

**THE EXPERIENCE OF CARING FOR A CHILD WITH A MEDICALLY-
FRAGILE CONDITION AT HOME: PERCEPTIONS OF PARENTS**

by

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ABSTRACT

This study was designed to discover and describe the experiences of parents who care for their child with a medically-fragile condition at home. The qualitative method of phenomenology was employed to elicit an understanding of the parents' experiences.

Data collection occurred through indepth interviews with six mothers and three fathers of six children who had a wide range of medically-fragile conditions and who were receiving in-home nursing respite support. Through a process of ongoing data collection and simultaneous data analysis, the experiences of the participants were described.

Parents' experiences of caring for their child with a medically-fragile condition were conceptualized as evolving through three critical time periods: hospital-based care, transition from hospital to home-based care, and home-based care. In addition, the parents' descriptions of becoming their child's primary caregiver were conceptualized as progressing through four distinct stages across the time frame of these three critical periods. In particular, the characteristics of supportive and conflictual parent - health care provider relationships were highlighted as an important element of the participants' experiences. The description and analysis of these components of the parents' experience provided the foundation for the analysis of the dynamics of parental caregiving for a child with a medically-fragile condition at home.

The dynamics of parental caregiving were conceptualized as a process of

balancing the nature of caregiving demands with the nature of parental caregiving.

The inherently fragile nature of the child's condition played a key role in the unique experiences of these families. Concepts central to understanding the participants' experience were discussed in relation to existing literature in this area. Implications for nursing practice, education and research were examined.

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CHAPTER ONE

INTRODUCTION TO THE STUDY

Background and Conceptualization of the Problem

It is estimated that 10% to 15% of infants and children who would have died from their illnesses only a few years ago now survive with a sequelae of chronic illness or disability (Gillette, Hansen, Robinson, Kirkpatrick & Grywalski, 1991; Urbano, vonWindeguth, Sideritis, Parker, & Studenic-Lewis, 1991). Sophisticated medical technology has contributed to the longevity of many of these children with medically-fragile conditions.

In recent years the focus of pediatric care has moved from hospital management of infants and children with medically-fragile conditions to home-based care. Anderson, Elfert, and Lai (1989) assert that both historical and economic factors greatly influenced the interrelated movements of rehabilitation, deinstitutionalization, and normalization. Anderson et al (1989) further affirm that "the theme of individual responsibility for self, versus a collective responsibility for the care of the individual" is inherent in these movements (p.258). The increasing trend towards deinstitutionalization of children with medically-fragile conditions coupled with financial incentives for early discharge has placed increased caretaking responsibilities on families and communities (Anderson, 1981; Feetham, 1986; Rawlins, Rawlins & Horner, 1990). Family members caring for these children are being asked to perform highly technical procedures traditionally performed by health

care professionals in acute-care settings (Sims, Boland, & O'Neill, 1992).

Furthermore, the acuity of children receiving home health care has risen dramatically over the past few years (Sims et al, 1992).

Families of children who meet the criteria of having a "medically-fragile" condition almost always require some form of nursing respite support in order to effectively cope with caring for their child at home. In British Columbia, the Ministry of Health established the Nursing Respite Program in 1988 as one effort to meet this need.

The Nursing Respite Program is funded by the Ministry of Health and provides support for families who have a child with a technologically-dependent and/or medically-fragile condition living at home. The community-based respite program provides both in-home and out-of-home support for children with complex and demanding care needs such as those requiring tracheostomies, ventilation, total parental nutrition, and palliative care (Hayes & Cook, 1991; British Columbia, 1988).

There is little information available regarding the parents' perceptions of their experiences, needs, and concerns with home-based care of their child with a medically-fragile condition. In addition, although the medically-fragile nature of the child's condition generally necessitates nursing respite support, there is a lack of research available on the impact of such services on families caring for their child at home (Joyce & Singer, 1983). In fact, Lyman, Wurtele, and Wilson (1985) indicate that home-care based services may lead to increased anxiety, impaired sleep, and restricted social lives for the parents of these children. Moreover, Libow (1987)

points to the fact that the presence of home care services is often disruptive to normal family functioning. The researcher's personal experience in providing nursing respite care services to children and their families has revealed similar findings.

Research indicates that there is a lack of continuity of care during the transition from acute care settings to home-based services. A study by Davis and Steele (1991) in the United States suggests that there is a considerable difference between the services currently provided to families of chronically ill children in the community and the services desired by these families. Moreover, parents often cite fragmented health care as a major problem in caring for their chronically ill children (Hobbs, Perrin, & Ireys, 1985; Strauss & Munton, 1985).

Traditionally, health care providers have relied on their own perceptions of the consumer's needs in planning and developing programs for children and their families, overlooking the family's perceived needs and concerns (Diehl, Moffitt, & Wade, 1991; Walker, Epstein, Taylor, Crocker, & Tuttle, 1989; Rawlins et al, 1990). This approach is insufficient when parents are taking increasing responsibility for their child's care. Deinstitutionalization of children with severe chronic disabilities places parents in the role of primary decision-makers, caregivers, and advocates for their children (Rawlins et al, 1990).

As health care professionals it is our responsibility to ensure that parents are prepared for the responsibility that is being placed on them. Eliciting family members' perspectives of their experience of caring for their child with a medically-fragile condition at home is therefore essential if we are to successfully plan, develop,

and implement effective health care services.

Problem Statement

There is a substantial amount of literature available concerning the chronically ill child and his or her family. However, there is a significant gap in our understanding of the experiences of parents who care for their child with a medically-fragile condition at home. In order to design and implement effective services, nurses and other health care professionals must recognize the importance of understanding the experiences of parents as communicated by them, rather than the preconceptions as reported by various professionals. This research study was motivated by the paucity of research examining the parents' perceptions of their experience of caring for their child with a medically-fragile condition at home.

Purpose

The purpose of this study is to understand and describe the experiences of parents who care for their child with a medically-fragile condition at home. Specifically, the primary objectives of this study are to gain a deeper understanding of the challenges parents face in caring for a child with a medically-fragile condition and how these parents manage their child's care at home.

Research Question

The following research questions were generated from the background and

conceptualization of the problem and a review of selected literature: 1) What are the challenges parents face in caring for a child with a medically-fragile condition at home, and 2) How do parents manage the care of their child with a medically-fragile condition at home?

Definition of Terms

Nursing Respite Services:

This study will focus only on those individuals receiving in-home respite care by registered nurses who are employees of a nursing respite agency. In-home services involve a Registered Nurse(s) coming into the family's home for a specified period of time, allowing the parent(s) time to leave the home or to pursue any activity within the home free from the responsibility of caring for the child with a disability (Cohen, 1982). At the onset of this study, the Nursing Respite Program was a relatively new program and no set criteria were in place to determine the number of hours per week of respite care which a family received. Rather, Nursing Respite Consultants, under the employment of the Nursing Respite Program, worked in conjunction with individual families and other health care professionals involved in the child's care to determine the family's eligibility for nursing respite services and the number of hours of nursing respite received.

Child With a Medically-Fragile Condition:

For the purpose of this study, the term child with a medically-fragile condition will be used to refer to any child from birth to nineteen years of age who has a severe

long-term disability which: (1) is attributable to a physical or mental impairment, or both; (2) is likely to be of lifelong or extended duration; (3) requires in-home nursing respite support services; (4) requires a high level of complex nursing care, including disorders which result in technology dependence such as the need for assisted ventilation, artificial airways, and parenteral nutrition and (5) is medically vulnerable and/or lacks resistance to influences capable of interfering with life. Families of children receiving palliative nursing respite services for the end stages of a terminal disease will not be included in this study.

Parents:

For the purpose of this study, parents will refer to the individuals (individual) who are the primary caregivers of the child at home. The term parent will include both natural or foster parents.

Assumptions

There are certain basic assumptions of this study which are outlined below.

- 1) It is assumed that there is an interdependence between a child, his or her family, and the environment. Moreover, the health care system is acknowledged as a major component of the environment of a family whose child has a medically-fragile condition (Feetham, 1986).
- 2) It is assumed that an individual's reaction to the environment is determined by their perception of the environment. Therefore, the impact of a child's illness on the family is best established by asking family members to describe their perception of

the experience (Hymovich, 1981).

- 3) Parents have the ability to recall accurately their own experiences and the experiences of their child.

Limitations

A few limitations of the study have been identified. First, due to the limited time and funding available for the study, a homogenous sample of English speaking Canadians was selected in order to achieve saturation of categories more easily. Therefore, an obvious limitation is that this study was not enriched with the perspectives of different cultural groups.

Another limitation was that two of the fathers who could have participated in the study chose not to. This is of concern since the perspectives of fathers of children with medically-fragile conditions may not have been adequately represented in the study's findings.

Significance of the Study

The findings of this study will contribute to a better understanding of parental needs and concerns regarding the care of their child with a medically-fragile condition at home. Information generated from this study will provide nurses and other health care workers with direction for planning, developing, and implementing services that are responsive to families' perceived needs and concerns.

Summary

The increasing trend towards deinstitutionalization of children with complex health care needs has placed increased caretaking responsibilities on families and communities. In order to facilitate families meeting this challenge, health care providers must understand the family's perception of their experience and management of their child's care at home. This chapter has presented the background and conceptualization of the problem, indicating the paucity of literature which addresses the parents' perspective of caring for their child with a medically-fragile condition at home. Thus, the purpose of the study is to understand and describe the experiences of parents who care for their child with a medically-fragile condition at home. The significance of the proposed study is that it will contribute to a better understanding of the needs and concerns of this population.

In the following chapter, a critical review of pertinent literature will be presented. Chapter Three will focus on the research methodology utilized to address the research question. In the fourth chapter a description and analysis of the participants' experiences will be explored. A discussion of key concepts of the study in relation to existing literature will be generated in Chapter Five. The final chapter will explore the conclusions derived from the study and the implications for nursing practice, education, and research.

CHAPTER TWO

REVIEW OF SELECTED LITERATURE

Introduction

In this chapter, a review of selected literature pertinent to the topic of interest will be presented in order to situate this study in the current body of knowledge related to the experience of parents who care for a child with a medically-fragile condition at home. A search of existing literature in nursing and related disciplines revealed a scarcity of literature which specifically focused on the experiences of parents caring for a child with a medically-fragile condition at home. Only three studies were found which examined the parents' experiences of caring for a child with a medically-fragile condition. Therefore, the existing literature examining the more general experiences of families caring for a child with a long-term or chronic condition (non medically-fragile) will be included in the review of the literature. Specifically, relevant literature pertaining to the impact of a child's long-term condition on the family will be examined. This will be followed by an exploration of theoretical and research literature which focuses on how families cope with caring for a child with a long-term illness. Next, a review of the literature which describes the needs of families caring for a child with complex health care needs will be put forth. Finally, the literature related to home-based support services for families caring for a child with a long-term disability will be examined.

Impact of a Child's Chronic Condition on the Family

It is well recognized that a child's chronic illness not only affects the child's functioning, but has ramifications for all members of the family system (Kazak, 1989). In addition, Andrews and Nielson (1988) assert that: "The degree of disruption of the family depends on the nature, severity, length, prognosis of illness and parental coping: support systems, fiscal resources, educational background, previous experience with illness and a variety of individual definitions" (p. 112).

Three studies which examined the impact of caring for a child with a medically-fragile condition on the family were Wills (1983), Aday and Wegener (1988), and Thomas (1986). Wills (1983) utilized a descriptive exploratory design to examine the concerns and needs of mothers caring for an infant with a tracheostomy during the transition from hospital to home-based care. Data was collected through a semi-structured interview with eight mothers. Participants in this study reported feelings of isolation and being overwhelmed with the child's caregiving requirements. One mother reported not leaving the home for any social event for almost six months. Other participants described complete lifestyle changes and an inability to resume their previous lives. Mothers also reported chronic sleep deprivation related to "vigilance" and the need for the infant to be suctioned frequently (Wills, 1983).

The results of the preceding study provide valuable insight into understanding the experiences of mothers caring for a child with a medically-fragile condition at home. Limitations of the study include a focus on the transition period from hospital to home-based care and a restricted sample of mothers of infants less than one year of

age. Further information is required from the fathers' perspectives and over a longer period of time in order to gain a clear understanding of these families' experiences.

Aday & Wegener (1988) investigated 138 families caring for a child who was ventilator-assisted. Through the use of semi-structured telephone interviews and mailed questionnaires, the co-investigators found that 95 percent of the caregivers perceived home-based care of the child to be a "positive experience", however they did consider the day-to-day experience of caring for their child as stressful and requiring numerous "adjustments" to accommodate the child's care requirements. These adjustments included: increased responsibility of the child's care, the tensions created by the entrance of a nurse caregiver into the home and family's life, and the "constancy" of demands involved in meeting the child's caregiving demands (Aday & Wegener, 1988). A limitation of the study was that the sample was limited to caregivers of children who were ventilator-assisted. A critical review of the findings is also hampered by a lack of information regarding the nature of the children's caregiving requirements and the method of data analysis utilized.

Thomas (1986) examined the experiences of families caring for a child who was ventilator-dependent. The study involved a descriptive exploratory investigation of the consequences for the child and family of an "acute" chronic condition, ventilator dependence. Ethnographic interviews were utilized to collect data from adult family members (age 18 or older). A total of seven families were interviewed including: four families in which a child was ventilator dependent or assisted, two families of a child who had been weaned from the ventilator, and one family in which

the child who was ventilator-dependent had died. The children ranged in age from 22 months to 11 years of age, and all were cared for at home with support from health care providers. All but one of the families in Thomas' study indicated that they would go through the experience again and that "the child was worth all of the strain his condition imposed" (1986, p.173). Nevertheless, participants also described several "costs" involved in their experience of caring for a child who was ventilator dependent. These included: increased financial costs, privacy violation associated with the presence of health care providers in the home 24 hours a day, control struggles with the health care system and the insurance system, chronic sleep deprivation related to "constant vigilance" of the child and his health care needs, and feelings of isolation (Thomas, 1986).

A strength of the preceding research study is that it involves the perspectives of both mothers and fathers. One limitation of the study, noted by the author, was sample bias in that all seven children were male. Another drawback of the study is the inclusion of one family whose child had died and one family whose child had a progressive degenerative disease expected to end in death. Considering the small sample size, the inclusion of the notably different experiences of these two families may have greatly influenced the results of this study. Finally, a critical review of the results is limited by a lack of detailed information regarding the children's caregiving requirements and the nature of in-home support received from health care providers.

A considerable amount of theoretical and research literature exists which focuses on the impact of a child's chronic illness on the family (for example, Austin,

1990; Canam, 1987; Ferrari, 1986; Hymovich, 1976; Larkin, 1987; Libow, 1987; McAnear, 1990; Patterson, 1991). The impact of a child's chronic illness is often conceptualized in the literature in terms of demands placed on the family or the adaptive tasks families need to accomplish. Hymovich (1976), for instance, asserts that childhood chronic illness creates the potential for increased stress and family disruption. Based on her research of families of children with chronic illnesses, she concluded that in order for families to effectively cope with the crisis precipitated by their child's illness they must accomplish three main tasks: to understand and manage their child's illness; to help their child to understand and cope with their illness; and to meet the needs of both the ill child and other family members (Hymovich, 1976).

Canam (1993) identified eight common adaptive tasks facing parents of children with chronic conditions. These tasks included accepting the child's condition, managing the child's condition, meeting both the child's and other family members' normal developmental needs, coping with ongoing stress and periodic crises, assisting family members to manage their feelings, educating others about the child's condition, and establishing a support system (Canam, 1993). In an earlier study, Canam (1987) focused on the adaptive task of communication about the illness experience within the family of a child with a chronic illness. Findings from this study revealed that "the majority of parents do not talk about their own feelings or encourage their ill child or well children to talk about their feelings" (p. 20). Furthermore, this lack of communication was attributed to parents lacking the requisite knowledge and skills to effectively communicate their feelings to their

children (Canam, 1987).

It is assumed that the impact of a child's chronic illness on the family, as described in the review of the preceding literature, could also apply to families of infants and children with medically-fragile conditions. However, the needs of families of children with medically-fragile conditions may be more complex and therefore create more family disruption due to the vulnerability, severity and uncertainty associated with the child's condition. Similarly, parents of children with medically-fragile conditions may require different types of information and/or support.

Clements, Copeland, & Loftus (1990) examined critical times for families with a chronically ill child through the use of a grounded theory research design. Critical times were identified as periods of disequilibrium in which the child's needs increase dramatically (for example, the time of initial diagnosis of the illness, and times of exacerbation of or uncertainty related to physical symptoms) or when sources of support change dramatically (such as times involving relocation of the child, parental absence, or developmental changes).

Clements et al (1990) maintain that by anticipating specific critical times for families with a chronically ill child, health care professionals may be able to prevent or minimize the impact of some of these critical times. Alternatively, health care professionals may be able to maximize the effectiveness of their interventions by predicting common critical times for these families.

The findings of the preceding study can be applied to families who care for

their child with a medically-fragile condition at home. However, further information which specifically investigates critical times for families who care for a medically-fragile child at home is required. For instance, based on the findings of the preceding study it would be reasonable to assume that the transition of health care services from hospital to home-based care could be seen as a critical time for the family of a child with a medically-fragile condition. Information regarding other predictable "critical times" for these families is required. This knowledge will aid health care professionals in anticipating common critical times in order to successfully plan, develop, and implement health care services which are responsive to the needs and concerns of families caring for a child with a medically-fragile condition at home.

Family Coping Approaches

Exploring the coping approaches utilized by families of children with long-term illnesses contributes to one's understanding of how family members manage their child's care at home. In a previously described study by Thomas (1986), the researcher identified ten specific coping strategies utilized by family members of a child who was ventilator-dependent. Coping activities "illustrated the behaviors or cognitive processes family members used to reduce stress or strain temporarily or until an acceptable alteration or adaptation to a stressor occurred" (Thomas, 1986, p. 125). These coping activities included: persistence, denial in the service of hope, normalizing, humour, preparing, religious beliefs, doing it anyway, being there, using the system, and giving in (Thomas, 1986).

Barbarin, Hughes, and Chesler (1985), in a study carried out in Michigan, identified coping approaches utilized by 64 parents of children diagnosed with cancer. Data was collected through semi-structured interviews and a structured questionnaire. Results indicated that parents utilized the following coping strategies to deal with their experience: acceptance, problem solving, optimism, emotional balance, information seeking, reliance on religion, denial, and help seeking. Results of their study also indicated that husbands used denial as a coping strategy much more frequently than wives, and that wives utilized reliance on religion and information seeking much more than husbands.

A limitation in relating this study to the research proposed is that the experience of parents of children with cancer may vary considerably from the experience of children with medically-fragile conditions. Further information is required which specifically examines the coping approaches utilized by parents caring for children with medically-fragile conditions at home. By understanding how families cope with caring for their child at home, professionals will be better able to assist family members in developing or maintaining effective coping approaches.

Resilient families of children with long-term illnesses utilize coping approaches and other strategies to grow stronger as a result of the stress associated with caring for their child. Resilient families were defined by Patterson (1991) as having the ability to recover from adversity and adapt to change. Patterson (1991) identified nine aspects of resilient families who were able to adapt to the chronic stress associated with their child's caregiving requirements. These include: balancing the

illness with other family needs, maintaining clear family boundaries, developing communication competence, and maintaining family flexibility (Patterson, 1991).

It is assumed that families caring for a child with a medically-fragile condition at home also have the opportunity to grow stronger from the stress associated with their child's illness. However, further information is required to provide nurses with insight into what interventions best facilitate resilient family functioning in these families.

Needs of Families Caring for a Child with a Complex Medical Condition

There has been an abundance of research investigating the needs of families caring for a chronically-ill or disabled child at home. Diehl et al (1991), in a study carried out in the state of Florida, utilized a focus group interview technique to identify the perceived needs of parents of children with medically-complex needs. Care recipients ranged in age from birth to twenty-one years and had chronic debilitating diseases or conditions requiring 24 hour a day medical, nursing, or health supervision or intervention (Diehl et al, 1991). Eighty parental caregivers of children with medically-complex/technology dependent conditions participated in the study. Seventy-one of the participants were female and nine were male. Most of the children involved in the study were not receiving any type of formal respite services.

The results of the preceding study indicated that "the intensity of the care needed for these children impacted all levels of family relations and all family members" (Diehl et al, 1991, p. 172). Furthermore, increased marital breakdown, fragmentation of care, and lack of illness specific information were recurring themes.

Parents recounted that there was a definite need for centralization of information concerning financial assistance, access to medical equipment, and support groups. Another prominent theme was that there was a lack of information regarding home respite care and how to plan for the future. Moreover, the lack of respite care services was a frequent comment amongst participants.

The results of the preceding study are valuable in understanding some central issues for parents caring for a child with a medically-fragile condition at home. However, a drawback of relating this study to the research proposed is that none of the families were receiving any formal type of respite services, nursing or otherwise. Furthermore, most of the information obtained was from the children's mothers; further information is required from the fathers' perspectives.

Walker et al (1989) also investigated the perceived needs of families who had children with complex long-term health conditions in the state of Massachusetts. The authors utilized a mailed questionnaire to survey parents of children with a wide variety of chronic health conditions regarding their use of health services, health-related expenses, and ratings of the importance of health and support services. Parents of children with seizure disorders, cerebral palsy, congenital heart disease, and spina bifida comprised the largest groups when categorized by type of health condition. Analysis of responses revealed that 61 to 74 percent of parents rated the following services as very important: parent education on rights and entitlements, help in getting needed services, physical therapy, financial help, and information on financial resources (Walker et al, 1989). It is interesting to note that only 47% of

respondents rated respite care as very important, 16% rated it as somewhat important, and 37% rated it as not important. Results of the study indicated that "the perceived needs and rankings of important services by parents of children with a variety of chronic health conditions are more similar than different...the results reveal many perceived needs are linked to the stresses of having a child with a special health problem" (p.200).

The results of the preceding study provide valuable insight into understanding the needs of parents who have a child with a long-term health condition from their own perspective. However, there are three limitations in relating this study to the research proposed. First, the sample was predominantly white, middle class, and well-educated. Secondly, it is difficult to ascertain the degree of medical complexity of the children involved in this study. That is, it is doubtful whether the majority of these children could be considered "medically fragile". Finally, as with the majority of literature in this area, the study was carried out in the United States whose health care system differs considerably from the Canadian health care system. These drawbacks limit the generalisability of the findings to parents of children with medically-fragile conditions living in Canada, but suggest that it is important to understand the similarities and differences between the needs of these families and the needs of families of children with medically-fragile conditions..

Smith, Mayer, Parkhurst, Perkins and Pingleton (1991) examined the adaptation in families with a member requiring mechanical ventilation at home. Care recipients ranged in age from eighteen to seventy-four years. Caregivers were all

relatives of the individual who was ventilator-dependent and ranged in age from 20 to 74 years. It is important to note that no nursing or other formal respite services were available to the families studied.

Results of the preceding study identified both positive and negative themes regarding caregiving. Recurring positive themes included improved quality of life, confidence in caring for the ventilator dependent patient, and satisfaction with being able to care for the family member at home. Negative themes revealed the burden of caregiving, the dependence of the individual on the caregiver, resentment, and hopelessness (Smith et al, 1991).

Caregivers described a lack of spontaneity to take part in non-caregiving activities, the constancy of caregiving demands, and their feelings of being overwhelmed by caregiving responsibilities. In addition, the participants described less satisfaction with the functioning of their family unit the longer the patient received home ventilation. The need for increased flexibility in providing care and for respite care was expressed by the caregivers who participated in the study (Smith et al, 1991).

The preceding research study is valuable in providing recurring positive and negative themes regarding home-based care of individuals who are technology-dependent from the caretaker's perspective. A limitation of the preceding research, in relation to the proposed study, is that it deals primarily with adults who are technology-dependent rather than children. Furthermore, the families involved in the study were not receiving any in-home nursing respite support which could have

dramatically altered the study's results.

A major shortcoming of the research studies previously outlined is that they do not deal specifically with children with medically fragile conditions receiving in-home nursing respite services. Rather, the majority of the literature focuses on chronically ill children in general with differing types of respite support. It is possible that families caring for children with medically-fragile conditions may have differing needs due to the vulnerability and uncertainty associated with their children's health conditions.

Community Support Services for Families

Families of children who meet the criteria of having a "medically-fragile" condition almost always require home-based support in the form of nursing respite services. Respite is generally defined as an interval of temporary relief. Cohen (1982) defines respite care as "temporary care given to a disabled individual for the purpose of providing an interval of relief to the individual's primary caregiver(s)" (p. 8). Respite care can refer to both in-home service or out-of-home placement. Due to the concept of formal in-home respite services for severely disabled children being relatively new, little research has been done in this domain. Moreover, much of the literature that does exist on respite care services is incidental or anecdotal. Cohen's (1982) study of respite services for families of children with long-term conditions is one of the only research studies currently described in the literature.

Cohen (1982), in a quantitative study, investigated the utilization and

effectiveness of respite care services for families caring for a disabled child at home. Information was collected on utilization of respite care services, satisfaction with services, family characteristics, and family functioning. Data were collected on 357 families of children with cerebral palsy over a two year period. Data collection methods included a study questionnaire and structured interviews. It is important to note that there was a wide variety of respite care workers in this study including volunteers, college students and only some workers with limited training in medical care. Moreover, fifty-eight percent of the families received only out-of-home respite services. The remainder of families received either in-home respite services or a combination of both in-home and out-of-home respite support.

The results of Cohen's (1982) study indicated that parents found that "their satisfaction with life, hopefulness about the future, ability to cope with the disabled child in the home, and attitude toward the child improved with the use of respite care services" (Cohen, 1982, p. 9). Cohen (1982) found that respite care was effective in helping families to improve the mental health and social relationships of the parents. The respite care allowed the parents to "rest and recuperate, meet medical needs, and improve their relationships with other family members" (Cohen, 1982, p.9). Moreover, Cohen's (1982) results indicate that approximately twenty-five percent of the families interviewed perceived that they would not have been able to cope without the support of respite services.

The preceding research study provides valuable insight into respite services in general. It also provides much needed insight into the experiences of the families

from the parents' perspective. Nevertheless, a drawback of the preceding research, in relation to the proposed study, is that it does not deal specifically with children with medically-fragile conditions receiving in-home nursing respite support. Furthermore, there is a lack of detailed information regarding the data collection tools and the range of respite support received which makes a critical analysis of the results difficult.

Other research points to certain inherent disadvantages of respite care. Lyman et al (1985) indicate that home-based services may lead to increased anxiety, impaired sleep, and restricted social lives for the parents of these children. Furthermore, Libow (1987) points to the fact that the presence of health care personnel in the home can be intrusive and disruptive to normal family functioning. Clearly, further research is required which emphasizes the experiences of families caring for children with medically-fragile conditions receiving home-based nursing respite support.

Summary

A review of the literature pertinent to the topic of study has been presented. Various research and theoretical studies have pointed out the challenges families face in caring for a child with a long-term illness and how family members manage the care of their child at home. However, there is a limited amount of literature which specifically examines the experiences of families of children with medically-fragile conditions. It is likely that these families' needs may be different and more complex due to the vulnerability, severity, and uncertainty associated with their children's

health conditions.

A review of relevant literature also indicates that further information is required in order to provide nurses with insight into the coping approaches utilized by parents to manage the care of their child with a medically-fragile condition at home. In addition, nurses require a better understanding of the critical developmental and illness related transitions which these families experience so that nursing interventions are both timely and effective.

The limited number of research studies which have centered on the issues for families caring for children with medically-complex and/or technology dependent conditions suggests a dissatisfaction with the functioning of the family unit, fragmentation of care, privacy violation, chronic sleep deprivation related to constant vigilance, lack of illness specific information, need for centralization of information, lack of effective community support services, and feelings of resentment and isolation amongst the caregivers. Clearly, further information is required which examines the parents' perspective of caring for their child with a medically-fragile condition at home.

Although most families caring for children with medically-fragile conditions require community support in the form of respite services in order to effectively cope with caring for their child at home, there is a paucity of literature which examines the impact of respite services from the families' perspective. Some research studies have pointed to the need for respite services for families caring for a medically-complex child at home. Other studies have looked at the effectiveness of respite services in

general (primarily non-nursing) for families caring for a disabled or chronically ill child at home. Further information is required which focuses on the experiences of families receiving the support of in-home nursing respite services to care for a child with a medically-fragile condition. Moreover, further investigation of the reported inherent disadvantages of respite care is required.

In summary, an examination of selected literature points to a limited amount of research focusing on the parents' perceptions of their experience of caring for a child with a medically-fragile condition at home. Further information is required which examines this experience from the parents' perspective. Only by gaining a clear understanding of the experiences of these parents can services which are effective and responsive to their needs be designed and implemented.

CHAPTER THREE

METHODOLOGY

Introduction

A phenomenological method of inquiry was seen as appropriate for this study. "The phenomenological perspective is of particular value in clinical nursing research when there is a wish to understand how people perceive their situation" (Anderson & Chung, 1982, p. 42). Phenomenology is a methodology used to examine and describe human experiences as they are lived (Oiler, 1982). Moreover, phenomenology is an inductive research approach in which the investigator collects information from participants in as much depth and breadth as possible (Omery, 1983). It was for these reasons that this methodology was selected to examine the research question put forth in the proposed study.

A review of the sample selection process, inclusion criteria for selection of study participants, and a description of the participants will be presented first. This will be followed by an exploration of the data collection and analysis process. Finally, procedures for protection of human rights and measures of determining reliability and validity will be outlined.

Sample Selection

A theoretical sampling strategy was used to select potential study participants. This technique involves the selection of subjects for their ability and willingness to illuminate the phenomena of interest. Moreover, "the continued selection of subjects

is determined by the information obtained in the course of the study and the necessity for theoretical completeness" (Sandelowski, Davis, & Harris, 1989; Morse, 1986).

It was impossible to describe a priori the nature or number of the participants needed to reach theoretical saturation of themes. The final sample size was nine subjects, consisting of six mothers and three fathers. Final sample size was determined when saturation of data occurred and no new themes or patterns emerged (Sandelowski et al, 1989; Morse, 1986).

It was the intention of this study to interview both parents if they were both involved in the child's care. It was felt to be important to attain both the mother and father's perspective in order to have a complete understanding of the experiences of the parents of children with medically-fragile conditions. The majority of volunteers were mothers, the child's primary caregiver. Interestingly, the fathers who chose not to participate in the study were perceived by their spouses as not as involved in the child's care. In contrast those fathers who did participate were perceived as partners in the ongoing care of the child with a medically-fragile condition. One of the participants was a single parent, whose former spouse was no longer involved in the child's care, therefore only the one parent was interviewed.

Since one of the criteria for a child being denoted as having a "medically-fragile" condition was that he/she required in-home nursing respite support services, sample selection through the Nursing Respite Program appeared logical. A third party recruitment strategy was used to gain access to potential study participants. Specific Nursing Respite Consultants involved with the care of children with

medically-fragile/technology-dependent conditions in the Lower Mainland were approached to assist with the research study. A letter describing the nature of the study and how to contact the researcher if they were interested in participating, or would like more information was circulated to potential participants through the Nursing Respite Consultants (Refer to Appendix A). Introductory letters were sent out to eight families by two Nursing Respite Consultants. Six participants (including three groups involving both parents) subsequently contacted the researcher and agreed to be involved in the study.

Selection Criteria

Parent(s) of a child, aged between birth and age nineteen, with a medically-fragile condition were sought as study participants. The participants also had to meet some additional selection criteria. Due to the limited time and funding available, a homogenous sample of English speaking participants was sought. Furthermore, the parent(s) of the child had to live in the same home as the child. Additionally, the participants had to be able to speak to the evolving phenomena of interest. A further stipulation requested by the Nursing Respite Program required that the sample be further restricted to residents of Vancouver Island. This restriction was based on a concurrent study conducted by a team of other nursing researchers involving parent participants living in the Lower Mainland of British Columbia, who were also selected through the Nursing Respite Program.

A final inclusion criteria dictated that the first interview with the parent(s) would occur a minimum of two months following the original discharge of the child

from an acute care facility. This span of time was thought to be necessary for the parents to have had an opportunity to have lived the experience of caring for a child with a medically-fragile condition at home and to have reflected on this experience. Due to the complexity and unstable nature of these children's illnesses, many require repeated hospitalizations for exacerbations of their disease, infections, and/or for investigation of new problems. Therefore, the timing of the interview was based on the original discharge of the child from an acute-care setting to home-based care.

Families with a child who was receiving palliative nursing respite services for the end-stages of a terminal disease were not included in the study. The rationale for excluding families of these children was that their experiences were thought to be vastly different due to the approaching death of their child and the relatively short period of time they were in the program (four weeks on average).

Description of the Participants

A total of nine parents (three couples and three mothers) participated in this study. Participants lived in various communities across Vancouver Island, British Columbia. Demographic data were collected to provide a description of the study participants (Please refer to Appendix C). The mothers' ages ranged from 29 to 48 years, while the age range for the fathers who participated in the study was 40 to 49 years (the fathers' age range in general was 30 to 49 years; that is, including those who did not participate). One family had no other children besides the child with the medically-fragile condition and one family had one other child. The remaining families all had two children in addition to the child with the medically-fragile

condition. One of the mothers was divorced, and she lived alone with her two children. All of the other participants were married. One mother was engaged in full-time paid work, another mother was in the paid workforce part-time, and the remaining mothers did not work outside of the home. All of the fathers worked full-time outside of the home.

The children with medically-fragile conditions ranged in age from two and a half years to eighteen years. The children's underlying medical conditions included: Opitz-Friaz syndrome requiring a tracheostomy and enteral tube feeding; severe Cerebral Palsy including asthma, bronchitis, and recurrent acute pancreatitis requiring aggressive suctioning, respiratory treatments, and enteral tube feeding; complications from prematurity (born at 28 weeks gestation) requiring a tracheostomy and enteral feeding; severe eczema, asthma, and potentially fatal food and environmental allergies requiring frequent emergency interventions for anaphylactic shock; complications from severe prematurity (born at 26 weeks gestation) with malabsorption problems requiring enteral tube feedings and frequent hospitalizations; and Barter's Syndrome with Spina Bifida including progressive renal failure, post kidney transplant. Children ranged in age from two and a half years to eighteen years on initial interview. All of the children lived at home and all had had repeated hospitalizations for exacerbations of their condition.

Data Collection

Indepth unstructured interviews were conducted at times and locations

convenient to the participants. All except two of the interviews were conducted in the participant(s) home, usually in the living room or around the dining room table. The researcher acknowledged the demanding time schedules of the participants and attempted to be flexible to the needs and demands of the participants. One participant requested that the initial interview take place in her car as one of the respite nurses was caring for her child and she wanted to take advantage of the reprieve from child caregiving to go for a drive in the countryside. Another participant was interviewed in a hospital conference room as her child had been hospitalized for a reassessment of his treatment requirements.

Where appropriate, conjoint interviews of married couples were carried out. Conjoint interviews of married couples have been found to facilitate a climate of openness and trust, encourage mutual verification or modification of information offered to the interviewer, and disclose the couple's patterns of interaction (Sandelowski et al, 1989). Demographic data were collected on all participants (Refer to Appendix C for a copy of the Demographic Information Form).

A general, open-ended question was used to start the interview. An example of a question which was used is: What have been the challenges for you in caring for your (technology dependent/medically fragile) child at home? (Refer to Appendix D for examples of possible trigger questions used) The direction of the interview was determined by the participant(s) responses. In almost all of the first interviews, the parents enthusiastically and descriptively recounted their experiences with minimal prompting. Although the researcher had anticipated the interviews lasting a maximum

of one hour, the majority of interviews lasted one and a half to two hours, with two of the first interviews lasting approximately two and a half hours. Parents frequently made comments such as "no one has ever asked me about this before, usually they (health care providers) only want to know what problems we are having" or "talking about this is therapy for me, it helps to talk about things that we have been through". Throughout the interview, the researcher consistently sought out further elaboration and/or clarification on emerging topics put forth by the participants. When both parents participated in the interview the researcher also invited both participants to discuss similarities and differences in their individual experiences.

Interviews were audio-taped and transcribed verbatim. Second interviews were performed following analysis of the first interview in order to gain clarification of ideas, seek elaboration on certain areas, and/or seek verification of information received. Sandelowski et al (1989) indicate that second and subsequent interviews may need to be more or less structured depending on the data already collected and the intent of the interview. The timing of the second interviews was determined once the results of the first interview had been analyzed.

Field notes were taken in order to capture observations which were not possible to obtain on audiotape. The researcher journalled relevant ideas and details prior to each interview as part of the bracketing process. In addition, reflections of each interview were described as part of the field notes. This included descriptions of nonverbal expressions, the general "feeling" of the interview, and a reflection on emerging themes. Finally, information shared by participants during telephone calls

to set up or confirm home visits was recorded in the journal and was included as part of the data analysis. For example, on several occasions parents had to reschedule the interview due to their child's rehospitalization or an exacerbation of their child's condition.

Data Analysis

Data collection, analysis, and verification was performed in a systematic and ongoing manner. The data were analyzed using Anderson's (1992) recommendations for phenomenological data analysis. The audiotapes of the interviews were transcribed verbatim following each interview. Subsequently, each transcript was read through several times in order to obtain a sense of the whole and to demarcate areas which were unclear, required further clarification, or areas which were not sufficiently explored. The data were then scrutinized again, and each time a transition in meaning was perceived a meaning unit was used to code the data. For example, during the first set of interviews, several parents referred to "living in a fishbowl" or "in a glass house". This data was demarcated for further exploration and confirmation during the second interview.

Following this preliminary analysis, a second interview with the participant was conducted in order to gain clarification of ideas, seek elaboration on certain areas, and/or seek verification of information received. For example, the data from the first set of interviews revealed the emergence of several common "crises" or "turning points". In the second interviews these critical periods were clarified, revised, and confirmed by participants. Second interviews were also used to obtain

data on new areas. The results of the second interviews were then analyzed using the previously outlined steps. Subsequently, the results of the first and second interviews were compared. As well, the data collected from other informants was compared and similarities and differences were identified. The emerging categories were then compared with each other to ensure that they were comprehensive.

The final step of the analysis was to take the data collected to a higher level of analysis, from meaning units to broader, more abstract concepts or categories. Several of the previously defined concepts became collapsible into larger concepts or categories. The emerging categories were compared with each other to ensure that they were comprehensive.

A third interview with participants was not required as the researcher was able to clarify areas which were not well understood, obtain further data to reach saturation of conceptual categories, and verify information from the first interview and the emerging conceptual findings with participants during the second interviews. Any information which the informant added or deleted was assimilated into the findings. Hutchinson (1986) defines saturation as "the completeness of all levels of codes when no new conceptual information is available to indicate new codes or the expansion of existing ones" (p. 125).

Procedures for Protection of Human Rights

Several procedures were implemented to ensure the protection of the rights of the participants. Subjects were made aware of their right to request that certain parts

of the interview not be taped. Secondly, anonymity of the participants was protected through the use of code numbers on the transcripts. Furthermore, all identifying information was stored in a secured place and destroyed following the study to protect confidentiality of information obtained. Participants were also instructed of their right to withdraw from the study at any time (Please refer to Appendix B for a copy of the consent form).

The researcher was available and open to any questions or concerns regarding the study. Additionally, a letter stating the purpose of the study was given to each potential participant and a written consent agreeing to participate in the interview was obtained. It was made clear to each of the informants that there would be no consequences as a result of participation in or refusal to participate in the study. Finally, the results of the study were made available to the participants.

There were no known risks or benefits of the research study. Participants did, however, discuss the "benefits" from the study as a result of being able to speak about their experiences. Additionally, several parents discussed their feelings of satisfaction in realizing that by sharing their experiences they may indirectly improve the quality of care for children with medically-fragile conditions (through application of the study's findings).

Credibility and Fittingness

The truth value of qualitative research is determined by its credibility. A study is credible when individuals recognize the descriptions of a human experience as their own, or when other researchers recognize the experience when faced with it

after only reading about it in a study (Sandelowski, 1986). Furthermore, the applicability of qualitative research is determined by examining the fittingness of the findings. The criterion of fittingness is met when "findings can 'fit' into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences" (Sandelowski, 1986, p. 32). Moreover, the findings should be fundamentally embedded in the life experiences studied and should reveal both the typical and atypical characteristics of the data (Sandelowski, 1986).

Sandelowski (1986) put forth numerous strategies to ensure the truth value and applicability of a qualitative study. Several of these techniques were used in the proposed study. Specifically, the data gathered, the coding units and categories, and the examples used to present the data were deliberately and systematically examined for representativeness. Wherever possible, the participants' own words or descriptions, such as "living in a fishbowl", were used to code the data. In addition, the questions asked during the interviews were worded in such a way as to not direct the participants' answers. Moreover, observations described in field notes were used to assist in confirming or verifying interview data.

A non-hierarchical relationship with the participant was aspired for. Oakley (1981) supports this view in her statement "the goal of finding out about people through interviewing is best achieved when the relationship of interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship" (p. 41). The researcher attempted to

achieve a non-hierarchical relationship by interacting with all of the family members, including the children, during her home visits. Several participants commented on the researcher's nonjudgemental approach and apparent genuine interest in their experience. Moreover, the researcher's approach appeared to encourage parents to discuss their experiences openly and honestly. Participants made frequent statements such as, "I have never talked to anyone about this before, no one has ever been interested in hearing about it...". One mother vividly and openly described her previous suicide attempt, stating, " I have never talked to anyone but my psychiatrist about this...".

A conscious effort to "bracket" personal preconceptions of the experience was made in order to remain true and effectively attend to the participant(s) during the interviews. Additionally, a willful effort to ensure that the descriptions and interpretations of the data embraced both the typical and atypical characteristics of the data was made. Finally, in order to validate the researcher's understanding of the meaning of the experience, clarification and validation of findings from each participant was done on an ongoing basis. If the informants added or deleted any of the information obtained, the new data were assimilated into the results of the study.

Auditability

Sandelowski (1986) posits that the criterion of auditability be the measure of consistency of a qualitative study. "Auditability means that any reader or another researcher can follow the progression of events in the study and understand their

logic" (Sandelowski, 1986, p. 34). The auditability of a study is manifested predominately in the research report.

In order to effectively meet the criterion of auditability, a clear decision trail concerning the study from its inception to its end is demonstrated in the research report. To ensure auditability, the researcher described, explained, and justified what was done in the research study.

Confirmability

Sandelowski (1986) asserts that confirmability is the gauge against which the neutrality of a qualitative research study is evaluated. Confirmability is secured when the other criteria of auditability, truth value, and applicability are established. Moreover, confirmability refers to the findings of the study themselves and not the subjective or objective position of the investigator (Sandelowski, 1986).

In order to enhance the confirmability of the study, several strategies were carried out. Specifically, attempts to build a trusting relationship with the participants were made. The researcher displayed an interest in understanding the participants' experiences and attempted to suspend any moral judgement of the informants as described by Knaack (1984). In addition, emerging themes from the ongoing data analysis were presented to participants for feedback and/or confirmation of being representative of their experience. Further tactics which were used to augment the confirmability of the research include those previously outlined to satisfy the criteria of credibility, fittingness, and auditability.

Summary

The phenomenological method of inquiry utilized to investigate the experience of parents caring for a child with a medically-fragile condition at home has been described. A review of the theoretical sampling strategy implemented to select potential participants and the specific selection criteria were outlined. This was followed by a description of the data collection and analysis process including the interview process and the incorporation of field notes. Measures taken to protect human rights were then reviewed. Finally, methods utilized to ensure credibility and fittingness, auditability, and confirmability were put forth.

CHAPTER FOUR

CONCEPTUALIZATION AND ANALYSIS OF THE PARTICIPANTS' EXPERIENCE

Introduction

The goal of this study was to gain a deeper understanding of the experiences of parents caring for a child with a medically-fragile condition at home. The analysis of participant interviews revealed that although the experiences of each family differed, several common themes emerged. This chapter will present an analysis of the participants' experience as understood and conceptualized by the researcher.

This chapter begins with an analysis of participants' descriptions of the onset of their experience of caring for a child with a medically-fragile condition. First, a conceptualization of the three critical time periods described by parents in their progression from novice to expert caregivers will be explored. These were identified as: Hospital-based care: Initial diagnosis and treatment; Transition from hospital to home-based care; and Home-based care: Ongoing critical periods. Parents' descriptions of becoming the child's primary caregiver was conceptualized as progressing through four distinct stages across the time frame of these three critical periods. Moreover, due to the medically-fragile nature of the child's condition, the process of becoming the child's primary caregiver inherently involved developing ongoing relationships with health care providers. These four stages depict both the evolution of the parent from novice to expert caregiver and the concurrent evolution

of the parent - health care provider relationship. These stages were identified as:

Assigning the caregiver role: Blind faith; Preparing for action: Disillusionment and raising one's voice; Assuming the caregiver role: Learning caregiving expertise; and Adjusting to home-based care: Building supportive relationships.

In their description of Stage Four parents emphasized the importance of building supportive relationships with health care providers in the ongoing care of their child. Therefore, an indepth examination of the parents' descriptions of the characteristics of a supportive parent - health care provider relationship will be presented. This will be contrasted with an exploration of the parents' descriptions of the characteristics of conflictual parent - health care provider relationships. The description and analysis of these preceding components of the parents' experience lays the foundation for the major focus of analysis: The dynamics of parental caregiving for a child with a medically-fragile condition at home.

The dynamics of parental caregiving was conceptualized as a process of balancing the nature of caregiving demands with the nature of parental caregiving. This was envisioned as a see-saw in which the nature of caregiving demands is being counter-balanced with the nature of parental caregiving. Parents described the nature of caregiving demands as being shaped by three key factors: the fragility of the child's condition, the complexity of the child's care requirements, and the child's developmental needs. Comparatively, parents' characterized the nature of parental caregiving as being shaped by: the nature of family life, the nature of support received, and the nature of parental coping approaches.

During the initial critical period of diagnosis and treatment of the child's condition, the see-saw was conceptualized as being in a state of imbalance, that is, a state perceived by parents as exceeding their resources to cope with the demands of caregiving and characterized as endangering the child's well-being. As the child's condition improved and the parents became experts in the child's care, taking on the primary caregiving role, the see-saw moved towards a balanced state. Optimally, at the advent of the second critical period, the transition from hospital to home-based care, the see-saw was characterized as being in a balanced state. That is, the nature of the demands associated with caring for the child were counterbalanced by the nature of parental responses to these demands.

In a balanced state the relationship between the nature of caregiving demands and the nature of parental caregiving was described by participants as being in a state of flux since the nature of parental caregiving involved continuously readjusting to changes in the caregiving demands and to changes in the nature of family life. Moreover, the inherently fragile nature of the child's condition and the child's related susceptibility to exacerbations or deteriorations in his/her condition played a key role in the vulnerability of caregiving demands exceeding the parents resources for providing care, thereby returning the see-saw to a state of imbalance. Once the parents adjusted to the transition from hospital to home-based care, they described continuing to face ongoing critical events in which the child's caregiving demands exceeded the parents' resources for providing care.

In the remainder of this chapter, each of these components and their

relationship to each other will be described, analyzed, and substantiated with participants' descriptions of their experience.

Critical Periods in the Evolution of Parents as Expert Primary Caregivers

Parents described their experience of caring for their child with a medically-fragile condition as evolving over time. Moreover, due to the medically-fragile nature of the child's condition, the process of becoming the child's primary caregiver inherently involved developing ongoing relationships with health care providers.

The evolution of parents as expert caregivers occurred over three critical time periods. These three critical time periods were identified as: *Hospital based care; Initial diagnosis and treatment; Transition from hospital to home-based care;* and *Home-based care: Ongoing critical periods.* Moreover, the evolution of the parents from novice to expert caregivers and the concurrent evolution of parent-health care provider relationships progressed through four distinct stages across the time frame of these three critical periods (Refer to Figure 1., page 45). These four stages have been identified as: *Assigning the caregiver role: Blind faith; Preparing for action; Disillusionment and raising one's voice; Assuming the caregiver role: Learning caregiver expertise; and Adjusting to home-based care: Building supportive relationships.* These labels were derived from participants' descriptions of their experiences. The initial component of the label refers to the maturation of parent from novice to expert primary caregiver; the latter component refers to the evolution of the parent - health care provider relationship.

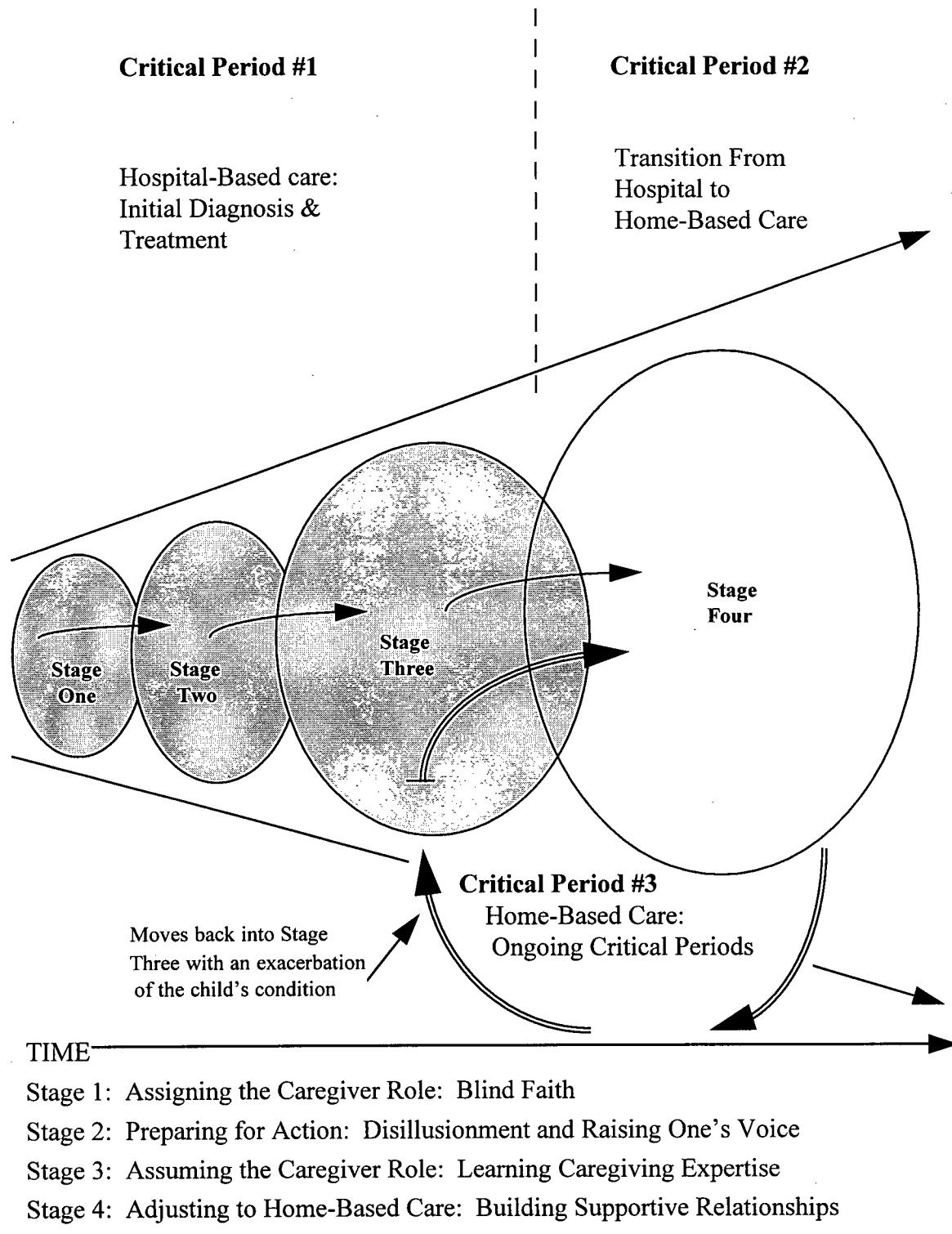
The stages were not viewed as evolving through discrete linear changes but rather as overlapping stages with the parents gradually progressing through each stage. The parents progressed through each stage at different rates and under different conditions, but the progression through each stage was confirmed by all participants.

The initial diagnosis and treatment of the child in a hospital setting comprised the first critical period. During this critical period, parents progressed through the first three stages in their evolution from novice to expert caregivers. The second critical period centered around the transition from hospital to home-based care of the child and involved the parents' progression through the fourth stage in their evolution as expert caregivers. The third critical period represents the ongoing refinement and mastery of the parent as expert caregiver. Each of these critical periods and their relationship to the stages of parent as expert primary caregiver will be discussed in the following section.

Hospital-Based Care: Initial Diagnosis and Treatment

The initial diagnosis and treatment of the child's condition in a hospital was viewed as the first critical period. It is important to note that this entire critical period took place in a hospital setting. It was during this period that the parents were introduced to health care providers and the health care system in relation to their child. Moreover, this was also the parents' first introduction to caring for a child with a medically-fragile condition. During this critical time period, the parents worked through the first three stages in their development as expert primary

Figure 1. Critical Periods in the Evolution of Parents as Expert Caregivers



caregivers: Assigning the caregiver role: Blind faith; Preparing for action: Disillusionment and raising one's voice, and Assuming the caregiver role: Learning caregiving expertise.

In order to gain a clear picture of the evolution of the health care provider - parent relationship, it is important to understand the context in which this relationship developed. For all of the participants, except one, the initial interactions with health care providers occurred in a hospital and surrounded the birth, diagnosis, and treatment of the child with a medically-fragile condition. Five of the six children were born with complex congenital abnormalities. It must be noted that this period was described as a time of intense distress for these parents. Many of the children were born with complex life-threatening illnesses which required treatment in intensive care units. Moreover, four of the children had extremely rare disorders which took months to diagnose, resulting in parents living through a prolonged period of uncertainty. During this period, several parents discussed scenarios in which they were told their child would not live, or that the child would be severely disabled with "little quality of life" if he or she were to survive. Several of these parents also recounted scenes in which they were given the option of no treatment which they perceived would have resulted in the subsequent death of their child. By understanding the context in which the health care provider - parent relationship evolved, one can better understand the parents' feelings of uncertainty and helplessness, and the stressfulness inherent in their experience.

In Stage one, Assigning the caregiver role: Blind faith, health care workers

provided the primary care for the child while the as yet inexperienced parents played a predominantly observer role. During this stage, parents described themselves as wholly dependent on the health care providers' knowledge and expertise in caring for the child. In Stage two, Preparing for action: Disillusionment and raising one's voice, parents began to assume an advocate role for their child. They also indicated a willingness to assume an increased responsibility for their child and his/her well-being. In the third stage of Assuming the caregiver role: Learning caregiving expertise, health care providers facilitated the parents' development into expert caregivers of their child. This included learning complex medical and nursing procedures specific to the child's care such as enteral tube feeding and tracheostomy care. At the end of this stage parents considered themselves expert caregivers of their child in a hospital setting.

Transition from Hospital to Home-Based Care

The advent of the fourth stage of Adjusting to home-based care: Building supportive relationships marked the transition into the second critical period in the parents' overall experience. This critical period involved the transition of caregiving from a hospital setting to home-based management of the child's condition. The caregiving demands during the beginning of this critical period had decreased; the fragility and complexity associated with the child's condition had become "manageable". The plan of care for the child had been clearly established and shown to be effective in meeting the physical needs of the child. Moreover, the priority of care had shifted from "life-saving" mode which characterized the beginning of the

first critical period to "managing" the child's condition. The child's developmental needs also began to play an increasing role in the nature of caregiving demands once the medical acuity associated with the child's condition became more manageable. Both parents and health care providers recognized the importance of meeting the child's developmental needs and this was one of the driving forces behind the transition of the child's care from hospital to home.

At the onset of this time period parents had developed into expert caregivers of their child in the hospital, however they considered themselves as inexperienced in terms of caring for their child at home. Parents needed to adjust to the change in setting from hospital to home-based care. The nature of parental caregiving in the stage of Adjusting to home based care: Building supportive relationships was largely influenced by the need for parents to meet the child's caregiving demands and the competing demands of family life. In order to do this successfully parents had to become adept at cultivating and mobilizing support from health care providers and others in order to effectively cope with the caregiving demands of the child and other family members. Parents also had to develop new coping strategies in order to successfully manage the child's changing care needs and the ongoing demands of family life. This major transition was considered a "critical" period since there was an increased risk of the child's caregiving demands not being met if the parents were unable to cope with the demands of this critical period.

A "successful" transition from hospital to home-based care was characterized by parents effectively balancing the child's caregiving demands with the competing

demands of family life through the development of strategies to maintain and mobilize support from health care providers and others, and the development or adaptation of coping strategies.

Home-Based Care: Ongoing Critical Periods

Subsequent to the child's initial discharge from hospital, parents described facing ongoing critical periods. These critical periods were triggered by events in which the child's caregiving demands exceeded the parents' resources for providing care. For example, an exacerbation or deterioration in the child's condition which the parents were not able to manage at home often resulted in a lengthy rehospitalization of the child until his/her condition had stabilized. Alternatively, a critical event could also occur if the parents' resources to respond to the caregiving demands was decreased. This could occur, for example, if the parents had insufficient support from health care providers and/or others to successfully manage their child's condition at home. Finally, a critical event could occur if competing family demands, such as the illness of another family member, taxed the parents' resources to manage the child's condition.

When a change in the child's condition required hospitalization of the child, parents were conceptualized as moving back into the third stage in order to refine their caregiving expertise in response to the change in the child's condition. Subsequently, the parents returned to the fourth stage in which they mastered the child's altered caregiving demands in the home setting. As in the child's initial hospitalization, this caregiving expertise was initially learned in an acute care setting

and then adapted to home-based care. This was conceptualized as the parents moving back into the third stage when the child was hospitalized, and then moving back into the fourth stage once the child was discharged home (Refer to Figure 1., page 45). That is, parents who were caring for a child with a medically-fragile condition continued to develop their expertise in both the hospital and home settings.

The Stages in the Evolution of Parents as Expert Primary Caregivers

As previously noted, parents' descriptions of their experiences of caring for a child with a medically-fragile condition were conceptualized as moving through four distinct stages. Each stage includes a description of the parents' assumptions regarding the role of health care providers, parental behaviours in relation to these assumptions, and the health care providers' behaviours as described by the parents. Each stage will be presented in detail and substantiated with examples from the participants' experiences.

Assigning the Caregiver Role: Blind Faith

All of the participants referred to their initial interactions with health care providers as characterized by a "blind faith" in the physicians and other health care providers involved in the care of their child. This was so, even though the children of the parents in this study had different health conditions of differing severity, and were cared for in different treatment environments. It is important, however, to emphasize that all of the parents perceived their child's condition to be medically-

fragile. Caregiving was also extremely complex during this stage. Five of the six children in this study were initially cared for in an intensive care unit setting in which the priority of care was stabilizing the child's life-threatening condition. It is not surprising, then, that the parents related feelings of "being overwhelmed with all of the wires and tubes", "being frightened to touch the child", and "never knowing if the child would live or die" during this stage.

Parents related their perspective of physicians during this period to that of a "god" - denoting qualities of power, infallibility, and all-knowingness. Parents also believed that health care providers, and particularly physicians, were acting in what the parents would consider the "best interests" of the child. One mother noted:

*M: We were trained, or at least my generation was trained that doctors are god-like. Whatever they say therefore is the gospel

*Abbreviation Key

M:	= mother
F:	= father
R:	= researcher
A	= child with medically-fragile condition
Dr. P	= physician (relationship to child or medical specialty will be noted in brackets) eg. Dr. P (child's pediatrician)
()	= nonverbal of F or M
*	= omissions to preserve confidentiality

Another mother, in reference to her child's initial hospitalization stated:

M: For those first four months I thought the doctor was God.....

Parental behaviours during this stage reflected their view of health care providers as all-knowing and infallible. In this stage, parents assigned their primary

caregiving role to health care providers. Parents described their behaviours as predominantly passive and as "observers", "watchers", and "onlookers". Parents described how they stood by their child's bed day after day, waiting for their child to get better. They spoke of being intimidated by the technological support and caregiver expertise required to care for their child. The nature of parental-child interactions during this stage were primarily orchestrated by health care providers. In the Intensive Care Unit setting, health care providers determined when parents could see their child and the nature of parental interactions with the child.

Health care providers were seen by parents as acting as primary caregivers for the child and were primarily responsible for the decision-making regarding the day to day care of the child. Parents perceived the health care providers to be "in control" of the situation.

As they reflected upon their initial interactions with health care providers, parents described feeling "shielded" from information, or feeling "left in the dark" regarding their child's condition or treatment regime. One mother explained:

M: I think doctors and nurses try to shield parents from information...I had so much trouble getting anyone to tell me what was going on, nobody would tell me what was going on with A, I wanted to know what was wrong with him. I didn't even know what was wrong with him, for five months no one would tell me what was wrong with him. I watched him lie there, he was grey, he was having trouble breathing, and we didn't even know what was wrong with him...

Another mother remembered:

M: I wanted to be knowledgeable about it (the child's condition)...they (health care providers) didn't want to tell me anything, they didn't know anything but they didn't want to tell me stuff. I wanted to know everything...

In retrospect, some participants viewed "shielding" them from information as a paternalistic characteristic of health care providers. That is, health care providers were seen as protecting them from too much information, especially when the information could be seen as devastating or tragic. Other parents viewed these actions as a means in which the health care providers tried to control or dominate their child's care. Parents stated that by being shielded from pertinent information about their child's condition and care requirements that they continued to believe that the health care workers were providing their child with the best possible care. That is, they believed that health care providers mutually agreed upon what was best for their child based on their experience and education.

Preparing for Action: Disillusionment and Raising One's Voice

Parents moved from the initial stage of Assigning the caregiver role: Blind faith into the subsequent stage at different rates. However, for most participants the shift in their perspective of health care providers and their own role as parents started when they began to realize that their perspectives differed from the perspectives of some health care providers regarding: the parental role, what was considered "appropriate" care and treatment of the child, and the value placed on the child and his/her well-being. The realization that health care providers were not "all-knowing" or "infallible" shifted the parents into a period of disillusionment.

Parents' disillusionment with health care providers during this stage was described by all participants. Parents discussed how they realized that health care

providers were "human", that not all health care providers were "created equally".

During this stage, parents related how they began to notice inconsistencies in the care their child received from health care providers and differences in the way health care providers valued the child. One mother discussed her realization that her child's condition was deteriorating and that the physicians did not really "understand what was wrong with her child". She recalls:

M: After going to the hospital every day and seeing that his condition was not changing, and that he was getting worse, I began to realize that these doctors really didn't understand what they were doing. That they did not understand what was wrong with him, and therefore that I did not understand what was wrong with him. So, I had to raise my voice.

Parents reacted to their feelings of disillusionment by "raising their voice" or by beginning to advocate for the rights of their child, and by preparing to assume the primary caregiver role. Several participants discussed their realization that all health care providers did not value their child's life to the same extent that they did as parents and how they "fought" for their child's right to treatment. For example, one mother discussed her "battle" with health care providers over the treatment of her son who required a tracheostomy in order to live.

M: I had to fight for the trach (tracheostomy), I had to fight for them just to figure out what was wrong with him because he kept extubating himself...he extubated himself about five times and stopped breathing, well they wouldn't do anything.

Parents used such descriptive words as "raising my voice", "putting my foot down", and "threatening" to describe their behaviours during this stage. Other parents referred to this period as a "battle" or "war" indicating the antagonism and opposition that characterized their experiences and their increased participation in

their child's care.

In this stage, parents prepared to assume the primary caregiver role. Parents' behaviours reflected their perception that they needed to protect and advocate for their child. Parents "put their foot down" or "threatened" health care providers as a means of ensuring that their child received the type and quality of care that they considered to be necessary. Parents described "raising their voice" in their interactions with health care providers because they perceived that their perspectives and values were not being heard or respected. Moreover, through these actions, parents indicated a readiness and willingness to take on increased responsibility for their child and his/her well-being.

One mother discussed her experience of "threatening" health care providers to "find out" what was wrong with her son whose condition had not been diagnosed after being hospitalized for four months.

M: I just had to get really crabby and tell them, "You think I am mad, don't get my husband mad because you will be reading about it in the paper.... That would have never happened, that was me threatening them. I told them that I would take him to * Hospital (another tertiary care hospital in another province) or * Hospital.... Like, if you do not tell me or find out what is wrong with him, I will take him to somebody who will..."

Relationships with health care providers during the initial part of this stage were characterized as antagonistic. Parents described health care providers as being "defensive" of their caregiving role, and antagonistic towards parents in response to parents advocating for their child. As this stage progressed, however, parents described health care providers as beginning to acknowledge the parent as a more active participant and stakeholder in the child's care. That is, health care providers

began to: involve parents to a greater degree in the care of the child, include parents in the day to day decisions surrounding the child's care, and to continually update and inform the parents regarding the child's condition and changes in care and treatment regimens.

Assuming the Caregiver Role: Learning Caregiving Expertise

As the parents assumed an increasingly active role in the care of their child they began to learn the child's complex care requirements, with the primary goal of developing caregiving expertise enabling them to care for their child at home. The initial shift into the third stage occurred when the parents began to view themselves as capable of taking on the caregiving role for their child. It was difficult for parents to pinpoint exactly when this shift occurred, since the transition from novice to expert caregiver was a gradual and lengthy process.

Parental behaviours during this stage reflected their progression from novice to expert caregiver of their child. Initially, parents described feeling overwhelmed with the reality of participating in the care of the child and some parents described assuming the caregiver role reluctantly. Participants discussed how they "didn't want to be a nurse". Several of the parents recounted instances or scenarios in which they tried to come to terms with learning and implementing highly complex medical or nursing skills. One mother explained:

M: I kept saying to the nurses, "I don't want to be a nurse, I have never wanted to be a nurse in my life, to me this stuff is disgusting..."

Another mother expressed the following feelings about learning how to care for her

child's stoma:

M: It was a nightmare for me...I had never done stoma care....At the very beginning I couldn't touch it, the first one he had looked like little puckered lips staring at you...It really bothered me...

As the parents progressed through this stage they described a change in their perception of the parental role from " I don't want to be a nurse" to seeing themselves as individuals who could perform highly complex medical or nursing procedures in the care of their child. One mother clearly articulated this shift in perception:

M: I think one of the things I have found is that when you first try to do things such as medical things for your child, that most people never assume they will have to do, like suctioning - shoving a tube down my kid's throat, or how will I put in a G-tube (gastrostomy tube), or catheterize, then I think something that kept me going was realizing that doctors and nurses are not genetically determined...such a simple thing, but it was so exciting when I realized that they are not genetically determined. If they can learn this then I can too.

Participants described their initial experiences of learning the "specifics" of the child's care as overwhelming and anxiety-provoking. This process often occurred over several months and involved learning such complex skills as suctioning, catheterizing, tracheostomy suctioning and cleaning, manual ventilation for a child with a tracheostomy, and emergency enteral tube insertion. For example, one participant discussed her anxiety associated with learning how to care for her child's tracheostomy:

M: I did my first trach (tracheostomy) change with Dr. P. (Pediatric Intensivist) and it was so scary I forgot what I did,...I know I did it but my adrenaline was pumping so hard and it was like I forgot and could not remember...and then I had to do trach changes and trach ties.

Several parents discussed their motivation to learn as much as possible about their child's care during this stage. Understanding various components of the child's condition and ongoing care needs empowered parents to further develop their caregiving expertise. The following excerpt clearly describes how one mother endeavoured to learn as much as possible during this period.

M: My whole thing was knowledge. I wanted to be knowledgeable about it (the child's condition)...I wanted to know everything. I read every page of his chart, I went to the library and studied up on it, I wanted to know what was going on. I wanted to understand it. The more knowledge about it that I had the easier it was for me to cope with it because I knew what I was coping with....I just learned, I just learned as much as I could.

As parents progressed through this stage they learned the skills and knowledge needed to care for their child and gradually increased their competence and confidence in caring for their child. At the end of this stage, parents considered themselves expert caregivers of their child in the hospital setting.

During this stage, parents viewed health care providers as facilitators, teachers, coaches, instructors, and disseminators of knowledge. In other words, parents recognized health care providers as experts in the care of the child and as individuals who could facilitate the parents' progression from novice to expert caregivers. At the onset of this stage health care providers continued to be viewed as the child's primary caregiver. Parents described how they "negotiated" with health care providers which aspects of care they would take over and the pace at which this would occur. As the parents developed into expert caregivers, they assumed that health care providers would gradually relinquish increasing caregiving responsibility, decision-making, and control over the care of the child. Because the child continued

to be hospitalized during this stage, health care providers continued to assume ultimate responsibility for the child.

Several participants described how they had to be "given permission" by health care providers before they could learn or participate in their child's care. Parents described scenes in which they were not given credibility or permission to learn their child's care until the child's physician gave them "permission".

M: I wanted to learn how to do all the things I would need to know to care for A at home...so they just wrote on the chart that mom can do whatever she wants, like teach mom whatever, teach mom whatever she wants to learn. It took a while, the nurses would look like: What are you doing? Are you suppose to do that? And I would just say, "Check the chart". At first it was a problem until I got the doctor (a pediatric intensivist) to write on the chart that it was okay for mom to do the care...And then they would, they taught me.

Another mother discussed the differences she perceived between the nurses in two separate critical care areas in terms of their "comfort" with the mother learning and providing the care for her child.

M: It wasn't bad in the ICU (intensive care unit) because that was the whole point of why I was there. I would call for back-up (when the child required tracheal suctioning and manual ventilation) and then the nurses would come and help me and they would say "Oh mom, relax - you are doing good" and they would coach me and say, " You are doing it right" and "Hang in there", because they knew that I had to do this at home if this was going to happen. Whereas in the NICU (neonatal intensive care unit), it was " Move, move, I'll do it, I'll do it (from the nursing staff)..."

It is important to re-emphasize that the first three stages in the evolution of parents as primary caregivers encompassed the first critical time period in the parents' experience and occurred in an acute-care hospital setting. The following section will explore the final stage of Adjusting to home-based care: Building supportive relationships which marked the advent of the second critical time period and involved

the transition of caregiving from the acute-care hospital setting to home-based management of the child's condition. This critical period differs from subsequent critical periods in that it involves the parents initiation into caring for their child in the home setting.

Adjusting to Home-Based Care: Building Supportive Relationships

At the onset of the fourth stage, parents had developed into expert caregivers of their child in the hospital setting, however they considered themselves as inexperienced in terms of caring for their child at home. The child's caregiving demands did not significantly alter with the advent of home-based care, however, parents did need to adjust to the change in setting from hospital to home-based care. The nature of parental caregiving in this stage was largely influenced by the need for parents to meet the child's caregiving demands and the competing demands of family life. Although there was a shift from "life saving" to "management" of the child's condition, the fragile nature of the child's condition was such that care demands could vary from day to day. Parents had to become adept at mobilizing support in relation to caring for their child at home and in meeting the needs of other family members. Parents also had to troubleshoot and develop new coping strategies to effectively manage the care of their child at home.

For many parents, the initial transition of the child's care from hospital to home-based care was considered one of the most stressful events they experienced. In addition to adjusting to the change in setting in caring for their child, parents also

faced the challenge of incorporating the child and his/her care into their "normal" family life at home. The parents discussed how they had become accustomed to the hospital setting in which emergency aid was always readily available. Even with extensive discharge teaching and preparation from hospital and community professionals, all of the participants stated that they still felt unprepared for the transition from hospital to home-based care. The transition meant assuming the role as primary caregiver without the "safety net" of the hospital setting where support from health care providers was readily accessible.

One mother, whose child had a tracheostomy and required frequent tube feedings found it particularly difficult to manage the transition to home-based care of her child.

M: When he very first came home,I fed him every two to three hours...I could only give him about 60 c.c.s every two to three hours. Well he would aspirate and vomit every feed, so I would have on one shoulder the suction catheter, on the other shoulder I would have the ambu (resuscitation) bag, and I was trying to suction and bag and suction, and talk to the ambulance people all at the same time... And that was like every two to three hours that that would happen and I just felt, I was just so stressed out I couldn't deal with it...that was the biggest thing getting through the hurdles of that.

Another mother referred to the emotional distress and turmoil associated with her son's initial discharge home:

M: There was so many changes all at once. It was really a difficult time. I don't know how I got through it actually now that I think about it (laughs). I am amazed I am not a lunatic. Maybe I am and I don't know it...

Parental behaviours during this stage progressed from expert caregiver of their child in a hospital setting to expert primary caregiver of their child at home. This transition often took a minimum of several weeks in order for the parents to feel

confident in the new setting. Parents viewed themselves as the child's primary caregiver, the primary decision-maker regarding the child's care, and as "supervisors" of respite nurses and other health care workers who provided care for the child in their home.

A "successful" transition from hospital to home-based care was characterized by parents as expert caregivers of their child in the home setting. That is, parents had developed strategies to effectively deal with the child's caregiving demands and the competing demands of family life, had developed coping strategies, and had mobilized support from health care providers and others.

Continuing parent - professional relationships were essential given the child's medically-fragile condition and complex care requirements. During this and future time periods, parents viewed the role of health care providers as colleagues or partners in the care of their child. Participants indicated that they preferred to work with professionals who: respected the parental role as expert primary caregiver; respected the parents' perspective regarding the child's ongoing care and treatment; and valued the child and his/her well being, especially regarding life and death issues. In contrast, conflictual interactions were described as resulting when health care providers held perspectives that differed from the parents' perspectives on one or more of the following issues: the role of parents as expert caregivers; the child's ongoing care and treatment requirements, and the value placed on the child and his/her well being, particularly regarding life and death issues. If a relationship could not be avoided, conflict and struggles for control characterized parent-professional

interactions.

Although all of the participants indicated they shared a supportive and cooperative relationship with some professionals, this was not true of their relationships with all health care providers. Several participants discussed the process of trying to find health care providers that they could work with who respected their perspective of what was best for their child and demonstrated expertise in the management of the child's condition. The parents elucidated their difficulty in determining whether a certain professional respected the parental role, the parents' perspective regarding the child's care and treatment, and whether the professional valued the child and his/her well-being. One mother addressed this issue in the following statement:

M: When you go to a doctor for the first time, you ask them questions. You want to find out what their attitudes are. It is very difficult to find that out....You want a doctor who respects your child, believes they have a right to medical intervention in the same way anybody else would and it is not qualified by the fact they happen to have a disability....It is really difficult. It is really important that you know the attitudes of the persons who are working with your kids because you may not know that they are not giving your kid the kind of medical intervention they would give anybody else.

Parents continued to develop their caregiving expertise and endeavoured to build supportive relationships with health care providers in the ongoing care of their child. The participants' progression through the four stages in the evolution of parent as expert primary caregiver laid the foundation for their ongoing relationships with health care providers.

Characteristics of Supportive Parent - Health Care Provider Relationships

Parents required support from health care providers in order to effectively

manage the care of their child at home. When parents encountered difficulties and frustration rather than support in their interactions with health care providers, the strain of caregiving demands was increased. Moreover, without the support from health care providers, there was an increased risk for the nature of caregiving demands to exceed the parents' resources to cope with the child's caregiving demands and the competing demands of family life.

In general, parents endeavoured to develop supportive relationships with health care providers. Supportive relationships were defined by parents as collaborative, interdependent and non-hierarchial. In such relationships the participants felt that they were recognized as expert caregivers and the primary decision-makers regarding the care of their child. Health care providers were viewed by parents as experts in specific aspects of the child's care and as individuals with whom parents needed to collaborate in determining and implementing the best treatment and care alternatives for their child. One mother clearly elucidated the components of this type of relationship:

M: Everything is so specialized that it is difficult to know if everything is following the right path and if you have made the right decisions. You need someone to talk to and make sure that you have made the right choice. I don't expect doctors to make the decisions for you. I want to be informed so I know I am making the right choices, but you still need somebody to be like a sounding board sometimes...to ask the right questions so that you know that you are making the right decisions.

In the stage of Adjusting to home-based care: Building supportive relationships, parents were able to clearly identify several fundamental characteristics of supportive parent - health care provider relationships. These characteristics

included: honesty, empathy and understanding, and mutual respect.

Honesty.

Participants repeatedly pointed out the importance of honesty and openness in developing supportive collaborative relationships with health care providers. One parent expressed the importance of a physician being honest when he described what he thought the characteristics of a "good" physician encompassed:

F: A good doctor is one that admits when he doesn't know, a doctor that is willing to say, "That is beyond my field". I think that is what makes a good doctor, one that has compassion and one that admits that he doesn't know it all.

Another participant affirmed:

M: Don't be afraid to tell me you don't know. I mean we are all learning right, especially with A. There are only eight or ten kids like him, so its a learning thing. All they (physicians) have to do is tell me that and then I can understand it...

Finally, another participant gave an example of the importance of health care providers being honest about the extent of their knowledge and experience:

M: (Re Family Physician) He has been really good - he doesn't muck around and try to figure things out, if he has a question he phones over (to the tertiary care centre), he doesn't piddle around....Like at one point, there was bleeding from A's trach (tracheostomy) and Dr. P. phoned over because neither of us had had that happen with him before.. He said, this is what it might be but I am going to phone Dr P (child's specialist). So he phoned, and he was right. But he still felt the need to phone and make sure which I think is good that he did...

Health care providers who possessed individual traits of honesty and openness with parents appeared to be both respected and trusted by parents. Thus, honesty appeared to be an integral stepping stone to building an effective and supportive relationship.

Empathy/Understanding.

Supportive relationships also tended to be characterized by health care providers who were perceived as being empathetic and who had an appreciative understanding of the parents' experience. Moreover, parents considered it essential that health care providers demonstrate a family-centered perspective rather than focusing on the child in isolation. This was clearly expressed in one participant's statement:

F: In my experience, the key thing is to have a supportive physician who cares about the child and who cares about us as a family...he cares about the long term outcome of the child...that kind of support from a physician really helps...

Another participant provided a similar example, stressing the importance of an understanding health care provider approach:

M: I don't care how smart you are, I will give up a bit of brains for a little bit of good manners and a good rapport with the family...

Parents also discussed the importance of being honest with health care providers, and providing them with the most "accurate" and "detailed" information possible in order to develop a successful interdependent and collaborative relationship.

One mother explained:

M: The parent has a role to provide as accurate information as he or she possibly can, and as detailed information as possible to the physician. And the physician, on the other hand, I feel, has the responsibility to take that (information) and plug it into the science that he has, and pull out his perspective and validate that with the parent... When I go to the pediatrician, for the most part our decisions are joint decisions...

Mutual respect.

Participants indicated that a key ingredient of a successful collaborative

relationship with health care providers was mutual respect for each other's roles and expertise. One mother provided the following example:

M: It is a mutual respect thing. I know what his job is and he knows what mine is and we work together, some doctors just try to do everything. Like you are just a parent, you don't know what you are talking about...this is medical stuff, you have to listen to me. Well they have to listen to you too, its just not you having to listen to them. It is a two way thing. The same goes for Dr. P. (child's pediatrician), I respect what he does, he respects what I do, we work together. He asks me what I think and he takes that into consideration when making a decision. When you are the parent, you are the one with the child most of the time. Doctors are far away from it, they don't see most of the responses to what they have ordered...doctors need to listen to what parents have to say, it is important.

As indicated in the preceding statements, mutual respect went hand in hand with listening and valuing each other's opinions and experiences. One participant explained:

M: If you treat someone like they are intelligent you get the same back. I like it when someone listens to what I say, asks my opinions - because they are allowed their opinions and they might see it from an entirely different perspective.

As pointed out in the above participant's statement, it is important to note that parents did not expect health care providers to share the same perspectives as they did regarding the child and his or her care; however, they did expect health care providers to demonstrate a respect for their perspective regarding: the role of parents as expert caregivers, the child's ongoing care and treatment requirements, and the value placed on the child and his/her well-being.

Parents considered themselves as experts in the care of their child. As such, parents described preferring to work with health care providers who respected the parental role as expert primary caregivers. One mother provided the following

example of her relationship with her child's respirologist:

M: Dr. P was and still is very important. He does his doctoring thing and he lets me do the parenting thing, and he does not interfere. Too many of the doctors try to say you have to feed him this way and you have to do this and you have to do that, well you don't *have* (emphasis added) to do anything....I mean moms know things...

Another mother described the recognition and respect she received from in-home respite nurses regarding her expertise as the child's primary caregiver:

M; I have never been told by the nursing (respite) agency how to do nursing procedures... I teach suctioning and I don't care how anybody else is suctioned, I am the one who teaches it... When you do it as often as I do it you learn a technique that is really not as invasive...The nurses have always had the utmost respect for any procedure that I do and I have never had a nurse say, " We don't do it that way".

Finally, another mother described the respect she received from hospital nursing staff regarding the care and treatment of her child during a rehospitalization of the child for a deterioration in his condition.

M: I had a really hard time learning everything, but whenever I go back (rehospitalization) I always have a way that is better than theirs because I hate doing it. I am going to find the easiest and quickest way with anything...and the staff are so great because they come and ask me about the way that I do it, they make me feel like I have worth as a human, that I am intelligent, that what I think means something.

Another father described how recognition by his daughter's medical specialist regarding the parents' perspective on the ongoing care and treatment of the child was an important component of a supportive parent - health care provider relationship.

F: When we deal with doctors and nurses we are not scared to say, "What about this?", or "What about that?". Dr. P. has said to us many times, "You know as much about this (the nature of the child's condition) as we do now". He said, "you are asking us questions that are so practical that we as doctors sometimes overlook".

Specialists were often characterized as having a knowledgeable appreciation of the family's experience and as valuing the child's well-being. This was not particularly surprising as many of the parents initially learned how to care for their child under the supervision of health care "specialists". Moreover, as the parents developed further knowledge and expertise in caring for their child, the more critical they became in judging a health care provider's knowledge base and provision of care. One mother provided the following comparison between "specialists" and "general practitioners" regarding the value placed on the child's well-being:

M: A goes to a ton of specialists and I have found all of the specialists to be really open, whereas the G.P.s (general practitioners), a lot of them seem to have really poor attitudes towards our kids, but the specialists all seem to value them.

Parents stressed the importance of building supportive collaborative relationships with health care providers in managing the care of their child at home. Honesty, empathy and understanding, and mutual respect were identified as important ingredients to the development of a supportive collaborative relationship between health care providers and parents.

Characteristics of Conflictual Parent - Health Care Provider Interactions

Parents described three specific areas in which conflictual interactions occurred between themselves and health care providers. Conflictual interactions were described as resulting when health care providers held perspectives that differed from the parents' perspectives on one or more of the following areas: the role of parents as expert caregivers; the child's ongoing care and treatment; and the value placed on the child and his/her well being, particularly regarding life and death issues. It is

important to emphasize that parents did not expect health care providers to share the *same* perspectives, rather to respect the parents perspective. However, conflictual interactions often resulted when health care providers *demonstrated*, through their attitudes, statements or behaviours, perspectives which clashed with the perspectives of the parents in relation to one or more of these areas. Each of these areas of conflictual interactions will now be presented and substantiated with excerpts from participant interviews.

Discrediting the role of parents as expert primary caregivers.

Parents described several conflictual interactions with health care providers which they perceived as resulting from differences in the perception of the role of parent as expert caregiver. Parents related incidents in which health care providers discredited their caregiving expertise. In particular, participants made numerous references to incidents in which health care providers were seen as discrediting the parental role by using negative stereotypes or labels. One father, whose child had extreme allergic reactions involving weeping eczema and anaphylactic shock explained:

F: Probably the hardest thing is to get health care professionals in general to believe you as parents and to not think you are a non-compliant parent, but to give validity to what you are saying...I think so many people, even nurses, they initially look at her eczema and think, "Oh if you would only give her to me I could go home for a weekend and have her all cleared up". Like, "What's the matter with you people?"...I'm sure they think we live in a pig sty...I think there is definitely a belief (by health care professionals) that most children that have repeated hospitalization are there because of dysfunctional families, noncompliance as far as treatments and medications...I think health care providers can be quite stereotypical and I think people need to back up and stop sometimes and pay attention to people not just put them into "that" group when they walk in the door.

Other parents indicated similar frustrating experiences in which health care providers appeared to have a knee-jerk reaction to label them as "non-compliant" or "dysfunctional" parents. Parents described these actions as indicating a lack of respect for the parents' role as expert caregivers. Moreover, through these actions, parents perceived health care providers as discounting the many difficulties associated with managing the child's medically-fragile and complex condition at home. Conflicting relationships were often the result of health care providers' stereotypical characterization of parents.

Parents also described conflicting interactions stemming from health care providers who appeared to discredit the parental role by minimizing the parents' expertise in caring for their child with a medically-fragile condition. Parents reported frustration with professionals who were not respectful of their ability to notice minute changes in the child's condition. Parents reported feeling "angry" and "obstructed" when this occurred since treatment would not be initiated until the health care providers conceded that a problem actually existed. For some parents, this resulted in parental feelings of disempowerment and helplessness. Others reacted by "raising their voice" and "fighting" for someone to respect their caregiving expertise and take their concerns seriously. One mother provided a clear example of her experience in trying to get health care professionals to treat her child's infected jejunostomy tube exit site (the child was dependent on enteral feeds via the j-tube for nutrition).

M: Don't talk to me like I am an idiot. Don't be patronizing when I say its purulent. I know what I am talking about. I have to...I want to save him.

The same participant pointed out instances in which her child's condition had to have

significantly deteriorated before health care providers took her concerns seriously.

M: Obviously it (infected j-tube site) needs investigating so I am going to take him in tonight and see if I can get someone to listen and if I can try to get a referral. But it is hard. It would be better if it did get real good and angry looking. Then I am believed. Then we get treatment...

Another participant related similar experiences:

M: What I find incredibly frustrating ...I get very annoyed when people keep telling me she is getting better, when I don't feel that she is getting better, and that doesn't mean I want to keep her sick, but it discredits the problem again...

Divergent perspectives on the child's ongoing care and treatment.

Parents also described conflictual interactions that were attributed to health care providers who demonstrated divergent perspectives from parents in relation to the child's ongoing care and treatment, and/or health care "institutions" or "systems" whose mandates or policies did not recognize the parents as full partners in the care of the child. Parents described their general dissatisfaction and frustration with the "policies" and "rules" of health care institutions or systems which did not respect the parents' perspectives regarding the support parents required to care for their child, and with health care providers who did not appear to have an appreciative understanding of the child's care or treatment requirements.

Parents explained their feelings of frustration and anger which occurred when they were " forced" to "jump the hoops" or "fight the systems" in order to receive the support they required to care for their child at home. Parents described repeatedly "battling the system" in order to receive the necessary support services to adequately care for their child at home and the stress associated with these conflictual

interactions. Sometimes it was more stressful fighting for support services than it was worth. One mother noted:

M: Nothing comes easy. It's like you have to sign here and then I have to talk to this office and this supervisor has to talk to this supervisor and on and on. And then they (health professionals) say "Oh, we don't usually do it that way". So I have to get that authorized for this office and so on. Its such a big hassle. Its like forget it. I would rather go crazy. I mean what is worse? Being stressed out with your child or being stressed out with your child *and* (emphasis added) being stressed out from getting all of the help that you need to look after your child - its just crazy.

Another mother reported a similar experience with a "support" service:

M: If I phoned for whatever reason I got sent from person to person to person and nobody would know what I was talking about. It was just too confusing and too disorganized....I still don't like to deal with them. If I have to I will do whatever needs to be done on my own.

One mother discussed her frustration with the amount of time it took "fighting the 'support' systems":

M: I guess what takes up most of the energy is fighting the systems that are out there. There are a lot of systems out there and they are all entrenched. They are not set up to look at the needs of the child, they are there to serve their own benefit, and everyone of them has rules that don't benefit the children even though without the children they wouldn't be there...They all have benefits, but they all have a lot of negative benefits: negative things that go along to serve the system which don't serve the children or their families.

The preceding examples indicate the parents' descriptions of what occurs when the bureaucratic restrictions of health care institutions/systems do not support parents in obtaining the care and treatment services their child requires.

Several of the parents specifically mentioned their frustration with accessing emergency medical care for their child. When a change or exacerbation in the child's condition occurred, the child was generally taken to the Emergency Department of a

local community hospital. Frustration resulted from the parents' perceptions that the "system" dictated that their child had to be assessed by numerous medical professionals with little or no knowledge about the child's presenting illness before he or she was seen by a specialist who could effectively treat the child's condition.

When health care providers were seen to limit access to appropriate treatment, parents discussed feeling angry and frustrated. This was underscored by the parents' perception that they held more expertise and knowledge about the child's condition and treatment regimen than the medical professionals assessing their child and that this expertise was not respected by health care providers. It was the parents' view that if the specialists were called to see the child initially, that neither the parent or child would have to endure hours of waiting while countless physicians attempted to figure out what to do. One mother presented the following description:

M: Emergency - that is just the biggest nightmare word because you know if you go there for even the most simple thing you will be there for hours and hours and hours because you will be passed from person to person because nobody wants to touch you...I mean nobody can be an expert on everything, it is just stupid.

Another mother noted:

M: When A was two and a half, we went to the Emergency Department because his G-tube (gastrostomy feeding tube) had come out. I knew we had to have it in by three hours or he would have to have another operation. I kept on saying, "We have to put a Foley catheter in (to keep the g-tube exit site open) and nobody would do it. They kept going higher and higher (up the medical hierarchy). First the intern, then the residents...What is the sense of an Emergency Department? (The mother and sister ended up inserting the foley catheter themselves in the Emergency Room)....Its that kind of stuff that drives you crazy as a special needs parent, you go there knowing that you probably know more than they do but that you are not going to be believed. Its a catch twenty-two.

Another participant expressed her frustration with "the system", "forcing" her to interact with physicians at a local medical clinic who lacked knowledge and expertise in the management and treatment of her child's condition. The mother perceived that this interaction was necessary in order for her child to be referred to a specialist. She explained:

M: I have no faith in the doctors that I am going to see at the drop-in clinic. I know they know nothing. I know a hundred times more about duodenostomies than they do and it seems to me so stupid that I have to go there...I would rather go to the specialist. I mean they are going to have to send me there, they are not going to be able to deal with it. I know that. Its just a waste of time for everybody, waste of time, waste of money, everything, and I just resent having to do it...and it always seems to be that way...

Parents emphasized that the rare and unique nature of many of the children's medical conditions and caregiving requirements contributed to a perceived shortage of health care providers knowledgeable about the management and treatment of the child's condition. This scarcity of experts in the management of the child's condition was accentuated since all of the families lived a significant distance from a pediatric tertiary care centre which was accessible only by ferry, plane or heli-jet. Although some parents would have preferred to deal only with specialists in their child's condition, the health care system and/or the family's geographical location often dictated that the child initially be seen by general practitioners who parents perceived as inexperienced in the nature of the child's care and treatment requirements. This perception of having no choice but to interact with health care providers who lacked expertise in the child's care was a major source of conflict for parents. Moreover, it underscored the perceived lack of respect parents received from health care providers

and the health care system in general in caring for their child at home. One mother described her frustration with the lack of physicians in the family's geographical location who were knowledgeable about her son's condition:

M: I am amazed that they don't cover those things better in medical school. Like the one physician who had never seen a duodenostomy until he seen A. That gives you a very scary feeling. Like "Oh, good, I am *supposed* (emphasis added) to go to you and you have never seen one before". That really bothers me a lot... especially in * (geographical location). The lack of specialists, the lack of anyone that knows anything about kids like A. I mean it is really hard to travel. I don't feel we should have to live in * (city with a pediatric tertiary care centre) to get decent medical care.

Differences in perspectives between parents and health care providers also existed in relation to the hospital care of the child, often resulting in conflictual interactions. As experts in their child's care, parents described becoming increasingly vigilant of the care and treatment provided by health care workers when the child was hospitalized. Participants associated hospitalizations with increased vulnerability for their child due to their perception that health care providers were not familiar with the nature of the child's condition or caregiving requirements. Moreover, parents expected to be recognized and respected as the primary decision-makers and caregivers for their child, even in the hospital. One mother explained:

M: The majority of parents that I know never leave their kids in hospital because it is when they are most vulnerable. I do all of the care when A is in hospital. I just come home at night to get my sleep.

Another mother compared the care her child received in hospital to that provided by respite nurses at home:

M: When A is hospitalized I always stay with her because there is never any consistency in her care. I think that her most dangerous time is when she is in hospital or in a respite hospital....that is when she is the most vulnerable and it

is always when she gets pneumonia and things like that...the nurses in the home are here all of the time and after so many visits they learn exactly how I want it done...I think its great for parents to be real particular when it comes to their kids...

Divergent perspectives on life and death issues.

Divergent perspectives between parents and health care providers on the value of the child and his/her well being, particularly regarding life and death issues, was another ongoing source of conflict. Parents discussed the importance of understanding health care providers attitudes and values in relation to life and death issues pertaining to the child. One mother explained:

M: It is really important that you know the attitudes of the persons who are working with your kids because you may not know that they are giving your kid the kind of medical intervention they would give anybody else. I have been finding this more and more with some local doctors. There have been children that have died because their life is not valued, *they* (health care providers) do not see them as having value so it would be better to let them slip away...*their* (emphasis added) value of this person's life. They may not tell the parents about what medical interventions there are, they are not giving parents the choice. They are not respecting the parents choice in what would be the best thing for this child. *They* (health care providers) are making their own determination as to what should be done for this person with a disability...but you do not really know how your doctor feels about your kid until you are in the middle of a medical crisis...

Other participants described vivid interactions with health care providers who the parents perceived did not respect their perspectives concerning life and death issues regarding their child. One mother put forth the following example:

M: (Re: a trip to the Emergency Department for a severe condition) We were there (Emergency Department) seven hours before finally the pediatrician on call came and he came to my husband and me in my room and said, "I just thought you would want to know that I think it is a waste of life support to put children like your son on it and that if another child came with a better chance

of living it would be on your heads that he didn't get hooked up" ...How dare he do that? ...Parents don't make that choice, at least not in Canada...And he said, "I refuse to treat your son", and I said, " I refuse to have you treat him, I want to see somebody else". And he said, "then you can wait for the next shift change". And I went, "Gladly". And I am really glad that I did that because *if he thinks in his mind that A is an idiot, what use is he as a doctor?* (emphasis added)...No one has the right to talk to anyone like that...

The preceding example illustrates the parents' feelings of anger and outrage when they perceive that a health care provider bases his or her actions solely on their personal assumptions, values or beliefs, irrespective of the family's or child's perspective. Parents described such actions by health care providers as infuriating, resulting in parents advocating for the rights of their child. Furthermore, such actions, even by a small percentage of professionals, led parents to distrust other health care providers, making further interactions cautious and guarded.

Another couple provided two contrasting interactions with health care providers revolving around life and death issues.

M: When A was born we were given a choice to make. Our doctor (pediatrician) who has been excellent and stayed with us all of the way told us that we had the choice of either letting natural causes take place which would have meant that A would have developed spinal meningitis and then within 3-4 days she would have passed away or we could take what he called the "All American Route" where he would send her to * (pediatric tertiary care centre) where they would close up the protrusion of the spina bifida, and that he would stick with us either way.

This anecdote describes how an honest and supportive relationship with the child's physician played a key role in supporting the family in making a critical decision regarding their child's life. The physician in this example was seen as providing significant support through his collaborative approach and respect for the family's perspective. This is in sharp contrast to the same family's experience with another

physician:

F: I remember one of the doctors who was a neurosurgeon said that we had made the most devastating and tragic decision of our lives, that we should never have ever chosen treatment, that we should have put A into * (an residential institution for severely disabled children) and forgot that she was born. These are memories that ring out in my mind...

This example clearly illustrates a health care provider who was perceived to judge the family's actions based on his/her own values, assumptions, and beliefs. As noted by the above participant, experiences such as these were vivid and difficult to forget, resulting in further distrust of health care providers in general.

The preceding anecdotes are representative of conflictual relationships between health care providers and parents. The two parties disagreed as to the value of and capabilities of the child with a medically-fragile condition . This led parents to "raise their voice" and advocate for the value of the child and his/her well being, and that the parents' concerns regarding the child's health be taken seriously.

The components contributing to conflictual relationships between parents and health care providers have been explored in detail. In order to effectively cope with the nature of the child's caregiving demands parents require ongoing support from health care providers. Supportive parent - health care provider relationships strengthen the parents' resources to respond to the overwhelming nature of the child's caregiving demands. When parents encounter difficulties and frustration rather than support in their interactions with health care providers the strain of the caregiving demands is increased. This may result in a state of imbalance in which the nature of caregiving demands exceeds the parents' resources for providing care.

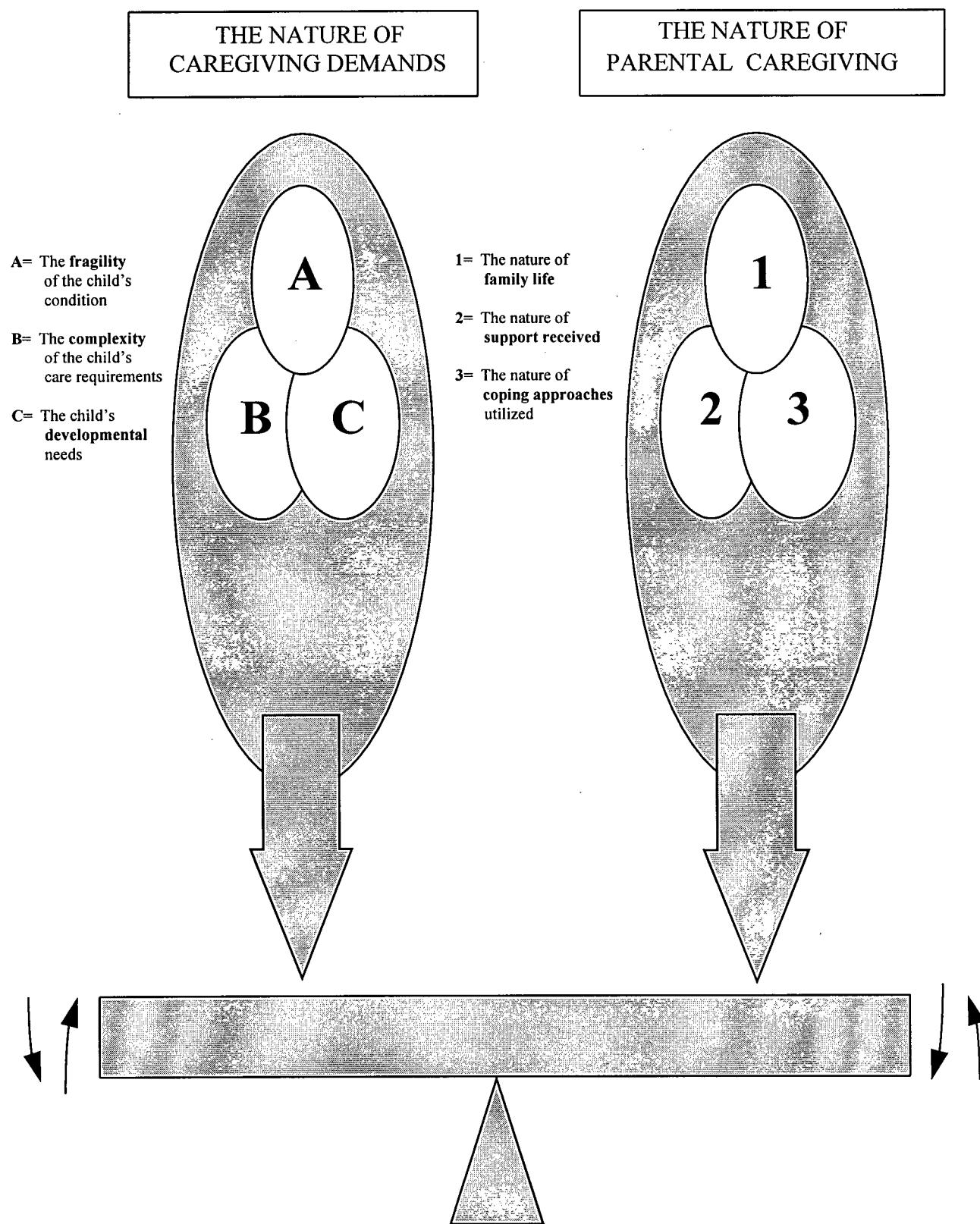
The preceding sections have explored the parents' description of the onset of their experience which involved their evolution as expert caregivers and the concurrent evolution of the parent - health care provider relationship. In addition, parents emphasized the importance of building supportive relationships with health care providers in the ongoing care of their child. An indepth examination of the parents' descriptions of the characteristics of a supportive parent - health care provider relationship was presented. This was contrasted with an exploration of the parents' descriptions of the characteristics of conflictual parent - health care provider relationships. The preceding conceptualization and analysis of this aspect of the parents' experience lays the foundation for the major focus of the chapter: the dynamics of parental caregiving of a child with a medically-fragile condition at home.

The Dynamics of Parental Caregiving

The over-riding theme that was conceptualized from participants' descriptions of their experience was the *dynamics of parental caregiving of a child with a medically-fragile condition*. The dynamics of parental caregiving was conceptualized as a process of balancing the nature of caregiving demands with the nature of parental caregiving. This was envisioned as a see-saw with the nature of caregiving demands on one end being counter balanced with the nature of parental caregiving on the other end (Refer to Figure 2, page 81). The see-saw is considered to be in a dynamic state in which the nature of parental caregiving is constantly readjusting in response to the child's changing care demands. Moreover, just as the nature of caregiving demands

Figure 2. The Dynamics of Parental Caregiving

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influences the nature of parental caregiving, the nature of parental caregiving also influences the nature of caregiving demands.

Figure 2 (page 81) illustrates that both the nature of caregiving demands and the nature of parental caregiving are shaped by a complex set of factors. Participant descriptions indicated that the nature of caregiving demands is influenced by three key factors: the fragility of the child's condition, the complexity of the child's care requirements, and the child's developmental needs. The complement of these three factors differed across participants. For example, for some families the degree of fragility associated with the child's condition was the most influential factor impacting on the nature of caregiving demands, whereas the complexity of care required was the most influential factor in another family. Moreover, the impact of each of these factors was characterized as changing over time. For example, the child's developmental needs may have been of primary influence for the family when the child was a preschooler, but took on less significance as the child reached school age. Finally, the factors were conceptualized as discrete yet interrelated. For example, the degree of fragility associated with the child's condition was influenced by the child's developmental needs and the complexity of care required.

The parental caregiving response was also seen as influenced by three key factors: the nature of family life, the nature of support received from others, and the nature of parental coping approaches. These three factors shared the same characteristics as the factors which shaped the nature of caregiving demands. That is, the complement of factors differed across participants and over time, and were

characterized as discrete yet interrelated. For example, the nature of family life may have been considered of primary influence for a single mother with three other children whereas the degree of social support received from others may have had the greatest impact on the caregiving experience for another family.

These three dimensions of the nature of parental caregiving have been conceptualized as dynamic and evolving over time. For example, the experience of caring for the child occurred within the evolution of individual family life. Therefore, as the nature of family life changed, the nature of parental caregiving also changed.

During the initial critical period of diagnosis and treatment of the child's condition, the see-saw was conceptualized as being in a state of imbalance, that is, a state perceived by parents as exceeding their resources to cope with the demands of caregiving and characterized as endangering the child's well-being. As the child's condition improved and the parents became experts in the child's care, taking on the primary caregiving role, the see-saw moved towards a balanced state. Optimally, at the advent of the second critical period, the transition from hospital to home care, the see-saw was characterized as being in a balanced state. That is, the nature of the demands associated with caring for the child were counterbalanced by the nature of parental responses to these demands.

In a balanced state the relationship between the nature of caregiving demands and the nature of parental caregiving was constantly changing since the nature of parental caregiving was continuously readjusting to the changing caregiving demands.

Moreover, the inherently fragile nature of the child's condition and related susceptibility to exacerbations or deteriorations of the child's condition played a key role in the vulnerability of caregiving demands exceeding the parents' resources for providing care, thereby returning the see-saw to a state of imbalance.

It is proposed that this is one of the key factors which differentiates the experience of parents of *medically-fragile* children from parents of children with long-term conditions which are not medically-fragile. To differentiate, parents of children with non medically-fragile conditions have a greater opportunity to move into periods of stability (Clements, Copeland, & Loftus, 1990) in which both the nature of caregiving demands and the nature of parental caregiving is characterized by an increased sense of order and organization.

For families in this study, a balanced state indicated parental coping effectiveness. Coping effectiveness was based on the perception that parents were able to manage the child's condition and maintain both the child's and family's well being. In contrast, coping ineffectiveness was indicated by a state of imbalance which could have resulted from a variety of factors which either increased the impact of caregiving demands or decreased the impact of parental caregiving.

Following the child's initial transition from hospital to home, the nature of the child's illness trajectory was characterized as a baseline of vulnerability punctuated by multiple and successive critical events. A critical event was conceptualized as a state of imbalance in which the child's caregiving demands exceeded the parents resources to provide care. For example, if an exacerbation or deterioration of the child's

condition required the child to be hospitalized, parents were conceptualized as moving back into the third stage to learn the child's revised caregiving requirements. Subsequently, the parents were viewed as moving back into the fourth stage once the child was discharged home.

The Nature of Caregiving Demands

The fragility of the child's condition, the complexity of the child's care requirements, and the child's developmental needs were described by participants as distinct yet interrelated factors influencing the nature of caregiving demands. For example, a child who was dependent on a tracheostomy to breathe was considered medically—"fragile" due to his/her vulnerability to multiple elements which could obstruct his or her airway and be potentially life-threatening. In contrast, the actual day-to-day care requirements of this child were not considered as complex as that of a fifteen year old child who had spastic quadriplegia and whose care included: regular diapering, respiratory nebulizer treatments and suctioning a minimum of every two to four hours, enteral tube feeding every three hours, chest physiotherapy four times a day, and range of motion exercises twice a day. All of the children in this study were considered to have medically-fragile conditions, however, there was a considerable variation in the degree of complexity involved in the care of each child and the child's developmental level. Each of these factors will now be presented, described, and illustrated with excerpts from participants' descriptions.

The Fragility of the Child's Condition

One of the key differences between the children in this study and children with chronic illnesses in general is the medical fragility associated with the child's condition. The nature of the child's condition ranged from being technology-dependent, such as requiring a tracheostomy to be able to breathe, to requiring enteral feeding in order to maintain nutrition, to having multiple potentially fatal allergies requiring immediate intramuscular injections of adrenaline and emergency trips to a hospital several times each month. The fragile nature of the child's condition, characterized by an increased vulnerability to medical crises and an unpredictable nature and trajectory of the child's condition, underpinned the unique nature of the participants' experiences. Whereas parents of children with relatively controlled long term health conditions such as rheumatoid arthritis or diabetes mellitus might anticipate an illness trajectory characterized by a baseline of stability punctuated by generally non-life threatening exacerbations or deteriorations of their child's condition, the illness trajectory of the children in this study was characterized by a baseline of vulnerability punctuated by multiple unpredictable life-threatening critical events. Thus, the degree of fragility associated with the child's condition was shaped by two distinct yet interrelated characteristics: vulnerability and unpredictability.

Vulnerability.

The child's health condition was characterized by vulnerability which was described as an increased susceptibility or lack of resistance to medical crises. The vulnerability associated with the child's condition was viewed as constant with the

degree of vulnerability primarily dependent on the nature of the child's underlying condition. For example, a child with a tracheostomy was perceived as being at risk for sudden death if his or her airway became obstructed. In contrast, a child with progressive renal failure or a child dependent on enteral nutrition for nourishment was not perceived to be at the same risk for "sudden" death, but rather at an increased risk for significant deteriorations in his or her condition.

The vulnerability associated with the child's condition was also described by participants as changing over time as the nature of the condition changed. For example, the parents of a child whose condition was characterized by progressive renal failure, described the child's condition as becoming increasingly "fragile" as the renal failure progressed. In contrast, the mother of a preschool child with multiple congenital anomalies including the need for a tracheostomy, described her son's condition as going along for two to three months with little change in caregiving demands and then requiring several successive hospitalizations for a recurring respiratory infection.

Some participants provided analogies to their experience as characterized by extreme instability such as "being on a see-saw" or in a "rocking boat". These statements provide insight into the vulnerable and precarious nature of the participants' experience of caring for their child with a medically fragile condition at home. The emotional distress associated with this experience primarily resulted from the perceived risk of death or further deterioration of the child's already compromised condition. One mother provided a vivid description of her perception of the

vulnerable nature of her child's condition, the ongoing exacerbations and changes in the child's condition, and the immense physical and emotional strain involved in the nature of parental caregiving.

M: It's like being on a see-saw. I'm never in the middle, things are never normal and kind in my life ever. I'm either in the middle of a crisis cause he is really sick or I'm so exhausted that I'm hysterically stupid. I can't even remember what normal people live like anymore. Everything is an emotional extreme. I hate it. I mean I love my son but I hate my life.

Another participant provided some insight into her feelings of being overwhelmed with the nature of her child's condition and her difficulty dealing with anything extra, that is, anything that was above and beyond her "coping threshold". Her example points to the precarious balance between the nature of caregiving demands and the nature of parental caregiving.

M: You are constantly upset and worried and tired and so that if anyone does anything that rocks the boat even more... You tend to get angry at anyone that adds more stress to the family. Sometimes its just normal activities...I find myself if anything else happens I can't deal with that, things that other people would ride with more easily, kind of roll with the punches - it's a lot harder to do...

If the nature of caregiving demands exceeds the parents resources for providing care, the relationship between caregiving demands and the nature of parental caregiving moves into a state of imbalance. This often occurred, for example, with an exacerbation of the child's condition which the parents were unable to manage at home. An exacerbation of the child's condition generally resulted in the hospitalization and treatment of the child by health care providers in order to sustain the child's life, prevent further complications of the child's condition, and assist in returning the dynamics of parental caregiving to a balanced state.

Exacerbations or deteriorations of the child's condition requiring additional support from health care providers and others was a common occurrence for these families. One mother discussed the ongoing nature of the "crises" in her family's life in relation to the ill child.

M: I guess the hardest thing is there is always another crises. Like six months down the road you can bet your bottom dollar and once you get used to that you know that there is going to be battle after battle after battle after battle...

Re-hospitalizations of the child were stressful on the family for several reasons including: the uncertainty of how the child would cope with the exacerbation or deterioration of his or her condition, the increased emotional distress associated with the child's change in health status and with being away from home and/or separated from each other, and the uprooting of family routines and rituals. Due to the severity of the child's underlying condition, re-hospitalizations often lasted for extended periods of time, sometimes for weeks or months.

One participant described the distress, uncertainty, and family disruption associated with exacerbations of her child's health condition:

M: Every time they (children with complex health conditions) have a crisis, a major crisis - so many times for our kids it takes so long to diagnose what is wrong ... the more complicated they are the longer it takes to figure out what is happening to their body this time, and that is really, really stressful when you go for months wondering what is wrong, what is happening, what do we do, and who would we contact now. Should we bug another doctor for another test or do we wait... I find those times are really stressful, a change in medical status, and there are so many for our kids that those times are very consuming, it is like you have this mystery puzzle thing and you are trying to put it together and figure out what is wrong with them and it often takes so long to figure it out... and when they are in hospital of course you are never at home and everything falls apart, so many kids spend so long in hospital that you have to move to * (city with tertiary pediatric care centre) and stay for

several weeks and then you come home and then you go back and you go home and then go back and then you finally bring them home.

One couple described the impact on their family unit as a result of the re-hospitalization of their child who had progressive renal failure:

F: ...I went through a real hard time when A was started on peritoneal dialysis. (We were told) each week we would be going home shortly (chuckles) and then something else would happen...we spent nine weeks in * (tertiary care hospital)...I remember breaking down one day, it just whipped me.

M: She was in the hospital nine weeks and we would be on the phone everyday, the boys (child's siblings) were trying to cope and Dad was trying to be mom and dad, and be strong so that he wouldn't upset me on the phone and I didn't upset him on the phone.

F: M (mother) and I are one, and when we are separated and part of one of us is there and part is here, we have that desire to be together. We look to each other for strength...But employment pressures say that I have to be here; financially I have to be here in order to keep up. It would be nice if we were able to just cut that portion of time out and say well you don't have to be financially responsible for anything, go over and be with M and take the boys with you. But that is not possible. That is not reality...

Another participant discussed the emotional distress involved in the re-hospitalization of her son and its association with a progressive deterioration of his condition:

M: (with a recent hospitalization) It was really upsetting. I guess more stuff just came home to me. I try to think that he is not as touch and go a thing as it is...it really came home what a big deal it is again (the child's condition). It was just scary all over again - his whole existence...like to my mind we are going downhill. we went from partial eating to ngs (nasogastric tube feeds) to gastrostomy, from gastrostomy to J (jejunostomy) tubes. Excuse me, but we are not going in the right direction, its not a good feeling...

The preceding section has explored the vulnerability associated with the child's condition and its relationship to the dynamics of parental caregiving. The following section will examine the unpredictable nature of the child's condition with illustrations

from participant interviews.

Unpredictability.

Unpredictability was viewed as the second element characterizing the fragile nature of the child's health condition. Unpredictability was described as "a lack of a predictable map" as to the trajectory of the child's condition and the resultant nature of caregiving demands.

The unpredictable nature of the child's condition was often related to the unique and rare nature of the child's condition which made it very difficult to anticipate with any certainty the child's future prognosis or capabilities. For example, one child had a congenital syndrome that was reportedly so rare that only three other children in the world had been diagnosed with the same condition. Another child had a syndrome that had only been reported eight times in the medical literature. Parents described a great deal of frustration as a result of the unpredictable nature of their child's condition. One mother, in a frustrated tone of voice, discussed the uniqueness and unpredictability associated with her son's condition in the following statement:

M: In A's case you can't put cerebral palsy, you can't put anything in that little blank as to his condition because we don't have a nice tidy little summing up thing...We don't know with any certainty what the future holds...

Parents described how the unpredictable nature of the child's condition contributed to their feelings of uncertainty regarding the child's care and future well-being. One participant described his frustration with his daughter's rare condition, the uncertainty associated with how to help her, and the feeling of running out of options:

F: Sometimes it seems like such a waste of time, we don't solve anything, explaining the whole thing to one physician after another, its kind of accepted now, maybe a prayer will work, we tried a faith healer, tried acupuncture, she has tried all of the other alternate holistic medicines, I just trust in God or some faith or something, the guardian angel up there will fix her up... so my belief systems have been shot...

Finally, another mother described her feelings of uncertainty about her son's condition and her fears surrounding his progressive deterioration:

M: I don't know what kind of chances my child has, what his prognosis really is. My biggest fear is that he might die...I don't know. I know we are going downhill (re: A's health status), but I don't think forever...

The unpredictable nature of the child's condition was characterized by parents' feelings of "not knowing" how the future would unfold or when another critical event would arise. The unpredictable nature of ongoing critical events was directly related to the vulnerability associated with the child's condition. For example, the parents of a child with multiple potentially fatal allergies described their feelings of "never knowing" when the child would develop a sensitivity to a new food product which could potentially result in an anaphylactic crisis. That is, the inherently vulnerable nature of the child's condition increased the risk of the occurrence of an unpredicted critical event. Similarly, the mother of a child who was dependent on a jejunostomy tube for nutrition described "never knowing" when the feeding tube might become dislodged - resulting in an emergency trip to a distant pediatric tertiary care centre. This mother provided the following example relating the constant uncertainty she faced in managing her child's condition:

M: You have got to pray that there are no emergencies and that the tube doesn't come whipping out. Just travelling and stuff, or if the tube comes out before Christmas and we get stuck at * (tertiary care hospital) over Christmas

- there is a very strong possibility that that might happen. Its (the tube) tried to come out something like nine times already...*its kind of hanging over my head*, (emphasis added) and its hanging over A's too...he is really worried...

Participants used phrases like "hanging over my head", "never knowing when something bad will happen", and "its constantly in the back of my mind that something could happen" to describe their feelings of anxiety and uncertainty surrounding the unpredictable nature of ongoing critical events. When a critical event did occur, a state of imbalance existed in which the nature of caregiving demands exceeded the parents' resources for providing care. This resulted in parents seeking additional support from health care providers and others to return the relationship between the nature of caregiving demands and the nature of parental caregiving to a state of balance.

The nature of caregiving demands was largely influenced by the inherently "fragile" nature of the child's condition. Given the fragility associated with the child's condition, the child needed to be monitored for any changes in his/her condition or for possible threats to his/her well-being. For example, the parents of a child who was dependent on a tracheostomy explained that they "could never relax" and described being "hypervigilant" in assessing for objects in the child's environment which could occlude the child's airway. Another mother described how she closely monitored her son's actions when he was around water to ensure that no water entered the child's tracheostomy which could potentially result in an airway obstruction. This was especially important since both of these children were preschoolers and could not be responsible for monitoring their own safety or health

care needs.

The need for constant monitoring was the most frequently discussed care demand resulting from the fragility of the child's condition. Many of the parents discussed the chronic sleep deprivation they experienced as a result of the twenty-four hour a day monitoring that their child required. Although all of the parents interviewed did receive some degree of nursing respite support, often this was not perceived as sufficient to provide them with adequate periods of rest or recuperation. Moreover, parents described feeling shouldered with a great deal of responsibility since the child's health and well-being required constant supervision. One mother explained:

M: I don't like doing nights, eventually my nights (nursing respite support) will be backed off, and so when you don't have nursing staff at night then what happens - I have to do it myself. I have to get up and suction and I don't have a problem doing that, I have a problem hearing him ... and if he is having trouble I could miss it and I don't think I would be able to live with myself if something happened to him and it was my fault.

R: So how do you try and manage nights then?

M: I put the monitor on, I lay on the couch, I turn the monitor on as loud as I can....And I try not to go to sleep. Sometimes I nod off but I'm consciously thinking don't go to sleep, you have to hear him. So I'm fighting with myself the whole night to just hear him and try to concentrate. I don't really sleep when I have to do a night, I'm scared to...You know I would feel real bad if he needed me and I wasn't there.

As noted in the above statement, several parents described feelings of anxiety in relation to their understanding that the number of hours of nursing respite support received would gradually diminish following the child's initial discharge from hospital to home-based care.

Almost all of the participants described the sleep deprivation they experienced

as a result of their child's fragile health status and resultant caregiving demands. One father noted:

F: Some nights I wasn't sure if I had slept at all....I remember looking at my watch and A was crying at three o'clock and you go back to bed at four fifteen and you are up again...sometimes you wake up and you say, "I'm not sure if I slept"...

Another participant discussed the physical exhaustion she experienced which was associated with her child's fragile condition and *constant* care requirements.

M: I never have a night off. The nurse comes at eleven o'clock at night and leaves at seven in the morning. Well, am I supposed to go partying then? (laughs) ...People don't understand. They see you all the time and they say "you look really tired". I say, "Yes, I am exhausted" ...people complain about looking after a normal kid that you really don't have to do that much for, you can go to sleep at night. Even when the nurses are around, when A gets really ill, I have to get up and help them, *I don't have the peace to sleep well* (emphasis added). I'm always listening for him choking, or hearing alarms going off...

The preceding sections have examined the characteristics of vulnerability and unpredictability which comprise the nature of the fragility associated with the child's condition. In addition, the resulting impact on the nature of caregiving demands as a result of the fragile nature of the child's condition was explored with examples from participants' descriptions of their experience. The following section will explore the impact of the complexity of the child's care requirements on the nature of caregiving demands and the nature of parental caregiving.

The Complexity of the Child's Care Requirements

The complexity of the child's care requirements was identified as a key factor shaping the nature of caregiving demands. Parents described the complexity of caring for their child in relation to the child's direct care needs and the coordination of the

child's care and care requirements.

Parents described the nature of the child's care requirements as "difficult", "complicated", and "complex". Several caregiving demands were primarily related to the complex nature of the child's direct or indirect care needs. Parents discussed the immense physical demands of caring for the child at home including lifting, toileting, suctioning, bathing, and feeding. For example, one couple discussed how physically taxing it was to care for their daughter with multiple disabilities at home.

M: Caring for A is very physically demanding, she weighs a ton...even now we help her in and out of the bathtub, physically we support her all of the time.

F: ...I think my wife is most likely the one that takes so little credit for all that she has done with A. She has worn out two washing machines with A...there have been maybe two months in A's whole life that she hasn't had a wet bed...

M: ...Considering that she didn't walk until she was six, there was a lot of carrying, and even after she was walking she was not very sturdy on her feet.

Another participant described the physically demanding care requirements of her eighteen year old daughter who had multiple disabilities:

M: Now it is very difficult to do the things she used to do, I mean she is as big as me and she is incontinent...Now we tend to keep any excursions fairly short, about 3 or 4 hours, so that she doesn't need to be changed when she is out because you need too many people to do it or it is so difficult to do it yourself, I mean I could do it but...

Parents also discussed the time-consuming nature of the child's care using such words as "constant", "continuous", and "ongoing" to describe the nature of care their child required. For example, one participant recounted how her child required bolus enteral tube feeds, suctioning, and medication treatments every two to three hours, twenty-four hours a day. Another participant described her feelings of resentment

surrounding the complex and time-consuming nature of her child's care requirements:

M: I am so angry. I resent all the little things that I am denied, the ease with which other people plan their lives is denied to me. Everything takes such planning, the simplest thing. And if you are out with him (A), and you have got to give him his meds and its on a day that he is not feeling good and you go into the washroom, you have to use syringes and put things in tubes - I just find I am doing a lot more, its too hard a thing to take the bag of medicine, to take the wheelchair, to take him, and then my purse, and get dropped off at a mall and just the basic logistics - I don't get in half the stores, he doesn't fit, just the whole thing.... I really resent all of the care I have to do and all of the planning and all of the going to the hospital with him and everything. Constantly thinking about stuff, that is the thing I hate...I have always got to remember meds, remember to do the meds, remember to do the dressing changes, remember to reorder supplies, these are not normal parts of life...

The child's complex care requirements commonly impacted on the degree of spontaneity that the parents had in caring for their child, in meeting their own needs, and in meeting the needs of other family members. If the child's condition was becoming more complex, as was the case for many of the participants, the loss of spontaneity was often even more pronounced and often resulted in feelings of frustration for family members. For example, one mother described her frustration and "rage" with the increasing complexity of her daughter's care as the child aged.

M: ...When you first have to do something new it is very, very hard, such as even bringing along the new pieces of equipment, like when A had to start being suctioned, it was like one more stupid piece of equipment that I had to carry with me...Are you nuts, look at the size of her wheelchair...and when she started having to have chest physio every day and it can't be missed, and then going onto her mask and nebulizer stuff and I thought how can I ever fit this in...I mean you *rage* (emphasis added) against the new stuff, the new difficult thing your child needs as she regresses or gets worse...

Another mother described the loss of spontaneity and increasing complexity of caregiving associated with her child growing "bigger" and her condition becoming more complicated.

M: One of the biggest challenges is having to think about all of the things that you have to do for her before you can go out and do things. Families are generally pretty spontaneous with able bodied kids - you can pick up and go and do things, but with A over the years *its become more and more complicated to simply do whatever most other families do* (emphasis added)... I think the biggest challenge is doing it and doing it with all the equipment A needs and just getting it done. They need so much planning, I think that has made it harder....Parents have to know that if something is really difficult when their son or daughter is a child, it is not going to get easier just because they are an adult...actually it gets harder...its not that she lost a skill, its that she got bigger and its easier to do a lot of these things when people are little.

Another component of the complex nature of caregiving was coordinating all of the services and equipment which the child required. Participants compared the amount of time and effort it took to coordinate all of the services that their child required to that of "working a full time job". Parents described the complex and time-consuming process of "hiring", "training", and occasional "firing" of alternate caregivers for their child. One participant provided the following anecdote:

M: I had to get them to agree, I had to get funding, I had to hire nurses, I had to interview them, had to train them, and then there is the everyday stuff - do it this way, not this way - you know training the nurses is an ongoing thing. It just doesn't quit after the first time you train them, they have to get used to him, he has to get used to them. Some he likes, some he doesn't so I had to fire one of them you know... you have an interview with the nurse, you think they are great, they start working, you can't deal with them. They don't learn fast enough or they don't do it the way you are teaching them or you have a personality conflict or something, I mean that is life...sometimes it works out and sometimes it doesn't and when it doesn't you have got to start all over again and start interviewing and retraining and its just a lot of work, it doesn't stop, its always ongoing.

Another mother described the time-consuming role of "coordinator" of her child's care.

M: Most of us (parents of children with complex health care needs) see ourselves as coordinators... We constantly organize services and are meeting with people constantly to tell them what our kid's needs are and to get things

done in a way that suits us. It becomes part of your life - learning how to get along with all of these different groups and agencies....

Finally, another mother compared the complex and time-consuming nature of coordinating her child's care to "running a full-time business":

M: I mean even now that A is three years old I deal with that stuff every day - I am on the phone, I have got three different social workers, and there is nursing respite, and the nursing company, and * Hospital (pediatric tertiary care hospital), and all the doctors. It is just not simple, *it is like running a full-time business* (emphasis added) is what it is like...

The characteristics of the complexity of the child's care requirements have been examined including a specific examination of the complex nature of the child's direct care needs and the coordination of care services and equipment. Clearly, the complexity of the child's care requirements is a key factor in the nature of caregiving demands, and a major influence in determining the balance between the nature of caregiving demands and the nature of parental caregiving. The following section will examine the influence of the child's developmental needs on the dynamics of parental caregiving.

The Child's Developmental Needs

The third and final component of the nature of caregiving demands was the nature of the child's developmental needs. Parents described the immense amount of energy and time they invested in responding to the child's developmental needs. Many of the participants referred to this as "ensuring" or "promoting" the child's "quality of life". One mother provided the following description of what she views as "quality of life" for her child who was born with multiple congenital anomalies including a malformation of his airway requiring a tracheostomy:

M: I see quality of life for A as being going out to play, playing on the swings, riding a bike, going to the beach, going fishing, going on a boat, driving the boat, driving the car.... I mean when you have a special needs kid you have so many people telling you all the things you can't do, I mean basically they want you to sit in the house and do nothing, well you can't do that, you will go crazy - so you just try to be normal.

As noted in the above participant's description, parents commonly utilized normalizing strategies to promote the child's quality of life as evidenced by statements such as "just try to be normal" and "treat him like any other little boy". Another participant, in reference to encouraging her son's quality of life, provided the following advice to parents in a similar situation:

M: Treat him like a normal child, like a perfectly typical kid whose got no trach (tracheostomy) or no G (gastrostomy) tube or whatever the problem seems to be... Treat him as normally as you can, there is always going to be exceptions, but don't pussyfoot around them, don't spoil them.

Another participant emphasized the importance of being innovative and creative in fostering her child's participation in "normal" activities while continuing to ensure his physical safety.

M: Even now, A isn't supposed to go to the beach. He is not supposed to play in the water, you have to really wrap all these things around his trach when he goes to the beach because you don't want to get sand in there. Well, you work around all of that stuff - A has ridden a motorcycle, he has been in the boat, he has been on the beach, he has been in the water. I let him play in the water, he is laid down in the tub with water in it. *I just let him do anything he wants, we just do it carefully* (emphasis added)... because he is a normal kid, he wants to do things, he wants to experiment. I mean, he has got water in his trach and he coughs and coughs and coughs but then he never does it again, he knows, he polices himself a bit more now... So I believe in quality of life as well, so I mean you can't just put him in a glass house.

In contrast to some parents "normalizing" strategies, other parents fostered their child's developmental growth by encouraging their child to "experience

happiness in whatever she [or he] can do". One participant provided some insight into this perspective:

M: We often look at our kids when they are little as helping them to get better when they are the way they are. They don't see themselves as disabled, they see themselves the way they are and accept that as their body...And then we work at trying to correct their body and what does this do to their self-image? I think A has been raised primarily by able-bodied people and she does get frustrated and she is aware of her disability... Somebody once thought that she should not be with normal kids because she would get jealous and be upset because they could run and play and she couldn't do that. Kids don't feel like that...She may want to do those things but she has learned to do things in other ways and *experience happiness in what she does* (emphasis added)...

Parents described trying to "juggle" or "balance" the caregiving demands arising from the child's developmental needs with those associated with the fragility of the child's condition, the complexity of the child's care requirements, and the competing demands of family life. Promoting the child's developmental needs was viewed as a priority for parents, often taking precedence over the competing demands of family life. For example, one mother explained how housework took a back seat to playing with her preschool-aged child who required constant supervision due to his dependence on a tracheostomy.

M: For me, (quality of life) is just being as normal as he can (be), and that is why I had the home-maker in because its hard for me to stay on top of the housework and let him be normal because a normal little boy, a boy without a trach (tracheostomy), would be able to go outside and play in the backyard. I have to be at least within hearing of him so I have to go outside with him, I can't just send him outside. And he loves to go outside and play so in the end its more important for him to be normal and go outside and play than it is to have a clean house... That is what his quality of life for me is: To treat him just like any other kid, any other little boy... letting him go outside, play. I just have to be there, I have to be able to hear him or see him...

During an acute exacerbation of the child's condition, the parents discussed

how the child's developmental needs tended to take on a role of lesser importance to the caregiving demands related to the child's fragile condition and complexity of care requirements. This was clearly evidenced in the initial treatment and hospitalization of the child in which the focus of care was on sustaining the child's life and preventing further complications of the child's condition. As the child's condition improved, further emphasis was placed on fostering the child's developmental needs. This pattern tended to repeat itself with each new exacerbation of the child's condition.

A large proportion of the caregiving demands arising from the child's developmental needs involved fostering the child's progression through major developmental transitions. There were several common developmental transitions which the participants discussed including: entering the educational system, transitions within the school system (e.g. elementary to junior high school, junior high to senior high school), and launching the child out of the family home. These events involved a change in the child's environment. For example, the transition from entirely home-based care to school-based care during the day.

Developmental transitions were a source of major upheaval for the family unit as the child and family had to seek out new forms of support and develop further coping strategies in order to cope with each new developmental transition. Although these developmental transitions also occur in the lives of children without disabilities, the nature of the child's medically-fragile condition accentuated the vulnerability associated with these events. A state of imbalance could result if the caregiving

demands associated with the developmental transition, in addition to the competing caregiving demands, exceeded the parents' resources for providing care. If this occurred, the developmental transition would be viewed as a critical event requiring external support to return the relationship between the nature of caregiving demands and the nature of parental caregiving to a state of balance.

Many parents described the benefits of anticipating and preparing for future developmental transitions in order to decrease the distress and uncertainty associated with the transition. In particular, participants discussed the planning and preparation involved in the transition of the child into the educational system. This transition generally started at the preschool or kindergarten level. Preparing for this transition was especially difficult if it was the first time a child with a medically-fragile condition had entered the school system in the family's community. If this was the case, parents had to perform the difficult task of breaking new ground. One mother provided a summary of her experience of negotiating her child's entrance into preschool:

M: Since I moved here I have been working on it (since the child was two years old)...In order to go to preschool with a level three kid, you need to have an RN ... Well, who is going to pay for an RN for preschool, right, so that was the first dilemma. How is he going to go to preschool without having mom hang around? So you start by writing a lot of letters and getting other people to advocate for you, infant development, and speech, and those kind of people, you get them to advocate for you and you tell them what you are doing and you tell them what you are trying to get and ask them to advocate for you.

As noted, in the above participant's statement, a large part of anticipating and preparing for future developmental transitions was gaining the support of others to

advocate on behalf of the child. Another participant provided a similar example of how she networked with key individuals in a new community in order to gain support for integrating her child into a regular school system:

M: When we move, we make a point of going out and meeting new people and introducing ourselves, especially through parent groups. I find out who the movers and shakers are in the area that are interested in the integration field. I had hundreds of names before we moved...you have to make your contacts and I did the same thing locally, I found parents who thought the same way I did and we went to the parent group and found out who wants their child integrated...you build a network of people to help you cope.

One mother, whose daughter was eighteen years old, was anticipating the developmental phase of launching the child out of the family home. This process included exploring different alternatives of how the child could live on her own when she turned eighteen. The mother had been anticipating this major event since the child was thirteen and was already exploring possible alternatives. The mother discussed her experience with this process:

M: I guess another turning point has been in the last year in terms of trying to plan for when she leaves home... And that is very difficult, in terms of trying to find a way for her to live that would give her independence and not succumb to the thought that nobody can look after her but a nurse and that she probably will have to go into an institution and trying to fight that and try to find a way for her to live in the community and get the support that she needs in the community... I'm going to a conference that does planning for the future for children with disabilities...and we will be discussing how to plan for her future and how we can include her in the decision making.

Preparing in advance for future critical events was beneficial to parents and the child. Parents discussed how planning for major transitions resulted in a smoother transition which decreased the distress and uncertainty associated with the actual event. One mother provided the following example:

M: I think that the more that we do this (plan for future transitions such as "transition into high school and out of high school") the easier it becomes because it is with the knowledge that they (the school system) know your kid is coming and that they accept your child and that they are going to help. Just the knowledge that they are going to work with you and that they are not going to be judgmental and will accept the kids into the school. I think that makes such a big difference.

The final determinant of the nature of caregiving demands, the child's developmental needs, has been presented and described with illustrations from participants' experiences. Specifically, the utilization of "normalizing" strategies to promote the child's developmental growth has been examined. Moreover, the relationship between the child's developmental needs, the fragility of the child's condition, and the complexity of the child's care requirements has been put forth. Finally, the caregiving demands related to the progression of the child through major developmental transitions has been explored. The following section will present the nature of parental caregiving which acts to counterbalance the nature of caregiving demands.

The Nature of Parental Caregiving

The preceding portion of the chapter provided a detailed description of the nature of the child's caregiving demands. The following section will explore the nature of parental caregiving which was conceptualized as counterbalancing the nature of the child's caregiving demands (Refer to Figure 2, page 81). Participants' descriptions indicated that the nature of parental caregiving was influenced by three key factors: the nature of family life, the nature of support received from others, and

the nature of parental coping approaches. Each of these components and their relationship to each other and to the nature of the child's caregiving demands will now be presented, described, and illustrated with the participants' descriptions of their experience.

The Nature of Family Life

The nature of the parental caregiving response was largely influenced by the nature of family life. The participants in this study described their family life by contrasting it to what they considered "normal" family life to be like. Parents discussed the impact of caring for the child on the family unit in their description of their different roles, responsibilities, and relationships. Of particular note was that all of the women in this study viewed themselves as their child's primary caregiver. As a result, their roles, responsibilities, and relationships were often significantly more affected than their husbands or that of other family members. In addition, parents put forth the metaphor of "Living in a Fishbowl" to describe the nature of their family life. This metaphor describes the constant scrutiny, isolation, and lack of support which were significant elements of the participants' experience of family life.

Women as primary caregivers

The women in this study viewed themselves as their children's primary caregiver. As a result, their roles, responsibilities, and relationships were often significantly more affected than their husbands or that of other family members. This was particularly true for those women whose children were toddlers or preschoolers and therefore had not yet entered the school system. For these women, the role of

caregiver was often all-encompassing as the nature of the child's condition insisted on constant supervision and care. As a result, the woman's previous roles and identities were often eclipsed by the caregiver role.

One mother compared the differences between her and her husband regarding the caregiving role.

M: (The differences in our experiences) are huge, even to this day. I didn't know until maybe a year ago - A had been home for a year, but F (child's father/participant's husband) wouldn't bathe him because it scared him. I thought he just didn't want to do that, so I never knew that until he told me. It wasn't in my frame of reference to be scared of it because I was there from day one. I was there and I was bathing him and I was suctioning him and I was learning his trach (tracheostomy) ties, not that I wasn't scared learning those new things ...but because I was there it just came to me easier than it did to F, because F was lucky if he could come out every second week for a day....He still doesn't bathe him, but now I know why so its not such a big deal to me. There are (other) things like doing A's trach (tracheostomy) ties, I do them by myself now most of the time, ninety per cent of the time...

The above statement provides evidence for participants' assertions that health care providers assumed that the mother would be the primary caregiver, was "trained" to be the primary caregiver, and subsequently became the primary caregiver. This scenario was commonly described by the participants interviewed.

Although the Nursing Respite Program (NRP) provides some intermittent relief from caregiving, it was not extensive enough to allow the primary caregivers, generally mothers, of preschool age children to resume their previous roles or careers. One mother, whose son was two and a half years old, highlighted how her son's care took precedence over other aspects of both her personal and family life.

M: When I am at home I am tied to him, I just can't let him go out and play like other kids, I have to be there with him, I have to at least be within hearing distance...and he is two and a half years old - he wants to go ride his

bike and play with the kids and have fun and I let him, so needless to say the housework doesn't get done...

The women in the study whose children attended school on a regular basis appeared to have more freedom to pursue other roles or interests. One mother, whose son had recently started preschool, discussed the increased freedom she had to pursue other activities since her child started preschool.

M: ... I also started taking some courses. I am also starting to meet people. I am trying to get out, and now that A is in preschool twice a week I try to use that time, I go to school exactly the same time he does...I find these activities help with self-esteem...

The same mother discussed how nursing respite allowed her to take a break from her "nursing" role and helped her to fulfill her "mother" role with her son:

M: It is not to be away from him...sometimes I just want to be a mom, I don't want to be a nurse...I want to do the mom stuff, not the nursing stuff, and its nice to just have the nurse do the nursing stuff and I'll be the mom and so its not that I want to be away from him, its that I want to be away from doing the medical stuff.

One mother gave up her career in order to care for her son. Although the child was eight years old and did attend school when he was well enough, he was often absent from school due to extended hospitalizations for exacerbations of his condition. The loss of income associated with the mother being unable to pursue her previous career had a great impact on the family when added to the other financial costs on the family unit associated with caring for a child with a medically-fragile condition. The couple explained:

M: ...I had to give up a career, sure we are lucky, we finally got on the At Home Program, we were rejected twice...we will never own a home, we will never have savings, we will never have anything because there is a lot of stuff not covered, in fact they just changed it so more of his meds are not

covered...we have to pick up the cost...

F: We take loans out, we will just have enough left to pay off the loans and that will be it.

M: Well we never get them paid off, eventually we get them down, another emergency comes up...

The same mother vividly described her resentment over the loss of her personal identity that occurred as a result of becoming her son's primary caregiver.

M: I feel like I'm divided into a lot of compartments and the one that is me (laughs) that door is locked and chained and bolted and God knows when I will get a chance to be that again, and that is the thing I resent.

The remaining three mothers had children who regularly attended school. These mothers described their increased freedom to pursue other activities and to develop new roles or relationships. One mother resumed a full-time career, another worked part-time, and the other resumed her involvement with several volunteer community services.

Different roles, responsibilities, and relationships.

Analysis of participant interviews revealed that parents described their family life in contrast to a "norm". Most often, parents contrasted their current lifestyle with their family life prior to becoming the primary caregiver of a child with a medically-fragile condition. All of the participants discussed how family and individual roles, relationships, and responsibilities had changed as a result of the home-based care of their child. As previously described, the parents' responsibilities changed dramatically as they took on the role of primary caregivers for their child at home. Parents partially attributed the differences in roles and relationships to the overwhelming nature of the child's caregiving demands and subsequent lack of time

and freedom to pursue other roles or relationships. Parents described the child's caregiving demands as often taking precedence over the competing demands of individual and family life. Time and energy were often absorbed in trying to respond to the child's caregiving demands resulting in decreased resources to respond to the competing demands of family life.

Parents also described the differences in their lifestyle and relationships as a result of their restricted ability to participate in spontaneous activities with others due to the difficulties they faced in trying to arrange alternative caregiving services without advanced planning and preparation. Parents discussed "not having a lot of time or freedom", not being able to "do anything spontaneously", and "needing to know a month in advance" in order to plan an event with others. In particular, parents described a lack of time and energy to foster one's individual or marital well-being. One mother, whose child's condition included severe asthma, allergies, and eczema provided the following example of the all-encompassing nature of her child's caregiving demands:

M: You don't have a lot of time or freedom. When I first met him (her husband) I used to run six or seven miles a day. Now I don't have the time for much recreation. Between shopping and extra meal preparation and trying to make all those additional things that she needs to take to school, plus cleaning, the medications, all of the trips to the physicians, and for a long time she was given light therapy which is a daily business, right now she is going for allergy shots and that is twice a week, and then there is the additional time that you have to sit, holding her so that she won't scratch as much....

Another mother described her frustration with the lack of spontaneity and freedom to spend time alone with her husband due to the nature of the child's caregiving demands and the perceived inflexible nature of available nursing respite services.

M: One of the things that is very hard is booking nurses. You are expected to book a month in advance. I mean nobody lives their life a month in advance. If someone calls and asks you out for dinner they don't call a month in advance... you can't do anything spontaneously and I think that is very, very difficult... For instance, I wanted to go hiking, and I had booked somebody, it is really hard to know a month in advance when its going to be nice weather to go hiking... If my husband and I plan to do something and book a nurse hoping that we are able to do it, and then if you can't, you are stuck in the house all day with another person...

Participants also described the obstacles they encountered in their ongoing relationships with others which they largely attributed to the nature of their child's caregiving demands. Parents attributed the difficulties they experienced in maintaining and fostering previous relationships to several factors including a lack of time and energy due to the overwhelming nature of the child's caregiving demands, and a perception that they shared little in common with others due to the all-encompassing nature of the child's care. Parents discussed living in "an entirely different world" and "forgetting what normal things are". One mother provided the following insight into this experience:

M: Its just a different, entirely different world that you live in all of the time, I forget what normal things are...my daughter said her friend's mom thought that maybe I would like to go to bingo one night, the four of us could go, and I said "Oh, I would love to but you know we are going to plan it way in advance because I have to get a nurse or someone in to babysit, its not like I can do something that simple, and that is what people don't understand. They can decide the night before and I can't, I'm sorry....you just don't have that option.

Another participant discussed how a lack of time, physical exhaustion, and the other "differences" between her life and the lives of other individuals contributed to her feelings of isolation and her lack of social relationships.

M: I do feel really isolated, I normally have been really involved at his

school, I did a lot of volunteer work and stuff but I haven't this time, I just find I am so tired all of the time, and I don't know - they live such different lives from me, I just don't have anything in common with them. I can't talk about my life to other people, I know it makes them uncomfortable, or you can pretend it doesn't exist which is something that I find makes me uncomfortable, or just not go places - its hard...

Participants discussed the increased tension on their marital relationship resulting from the strain of the child's caregiving demands. Participants pointed to the lack of available time and energy to nurture the marital relationship. Several participants discussed the need for extended periods away from the child's caregiving demands in order to be able to rejuvenate their personal and marital well-being. One mother provided the following insight:

M: You can't expect families to stay together if they don't get to go away together... If parents want to go away for the weekend, they would have to not have nursing (respite) at night in order to go away. That is, not have nurses at night for three to four nights before they went away...and then be chronically sleep deprived for the whole time they are away - they would sleep through the weekend because they haven't been able to sleep for three or four days...This is ludicrous, this is not supporting families...

Another participant discussed the differences in her marital relationship which she attributed, in part, to the immense physical and emotional strain of the child's caregiving demands. The participant pointed out that the increased tension resulting from marital discord added to the emotional strain of responding to the child's caregiving demands.

M: Our marriage, we have separate bedrooms, we spend no time together... There is very little left, well there is nothing left, and that is another thing that makes your life hell.

Finally, participants also discussed the impact of the child's caregiving demands on the child's siblings. One mother noted:

M: I think that our boys (the child's siblings) were the ones in the end that possibly didn't get the attention that they maybe deserved or that as parents we should have given them. I think that there are some failings in that area of my life and that if I were able to turn my clock back to day one that I would change, but I don't know a parent that wouldn't do that.

The participant went on to provide an example:

M: Something that we really struggled with was when A was a baby in the hospital for six months - you want to be here with the boys, you want to be there with A, and there is no way you can do it. I mean you have to make the choice but you just wish you didn't.

The preceding sections have described the different roles, relationships, and responsibilities which the participants delineated in relation to their family life, including a specific examination of the impact on the mother as primary caregiver of the child. The parents' descriptions of their changing roles, relationships, and responsibilities point out the influence these elements have on the nature of family life and consequently on their ability to respond to the child's caregiving demands. Clearly, the nature of family life is a key determinant of the nature of parental caregiving. If the nature of family life is such that it impedes the ability of the parents to respond to the child's caregiving demands the balance between caregiving demands and parental caregiving is perceived as moving into a state of imbalance requiring additional support before being able to return to a state of balance. The next section will explore the participants' experience of "living in a fishbowl" which was identified as a key factor in the nature of family life.

Living in a fishbowl.

Four of the six families described their experience as similar to "living in a fishbowl" or "living in a glass house". This analogy was confirmed by the other two

sets of parents as being representative of their experience. Parents described what they meant by "living in a fishbowl" as including two main elements: a) constant scrutiny, and b) isolation and lack of support. In order to provide a clear description of the participants' experience, each of these characteristics will be presented separately.

The first characteristic of the theme of Living in a Fishbowl, constant scrutiny, is related to the entrance of health care providers and others into every element of the family's personal life, and the perception that the family is constantly being examined or scrutinized by health care providers and others. Participants discussed feeling as though their personal lives were viewed as an "open book" for professionals to scrutinize. Other participants referred to the large number of health care providers involved in their child's care and the constant turnover of these care providers. The child's complex health care needs necessitated family boundaries to become highly permeable in order for multiple professionals to become involved in the child's daily care. However, the entrance of numerous health care providers such as nurses, occupational therapists, physical therapists, and social workers into the family's life significantly disrupted normal family routines and rituals, altered the family's identity, and, at times, compromised the integrity of the family unit. If family functioning became significantly impaired, it altered the ability of the parents to respond to the child's caregiving demands.

Like fish in a glass bowl, participants discussed feeling like their family was under constant scrutiny by others, particularly health care providers. One mother

clearly described the constant scrutiny she felt when her daughter was hospitalized with an exacerbation of her condition:

M: You never realize until you are in this situation that you are in a fishbowl...So every action that you do from talking to the person that is doing your admission, and each hospital admission that you get, just sitting with your feet up on the chair because you are tired, is examined and looked at...people are standing and watching your behaviours all of the time... and if you are rushed or hurried and you say to your child, "Sit down I want to do your hair because I have to go to work!", but if you say it like that its a "problem" ...that then becomes abnormal behaviour when you are in this fishbowl because every action is being scrutinized so critically...I think that is pretty dangerous.

The above anecdote describes the constant scrutiny by health care professionals that many participants discussed. For most participants the perceived scrutiny by health care providers not only occurred in the hospital but in their own homes as well. Moreover, the preceding participant's statement outlines her perception of how such careful scrutiny of the family, taken out of the context of the family's experience, can lead to erroneous assumptions about the family or specific family members.

All of the participants referred to the disruptiveness to the functioning of the family unit caused by in-home nursing respite. One participant explained:

M: My husband can't stand the nurses being in the house, he hates them,...it is just an intrusion, an incredible intrusion into our home and he doesn't like it.

Another participant discussed the impact on her marital relationship of in-home nursing respite.

M: I think the hardest thing is having somebody in my home, its not easy...How do you make love with somebody in your house when there is someone else there?

Another mother commented similarly:

M: Even if my husband and I got along, which at the beginning it wasn't as bad as this, but you can forget about sex because you feel really stupid with someone (respite nurse) walking around the house all of the time....If you want to have a fight, you can't really because someone is there...

One mother provided the following description of the disruption to typical family routines as a result of having in-home nursing respite for her child.

M: It is really hard to have an argument when somebody else is in the house. I'm really glad that my kids are older because they fought a lot when they were little. I mean I would be devastated if I yelled at my kids with someone in the house, yet everybody yells at their kids. I yelled at my kids... God, if I had somebody else in my house I know that I would have died of guilt when they were little, even now I try not to clean before nurses come - that is really hard.

Another component contributing to a sense of constant scrutiny for participants was the visibility of the child's health condition and resultant care requirements. Five of the six groups of parents interviewed had a child with a visible health condition requiring specialized medical equipment or aids such as a tracheostomy, a wheelchair, or an enteral feeding tube. Many parents discussed feeling like they "could not blend in", or like they "stuck out like a sore thumb". The parents' perception that their child "stood out" in public places contributed to their sense of being constantly scrutinized. One participant provided a clear example:

M: You have no privacy. Everywhere you go, you are just walking down the street and you are having one of those days where you would really like not to be noticed. It is possible that you (points to researcher) could have that. But no, we stick out like a sore thumb and it is especially worse when he is sick...we can never just blend in...

Another mother provided a similar example:

M: You are just so different from everybody else who lives around you, people tend to stare at you all the time so you don't go to public things anymore, you never eat in a restaurant because you can't. He drinks and

starts choking and throws up or whatever...you just don't get to do things that other people take for granted and if you go anywhere people treat you as if you are doing something wrong, you are taking a sick child out in public...It is just at every stage of life, it literally affects everything, even filling prescriptions at the drug store for him (laughs), I mean other people are getting a bottle and I walk out with a case (laughter) ...you can't go anywhere and blend in, that is the thing I hate the most.

The "constant scrutiny" described by participants interfered with the normal functioning of the family unit and increased the strain associated with responding to the child's caregiving demands. The second component of what was described as "Living in a Fishbowl", isolation and lack of support, had a similar effect on the dynamics of parental caregiving.

Parents described their feelings of isolation and a perceived lack of support as comprising the second component of the living in a fishbowl phenomenon.

Participants discussed feeling isolated from others as a result of several factors including: a lack of support by family or friends who did not understand the family's experience; the uniqueness of the child's condition and/or the family's experience; the lack of time or spontaneity to foster old relationships or build new ones; and stigma, others not wanting to be associated with the child or family due to the child's disfigurement or disability. These factors contributed to a lack of social integration; parents expressed feelings of being isolated in "their fishbowl".

One participant, a single parent raising her child, vividly described her feelings of isolation from family and friends and her perception of "being alone" in caring for her son:

M: Well my family has not been very helpful at all because they are all two thousand miles away. And my mom, she first came out when A was in the

hospital and then for a week after I came home with A. But then she was really freaked out too, she didn't have any concept of what this medical stuff was going to be like and him being home and she's watching me do this and she is like "Oh my God"....She couldn't handle it. I even wanted to write a will to have somebody look after my kids if I passed away - nobody wants to do it. I've asked everybody in my family. I have given them time to think about it - they all call back and say, "Forget it, I don't want your life, it is so crazy"...

R: That must have been difficult for you to hear.

M: Well yeah, I was mad at them for a long time. I even told my brother I was mad at him because he didn't even phone me and just say "Are you doing okay?", "Are things okay?" And people don't know what to say, they stay away because it is easier...And you find out who your friends are real fast...

Several participants related their feelings of isolation to the uniqueness of their child's condition and the lack of understanding others had of their experience.

M: I wish there was some kind of support group for people that don't fit into other support groups (laughs). I mean that is what is needed. Why does everything have to be divided into little categories. Why can only CP (Cerebral Palsy) kids and parents go to this group and only this type of kids to this group, it leaves an awful lot of us out there all on our own, and our kids don't have to have similar illnesses to share a lot in common....We share the same isolation, we share the same kind of depression, the fact that you just don't know, like will this ever end, and money stuff, everything. I mean I would love to meet someone that I could just phone up and say I am having a really bad day today, I just want to talk...

Another participant vocalized similar frustrations:

M: I don't go to support groups because I don't fit in, if they are all Down's people (parents of children with Down's Syndrome), my son is so bright. If they are all kids that can't walk, well he can, he didn't use a wheelchair until just recently...there is no where for me. There should be. There has got to be more people like me whose kids are different, someone should try to get us together, we need each other.

Finally, another mother discussed her feelings of isolation in relation to others not understanding her family's experience, and a lack of time and energy to foster social relationships.

M: When I meet other people with kids that are always going to be sick, and we talk, you say its just so hard, you can't even talk to the grandparents or anything because they don't understand, I mean people don't understand why we can never do things on the weekend because one of us has to stay up at night and then the other one watches him in the mornings so that one can get a few hours sleep, so weekends for us are not the time to invite us anywhere to do anything, its when we don't have nursing (respite)...

Several participants discussed a lack of support from friends and family members who had previously been supportive. Participants attributed this to a variety of factors including others not knowing how to react, a lack of understanding by others of the family's experience, a lack of spontaneity to foster social relationships, and stigma - not wanting to be associated with the child due to disfigurement or disability. It is important to note that not all of the participants interviewed shared this experience to the same extent. One participant provided a vivid description of the degree of isolation her and her husband have experienced since their child was discharged home from hospital.

M: Like, if you (points to researcher) go home tonight and your husband says, John phoned, we are invited to their house for dinner tomorrow night, even if you have kids, it wouldn't be that big of a deal. Its a "no" (emphasis added) for me, I know. And there are not going to be any Johns, we have no friends, we have no-one. People didn't know how to handle it when A was born, they all wanted him to die, and when he didn't they didn't know what to do. There were no baby showers, there was no acknowledgement that he even existed. My grandparents, my father, he does not even see me - he said to put a pillow over his face - it would do him a service...what kind of a life does he have and that I have no right to keep having them (health care providers) do more to him. My in-laws come over maybe three times a year. We are to phone them if he is dying. I'm not to phone when he goes to the hospital, I'm not to phone when he is sick because it is too stressful for them, so there is no support there...and it has all changed since A has been born. Before that they were not my idea of a really close family, but they spent time together and we had dinner with them often and things like that.

The same mother provided further insight into her feelings of isolation:

M: You learn not to talk to other parents about it (the child's condition) because it scares them. The biggest thing that I find is that I am so isolated, I don't have anyone to phone up or have a coffee with or do anything with....the more time consuming A's care is, the more times I am away at the hospital for extended periods, you can't have normal friendships with people, and people quite often are afraid of him. They are afraid of the responsibilities surrounding him, like if he comes to my house and something happens, will he die at my house kind of thing, and you have to say no, the worst case scenario is his tube coming out, or he might throw up, or he could get diaphoretic and turn a funny colour and those things are simple to handle....

Finally, another participant discussed the sense of isolation resulting from a loss of spontaneity to do things with others and the amount of planning involved in arranging alternative care for their child.

M: You can't decide on the spur of the moment that we are going to go to a movie and call a baby-sitter because you can't leave basically without some supervision by someone with experience...everything we do has to be pre-thought about and pre-booked and there is not a lot of fun thinking well, I want to go to a movie in two weeks from now on a Friday night...or people will phone and say can you come for dinner tomorrow night and you go "Well, its Friday night, the nursing respite is not open, I can't book any hours on a Saturday, so no we can't come on a Saturday night".

The preceding section has discussed the metaphor of "living in a fishbowl" which parents utilized to partially describe the nature of their experience. The constant scrutiny, isolation, and lack of support described by participants clearly played a key role in determining the nature of family life, and consequently the ability of the parents to respond to the child's caregiving demands. The constant scrutiny experienced by family members disrupted family relationships and functioning as well as contributed to the emotional strain of caregiving demands. The perceived isolation and lack of support described by families contributed to a sense of social isolation, adding to the burden of caregiving. If parents are unable to counterbalance the

impact of these influences by cultivating supportive relationships and utilizing effective coping approaches, the nature of caregiving demands exceeds the parents' resources to provide care and results in a state of imbalance (that is, a critical event). The next section will explore the nature of support received by parents and its impact on the dynamics of parental caregiving.

The Nature of Support Received

Building supportive relationships with health care professionals and others was described by all of the participants as effective in helping to cope with the nature of the child's caregiving demands. As described in the fourth stage of the parents' evolution as expert primary caregivers, developing supportive relationships with health care providers was an ongoing challenge for parents. Moreover, supportive parent - health care provider relationships positively influenced the parents' ability to balance the nature of caregiving demands with the nature of parental caregiving. Parents described supportive relationships with health care providers and others as helping to offset many of the challenges that they faced, specifically, the fragile nature of the child's condition and associated ongoing critical events. Other participants identified supportive relationships as beneficial in countering feelings of isolation related to: a lack of support from family or friends, the uniqueness of the child's condition and/or the family's experience, the lack of freedom and spontaneity to foster old relationships or build new ones, and stigma, others not wanting to be associated with the child due to the child's disfigurement or disability.

Cultivating support was perceived by parents as an active process of seeking

out both physical and emotional support from others. Parents referred to "cultivating friends" and "building networks". Participants explained that being honest with themselves and others about requiring support, and allowing others to help were important prerequisites to obtaining the support they required. One mother provided the following example:

M: I cultivated friends....I think that having the support there was one of the biggest things that we had, I had a really good support system of friends and a parent group.

Another participant commented on being honest about the parental caregiving experience in order to obtain support from others:

M: This may not work for some people, but I am incredibly open about what is happening in my life and I find I get more support about it than if you try and keep it all to yourself...so it is okay to say, "I have been up all night" in my position (at work). Obviously you don't go in there everyday and say that but if you are really tired you can say, "I'm tired because she has been awake all night", you don't have to have this big front for people.

Participants generally discussed two broad categories of support: emotional and physical. Each of these will be discussed separately in the following sections.

Emotional support.

Emotional support was usually characterized by "talking about it", "venting", and "validating feelings". Emotional support was beneficial in decreasing the parents' feelings of being overwhelmed with the child's constant care needs and in providing acknowledgement and validation of their feelings and experience. One mother provided an example of how talking about her experience was her "therapy":

M: The thing that helps me the most is talking about it, talking to my girlfriends, and talking to people. I just vent it, sometimes they don't want to hear it, well I don't care, I'm talking about it because it makes me feel better,

that was my therapy...

Another participant discussed the emotional support his family received through the Christian community his family belonged to:

F: We have a very supportive Christian community behind us, people that pray with us and support us and a wonderful fellowship that we belong to that has been so good to us, it helped us to go ahead.

Several participants sought out professional counselling services to assist them in coping with the impact of caring for their child at home. One mother provided the following advice to other parents in similar situations:

M: If it is really hard, go and see a counsellor, go and get some professional help. Don't hesitate. Don't let it drag on too long - whether it is a problem with the management of a sibling or one of the parents is having a tough time handling this special needs kid, or having trouble accepting him, whatever...we did it for a while and it was definitely helpful, I wish we had gone sooner.

Finally, several of the participants discussed the importance of having someone to talk to who shared a similar experience. Parents discussed how they derived emotional support from attending parent support groups and talking on an individual basis to other parents who had a child with a similar condition. For example, one mother discussed the support she received from attending a parent support group:

M: I always belonged to parent groups and that made a tremendous difference....When A was little I helped start a support group for parents whose kids were disabled and I am still with one, I find it very helpful...

Other participants discussed the support they received from others who could truly understand and validate their feelings and experiences.

M: I have a good friend who also has a child with special needs, she is really good when I want to blow off some steam about H (husband) or A or about a nurse or about the --program, or whatever...

Another participant provided a similar comment:

F: I think for some people in this situation the pain is so phenomenal that they can't see it ever going away and I think sometimes they can talk to another person and talk to other people who maybe have been in similar situations. I think it can validate how they are feeling and those people can say to them, "Yes, that pain is so excruciating", and so its not that they are doing anything to change their minds, all they are doing is validating the feelings they have inside.

Physical support.

Physical support tended to focus on assistance in the direct or indirect care of the child. This included gaining help with washing and ironing clothes to nursing respite services to care for the child. The physical support from others provided intermittent relief from the intense pressures associated with managing the child's care at home. One mother provided the following example:

M: I have always tried to let other people help, when she was little it took two hours to feed her and I had a three and four year old and so I called a women's church group and asked them if they would come and help me....and they did, they organized women to come and helped with washing and ironing and things like that, and if somebody offered to do the mending, I would say "sure". You can't have a whole lot of pride when it comes to this stuff. And then when things got really bad I would call my family and ask them to come up and help for a weekend and I think that made a big difference.

The support parents received from the NRP was primarily viewed as physical support in the direct care of the child. Parents discussed the advantage of nursing respite support as allowing them to fulfill other roles or to take a break from the all encompassing care of the child. One mother provided an example of how she utilized the NRP to "take some of the pressure off" from the physical burden of caring for her child at home:

M: Personally, for me, I have found it to be really, really helpful. It allows

me to work part time and also to pursue some of my other interests...When we plan to go out she (A) doesn't have to be ready for bed, nothing has to be done, because now the nurses are here. I leave huge lists of things that they have to do so that she is ready for school the next day... so it takes a tremendous amount of pressure off me to know that when I go out I don't have three million things to do when I come back home because they do a lot of things.

The preceding section has explored the importance of the nature of support that parents receive from health care providers and others in balancing the nature of caregiving demands with the nature of parental caregiving. Supportive relationships were shown to play a key role in the dynamics of parental caregiving, offsetting many of the caregiving demands and competing family needs. Finally, the characteristics of both physical and emotional support were put forth with examples from participants' descriptions of their experience. The next section will examine the final determinant of the nature of parental caregiving - the nature of parental coping approaches.

The Nature of Parental Coping Approaches

The preceding section explored the impact of the support received from health care providers and others on the dynamics of parental caregiving. This section will examine the participants' use of coping approaches to cope with the challenges of caregiving demands and competing demands of family life. The following parental coping approaches will be presented, described, and illustrated with participants' descriptions of their experience: Ongoing Education, Identifying the Warning Signals and Taking A Break, Maintaining a Positive Focus, Just Doing It, and Fostering the Integrity of the Family Unit. Other parental coping approaches utilized by participants have already been discussed in preceding sections of the chapter. These

include anticipating and preparing for developmental transitions, and cultivating support.

Ongoing education.

The participants in this study viewed themselves as experts in the care of their child. All of the participants discussed how ongoing education regarding the child's condition, care requirements, and other related issues, was important in managing the child's fragile condition and in coping with the uncertainty associated with the child's future health. Ongoing education included networking with other parents or professionals who were knowledgeable about their child's condition or treatment regimens, and included keeping current on changes to treatment regimens and new research findings pertaining to the care of the child. One mother provided the following example:

M: You have to know as much as you can possibly know about the subject matter (the child's illness and treatment) so that you are an informed consumer, which I think for a lot of people is really difficult.

One mother found it helpful to be well informed regarding current treatment modalities or research on her child's condition.

M: I feel it is my business to learn every single thing I can about these conditions, so I feel quite well versed in allergies, eczema, and asthma....I have read most of the relevant literature that is out on it...

Ongoing education relevant to the care of their child enabled parents to cope more effectively with caring for their child. Participants also found it advantageous to educate others about their child's condition and health care needs. For example, one mother described her combined roles of both teacher and learner:

M: I mean I have pediatric R.N.s working for me in the house but I still have to be up on everything so as things change, as medical supplies change, if anything changes - I have to teach them...I am far from a medically trained person, but I am patient-specific as they call you in the hospital so you just have to be up on it all the time so you can train them.

Another mother discussed the ongoing nature of her role in educating others about issues surrounding her child's care:

M: We (parents of special needs children) do a lot of teaching and we just do it day to day with our kids... we are teaching all of the time... we do a lot of teaching through the parent group, with volunteers that work in the summer camp program, we have done some teaching with the Board of Education, meeting with teaching aides in the schools and doing some teaching - actually being asked to do things like that...

Educating others was also an approach utilized by some participants as a means of assisting others to understand their child's condition. For some participants, educating others was an effective strategy in decreasing the stigma associated with the child's condition. One mother provided the following example of how she coped with individuals who asked her about her child's condition.

R: Are there times when you don't want to have to explain A's condition?

M: No, I just tell them details and then that makes them go away or sometimes people are really interested. They will say, "Why does he look like that?". Well, I don't say because he has medical problems, I say because he has a bilateral cleft lip and palate. And they say "How come he has got that?"... Then I just say, "He was born like that and its called a birth anomaly", and then I just tell them. *People look at other people because they don't have information. If they have information they can start looking past the medical stuff and start seeing the person* (emphasis added), ...At least that is what I think. I don't know if that is true but it is what I feel, what I sort of notice.

Not all parents reacted similarly to other people's questions about their child's health. For instance, the following mother's perspective was quite different than that provided in the preceding example:

M: I don't think my job is to educate the world, I do the things that she needs to have done, for instance, I have tube fed her on the beach, in the libraries, in malls...we just do it , but I don't think my job is to educate everybody out there...If someone asks me I am polite but I do get really annoyed when people say, particularly adults, well what is wrong, what is the matter with her? If I am in a bad mood, I will turn around and say nothing, nothing is the matter with her, she is just wonderful. If it is a child, I will be a little more sympathetic, I have no problem with kids asking about why she doesn't move and I can explain all of that really well, but I don't think I am out there to educate the whole world and I try not to discuss her disability too much in front of people because she doesn't like it and she will get angry.

Identifying the warning signals and taking a break.

All of the participants discussed the physical and emotional demands associated with caring for their child at home. When asked about how they coped with this task, most of the participants discussed the importance of taking a break or stepping back to regain a sense of perspective of their situation. This coping approach provided parents with an opportunity to regain their strength and to renew marital and family relationships. Taking a break from caregiving demands also assisted in decreasing the stress and strain associated with the child's intensive care requirements. Participants described taking a break as a "relief of the worries", "a release", or a break which "takes some of the pressure off".

The first component of this coping approach is referred to as Identifying the Warning Signals. One participant referred to "identifying the signals of when you need to take a step back". Participants described these "warning signals" as "feeling yourself falling", "going into depressions", or "feeling like walking away". One mother provided the following example of the warning signals which she experiences when she needs a break:

M: I recognize now when I start to feel depressed and I know when I am feeling that way, I know as soon as I think my friends don't like me anymore (laughter), and I think if I'm driving down the road and go, "What would happen if I swerved in front of that truck?" - I know I am slipping (laughter) and I know that I need to do something and I need to either get away or tell A she has got to go for respite for a week or two...*you learn to identify the signals of when you need to take a step back* (emphasis added) and I try not to feel guilty for doing that.

Another mother provided a similar example of the feelings she has when she realizes she needs a break:

M: I feel like walking away, and its really hard to acknowledge those feelings, the guilt, just saying it....Like right now, I want some time for me, everyone asks me, "What do you want for Christmas?", and I haven't even made a list. I don't want anything, but what I would really like is a weekend away by myself somewhere, prepared meals, the whole nine yards, and not to have to worry. Knowing that A is going to have a good time, that would be a really big deal. Just something to take some of the pressure off, that is what I need, like we need a release right now, like we need something good to happen...

The second component of this coping approach involves giving one's self permission to take a break and then actually carrying through with taking a break.

Although all of the families in this study were receiving in-home respite support from the Nursing Respite Program which they found helpful in coping with the day to day care of their child, participants did not feel that the NRP provided adequate respite from the constant physical and emotional demands of caring for their child. "Taking a Break" ranged from going to the gym or taking courses out of the home to taking extended periods away from the child. Parents pointed out that decisions to take a break were often associated with feelings of guilt, but were perceived as necessary in order to cope with caring for their child at home.

One mother provided some insight into the benefits of taking time for self:

M: Well I actually stopped watching soap operas and I started going to the gym. I started working out - I work out 3 or 4 times a week and that helps with the stress. I also started taking some courses. ...I find (these activities) help with self-esteem. Going through all this stuff with A you can feel yourself falling, you can feel yourself going into depressions, boo hoo poor me, I feel really terrible, I hate myself, so I can feel it coming so I quickly do things to get myself out of it...laying on the couch watching soap operas just does not cut it...its nice to do that (watch soap operas), I still do that maybe once a week now, I'll just veg....Just some time to not think about anything, just rest my brain for a while...

Another participant discussed the importance of taking breaks when her child is hospitalized for extended periods of time:

M: What I try to do every once in a while is I'll try and take a day off and just not come in, just go and do something for the day and then just phone and make sure everything is okay.

Finally, one mother provided the following advice to parents of children with complex health care needs:

M: One thing that I would advise other parents to do is to take time away and renew yourself, I think that is a big thing, its hard to leave your kids but they survive and they get used to going to other places.

Maintaining a positive focus.

All of the participants identified "Maintaining A Positive Focus" as an effective approach to coping with the adversity they faced. Parents discussed various methods of maintaining a positive focus in order to cope with accepting the child's condition and its resulting impact on individual family members and the family unit as a whole. This coping approach allowed family members to perceive their situation in a manner which made their experiences more manageable and allowed them to derive positive meanings from their situation.

Three common subcategories of Maintaining a positive focus were identified

as: Attributing a positive meaning, Focusing on the positive, and Celebrating the rewards. Each of these themes will be discussed separately and elucidated with examples from participant interviews.

Attributing a positive meaning to their circumstances or experiences was described by almost all of the participants. Parents discussed deriving "a sense of higher meaning" or "purpose" from the challenges associated with caring for a child with a medically-fragile condition at home. Parents referred to "a reason I was chosen for this", "the Lord sent A to us for a very special reason" or a "faith in a higher purpose". For example one participant stated:

M: Well, I don't go to church but I do believe in God and I always believed that there was a reason why I was chosen for this and it must be because I am stronger than somebody else, even though I had my weak moments and I cried my eyes out.

One father expressed his belief that God had sent his daughter for "a special reason" and his view that the resulting circumstances were a result of "God's will":

F: With our belief in the Lord we feel that the Lord sent A to us with a very special reason and... since she was born we have seen nothing but a display of circumstances in our lives that people may say, well that is circumstance. But the circumstances have been too many to say well its just a coincidence. I think its been the Lord working in our lives in many ways...I could take you through eighteen years of wonderful experiences that we have had....I don't think we could have made it through her rehospitalization without it (faith in God). We just knew that this was something that God had taken us to do and we had to rely on him...If I didn't have the Lord I am sure that I would be either an alcoholic or a drug addict. Now if that is a crutch, I want to have a crutch.

In comparison to the preceding anecdote, another participant expressed the frustration and difficulty she had in accepting her own circumstances and in being unable to accept that her son's illness could be "God's will" or for a "higher

purpose":

M: (Mother comparing herself to another mother who dealt with her son's illness and eventual death through her faith in God) I envy her religion. I think that is the one thing I truly envy her. I don't have it, I don't understand how people can believe in God and then also think God causes these things to happen. That is where I have the problem. What kind of a sick entity would do something like making children suffer - anyone suffer, but especially children. So although I believe there is a God, in a way I don't believe like she does. I mean she believes in God completely, I can't. I just don't have that kind of faith...

Other participants attributed a positive meaning to their situation by focusing on the positive changes that have resulted from their experiences. This was often referred to as "changing it for the next person". One mother explained:

M: Just like today I am talking to you and this is therapy for me and this is what gets me through and its to tell people what it is like and maybe try to change it for the next person so that they don't have to go through all of that.

Another mother commented similarly:

M: Because I work in public health I have a lot of contact with people with allergies, so I feel that I have at least been able to help those people. So maybe that makes it feel okay a little bit for me, or its the way I rationalize having this difficulty...that it is not all without a purpose...I get positive feedback because I can be of assistance to other people...

Another common coping approach which participants utilized was focusing on the positive aspects of their situation. For some parents this was similar to "looking at the glass as half-full rather than half-empty". This approach also included minimizing negative experiences or problems and focusing on "waiting out the down times". For others, it incorporated recognizing individual and family strengths. Parents explained how focusing on the positive enabled them to cope with the day to day challenges and multiple crises which they faced.

One mother explained her reasoning for focusing on the positive:

M: If you have a problem you either let it really pull you down or you can think, well I have got it and you might like it to go away but its not going to go away, so what can we do to make it positive and use those features.

Other participants discussed how they utilized downward comparisons to put their circumstances into a broader perspective:

M: To survive you don't lie, but you condition yourself to think I don't have it that bad, it could be worse, you know, my kid could have leukemia, he could have cancer...

Several participants discussed a coping technique of "waiting out the down times" and recognizing the transitory nature of critical events. One mother provided a clear description of this approach:

M: I realize now that we have gone through so many up and downs that when its down and I don't feel like our marriage is going to last or something then I think, but I know I felt that way two years ago (laughs) and it did and that this is just a transitory thing, and that everybody feels like that sometime in their life and if you can just wait then at some point things are going to get better, it can't stay like this forever. And then things improve and you get more rest, the crisis you were going through passes and then all of a sudden you start feeling better and you think, hey, well I really do love this person, and I really do like my kids and you realize it was a transitory thing. When you are in the middle of it, it doesn't feel transitory but I think if a lot of people could wait it out and wait out the down times then things get better...its important to keep a positive focus through the down times.

Another participant described a similar perspective:

M: I mean I always do get through them (crises), I realize that now, and I am learning I just have to ride it out. I remind myself that I am doing everything right, I'm taking really good care of him, I'm doing everything right. That if somebody else had to live or step into my shoes, they would feel like this...

Finally, other participants maintained a positive focus by recognizing individual and family strengths which contributed to their self-confidence and self-

esteem. One participant provided the following example:

M: When we moved away from our families to a place that was very isolated I learned to do a lot of things myself and recognize that I was a pretty strong person and that I could cope with all of this in a strange place, in a strange culture, and do it.

Celebrating the rewards is the third and final component of the coping approach of Maintaining a positive focus. This theme focuses on acknowledging and celebrating the positive contributions the child has made in the lives of the family members and others. Participants enthusiastically recounted several examples of the rewards which their child brought into their lives.

One mother excitedly described the joy that her child had brought into her life:

M: Just having him (A) has been a reward. He has got to be the most joyful kid, he is so good natured, and he is so fun and he is so funny...he has filled my life up. I mean its like before I had him it was empty, I didn't know it was empty (laughs) but it was, it is just so amazing...He has been the light of my life.

Another father provided the following observation:

F: We have made a lot of sacrifices but I wouldn't change my life for yours. I mean we have been through so much that is good...Our life has been exciting, it has been eventful. We have met people that we would never have met if we had just had quote unquote "normal" children...

Parents also enthusiastically described the child's abilities, rather than focusing on the child's limitations. It was evident from the participants' anecdotes that celebrating the child's abilities was a key component of maintaining a positive focus.

One mother recounted the following story with zeal and excitement:

M: A year and a half ago she went skiing, she used a model ski similar to a sled...she actually went down the mountain...we would suction her at the bottom and then go up on the ski lifts, suction her at the top and go down the hill, and she wasn't afraid...it was extremely exciting...I have lots of pictures,

it was great.

Another participant emotionally described how his daughter had greatly surpassed the physicians' prognosis of what she would be able to do:

F: I go back constantly, almost daily, to the fact that the doctor told us at one time that she would never be anything, she would be a vegetable, she wouldn't walk, she wouldn't talk, she wouldn't sing, she wouldn't do anything. And when I see her singing in church, and when I see her walking and when I see her laughing ... and it blows me away, and that is as simple as it is. She is a gift directly from the Lord...

Finally, participants also discussed the positive impact that the child had on other family members, particularly siblings. For example:

M: I think they (siblings) have learned an incredible amount of tolerance... I think they learn so much from it. I don't think it is a negative experience... the kids from the parent group all seem to be really tolerant and great kids...they often go into a field of work where they can continue to be involved with kids with special needs...My son is a very giving person, and I think he has learned that from his sister (A)...they are both very sensitive and caring and I think that A has encouraged them to be that way.

Just doing it!

Several of the participants shared a common coping approach referred to simply as "you just do it". This phrase refers to the persistence parents demonstrate in coping with both changes in their child's care or treatment requirements and with major transitions or crises. One mother provided the following example:

M: You do it. I look back on it and I don't know how I did it. I don't remember a lot of things...I mean I look back and I think my gosh, I don't know how I did it, but you do, you just do it and you survive.

Several participants discussed how they persevered in managing a critical event but then "fall apart" once the event was over. One mother explained:

M: I have to deal with it, I have no choice. Believe me I would like not to.

During the crisis I deal with it, I cope, and then I fall apart. I wallow in self-pity for a good twenty-four hours...

Parents of children with progressive illnesses discussed their "rage against the new stuff". This refers to their feelings of being overwhelmed with each new piece of equipment or increasing care requirements of their child as his or her condition changes or deteriorates. One mother explained the process involved in accepting the changes in her child's care requirements and the persistence required to cope with these events:

M: ...When you first have to do something new it is very, very hard, such as even bringing along the new pieces of equipment.... But if you can get past the first three weeks, you have got it made, at some point in time you get used to it and it becomes second nature, but it does seem really hard at first - like you will never be able to do it...I mean you rage against the new stuff, the new difficult thing your child needs as she regresses or gets worse, but at some point you get used to it, it just becomes part of life...and then its not so bad and you get by.

Fostering the integrity of the family unit.

Preserving the integrity of the family unit was one of the key challenges which participants discussed. In particular, parents described the difficulty and frustration they experienced in dealing with the loss of privacy they faced and the lack of time and energy available to maintain normal family routines and relationships.

Participants attempted to cope with these challenges in a variety of ways. Although the coping strategies utilized differed amongst participants, they shared the common goal of preserving the integrity of the family unit.

One mother provided a clear example of how she attempted to manage the disruption to normal family routines as a result of the entrance of respite nurses into

the family home:

M: It wasn't until very recently that my husband said that he didn't like the nurses being here, so I have been asking the nurses to take a more back seat role. Now I tell them you go through the living room to go to the kitchen,...if she (A) is watching t.v. with her dad - listen to her breathing and suction her during the commercials...keep the lid down on the suction, don't stand in front of the t.v., don't start talking to him in the middle of the t.v. program, this is what he does to unwind so don't go chatting to him while he is watching t.v....

In contrast, a father described how utilizing the Nursing Respite Program to care for his child enabled him and his wife to focus more time and energy on nurturing their marital relationship:

F: The Nursing Respite Program that we had while A was on dialysis was by far the single program that did the most for our family. It certainly allowed a lot of things to happen in our family that never ever happened before. That was the fact that M (mother/spouse) and I could go out and not be worried about having A at home going through a situation that somebody did not know how to handle... We were able to go out and it relieved us of our responsibilities on Tuesday and Thursday evenings... It really helped. M (mother/wife) and I almost got back on perspective, ...it allowed me to look at the bigger picture, M and I could do things together as a couple...

Another participant discussed the importance of making time for and fostering the marital relationship:

M: I think the thing that made a big difference was we (the woman and her husband) always tried to go away and leave the kids and go off and do something...

In providing advice to another family in a similar situation, another participant described the importance of "not giving up on each other" and of making family relationships a priority.

M: Don't give up on each other (other family members). Don't be afraid to talk to other people, don't be afraid to tell other people when you are upset and worried or concerned, and get yourself a network, a friend, professionals,

people that can help you through it, but never give up on each other.

Several participants shared their approaches in meeting the needs of the child's siblings. Perspectives differed as to how to best meet the needs of other children in the family. For instance, some parents felt it was necessary to spend separate time away from home with their other children. One mother provided the following example:

M: A always, usually, goes away (for respite care) in the summer when we go on vacation or in the winter she doesn't always go with us, particularly if it is a longer trip. I might choose to take her and the other kids and do something, but generally when we go on a vacation and we are taking the (other) kids she doesn't always go...I mean she has been to Disneyland but the other kids have been more often...we tend to go away without her because you can not do a lot of things with her, especially now that the other kids may want to be doing much more active things that she could never participate in, she is just too big, too heavy, and does not have the stamina...

Other participants discussed how they made a conscious effort for family activities to be those in which the child with the medically-fragile condition could also participate. One couple provided the following example:

M: It comes down to making choices. We could have been skiers but we chose not to be because it would have been impossible for A...

F: I think the circumstances helped us to choose those things. Its not that we did not become skiers because we did not want to and it was a choice, I think that we realized that likely we had a purpose in life where our particular situation warranted that we involved A in what we did rather than choose to say, "o.k., A has a disability, but we can leave her and M (mother) and I and the boys can go skiing". So we chose not to do that.

It is important to note that participants differed greatly in the approaches they utilized to foster the integrity of their unique family unit and that these coping approaches changed over time. However, participants did share in common the priority they placed on preserving the integrity and cohesiveness of the family unit.

The preceding section explored the use of specific coping approaches by participants to cope with the challenges of caregiving demands and the competing demands of family life. The parental coping approaches of: Ongoing education, Identifying the warning signals and taking a break, Maintaining a positive focus, Just doing it, and Fostering the integrity of the family unit were presented, described, and illustrated with participants' descriptions of their experience. The use of these coping approaches were significant determinants of the balance between the nature of caregiving demands and the nature of parental caregiving.

Summary

This chapter has presented an analysis of the participants' experiences as understood and conceptualized by the researcher. This chapter began with an analysis of how participants recounted the onset of their experience of caring for a child with a medically-fragile condition. First, a conceptualization of the critical periods in the evolution of parents as expert primary caregivers was described. Parents' descriptions of becoming their child's primary caregiver was conceptualized as progressing through four distinct stages across the time frame of these critical periods. In particular, the characteristics of supportive and conflictual parent - health care provider relationships were highlighted as an important element of the participants' experience. The description and analysis of these components of the parents' experience set the scene for the major focus of the analysis: The dynamics of parental caregiving for a child with a medically-fragile condition at home.

The dynamics of parental caregiving was the major focus of the participants'

experience in the home-based care of their child. The dynamics of parental caregiving was conceptualized as a process of balancing the nature of caregiving demands with the nature of parental caregiving. Parents described the nature of caregiving demands as being shaped by three key factors: the fragility of the child's condition, the complexity of the child's care requirements, and the child's developmental needs. Comparatively, parents characterized the nature of parental caregiving as being shaped by: the nature of family life, the nature of support received, and the nature of parental coping approaches. Each of these components and their relationship to each other was described, analyzed, and substantiated with participants' descriptions of their experience.

CHAPTER FIVE

DISCUSSION OF KEY CONCEPTS

Introduction

This chapter will present an indepth discussion of selected key concepts which were described in Chapter Four. The evolution of parental caregiving and the concurrent evolution of parent - health care provider relationships laid the foundation for the parents' ongoing experiences of caring for a child with a medically-fragile condition at home. The stages in the evolution of parents as expert caregivers will be discussed indepth utilizing existing theoretical and research literature to enhance the understanding of these findings. Next, a detailed investigation of parent - health care provider relationships will be presented, with a focus on the convergent and divergent paradigms which are at the root of parent - professional interactions. Finally, the major focus of the findings of this study centered on the dynamics of parental caregiving of a child with a medically-fragile condition who was cared for at home. An exploration of the unique findings of this experience in relation to the nature of caregiving demands resulting from the fragility of the child's condition and the complexity of the child's care requirements will be presented. In addition, an investigation of the nature of family life in relation to the parents' experience of "living in a fishbowl" will be put forth. Emphasis will be placed on the relationship of these findings to existing theoretical and research literature introduced in Chapter Two as well as additional literature related to the central concepts described in this study.

Parents as Expert Primary Caregivers and Their Relationships with Health Care Providers

Parents identified their experience of caring for their child with a medically-fragile condition as evolving over time. Participants recounted the onset of their experience, involving their evolution from novice to expert caregivers and the concurrent evolution of the parent - health care provider relationship, as progressing through four distinct stages. The evolution of parents as expert caregivers and the maturation of relationships with health care providers played a pivotal role in the parents' overall experience, colouring the remainder of their experience of caring for a child with a medically-fragile condition at home. Parents' descriptions emphasized the interrelated nature of their development as expert caregivers and the development of their relationship with health care providers. An exploration of the parents' experiences of progressing through these stages enhances one's understanding of the parents' experience of caring for a child with a medically-fragile condition.

The parents' descriptions of the stages they progressed through in their development as expert primary caregivers for their child supports the work of Thorne and Robinson (1988) in their study of the development of relationships between family members and health care providers. Their findings are a product of two distinct research projects; one study examined the experiences of families having an adult member with cancer, the other explored the meaning of hospitalization for parents of a child with a long-term health condition. The total sample size was comprised of 26 members from 14 families. Thorne and Robinson (1988) conceptualized the

relationship between family members and health care providers as evolving through three identifiable stages which they labelled as: naive trust, disenchantment, and guarded alliance. The parents' descriptions of their evolution as expert primary caregivers will be discussed in relation to Thorne and Robinson's (1988) stages of health care relationships and other research investigations in this area.

The first stage in the evolution of parents as expert caregivers was described as Assigning the caregiver role: Blind faith. Parents referred to their initial interactions with health care providers as characterized by a "blind faith"; that is parents believed that health care workers were acting in the "best interests" of the child. Parents described their behaviours during this stage as "onlookers", "watchers", and "observers", assigning the care of the child to health care providers who they perceived were providing the child with "the best possible care". This stage supports Thorne and Robinson's (1988) stage of naive trusting which was characterized by family members implicitly trusting that all health care providers would act in the ill member's best interests, assuming a passive role while they became familiar with the professional care setting.

For the participants of this study, the context of the Intensive Care Unit (ICU) setting accentuated the parents' blind faith in health care providers. Parents recounted being "intimidated" and "overwhelmed" by the technological support and caregiver expertise required to care for their child with a medically-fragile condition. The intimidating nature of the ICU setting, the precarious nature of the child's condition, and the high level of caregiving expertise required to care for the child all magnified

the parents' initial feelings of "blind faith" in health care providers. Moreover, in the ICU setting, parental-child interactions were largely determined by health care providers which contributed to the passive role of parents.

The second stage was referred to as Preparing for action: Disillusionment and raising one's voice which compares to Thorne and Robinson's (1988) stage of disenchantment. They found that family members were propelled into this stage when they began to understand that health care professionals held different perspectives and expectations of the parent - professional relationship. This finding is corroborated by parents in the present study who described the shift in their perspectives of health care providers and their own role as parents as occurring when they began to realize that professionals held different perspectives regarding: the parental role, the care and treatment of the child and/or the value health care providers placed on the child and his/her well-being. Thorne and Robinson (1988) described the stage of disenchantment as characterized by frustration, fear, and dissatisfaction with care. This is verified by the participants' descriptions of their actions during this stage as "raising their voice", "putting their foot down", "threatening" and "having a battle" to ensure that their child received the type and quality of care that they considered necessary.

Thorne and Robinson (1984, 1988) point out that this stage poses a dilemma for family members as they recognize that they may be putting the ill member at greater jeopardy by alienating health care professionals, but realize that the quality of care may be unsatisfactory unless they are assertive in their advocacy on behalf of the

ill member. This was evident in the present study in the parents' descriptions of their interactions with health care providers during this stage. Parents described "needing to fight for their child's right to treatment" and "threatening" to take their child to another tertiary care facility in order to ensure the child's well-being. Parents explained that these aggressive actions were perceived to be necessary in order to ensure the child's well-being.

Robinson and Thorne (1984) discuss the positive functions of the family members' aggressive actions during the period of disenchantment as allowing them to obtain the information they require and to be able to influence the care provided to the ill member. This finding was corroborated by parents in the present study who described the result of "raising their voice" and "putting their foot down" as effective in mobilizing health care professionals to "find out what was wrong with the child". These actions were also effective in motivating health care providers to be open and honest with the parents regarding the child's condition and prognosis, rather than "shielding" the parents from information which was characteristic of health care providers' actions in Stage One.

As a result of the fragile and complex nature of the child's condition, parents in this study described progressing through the third stage of Assuming the caregiver role: Learning caregiver expertise. This is an element of the parent - health care provider relationship which is not addressed in Thorne and Robinson's (1988) study. It is suggested that the medically-fragile nature of the child's condition accounted for this additional stage in the evolution of the parents as expert primary caregivers. The

nature of the child's condition was such that parents needed to learn highly complex medical and/or nursing skills in order to be able to care for their child at home; this differentiates the caregivers of individuals with medically-fragile conditions from those who care for individuals with long-term health conditions in general. The development of parental caregiving expertise for a child with a medically-fragile condition is a unique experience of this population as parents must learn complex medical and nursing skills and gain specialized knowledge in order to care for their child at home.

Thorne and Robinson (1988) describe the progression into the third stage of "guarded alliance" as resulting from the extremely uncomfortable nature of the stage of disenchantment, and the family members' realization that this antagonism must be resolved due to the long-term nature of the ill member's health condition. Participants in this study described needing to maintain workable relationships with health care providers in order to learn how to care for their child at home. The parents described their relationship with health care providers during Stage Three as similar to that of "coaches" or "teachers". Parents remained dependent on health care providers to facilitate their progression from novice to expert caregivers. However, parents also described demonstrating increasing confidence in asserting their parental role with health care providers during this stage. Parents described "negotiating" with health care providers which aspects of caregiving they would take over and the pace at which this would occur. This relates to Thorne and Robinson's stage of guarded alliance which was described as: "the reconstruction of trust on an informed, rather

than naive, level and enabled cooperative caring that accommodated both the family perspective and the professional medical perspective" (1988, p. 298).

All the participants in this study described achieving a guarded alliance with some health care providers, but this was not true of their relationships with all health care providers. This is consistent with the findings of Thorne and Robinson (1988) and the findings of Knafl, Breitmayer, Gallo, and Zoeller (1992) who found that the caregivers of chronically ill family members continued to have isolated negative interactions with specific health care providers, even though they had attained a relationship of guarded alliance with the majority of health care professionals.

The final stage in the evolution of parents as expert caregivers, Adjusting to home-based care: Building supportive relationships, focuses on the transition from hospital to home-based care and subsequently involves the ongoing critical periods which these families face in caring for their child at home. Parents described their progression from expert caregiver of their child in a hospital setting to expert primary caregiver of their child at home. This was considered one of the most stressful periods by parents as they learned to care for their child without the safety net of the hospital setting in which emergency aid was readily available.

In Stage Four, parents described their view of health care providers as partners in the care of the child and described entering into new relationships with health care providers cautiously, seeking out health care providers who they deemed as competent and who demonstrated a collaborative approach in their interactions with parents. This is consistent with Thorne and Robinson's (1988) stage of guarded alliance.

However, whereas the participants in Thorne and Robinson's study described professional "competency" almost exclusively in general "human" qualities such as an interest in the client's case, the participants in this study provided more specific characteristics of health care providers with whom they preferred to interact. These characteristics included: honesty, expertise in the child's condition and caregiving requirements, and respect for: the role of parent as expert caregiver, the parents' perspectives regarding the ongoing care and treatment of the child, and the value of the child and his/her well-being.

The parents in this study considered themselves experts in the care and treatment of their child and sought out health care providers who they regarded as experts in their child's care. Given the fragile and complex nature of the child's condition, parents considered it imperative that health care providers demonstrate expertise in the care and treatment of their child's condition. This verifies Thomas' (1986) findings in her study of parents caring for children who were ventilator-dependent at home. Thomas (1986) found that as family members became experts in their child's care requirements they began to evaluate the competency of health care providers in an effort to ensure their child's comfort and safety.

Due to the uniqueness of the child's condition and relative lack of "specialists" in the child's care, parents described often feeling frustrated and obstructed in accessing emergency health care for their child during ongoing critical periods. These findings point to a key difference in the experience of caregivers of children with medically-fragile conditions from those with long-term health conditions in general.

Wheeler and Lewis (1993), who studied the home care of children with medically-fragile conditions in home versus rural areas, confirm the importance of accessibility to pediatric specialty care services in the care of this population. Their study indicated a shortage of pediatricians and other specialists, especially in rural areas, who could provide medical follow-up and emergency treatment for children with medically-fragile conditions. Moreover, their findings indicate that much of the medical care of this population is "delivered by family practitioners who may not feel competent to follow a child with chronic and complex health care problems" (Wheeler & Lewis, 1993, p.21). These findings are consistent with the parents' descriptions of accessing emergency medical care when they lived a minimum of several hours from a pediatric tertiary care centre.

Parent - Health Care Provider Relationships:
Supportive and Conflictual Interactions

Findings of this study indicated that continuing parent - health care provider relationships were essential given the child's medically-fragile condition and complex care requirements. Parents required ongoing support from health care providers in order to effectively manage the care of their child with a medically-fragile condition at home. Parents indicated that they endeavoured to develop supportive relationships with health care professionals which they defined as collaborative, interdependent, and non-hierarchical. Parents described the characteristics of a supportive health care provider as one who was honest, understanding and empathetic, and who

demonstrated a respect for the parents' perspective regarding: the parental role as expert primary caregiver; the child's ongoing care and treatment requirements; and the value of the child and his/her well-being.

The findings of this study in relation to the characteristics of supportive parent - health care provider relationships add to the work of Thomas (1986), in her study of parents caring for a child who was ventilator-dependent. Thomas described evidence of convergent and divergent paradigms between families and health care providers. She defined convergent paradigms as: "instances where families and health care providers appeared to be operating 'on the same wavelength'. Interactions were based on similar assumptions concerning roles, responsibilities, or the task to be completed (Thomas, 1986, p. 93). Moreover, Thomas (1986) found that convergent paradigms tended to result in more positive working relationships between parents and health care providers. Empathy and the capacity to respect an individual different from oneself were important characteristics of convergent paradigms.

The findings of this study also support the work of Knafl et al (1992) in their study of 102 parents of children with chronic illnesses. The co-investigators found that while parents valued and needed professionals' expertise, that they preferred that this expertise be communicated in a manner which conveyed both compassion and respect for the family's experience. Moreover, parents described preferring to work with health care providers who communicated a sense of empathy and genuine concern for the family's experience and who acknowledged and enhanced the parents' competence in caring for the ill child. (Knafl et al, 1992).

Wong (1991) also confirms that one of the most effective means of supporting families of children with medically-fragile conditions is to develop parent - professional relationships which incorporate agreed upon roles in the pursuit of joint interests and common goals. Wong (1991) describes three health care provider tasks which facilitate parent - professional partnerships: acknowledging the parents' overall competence and their unique caregiving expertise; listening to the parents' perspectives regarding their needs and aspirations in relation to their child, before providing recommendations or making decisions; and ensuring that formal and informal ongoing evaluation mechanisms are in place to encourage continuing communication and collaboration between family members and health care providers.

The preceding health care provider tasks outlined by Wong (1991) are similar to the characteristics of supportive health care providers as described by the participants in this study. Moreover, it emphasizes the importance of evaluating ongoing parent - professional communication and collaboration. Parents in this study often described their feelings of being abandoned by health care providers once their child was discharged home, and their perceptions of needing to "jump the hoops" and "fight the systems" in order to receive the support they required in the home-based care of their child. Parents described how "no one ever calls to just see how we are doing". This points to a need for further parent - health care provider interactions which focus on understanding the parents' perceptions of their experience and caregiving needs rather than basing interventions on health care providers' perceptions of the parents' caregiving experience. Haas, Gray, and McConnell (1992) confirm

the need for family - health care provider collaboration concerning policy development, program implementation, coordination of services, and program evaluation. Their findings affirm, "Parents are the experts on the experiences of using systems of care. No one knows more about what it is like to receive a service than the person who is receiving that service" (Haas et al, 1992, p. 53).

Parents emphasized their perceptions of specialists in the child's condition as demonstrating a knowledgeable appreciation of the family's experience and as valuing the child and his/her condition. Parents differentiated between medical generalists and specialists, referring to generalists as "having poor attitudes towards our kids" (with special health care needs) compared to specialists who "all seem to value them". This is an interesting area for exploration. It is not particularly surprising that health care specialists who have invested an enormous amount of time and energy learning about and working with this population would be perceived by parents as one of the family's greatest advocates. In a sense, the role of specialists in children with medically-fragile conditions is dependent on being able to develop relationships with these families, just as families of children with medically-fragile conditions depend on specialists in their child's condition to provide their child with ongoing care and treatment, thereby establishing an interdependent relationship. Parents described sharing similar perspectives with medical specialists regarding the care of the child. Again, this is not surprising as parents developed into "patient - specific specialists" under the instruction of professional health care specialists. Parents considered themselves as experts in the care of their child. As such, parents preferred to work in

partnership with health care providers who also demonstrated expertise in the care of their child and who respected the parents' caregiving expertise.

In contrast to supportive parent - health care provider relationships, conflictual interactions were described as resulting when health care providers demonstrated through their attitudes, statements, or behaviours, divergent perspectives regarding: the role of parents as expert caregivers; the child's ongoing care and treatment requirements, or the value of the child and his/her well being, particularly surrounding life and death issues. If a relationship with individuals who demonstrated divergent perspectives in relation to any of these three areas could not be avoided, conflictual parent - professional interactions often resulted.

The results of this study in relation to conflictual parent-health care provider interactions contributes to Thomas' (1986) findings of divergent paradigms between health care providers and parents. She reported divergent paradigms illustrating differences between the family's world view and the health care providers' world view and that these differences in perspectives resulted in incongruent behaviours which often led to conflict and struggles for control over the child's care. Specific divergent paradigms existed in two main areas: divergence in the perception of life and death issues and divergence related to defining the family's role in relation to the child who was ventilator-dependent (Thomas, 1986).

The findings of this study indicated incidents in which health care providers were perceived to demonstrate a lack of respect for the parents' perspective regarding the value of the child and his/her well-being. The interactions which stood out most

in parents' memories involved discrepancies surrounding life and death issues. These results parallel the findings of Thomas' exploration of the experiences of families providing home-based care for a child who was ventilator-dependent. Thomas (1986) found divergent perspectives between parents and health care providers in relation to the lack of consideration health care providers demonstrated in providing care to the child. One family discussed the example of how a lack of consideration of potential discomfort or harm to the child, evidenced in the avoidance of the simple task of changing a diaper, was difficult for family members to accept. As in the present study, Thomas (1986) found that such actions by health care workers were difficult to forget and resulted in cautious and guarded interactions between parents and health care providers.

Parents described numerous conflictual interactions with health care providers which they perceived as resulting from differences in the perception of the role of parent as expert caregiver. Parents recounted specific incidents in which professionals discredited or minimized their caregiving expertise. The majority of these interactions occurred in a hospital setting in which the child needed to be re-hospitalized for an exacerbation or deterioration of his/her condition. Parents, who had developed caregiving expertise under the supervision of health care providers, described "fighting" with health care providers to respect their caregiving expertise when their child was re-hospitalized for an exacerbation of his/her condition. Robinson (1985) refers to this as a double bind:

When chronically ill children are hospitalized, parents are often forced to

relinquish their roles as primary health providers to hospital staff. In addition, health professionals may ignore parents' expertise in the care of their children. A double bind exists when parents are expected to care for their children at home yet are ignored in hospital treatment regimens. (p. 112)

Parents contrasted between their interactions with health care providers who cared for their child at home and those who cared for the child when he/she was re-hospitalized. In the home-based care of the child, parents described instances indicating that they had the control or power to determine which health care providers would work with their child and how this care would be provided. In contrast, parents described struggles with health care providers in hospital settings over issues of control and decision-making in relation to the child's care. Parents did not expect to "be in charge" of all of the child's care in the hospital setting, rather they preferred to work as partners in caring for the child. That is, parents expected to be respected for their caregiving expertise in a similar way to the respect they had for the caregiving expertise of health care providers, particularly respite nurses, who cared for their child at home.

Several researchers (for instance, Darling, 1983; Dunst, Trivette, Davis & Cornwell, 1988; Nissim & Sten, 1991; Robinson, 1985; and Robinson & Thorne, 1984) have found that traditionally health care providers have been accustomed to dominating their interactions through the uncontested control over the client's care, and that parents who attempt to control their child's care within this system are often viewed as difficult and obstructive. Nurses have traditionally been bound by loyalties

to the medical model which perpetuates their advocating for the role of physicians and not clients, and taking personal offence to clients' rebellion against restrictive hospital agendas. Moreover, nurses who demonstrate an attitude of "knowing what is best for the child" promote a conflictual relationship with family members who question, demand or criticize the care and treatment provided (Darling, 1983; Robinson & Thorne, 1984).

Darling (1983) explains the "roots of misunderstanding" between parents and health care providers by utilizing a typology suggested by Parson's in 1951 in which the normative expectations accompanying the professional role is characterized by the traits of achievement, universalism, functional specificity, affective neutrality and dominance. On the other hand, the roles of parents of children with health care needs or clients in general are characterized by ascription, particularism, functional diffuseness, affectivity, and submission. For example, universalism is reflected in the bureaucratic nature of clinical settings in which there is a tendency to treat all clients in a like manner versus treating each client with respect to his/her unique personal situation. Parents resent this "universal" treatment which negates their child's unique characteristics and abilities. Darling (1983) also points out that the ritualized and bureaucratic routine of health care systems supports professional dominance. In contrast, parents often respond to this environment with feelings of powerlessness and resentment over the professionals' control over their lives (Darling, 1983).

The findings of this study and of other existing theoretical and research literature examining conflictual parent - health care provider relationships points to

the need for changes in the way in which health care providers interact with families as well as changes in the agendas and policies of health care institutions and systems. Wong (1991) asserts that when conflictual parent - professional perspectives exist that it is essential that the professional's opinions are not imposed on the parents, rather time should be allowed for discussion between the two parties so that a mutual understanding can be achieved. Dunst et al (1988) confirm that even though health care providers' tendency to "rush in and fix" children and their families may seem expedient in terms of meeting the professional's perceived needs of this population, that in the long run it deprives families of experiences which could make them more competent and better able to meet the demands associated with caring for their child at home. Nissim and Sten (1991) confirm this finding emphasizing that nurses who enable and empower families in a proactive and positive manner facilitate family members becoming competent in the care of their child which in turn strengthens family integrity and provides the potential for a negative experience of illness to be turned into a positive growth experience for both the child and the family.

The Dynamics of Parental Caregiving

The major focus of the findings of this study centered on the dynamics of parental caregiving of a child with a medically-fragile condition who is cared for at home. A further examination of this area will enhance one's understanding of the findings. Specifically, an exploration of the nature of caregiving demands resulting from the fragility of the child's condition and the complexity of the child's care

requirements will be presented. In addition, an investigation of the nature of family life regarding the parents' experiences of "living in a fishbowl" will be explored in relation to relevant literature.

The Fragility of the Child's Condition

There is a substantial accumulation of literature which emphasizes how families adapt or cope with their child's long-term health condition (for example, Austin, 1990; Canam, 1987; Hymovich, 1976; McAnear, 1990; Patterson, 1991). Moreover, research in this area indicates that the illness trajectories of children with non medically-fragile long-term conditions are generally characterized by periods of stability in which the nature of parental caregiving is characterized by an increased order and organization interrupted by periods of disequilibrium in which the child's needs increase dramatically or when sources of support change dramatically (Clements et al, 1990). The results of the present study indicated a difference in the experience of the subgroup of parents caring for a child with a medically-fragile condition at home. Children in this study were described as experiencing an illness trajectory characterized by a baseline of vulnerability punctuated by multiple critical periods in which the child's caregiving demands exceeded the parents' resources to provide care. Moreover, rather than a baseline of stability, parents described their experience as a constant state of flux in which the nature of caregiving demands was continuously readjusting to the changing caregiving demands. The inherently fragile nature of the child's condition and related susceptibility to exacerbations of the child's condition

played a key role in the vulnerability of caregiving demands exceeding the parents' resources for providing care.

The fragile nature of the child's condition, characterized by an increased vulnerability to medical crises and an unpredictable nature and trajectory of the child's condition, underpinned the unique experience of the families in this study. Parents provided analogies to their experience as characterized by extreme instability similar to "being on a see-saw" or in a "rocking boat". The experience was characterized by increased emotional distress, uncertainty, and family disruption. Parents described how they could never relax and had to be "hypervigilant" in monitoring for any changes in the child's condition or threats to his/her well being. The child's need for constant monitoring resulted in parents experiencing chronic sleep deprivation and threats to their own personal health as a result. These findings substantiate the results of Wills (1983) study which found that mothers providing home care for a child with a tracheostomy regarded maintaining a patent airway as taking precedence over any other concerns related to the care of the child. In addition, mothers reported chronic sleep deprivation which was attributed to "vigilance" and the child's need for frequent care.

The findings of the present study clearly differ from the results of research examining the experiences of families caring for children with long-term health conditions in general which have tended to focus on the acceptance and management of the child's condition and means of incorporating the needs of the ill child into "normal" family life. The findings from this study indicated that the fragile nature of

the child's condition often resulted in family life revolving around the ill child rather than the management of the child's condition being incorporated into the nature of family life. This was evidenced by the parents' descriptions of the differences in their roles, responsibilities and relationships as a result of caring for a child with a medically-fragile condition at home.

Parents described the critical period involving the transition from hospital to home-based care of the child as one of the most stressful aspects of their experience. In particular, parents discussed their adjustment in caregiving demands related to the fragile nature of the child's condition. This was a period associated with heightened vulnerability and unpredictability. A study by Klein-Berndt (1991), which investigated one family's adaptation to caring for a child with a medically-fragile condition complements these findings. The mother of the child in this study described the transition from hospital to home-based care with the following vivid description: "Bringing her home from the NICU [neonatal intensive care unit] was like taking a poinsettia out of a green house when it is 30 degrees below zero" (p. 609).

The nature of the child's medically-fragile condition characterized as "unpredictable", "unending", and "always changing" creates a situation similar to the findings of Feinberg (1985) whose review of the experience of parents caring for children who were ventilator-dependent uncovered that, "the unpredictability surrounding the child's initial hospitalization and ventilation continues with home care; there is no closure to the illness episode as with acute illnesses and, even if relatively stable, the likelihood of the child experiencing a medical crisis and re-

hospitalization remains" (p. 372).

The Complexity of the Child's Care Requirements

The complexity of the child's care requirements was also identified as a key factor in the nature of caregiving demands. Parents described the complexity of caring for their child in relation to the child's direct care needs and the coordination of the child's care and care requirements. Parents recounted the incredible physical demands associated with home-based caregiving such as lifting, toileting, suctioning, and medication administration. Parents also discussed the time consuming nature of the child's care as "constant", "continuous", and "ongoing". The caregiving demands resulting from the complex nature of the child's condition and the fragile nature of the child's condition impacted on the degree of spontaneity that parents had in caring for the child, meeting their own needs, and in meeting the needs of other family members. The results of this study concur with the findings of Stutts' study of parents caring for children with technology-dependent conditions at home. Stutts (1994) found that a predominant concern for parents related to a lack of time to foster marital or personal well-being.

Parents also discussed the complex nature of coordinating all of the services and equipment which the child required. This included the time-consuming nature of hiring and training of alternate caregivers for their child. Parents referred to the coordination of services and alternate caregivers as similar to "running a full time business". This is a unique feature of families caring for children with medically-

fragile conditions at home. There is little research available that addresses this aspect of the parents' experience of caring for a child with a medically-fragile condition. Many research studies which have been carried out in the United States discuss the role of nurse case managers who take on the role of coordinating the multiple services required by this population (for example, Raulin & Shannon, 1986; Urbano et al, 1991). However, there is a paucity of literature which looks at parents who take on the role of case manager for their child in relation to the coordination of existing services. Results of a study by Aday & Wegener (1988) of parents caring for children who were ventilator-assisted at home did, however, support the additional stressors parents experienced in relation to the hiring of competent nursing support and coordinating nurses' work schedules.

Living in a Fishbowl

In describing the nature of their family life, parents used the metaphor of "living in a fishbowl" which was characterized by feelings of constant scrutiny, and isolation and lack of support. Parents described the constant scrutiny that they experienced as related to their perception of their actions being constantly examined by health care providers and others. This finding complements the increasing number of research studies indicating the intrusion of health care professionals on the privacy of family members caring for a child with a medically-fragile condition at home (for example, Aday & Wegener, 1988; Thomas, 1986).

The findings of this study concur with the results of Aday and Wegener (1988)

in their study of home-care of children who are ventilator-assisted. The co-investigators reported that caregivers described a tension between the support received from having nurse caregivers in the home and the corresponding loss of family privacy as a result of the nurses' presence. They referred to this as the "double-edged impact of support rendered by the presence of professionals in the home on the one hand and the infringement on family privacy on the other" (p.113).

Thomas (1986) found that the necessary intrusion of health care providers in the family's home placed an enormous strain on the family unit. Parents discussed their difficulty in keeping information confidential and also noted inhibited sexual intimacy when health care providers were in the home. These findings support the experiences described by parents in this study in such statements as: "The hardest thing is having somebody in my home, its not easy...How do you make love with somebody in your house when there is someone else there?" and "If you want to have a fight, you can't really because somebody else is there...".

Parents described their feelings of isolation and a perceived lack of support as comprising the second component of the living in a fishbowl phenomenon. Parents described feeling isolated from others as a result of several factors including: a lack of support by family or friends who did not understand the family's experience; the uniqueness of the child's condition and/or the family's experiences; the lack of time or spontaneity to foster old relationships or build new ones; and stigma, others not wanting to be associated with the child or family due to the child's disfigurement or disability. These factors contributed to a lack of social integration; parents expressed

feelings of being segregated in their "fishbowl".

No other references to the nature of family life being compared to "living in a fishbowl" were found in the literature on the experiences of parents caring for a child with a long-term health condition. However, several researchers have described the constant scrutiny and feelings of isolation and lack of support experienced by parents of children with medically-fragile conditions. Thomas (1986) in her study of families caring for a child who was ventilator-dependent found that isolation related to the families' necessary preoccupation with their child's care and the lack of support from families and friends was mentioned by all of the participants. Several other researchers (Aday & Wegener, 1988; Andrews & Nielson, 1988; Feinberg, 1985; & Teague et al, 1993) have reported that parents caring for a child with a medically-fragile condition at home saw friends and family less, social activities became less frequent due to the unpredictable needs of the child, and that it was difficult to find qualified individuals to care for the child.

Wills (1983) in her study of mothers providing home care for a child with a tracheostomy, reported mothers concerns regarding the need for support and feelings of isolation. Participants reported feeling resentful of other mothers who could do normal things like "walk the dog". Her findings also indicated that mothers described their entire lifestyles as changing and the concurrent grief they experienced over being unable to resume their previous lives. These results parallel the findings of the present study, particularly surrounding women as primary caregivers. As noted in the description of findings, mothers were the primary caregivers of all of the children in

this study. As a result, their roles, responsibilities, and relationships were often significantly more affected by the caregiving experience than that of other family members.

Parents emphasized that the support they received from the NRP and other community services was essential in order for them to care for their child at home. However, the constant scrutiny experienced by family members disrupted family relationships and functioning as well as contributed to the emotional strain of caregiving demands. In addition, the perceived isolation and lack of support described by families contributed to a sense of social isolation, adding to the already overwhelming burden of caregiving.

The findings of this study point to the parents' need for increasing support from health care providers and others in managing the care of their child with a medically-fragile condition at home. This is confirmed by existing research on the experiences of families caring for a child with a medically-fragile condition at home. For instance, Patterson, Leonard and Titus (1992) found that families caring for children with medically-fragile conditions at home experienced more negative effects on other family members' health when the child's care needs were high and when the support and resources required to meet the care demands were inadequate. In addition, an exploratory study by Youngblut, Brennan, and Swegart (1994) of families caring for medically-fragile children found that families reported a need for increased support, specifically regarding alternate child care arrangements, including daytime care, overnight care, and respite care. Clearly, further investigation into the support

required by these families in caring for their child with a medically-fragile condition at home is warranted.

Summary

An indepth discussion of selected key concepts described in Chapter Four has been presented. The stages in the evolution of parents as expert primary caregivers were discussed in relation to existing literature on the nature of health care relationships. Next, an indepth investigation of parent - health care provider relationships was presented, with a focus on the convergent and divergent paradigms which are at the root of parent - professional interactions. This was followed by an exploration of the unique findings of the parents' experience in relation to the nature of caregiving demands resulting from the fragility of the child's condition and the complexity of the child's care requirements. Finally, an investigation of the nature of parental caregiving in relation to the parents' experience of "living in a fishbowl" was put forth. Emphasis was placed on the relationship of findings to existing theoretical and research literature introduced in Chapter Two as well as additional literature reviewed as a result of the findings of this study.

CHAPTER SIX

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

This study was designed to discover and describe the experiences of parents who care for their child with a medically-fragile condition at home. Specifically, the primary objectives of this study were to gain a deeper understanding of the challenges these parents face in caring for a child with a medically-fragile condition and how these parents manage their child's care at home.

The increasing trend towards deinstitutionalization of children with medically-fragile conditions has placed increased caretaking responsibilities on families and communities. A review of the literature revealed a significant gap in the understanding of the experiences of parents who care for their child with a medically-fragile condition at home. Eliciting family members' perspectives of their experiences is essential in order to design and implement services which are effective and responsive to the needs of this population.

The qualitative method of phenomenology was employed to elicit an understanding of the parents' experiences, and to answer the questions: 1)What are the challenges parents face in caring for a child with a medically-fragile condition at home?, and 2)How do parents manage the care of their child with a medically-fragile condition at home?

Data collection occurred through indepth interviews with three couples and three mothers of six children with medically-fragile conditions. The children's

underlying medical conditions included: Opitz-Friaz syndrome requiring a tracheostomy and enteral tube feeding; severe Cerebral Palsy including asthma, bronchitis, and recurrent acute pancreatitis requiring aggressive suctioning, respiratory treatments, and enteral tube feeding; complications from prematurity (born at 28 weeks gestation) requiring a tracheostomy and enteral feeding; severe eczema, asthma, and potentially fatal food and environmental allergies requiring frequent emergency interventions for anaphylactic shock; complications from severe prematurity (born at 26 weeks gestation) with malabsorption problems requiring enteral tube feedings and frequent hospitalizations; and Barters Syndrome with Spina Bifida including progressive renal failure, post kidney transplant. Children ranged in age from two and a half years to eighteen years on initial interview. Guidelines for the protection of human rights and ethical considerations were adhered to.

All interviews were audio-taped and transcribed verbatim. Through a process of ongoing data collection and simultaneous data analysis, the experiences of the participants were described, and confirmed in subsequent interviews.

Parents began the portrayal of their experience by describing the onset of their experience of caring for a child with a medically-fragile condition. Participants described three critical time periods in their progression from novice to expert caregiver, identified as: Hospital-based care: Initial diagnosis and treatment; Transition from hospital to home-based care; and Home-based care: Ongoing critical periods. The parents' descriptions of becoming their child's primary caregiver was conceptualized as progressing through four distinct stages across the time frame of

these three critical periods. Moreover, due to the medically-fragile nature of the child's condition, the process of becoming the child's primary caregiver inherently involved developing ongoing relationships with health care providers. These four stages depict both the evolution of the parent from novice to expert caregiver and the concurrent evolution of the parent - health care provider relationship. These stages were identified as: Assigning the caregiver role: Blind faith; Preparing for action: Disillusionment and raising one's voice; Assuming the caregiver role: Learning caregiving expertise; and Adjusting to home-based care: Building supportive relationships.

In their description of Stage Four, parents emphasized the importance of building supportive relationships with health care providers in the ongoing care of their child. Parents described attempting to develop supportive relationships with health care providers which were defined as collaborative, interdependent, and non-hierarchial. Parents identified honesty, empathy and understanding, and mutual respect as three fundamental characteristics of supportive parent - health care provider relationships. In contrast, conflictual parent - health care provider relationships were described as resulting from health care providers who demonstrated divergent perspectives regarding: the role of parents as expert caregivers; the child's ongoing care and treatment; or the value placed on the child and his/her well being, particularly surrounding life and death issues. The description and analysis of these preceding components of the parents' experience laid the foundation for the major focus of analysis: The dynamics of parental caregiving for a child with a medically-

fragile condition at home.

The dynamics of parental caregiving was conceptualized as a process of balancing the nature of caregiving demands with the nature of parental caregiving. This was envisioned as a see-saw in which the nature of caregiving demands is being counter-balanced with the nature of parental caregiving. Parents described the nature of caregiving demands as being shaped by three key factors: the fragility of the child's condition, the complexity of the child's care requirements, and the child's developmental needs. Comparatively, parents' characterized the nature of parental caregiving as being shaped by: the nature of family life, the nature of support received, and the nature of parental coping approaches.

During the initial critical period of diagnosis and treatment of the child's condition, the see-saw was conceptualized as being in a state of imbalance, that is, a state perceived by parents as exceeding their resources to cope with the demands of caregiving and characterized as endangering the child's well-being. As the child's condition improved and the parents became experts in the child's care, taking on the primary caregiving role, the see-saw moved towards a balanced state. Optimally, at the advent of the second critical period, the transition from hospital to home care, the see-saw was characterized as being in a balanced state. That is, the nature of the demands associated with caring for the child were counterbalanced by the nature of parental responses to these demands.

In a balanced state the relationship between the nature of caregiving demands and the nature of parental caregiving was described by participants as being in a state

of flux since the nature of parental caregiving involved continuously readjusting to changes in the caregiving demands and to changes in the nature of family life. Moreover, the inherently fragile nature of the child's condition and the child's related susceptibility to exacerbations or deteriorations in his/her condition played a key role in the vulnerability of caregiving demands exceeding the parents' resources for providing care, thereby returning the see-saw to a state of imbalance. Once the parents adjusted to the transition from hospital to home-based care, they described continuing to face ongoing critical events in which the child's caregiving demands exceeded the parents' resources for providing care.

Conclusions

Several conclusions were drawn from the study's findings regarding the parents' experience of caring for their child with a medically-fragile condition at home. These conclusions are listed below.

1. Parents' experiences of caring for their child with a medically-fragile condition evolved over three critical time periods. These are: a)the initial diagnosis and treatment of the child's condition in a hospital setting; b)the transition from hospital to home-based care; and c)ongoing critical periods which occur subsequent to the initial transition from hospital to home-based care.
2. The process of becoming the child's primary caregiver inherently involved developing ongoing relationships with health care providers.
3. The evolution of the parents from novice to expert caregivers and the concurrent evolution of parent - health care provider relationships progressed

through four distinct stages across the time frame of the critical periods.

These four stages are: a)Assigning the caregiver role: Blind faith; b)Preparing for action: Disillusionment and raising one's voice; c)Assuming the caregiver role: Learning caregiver expertise; and d)Adjusting to home-based care: Building supportive relationships.

4. The dynamics of parental caregiving of a child with a medically-fragile condition were viewed as a process of balancing the nature of caregiving demands with the nature of parental caregiving.
5. The child's increased vulnerability to medical crises underpinned the unique nature of the experiences of parents caring for their child with a medically-fragile condition at home.
6. Re-hospitalizations of the child were stressful on the family for several reasons including: a) the uncertainty of how the child would cope with the exacerbation or deterioration of his/her condition; b) the increased emotional distress associated with the child's change in health status and with being away from home and/or separated from each other; and c) the uprooting of family routines and rituals.
7. Since the caregiving of the child occurred within the system of the family unit, stressors in other areas of family life impacted on the degree to which the parents could respond to the child's caregiving demands.
8. All of the mothers in this study viewed themselves as their child's primary caregiver. As a result, their roles, responsibilities, and relationships were

- often significantly more affected by the caregiving experience than that of other family members.
9. Parents described constant scrutiny, isolation, and lack of support as significant elements of their experience of family life.
 10. Supportive relationships with health care providers and others played a key role in offsetting the impact of the nature of caregiving demands and the competing demands of family life. Parents identified honesty, empathy and understanding, and mutual respect as three characteristics of supportive parent - health care provider relationships.
 11. Parents did not expect health care providers to share the *same* perspectives as they did regarding the child and his/her care, however they did expect health care providers to demonstrate a respect for their perspective regarding: a) the role of parents as expert caregivers; b) the child's ongoing care and treatment requirements; and c) the value placed on the child and his/her well being.
 12. The parents utilized several coping approaches to assist in coping with the challenges of caregiving demands and the competing demands of family life. These included: anticipating and preparing for developmental transitions, cultivating support, ongoing education, identifying the warning signals and taking a break, maintaining a positive focus, just doing it, and fostering the integrity of the family unit.

Implications

Many implications for nursing were derived from the description, analysis and discussion of findings. Specifically, implications for nursing practice, education, and research will be put forth in the following section.

Implications for Nursing Practice

There are numerous implications for nursing practice which can be derived from the findings of this study. Of primary importance, is that nurses and other health care professionals focus on understanding the experiences of families caring for children with medically-fragile conditions as described by them, rather than acting on the perceived needs of families as perceived by professionals. Moreover, nurses need to carry out assessments *with* families rather than *on* families and ongoing interactions should include anyone the family considers "family" or important individuals in the family's life (Bond, Phillips & Rollins, 1994). It is important that nurses collaborate with parents in identifying and prioritizing the family's needs and offer nursing care which is consistent with the parents' perspectives of their needs rather than working from the assumption that "the nurse knows best".

In working with families of children with medically-fragile conditions, nurses need to utilize a holistic and family-centered perspective which views the child's physical condition within the context of the whole person and within the context of his/her family and community. In particular, nurses need to take into account the needs of the whole family rather than focusing solely on the needs and concerns of

the child with a medically-fragile condition. In addition, nurses need to provide family-centered care which focuses on empowering the unique strengths and coping behaviours of each family. That is, nurses need to focus on the unique aspects of individual families rather than treating all families or children alike.

Initial Parent - Health Care Provider Interactions

During the initial diagnosis and treatment of the child's condition nurses and other health care professionals need to interact with family members in a manner which promotes collaborative relationships rather than fostering the blind faith and subsequent disillusionment in health care providers which was described so vividly by the participants of this study. During this period, nurses need to contribute to providing family members with an environment which is conducive to parents being able to work through their feelings of being overwhelmed with the technological support and expert caregiving that their child requires.

As the parents adjust to the child's condition and caregiving requirements, nurses need to work in partnership with family members in fostering parental caregiving expertise. Specifically, nurses need to set mutual goals with families in determining a plan of care which allows for parents to gradually take on increasing caregiving responsibility, decision-making, and control over the care of their child. In doing this, nurses need to avoid perpetuating the myth that women (that is, the child's mother) must be the primary caregiver of the child. Whenever possible, both parents should be encouraged to learn the caregiver role in order to increase the family's ability to cope with the care of the child once the child is discharged home.

Managing Transitions

The transition from hospital to home based care was described as one of the most stressful aspects of the family's experience. Nurses need to assist families in anticipatory planning of this and other major transitions. In order to do this effectively, nurses need to have an understanding of the family's strengths, coping behaviours, existing and possible sources of support, and the nature of family life including competing family demands. By helping families to anticipate and prepare for future events, nurses can assist in decreasing the distress and uncertainty associated with these transitions.

In planning the transition from hospital to home and in the ongoing home-based care of the child, nurses must have a sound knowledge base regarding existing services available to this population so that they can successfully assist families in exploring possible support services and resources. Nurses also need to problem solve with parents regarding contingency plans for possible events such as electrical shutdowns, medical emergencies, and cancellations of home nursing services (Hill, 1993).

Nurses can also play a key role in assisting family members to cope with changes in the nature of family life. Specifically, nurses need to help parents, particularly primary caregivers, to generate possible strategies to facilitate them in pursuing alternate activities or roles as is desired. This will contribute to the mental and physical well-being of the parents as primary caregivers. Nurses can also facilitate parent-to-parent support to decrease the sense of isolation associated with the

uniqueness of the child's condition and the nature of family life.

Nurses need to collaborate with other members of the interdisciplinary team as well as the parents in preparing for the transition of the child's care from hospital to home. In particular, nurses and families need to identify ongoing community services and resources which will be accessible to families in the ongoing home-based care of their child. Wheeler and Lewis (1993) encourage the designation of a primary physician for families caring for a child with a medically-fragile condition. This physician, who preferably lives in the family's community, can have frequent contact with the family, work in conjunction with other community-based professionals in the day-to-day management of the child's condition, and coordinate with medical specialists in tertiary care centres regarding the child's more acute-care needs. Together with the other members of the interdisciplinary team, nurses can also coordinate follow-up services for the child so that visits to different specialists can be grouped together - this is particularly important for those families living in rural areas.

Nurses can also assist families in fostering the child's progression through major developmental transitions such as entering the school system, transitions within the school system, and launching the child out of the family home. By working in partnership with families, nurses can assist in building effective community services to support families in the day-to-day care of their child and during developmental transitions and periods of increased vulnerability.

Ongoing Parent - Health Care Provider Relationships

In their ongoing relationships with family members, nurses need to demonstrate a spirit of cooperation and partnership in the care of the child and endeavour to build relationships which are collaborative, interdependent, and non-hierarchical. Nurses need to convey honesty, empathy and understanding, and respect in their interactions with family members. In particular, nurses need to demonstrate a respect for parents' perspectives regarding: the role of parents as expert caregivers, the child's ongoing care and treatment requirements, and the value of the child and his/her well being.

Nurses need to demonstrate leadership in empowering family members in their caregiving role rather than contributing to a sense of powerlessness. By utilizing communication skills which acknowledge and validate the parents' experience and caregiving expertise nurses can support families in coping with and growing from their experience. Moreover, nurses can build on family strengths by commending effective coping approaches and assisting family members in realizing and mobilizing the strengths of individual family members and the family unit as a whole.

Nurses and other health care providers need to support parents in their caregiving decisions. Professionals need to avoid imposing their own perspectives regarding the care of the child onto the family members. In particular, nurses need to avoid actions which could be perceived as discrediting the parental role or labelling parents with negative stereotypes. When conflicts arise between parents and health care providers, professionals need to take the initiative to discuss the differences in

perspective which exist and come to a mutual understanding of each other's perspectives. Moreover, Thorne and Robinson (1988) assert that nurses need to facilitate strategies which promote the progression of the relationship toward the cooperative caring that can occur in the stage of guarded alliance. In addition, nurses can play a key role in assisting family members to develop the skills required to build collaborative relationships with health care providers.

Nurses also need to take on the role of change agent in challenging the bureaucratic restrictions of health care institutions and agencies which conflict with the parents' ability to care for their child and/or place increased strain on the family unit. Nurses can act as leaders in the revision of health care agencies and systems to become more family-centered and better able to support the real needs of this population.

Nursing respite services through the Nursing Respite Program (NRP) were viewed by parents as an essential component of home-based care of the child. All of the families indicated that although they appreciated the support received from the NRP that it was inadequate in providing the support they required to care for their child at home. Perhaps most importantly, parents discussed the need for the NRP to base the number of nursing respite hours on the needs of the family rather than on the physical needs of the child. Parents also stated that they required more hours of nursing respite during critical periods, especially during the transition from hospital to home-based care when the child's caregiving demands were being incorporated into the nature of family life. Finally, parents discussed the need for increased flexibility

of respite services to increase the family's ability to participate in normal activities and maintain previous relationships, thereby decreasing the feelings of isolation by facilitating opportunities for social integration. Nurses need to pay attention to the concerns of families regarding the services provided by the NRP and to advocate for the support that parents require from community services in order to successfully care for their child at home. Inadequate support can lead to parental caregiver burnout which is detrimental to the physical and mental well-being of the parents, the child, and other family members.

Nurses also need to work with community health agencies to ensure that parents are provided with extended periods of respite in order to relieve parents of the exhausting demands of 24 hour/day care, and provide an opportunity for physical and emotional rejuvenation of caregivers. Equally important is the need for nurses to assist families to identify the warning signals associated with caregiver "burnout" and to support parents in arranging for extended periods of respite or increased utilization of alternate caregivers.

Parents also discussed the intrusive nature of in-home nursing respite services. Nurses and other health care providers need to be aware of family routines and rituals and to respect the privacy of family members when providing in-home nursing support. In addition, nurses need to respect the function of family boundaries and maintain a professional capacity when providing in-home respite care.

Finally, nurses and other health care providers need to ensure the development of formal and informal evaluation mechanisms and ongoing communication between

health care providers and family members. Open lines of communication between health care providers and parents, and ongoing evaluation of the parents' experience and the effectiveness of existing support services is essential in order to meet the needs of families caring for a child with a medically-fragile condition at home.

Implications for Nursing Education

There are several implications for nursing education which can be derived from the findings of this study. Clearly, nurses need to be educated about the experience of family's caring for a child with a medically-fragile condition at home. In addition, nursing programs need to include education on disease processes, caregiving requirements, and theories, issues, and concepts relevant to the increasing number of families caring for a medically-fragile child at home. For example, knowledge of the evolution of parents as expert caregivers and the concurrent evolution of the parent - health care provider relationship facilitates an understanding of the parents' experience and guides nurses to build collaborative relationships with family members.

There is also a need for ongoing education in both hospital and community settings in order to inform nurses regarding the family's experience and care requirements. Specifically, there is a need for an increased emphasis on preparing nurses for the home-based care of families caring for children with long-term health conditions from a family-centered perspective. Clinical Nurse Specialists (CNS) in the community and hospital settings are in ideal situations to provide education for

nurses providing care to these children in a variety of settings.

Finally, nurses require education and support to empower families in caring for their child. Specifically, nurses need to be educated regarding nursing interventions which acknowledge the family's experience and build on family strengths rather than limitations. These interventions include acknowledging and validating the family's experience and commending family strengths. Nurses also need to be educated regarding the benefits of building collaborative relationships with parents and how to incorporate this into their nursing practice. Finally, nurses need to be educated on their role as change agents in order to effectively challenge the bureaucratic restrictions of health care institutions and systems which conflict with the parents' ability to care for their child and/or place increased strain on the family unit.

Implications for Nursing Research

This study highlights several areas where further nursing research is required. For instance, further research which differentiates between children with different levels of medical fragility/technology dependency is required to understand the differences in experiences which might exist within this population. Longitudinal studies are also required to understand the experiences of families over time, beginning with the diagnosis of the child's condition and continuing through the many critical periods which these families face. This will also allow for further comparison between individual families. Specifically, how do the nature of caregiving demands differ over the different critical periods which these families face? How does the

nature of family life differ across participants and how does this relate to coping effectiveness? What impact do financial factors play in the dynamics of parental caregiving? Do experiences differ for families of different cultures or ethnic groups? These are only some of the questions that remain to be answered by further research into this area of study.

Further evaluation of existing support services, such as the Nursing Respite Program, would be beneficial in understanding the parents' perspectives of these services and their perceived effectiveness. Which resources do parents find most supportive in caring for their child at home? Which services do parents find least supportive? What gaps in support services or resources exist? In addition, further research is required which examines the distress families experience in relation to "support" services.

In addition, studies which include a description of health care providers' perspectives in relation to working with these families would be beneficial in shedding some light onto the supportive and conflictual interactions which occur between parents and health care providers. Future research could examine more indepth the characteristics which contribute to supportive relationships between parents and health care providers and how these characteristics change over time. Finally, further research is required which examines factors which support parents in their progression from novice to expert caregivers as well as the factors which impede this progression.

Summary

This study was designed to discover and describe the experiences of parents who care for their child with a medically-fragile condition at home. In Chapter One, the background and conceptualization of the problem was explored and the research question was introduced. In Chapter Two, a review of selected relevant literature was presented which revealed a paucity of research describing the parents' experience of caring for a medically-fragile condition at home. A review of the research method of phenomenology which was employed to address the research question was described in Chapter Three. In Chapter Four, a description and analysis of the participants' experiences was put forth. A discussion of the research findings in relation to existing theoretical and research literature was presented in Chapter Five. Finally, in Chapter Six a summary of the study was put forth, followed by a statement of the conclusions of the study and implications for nursing practice, education and research. The findings of this study contribute to a growing understanding of the experiences of parents who care for a child with a medically-fragile condition at home.

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APPENDIX A

Participant Information Letter

APPENDIX B

Participation Consent Form

APPENDIX C
Demographic Data Form

Appendix C

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The Challenges of Caring for A Medically-Fragile Child At Home:
Perceptions of ParentsDemographic Data

Participant Code No. _____

PARENTS**MOTHER:**

AGE: _____ EDUCATION _____ OCCUPATION _____

MARITAL STATUS _____

FATHER:

AGE: _____ EDUCATION _____ OCCUPATION _____

MARITAL STATUS _____

SIBLINGS:	AGE	SEX	PLACE OF RESIDENCE
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

CHILD WITH MEDICALLY-FRAGILE CONDITION:

DIAGNOSIS _____

AGE AT DIAGNOSIS _____

AGE AT INITIAL INTERVIEW _____

DATE OF INITIAL DISCHARGE FROM HOSPITAL FOLLOWING DIAGNOSIS
_____NUMBER AND LENGTH OF HOSPITALIZATIONS SINCE INITIAL
HOSPITALIZATION _____

DATE REFERRED TO NURSING RESPITE PROGRAM _____

DATE NURSING RESPITE PROGRAM SERVICES
INITIATED _____OTHER COMMUNITY AGENCIES
INVOLVED _____

APPENDIX D

Trigger Questions

SAMPLE QUESTIONS FOR INITIAL INTERVIEW

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General questions will be asked to elicit the parents perceived experiences. More specific trigger questions will be used to seek clarification or elaboration of a particular aspect of the parents' experience. Examples of questions which might be utilized follows.

1. Looking back on your experiences, what have been the challenges for you in caring for your child {will use child's name (*)} at home?
2. What impact has your child's (*) illness and home-based care had on him/her, yourself, and other family members?
3. What has been the most challenging experience for you and your family since you brought your child (*) home?
4. What has been the most rewarding experience for you and your family since you brought your child (*) home?
5. What strategies have you found most helpful in managing your child's (*) care at home?
(Examples of probe questions if necessary)
 - a) How have you managed your child's (*) health care needs on a day to day basis?
 - b) What strategies have you used to meet your child's (*) developmental needs and the developmental needs of other family members?
 - c) What have you found helpful in coping with the ongoing challenges associated with your child's (*) health care needs?
 - d) How have you managed your child's (*) health care needs with other family member's needs?
6. What formal or informal support systems have you found helpful in managing your child's (*) care at home?
7. Looking back at your experiences in caring for your child (*) at home, how do you see yourself coping with your child's care needs now compared to when he/she was first discharged from hospital?
8. What have been the major changes in your family life since your child (*) was first diagnosed with his/her health condition?

APPENDIX E

Ethics Approval