun activities with	1	2	3	4	5	6	7
u. I am responsible for helping provide for another person's needs	1	2	3	4	5	6	7
v. If I need advice there is someone who would assist me to work out a plan for dealing with the situation	1	2	3	4	5	6	7
w. I have a sense of being needed by another person	1	2	3	4	5	6	7
x. People think that I'm not as good a friend as I should be	1	2	3	4	5	6	7
y. If I got sick, there is someone to give me advice about caring for myself	1	2	3	4	5	6	7

Appendix F

Demographic Questionnaire (Foster 1996)

Demographic Questionnaire

Please answer the following questions about your family (Circle the number of your answer or fill in the blank). Let me remind you that all the information you give remains confidential.

Q1. How old is your chronically ill child? _____(years)

Q2. What is your chronically ill child's sex?

1 male
2 female

Q3. What is your child's medical diagnosis? _____

Q4. At what age was your child's health problem diagnosed? _____(eg. at birth, months or years etc.)

Q5. What grade is your child in at school? _____ (eg. kindergarten, grade three etc.)

Q6. What grade should your child be in at school? _____

Q7. Have you ever been told that your child is mentally disabled?

1 yes
2. no

Q8. Do you feel your child's activities are limited because of his/her chronic condition?

1 yes (please specify_____)
2 no

Q9. How severe do you think your child's condition is, compared to other children with the same illness?

1 more severe
2 less severe
3 about the same
4. I don't know another child with the same illness

Q10. Do you have other children ?

1 yes
2 no

Q11. Including your child with a chronic illness, how many children do you have in each age group?

___ Under 5 years of age
___ 5 to 13
___ 14 to 18
___ 19 to 25

Q12. How old are you ? _____ years

Q13. Which of the following best describes your present marital status? (Mark one)

___ married
___ common-law
___ single
___ separated
___ divorced
___ widowed

Q14. With whom do you live? (Check as many as apply)

___ with spouse or partner
___ With children (enter number)
___ With parents (enter number)
___ With other relative (enter number)
___ With unrelated people (enter number)

Q15. Is any other member of your household ill? (please specify who and nature of illness)

1 yes (specify) _____

2 no

Q16. To which ethnic or cultural group(s) do you belong? (check all that apply)

___ English
___ French
___ Canadian
___ Spanish
___ Portuguese
___ Vietnamese
___ Arabic
___ Italian
___ Cambodian
___ East Indian
___ North American Indian
___ other (specify) _____
___ Scottish
___ German
___ Ukranian
___ Polish
___ Dutch
___ Jewish
___ Hungarian
___ Chinese
___ Metis
___ Inuit
___ Irish

Q17. Were you born in Canada?

1 yes — GO TO QUESTION 19

2 no

Q18. When did you arrive in Canada?

1 less than one year
2 one to two years
3 three to four years
4 five or more years

Q19. What was the last level of school that you completed?

1 less than grade twelve
2 high school graduate
3 some university or college
4 university or college graduate
5 post graduate or professional degree

Q20. What is your approximate yearly family income from all sources?

___ $19,000 or less
___ $ 20,000 to $39,000
___ $ 40,000 to $59,000
___ $ 60,000 to $79,000
___ $80,000 or more

Q21. In general, how well does your family income currently satisfy your needs?

1 very well
2 adequate
3 not very well
4 totally inadequate
5 don't know

Q22. To what extent does your child's illness create a financial hardship for your family?

1 not al all
2 somewhat
3. a great deal

Thank you for taking the time to complete this survey.

Appendix G

Compiled Study Questionnaire

Children with Chronic Illness

Mothers Reports of the Day-to-Day Management of their Families

Christine C. Foster
RN, BScN.
MScN Candidate
University of Ottawa
726-1106

PERSONAL RESOURCE QUESTIONNAIRE (PRQ-85)

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In our everyday lives there are personal and family situations or problems that we must deal with. Some of these are listed below. Please consider each statement in light of your own situation. CIRCLE the number before the person(s) that you could count on in each situation that is described. You may circle more than one number if there is more than one source of help that you count on. In addition, we would like to know if you have had this situation or a similar one in the past SIX MONTHS, and how satisfied you are with the help you received.

==========

Q-1a. If you were to experience urgent needs (crisis), who would you turn to for help? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you had urgent needs (crisis) in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-2a.)

c. If you have experienced urgent needs (crisis) in the past SIX MONTHS, to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-2a. If you needed help for an extended period of time in caring for a family member who is sick or handicapped, who would you turn to for help? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you needed help in caring for a sick or handicapped family member in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-3a.)

c. If you have needed help in caring for a sick or handicapped family member in the past SIX MONTHS, to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-3a. If you were concerned about your relationship with your spouse, partner, or intimate other, who would you turn to for help? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you had concerns about your relationship with your spouse, partner, or intimate other in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-4a.)

c. If you have had concerns about your relationship with your spouse, partner, or intimate other in the past SIX MONTHS, to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-4a. If you needed help or advice for a problem with a family member or friend who would you turn to for help? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you needed help or advice regarding a problem with a family member or friend in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-5a.)

c. If you have needed help or advice in the past SIX MONTHS regarding a problem with a member or friend, to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED

Q-5a. If you were having financial problems, who would you turn to for help? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you had financial problems in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-6a.)

c. If you have had financial problems in the past SIX MONTHS to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-6a. If you felt lonely, who would you turn to? (Please CIRCLE all that apply.)

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you felt lonely in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-7a.)

c. If you have felt lonely, in the past SIX MONTHS, to what extent do you feel satisfied with the help you have received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-7a. If you were sick and not able to carry out your usual activities for a week or so, who would you turn to for help?

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. During the past SIX MONTHS, have you been sick for a week and not able to carry out your usual activities?

1 YES
2 NO (If NO, skip to Q-8a.)

c. If you have been sick for a week during the past SIX MONTHS to what extent do you feel satisfied with the help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-8a. If you were upset and frustrated with the conditions of your life, who would you turn to for help?

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you been upset and frustrated with the conditions of your life in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-9a.)

c. If you have been upset and frustrated with the conditions of your life in the past SIX MONTHS, to what extent do you feel satisfied with help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-9a. If you were having problems with your work at home or at your place of employment, who would you turn to for help?

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you had problems related to your work in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-10a.)

c. If you have had problems with your work situation in the past SIX MONTHS, to what extent do you feel satisfied with help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-10a. If you needed someone to talk to about your day-to-day personal concerns, who would you turn to for help?

1 PARENT
2 CHILD OR CHILDREN
3 SPOUSE OR PARTNER OR SIGNIFICANT OTHER
4 A RELATIVE OR FAMILY MEMBER
5 FRIEND
6 NEIGHBOR OR CO-WORKER
7 SPIRITUAL ADVISOR (minister, priest, etc.)
8 PROFESSIONAL (nurse, counselor, social worker, employer, etc.)
9 AGENCY
10 SELF-HELP GROUP
11 NO ONE (No one available)
12 NO ONE (Prefer to handle it alone)
13 OTHER (Please explain) _____

b. Have you needed someone to talk to about day-to-day personal concerns in the past SIX MONTHS?

1 YES
2 NO (If NO, skip to Q-11)

c. If you have needed someone to talk to about day-to-day personal concerns in the past SIX MONTHS, to what extent do you feel satisfied with help you received?

1 VERY DISSATISFIED
2 FAIRLY DISSATISFIED
3 A LITTLE DISSATISFIED
4 A LITTLE SATISFIED
5 FAIRLY SATISFIED
6 VERY SATISFIED

Q-11. Below are some statements with which some people agree and others disagree. Please read each statement and CIRCLE the response most appropriate for you. There is no right or wrong answer.

1 = STRONGLY DISAGREE
2 = DISAGREE
3 = SOMEWHAT DISAGREE
4 = NEUTRAL
5 = SOMEWHAT AGREE
6 = AGREE
7 = STRONGLY AGREE

STATEMENTS							
a. There is someone I feel close to who makes me feel secure	1	2	3	4	5	6	7
b. I belong to a group in which I feel important	1	2	3	4	5	6	7
c. People let me know that I do well at my work (job, homemaking)	1	2	3	4	5	6	7
d. I can't count on my relatives and friends to help me with problems	1	2	3	4	5	6	7
e. I have enough contact with the person who makes me feel special	1	2	3	4	5	6	7
f. I spend time with others who have the same interests that I do	1	2	3	4	5	6	7
g. There is little opportunity in my life to be giving and caring to another person	1	2	3	4	5	6	7
h. Others let me know that they enjoy working with me (job, committees, projects)	1	2	3	4	5	6	7
i. There are people who are available if I needed help over an extended period of time	1	2	3	4	5	6	7
j. There is no one to talk to about how I am feeling	1	2	3	4	5	6	7
k. Among my group of friends we do favors for each other	1	2	3	4	5	6	7

1 = STRONGLY DISAGREE
2 = DISAGREE
3 = SOMEWHAT DISAGREE
4 = NEUTRAL
5 = SOMEWHAT AGREE
6 = AGREE
7 = STRONGLY AGREE

STATEMENTS							
l. I have the opportunity to encourage others to develop their interests and skills	1	2	3	4	5	6	7
m. My family lets me know that I am important for keeping the family running	1	2	3	4	5	6	7
n. I have relatives or friends that will help me out even if I can't pay them back	1	2	3	4	5	6	7
o. When I am upset there is someone I can be with who lets me be myself	1	2	3	4	5	6	7
p. I feel no one has the same problems as I	1	2	3	4	5	6	7
q. I enjoy doing little "extra" things that make another person's life more pleasant	1	2	3	4	5	6	7
r. I know that others appreciate me as a person	1	2	3	4	5	6	7
s. There is someone who loves and cares about me	1	2	3	4	5	6	7
t. I have people to share social events and fun activities with	1	2	3	4	5	6	7
u. I am responsible for helping provide for another person's needs	1	2	3	4	5	6	7
v. If I need advice there is someone who would assist me to work out a plan for dealing with the situation	1	2	3	4	5	6	7
w. I have a sense of being needed by another person	1	2	3	4	5	6	7
x. People think that I'm not as good a friend as I should be	1	2	3	4	5	6	7
y. If I got sick, there is someone to give me advice about caring for myself	1	2	3	4	5	6	7

Management Style Questionnaire

Instructions: Please think about your child and your family over the last two months. For each question, you are asked to rate the frequency with which your child or family has believed something or done something by placing a slash (/) to cut the line somewhere between the two extremes labelled A LOT or A LITTLE- at the place that best corresponds to the answer that fits best for your child and family. For example, if you feel that the question describes your child/family a lot over the past two months, you should place the slash (/) at the A LOT end of the line. If you believe that the question sort of describes your child/family, you should place the slash (/) somewhere between the two extremes - closer to the A LITTLE end if it only partly describes your child/family and closer to the A LOT end if it pretty much describes your family. If the question hardly describes your child/family at all, you place your slash (/) at the A LITTLE end of the line.
Please remember -- there are no right or wrong (nor good nor bad) answers. You know what best describes your situation.

1. How much does your child's condition affect your family life?

a lot |----------| a little

2. How much do other people treat your family like they treat other families?

a lot |----------| a little

3. How much do you encourage your child to play with other children?

a lot |----------| a little

4. How routine does your child's home medical treatment feel?

a lot |----------| a little

5. How sure are you that your child has been correctly diagnosed?

a lot |----------| a little

6. How much does your child's condition affect how other children respond to your child?

a lot |----------| a little

7. How much do you encourage your child to attend school?

a lot |----------| a little

8. How much is your child like other children?

a lot |----------| a little

9. How much do other people find your family to be like other families?

a lot |---------- a little

10. How much does a child with a condition like your child's need to be treated differently because of the condition?

a lot |----------| a little

11. How much do you encourage your child to participate in extra curricular activities (eg., art, sports, drama, music)?

a lot |----------| a little

12. How reluctant are other people to include your family in an activity or event because of your child's condition ?

a lot |----------| a little

13. If your child did not have this chronic condition, how different would your family be compared to what it is like now?

a lot |----------| a little

14. How much should a child with a condition like your child's be treated like other children?

a lot |----------| a little

15. How much do other people find your child to be like other children?

a lot |----------| a little

16. How much of a hassle does your child's medical treatment create for your family's daily routine?

a lot |----------| a little

17. How much is your child like other children who have a similar condition?

a lot |----------| a little

18. How much does your child play with friends?

a lot |----------| a little

19.How much do you and your spouse/partner agree on how you see your child?
No spouse/partner ____

a lot |----------| a little

20. If your child did not have this chronic condition, how different would your child be compared to what she/he is like now?

a lot |----------| a little

21.How much of your family's daily activities have to be planned around your child's needs?

a lot |----------| a little

22. How much does your child participate in the same activities as his/her peers?

a lot |----------| a little

23. How much is your family like other families?

a lot |----------| a little

24. How much leeway in terms of your child's behaviour do you permit your child because of his/her condition?

a lot |----------| a little

25. IF YOU HAVE MORE THAN ONE CHILD : How much are your other children's activities affected by your child's condition?

not applicable___

a lot |----------| a little

26. How much is your family like other families who have a child with a similar condition?

a lot |----------| a little

27. How much do other people treat your child like they treat other children?

a lot |----------| a little

28. How much are your activities with your spouse/partner or other adults affected by your child's condition?

a lot |----------| a little

29. How much do you and your spouse/partner agree on how your child's condition and treatments should be managed?

No spouse/partner __

a lot |----------| a little

30. How much do other people find your family to be like other families who have a child with a chronic condition?

a lot |----------| a little

31. Do you belong to a support group or association related to your child's condition?

_____yes _____ no

IF YES: How active are you now in the support group or association related to your child's condition?

a lot |----------| a little

Demographic Questionnaire

Please answer the following questions about your family (Circle the number of your answer or fill in the blank). Let me remind you that all the information you give remains confidential.

Q1. How old is your chronically ill child? _____(years)

Q2. What is your chronically ill child's sex?

1 male
2 female

Q3. What is your child's medical diagnosis? _____

Q4. At what age was your child's health problem diagnosed? _____(eg. at birth, months or years etc.)

Q5. What grade is your child in at school? _____ (eg. kindergarten, grade three etc.)

Q6. What grade should your child be in at school? _____

Q7. Have you ever been told that your child is mentally disabled?

1 yes
2. no

Q8. Do you feel your child's activities are limited because of his/her chronic condition?

1 yes (please specify_____)
2 no

Q9. How severe do you think your child's condition is, compared to other children with the same illness?

1 more severe
2 less severe
3 about the same
4. I don't know another child with the same illness

Q10. Do you have other children ?

1 yes
2 no

Q11. Including your child with a chronic illness, how many children do you have in each age group?

___ Under 5 years of age
___ 5 to 13
___ 14 to 18
___ 19 to 25

Q12. How old are you ? _____ years

Q13. Which of the following best describes your present marital status? (Mark one)

___ married
___ common-law
___ single
___ separated
___ divorced
___ widowed

Q14. With whom do you live? (Check as many as apply)

___ with spouse or partner
___ With children (enter number)
___ With parents (enter number)
___ With other relative (enter number)
___ With unrelated people (enter number)

Q15. Is any other member of your household ill? (please specify who and nature of illness)

1 yes (specify) _____

2 no

Q16. To which ethnic or cultural group(s) do you belong? (check all that apply)

___ English
___ French
___ Canadian
___ Spanish
___ Portuguese
___ Vietnamese
___ Arabic
___ Italian
___ Cambodian
___ East Indian
___ North American Indian
___ other (specify) _____
___ Scottish
___ German
___ Ukranian
___ Polish
___ Dutch
___ Jewish
___ Hungarian
___ Chinese
___ Metis
___ Inuit
___ Irish

Q17. Were you born in Canada?

1 yes — GO TO QUESTION 19

2 no

Q18. When did you arrive in Canada?

1 less than one year
2 one to two years
3 three to four years
4 five or more years

Q19. What was the last level of school that you completed?

1 less than grade twelve
2 high school graduate
3 some university or college
4 university or college graduate
5 post graduate or professional degree

Q20. What is your approximate yearly family income from all sources?

___ $19,000 or less
___ $ 20,000 to $39,000
___ $ 40,000 to $59,000
___ $ 60,000 to $79,000
___ $80,000 or more

Q21. In general, how well does your family income currently satisfy your needs?

1 very well
2 adequate
3 not very well
4 totally inadequate
5 don't know

Q22. To what extent does your child's illness create a financial hardship for your family?

1 not al all
2 somewhat
3. a great deal

Thank you for taking the time to complete this survey.

Your contribution to this study is greatly appreciated. If you would like a summary of results, please print your name and address on the enclosed card (not on this questionnaire). We will see that you get the summary on the completion of the study.