CARING FOR A CHILD WITH A PROGRESSIVE ILLNESS
DURING THE COMPLEX CHRONIC PHASE:
PARENTS' EXPERIENCE OF FACING ADVERSITY

BY

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ABSTRACT

Due to improving health care, increasing numbers of children who are affected with a progressive illness are surviving for longer periods with a complex chronic condition (Mullins et al., 1991; Tucker & Roberts, 1990). A complex chronic condition is characterized by progression of the child's illness to a point such that they require specialized, time-consuming, and sometimes round-the-clock care. The terminal phase of illness, however, may be months or even years away.

The recent trend towards home care (Seaton, 1991) means that parents must attempt to meet their child's complex and multiple needs, as well as the many needs of the family as a whole. Continuous 24-hour care of these children is emotionally and physically exhausting for parents.

The purpose of this study was to explore and describe the experience of parents caring for their child with a progressive life-threatening illness during the time the child was living with a complex chronic condition. The naturalistic research design of phenomenology was chosen for the study's methodology.

Five mothers and three couples (mothers and fathers) of children with progressive illnesses participated in a series of interviews. Parents' perspectives on their experiences were elicited and transcribed. Their accounts became the data for analysis. Data collection and analysis were concurrent.

Parents' experiences of caring for their child were conceptualized as an ongoing process of "Facing Adversity", characterized by defining and managing adversity. This

thesis describes, from parents' perspectives, how adversity was defined and managed. Concepts of normalization and chronic sorrow are considered in the conceptualization, as are the challenges of caregiving (particularly of mothers) who faced many hardships in their role, including the myriad of changes or transitions related to the increased burden of care.

Parents' experiences with the health care system are examined. While parents felt there were enough services to meet the needs of their family, and that respite care was an especially valuable service, they were overwhelmingly frustrated with the bureaucracy involved with health care delivery. Existing respite care services only partially met parents' respite needs. Implications for nursing practice, education and research are identified.

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CHAPTER ONE: INTRODUCTION TO THE STUDY

Background to the Problem

Between 1988 and 1990, there were 1,606 deaths of children between the ages of one and 17 in British Columbia. Of these deaths, 21.5% (or 346) were due to a progressive life-threatening or degenerative condition (Davies, 1992).

While these illnesses ultimately lead to death, improving medical care has extended the lifespan of these children. In doing so, however, many of these children survive for longer periods with a complex chronic condition (Mullins et al., 1991; Tucker & Roberts, 1990). A complex chronic condition is characterized by progression of the child's illness to a point such that they require specialized, time-consuming, and sometimes round-the-clock care. The terminal phase of illness, however, may be months or even years away. The recent trend towards home care (Seaton, 1991) means that parents must attempt to meet their child's complex and multiple needs, as well as the many needs of the family as a whole. Continuous 24-hour care of these children is emotionally and physically exhausting for parents. As Crenshaw-Cutchins and Mease maintain, "fatigue affects not only one's physical well-being, but also one's ability to cope....[and] the child's illness may become overwhelming..." (1985, p.88).

Presently in British Columbia, a children's hospice is being designed to meet the needs of families of children with progressive life-threatening illnesses. "Canuck Place", due to open in 1994, will be North America's first free-standing hospice for children. "Our overall objective should be to help the children and their families

achieve the best quality of life, physical, emotional, and spiritual, throughout the lifetime of the child..." (Dominica, 1990, p.3).

The need for respite or "relief" by parents who care for children with progressive life-threatening illnesses has been documented (Crenshaw-Cutchins & Mease, 1985). Based on its prototype (Helen House - a children's hospice located in England), Canuck Place will offer parents intermittent respite care as needed throughout the course of their child's illness. "Periodic respite care can provide parents an opportunity to renew their strengths and to return to a very trying situation with refreshed spirits" (Eng & Davies, 1992, p.19). Two forms of respite care are being planned for Canuck Place. The first is in-house respite care, where families can plan to bring their child to Canuck Place to stay for one or two weeks. Secondly, the hospice program will attempt to mobilize existing home respite care services in the community. For example, the Nursing Respite Program (NRP) served approximately 44 palliative care pediatric clients throughout B.C. from its inception in 1989 until the end of 1992 (P. Otterman, personal communication, January, 1993). A goal of Canuck Place will be to ensure appropriate referrals are made to existing respite care services such as the NRP, and to provide teaching to health professionals as required, about the needs of parents who care for children with progressive life-threatening illnesses (B. Davies, personal communication, November, 1992).

This study was prompted by the desire to further existing knowledge of parents' experience in caring at home for a child with a progressive life-threatening illness during

the complex chronic phase. This knowledge may be used to help maximize the quality of care offered to these families by providing direction for programs and services to be offered by a children's hospice.

Conceptualization of the Problem

In utilizing the phenomenological method, the researcher is not seeking to validate any preconceived theoretical framework and therefore must approach the phenomenon to be explored with no preconceived expectations or categories (Omery, 1983). The researcher does, however, seek to conceptualize the problem by placing the phenomenon under investigation within its known context. This gives a background understanding of the area, and helps the researcher to defend the research question.

Caring for a child with a progressive life-threatening illness is extremely stressful for parents. A study of the literature reveals that a recent trend has been to group all types of chronic illnesses together under a general chronic illness category. Many authors do not differentiate between chronic illnesses such as Spina Bifida and Diabetes, and progressive life-threatening illnesses, such as Muscular Dystrophy (MD), Cystic Fibrosis (CF), and some malignant neoplasms (Clements, Copeland, & Loftus, 1990; Diehl, Moffitt, & Wade, 1991; Walker, Epstein, Taylor, Crocker, & Tuttle, 1989). However, further added to the daily demands of caring for a child with a progressive life-threatening illness who is living with a complex chronic condition, is the progression of the illness (and its concomitant demands) and the prospect of eventual death. For these reasons, families of children with progressive life-threatening illnesses

may possess a unique set of needs as compared to families of children with non-progressive chronic illnesses. It may be helpful for health professionals to distinguish them as a unique group rather than to include them in a general chronic illness category.

While some aspects of the illness experience may be similar for both groups, important differences should also be recognized. For example, respite care, defined as "a temporary relief service for families or primary caregivers" (Dewing, 1990, p.43), can be a valuable service for any family caring for a chronically ill child who requires specialized and time-consuming care, whether the illness is chronic or progressive and life-threatening in nature. This is because both types of families have a need to be relieved from the continuous caregiving and supervision of the child. However, the latter family may have a slightly different experience because of the progressive nature of the illness and the prospect of eventual death. These families may need a more flexible type of respite care service that can respond to the changing needs of the family as the illness progresses. Perhaps these families have different emotional and/or illness-related educational needs as well.

There is an emerging philosophy that recognizes families of children with progressive life-threatening illnesses as a unique group, and it has begun to address the specific needs of these families. This philosophy is children's hospice care. Corr & Corr (1988) broadly define children's hospice care as

a program or approach to care that seeks to maximize present quality of life by adapting principles of palliative care to children themselves, to their family members, and to other concerned persons who are coping with any of the following as they are related to a child: living with serious or life-threatening

illness, the imminent likelihood of dying, or the aftermath of death. (p. 6)

The term "hospice" extends beyond a facility to a philosophy of care from which that facility's services are derived. While the adult modern hospice movement began with Dame Cicely Saunders and her founding of St. Christopher's Hospice in 1967 (Hillier, 1983), the concept of children's hospice is relatively new. The first known free-standing hospice for children opened in England in 1982, and is known as Helen House.

Since the hospice philosophy is relatively new, few research studies have been put forth in this area. A retrospective study that examined families' perceptions of the care offered to them at Helen House identified a need for respite care (Woolley, Stein, Forrest, & Baum, 1989). This same study also assessed the impact of progressive life-threatening illness on the family, and whether a children's hospice was addressing their needs. What is noteworthy in the hospice literature is the overwhelming stress faced by parents as a result of the progressive and terminal nature of their child's illness, and the need for flexibility and continuity in the care provided to their family.

As Anderson states "...it is crucial for the providers of health care to understand the meaning of sickness to those experiencing it" (1981, p.427), and furthermore that "illness must be understood within the total context of the patient's life, including the social organization of the dominant health care system and the ideological structures underlying health care practices" (1986, p.1277).

With a hospice facility due to open in the winter of 1994 in B.C., it is timely to explore parents' experiences within a Canadian culture, from which certain needs (for

example the need for respite care) may be described. By exploring the lived experience of parents caring at home for a child with a progressive life-threatening illness, at a point in that child's illness where they are in a complex chronic, but not terminal, condition, health professionals may be further guided in the types of services required by these families. It is important for nurses to listen to parents who are experiencing first-hand the issues that arise in caring for a child with a progressive life-threatening illness. The success of programs developed by a children's hospice depends partially on the accuracy with which needs are assessed, and studying the lived experience from parents' perspective will lead to a better understanding of what it is like for them.

Problem Statement

There is little research that focuses specifically on parents' experience in caring at home for a child with a progressive life-threatening illness during the complex chronic phase. What has been done in this area addresses the concept of children's hospice within a British population. With a children's hospice due to open in B.C. in 1994, it is timely to explore these parents' experience within a Canadian culture.

Purpose

The purpose of this study is to gain deeper insight into the day-to-day experiences of parents caring at home for a child with a progressive life-threatening illness at a certain point in their illness trajectory. This point in the trajectory is when the child lives with a complex chronic condition, and is in need of specialized and time-consuming care, but is not yet in a terminal phase. The primary objective of this study

is to gain knowledge and understanding of how these parents manage their child's illness within their family structure, and what this experience is like for them, so that direction may be provided for the implementation of services by Canuck Place.

Research Question

What is the experience of parents caring at home for a child with a progressive life-threatening illness who lives with a complex chronic, but not terminal, condition?

Definition of Terms

Parent: biological or adoptive parent(s) (mother, father, or both) of a child with a progressive life-threatening illness, who has/have cared for this child for at least one year. A parent may be single, separated, divorced, married or widowed.

Child: a child of either sex who has a progressive life-threatening illness, and presently lives with a complex chronic, but not terminal condition. This child must be between the ages of two and seventeen, and living at home with at least one parent.

Home: any residential dwelling (i.e. not institution) in which the affected child and at least one parent lives.

Progressive life-threatening illness: a chronic illness, whose illness state involves a course of slow degeneration and premature death (Eng & Davies, 1992).

Complex Chronic

Condition: a state or period of time in which the child with a progressive life-threatening illness requires specialized and time-consuming care due to the advancement of his/her illness, but has not yet reached a terminal condition; this "state" may last for months, or years.

Specialized and

time-consuming care: care of a child with a progressive life-threatening illness that includes activities of daily living and health-related care needed to sustain life, promote comfort and growth, and/or prevent an otherwise quicker degeneration of illness, that requires specific training initially by a health professional; this care also requires that a trained caregiver must be available to attend to the child 24 hours per day.

Terminal Condition: the end-stage of a progressive life-threatening illness in which the child has three weeks or less left to live.

Children's Hospice: "Children's hospice is a concept of care addressing the physical, psychological, social, and spiritual aspects of the lives of people who have lost a child, as well as those aspects of the lives of children with life-threatening conditions and their families" (Armstrong-Dailey, 1990, p.338).

Hospice Respite

Care/Services: Support provided by a trained caregiver to parents of children with progressive life-threatening illnesses by relieving them from

the continuous 24-hour care of the child for a period of time.

Hospice respite care may be centre-based or may consist of the mobilization of existing community respite services.

**Respite Care/
Services:**

Support provided by a trained caregiver to parents of children with many types of chronic illness (i.e. not limited to families of children with progressive life-threatening illness) by relieving them from the continuous 24-hour care of the child for a period of time.

Assumptions

- 1.) Parents are concerned with the well-being of their child.
- 2.) Parents have the ability to reflect on their experiences and needs in caring for a child with a progressive life-threatening illness, and are able to articulate these reflections to the investigator.
- 3.) Parents understand the basic nature of their child's illness and that it is progressive and life-threatening.

Limitations

A limitation of this study was the lack of time available to parents, which resulted in two parents being unable to complete second interviews. Also, the 7:1 ratio of married to single participants is not reflective of the general population. Of concern here is that single parents of children who live with a complex chronic condition may face greater challenges in caring for their child, and yet they were not well represented

in this study. Furthermore, a low number of single-parent participants may indicate an even greater strain on available time.

Significance of the Study

The scientific significance of this study is that it will provide insight into parents' daily experiences at home caring for a child with a progressive life-threatening illness at a specific point in the illness trajectory. This research will contribute to an existing body of knowledge, and suggest direction for further research.

The practical significance of this study is that the findings may have implications for respite services to be offered through Canuck Place, and will guide nurses in community and hospital settings who care for children with a progressive life-threatening illness and their families by providing insight into parents' daily needs and experiences.

Summary

This chapter introduced the proposed research study. A background to the problem described how, with improving medical care, children with progressive conditions are living longer. As a result, these children spend more time living with a complex chronic condition, where their disease has progressed to such a point that they require specialized, time-consuming, and often round-the-clock care. Many authors do not differentiate between non-progressive and progressive chronic conditions. An emerging philosophy that recognizes families of children with progressive life-threatening illnesses as a unique group is children's hospice care. In conceptualizing the

research problem, it was noted that plans were under way for the opening of North America's first freestanding children's hospice in Vancouver, British Columbia. The research question "What is the experience of parents caring at home for a child with a progressive life-threatening illness who lives with a complex chronic, but not imminently terminal, condition?" was thus timely. The problem statement and purpose of the study were put forth, and relevant terms were defined. Assumptions and limitations of the study were described. Finally, the scientific and practical significance of the study were proposed.

CHAPTER TWO: LITERATURE REVIEW

Introduction

Literature is presented to provide a background to the phenomenon under study, and to ground the research question in a body of knowledge.

There is an abundance of literature describing various aspects of caring for a child who has some type of long-term illness. Most authors have not distinguished between chronic illnesses such as Spina Bifida, and progressive life-threatening illnesses such as MD or CF, but instead have grouped both types of illnesses under one category for their studies. Their findings do present information about what it is like to be a parent caring for a child with a long-term illness. As mentioned previously, some experiences for these two types of families may overlap, and thus the findings are relevant in so far as they describe that information that may be common to the two groups. Therefore, a number of these studies will be addressed in this review. These studies have been further grouped into sub-headings ("Parents' Perceptions of their Needs", "Adaptive Tasks", "Normalization", and "Critical Periods"). In analyzing their usefulness to this study, they must be examined closely for the guidance they provide to nurses who work with families of children with progressive life-threatening illnesses.

As previously mentioned, however, it is not entirely beneficial to group the two types of illnesses into one category. This is due to the fact that even in the complex chronic phase of a progressive life-threatening illness, families have to contend with changing needs as the illness progresses, and they continuously face the eventuality of

death. We must therefore look further to an emerging body of literature that focuses on children's hospice. It is comparatively much more sparse in amount, but it explores issues related specifically to caring for a child with a progressive life-threatening illness, and it is this particular population which is addressed in this study.

The literature will thus be reviewed under two main headings: a non-categorical approach to chronic illness, and a hospice approach which specifically addresses that population of children with progressive life-threatening illnesses. Under the "hospice approach" heading, a section on "home care" will be included, since this concept is relevant to the hospice philosophy.

Non-Categorical Approach to Chronic Illness

Parents' Perceptions of their Needs

Researchers have recently attempted to find common threads among what they group together as chronic illnesses, in terms of the perceived needs of these families.

Diehl et al. (1991) used a focus group interview technique to identify the needs of parents of children with medically complex conditions. These authors assert that children who have complex medical needs require an extraordinary quantity and quality of care, and that this care requires complex orchestration which places enormous demands on parents. Twelve groups of issues and concerns were identified in the study: family issues; illness-specific information; equipment issues; need for case management; financial assistance issues; varying child-education needs; medication and pain management; hospitalization issues; daily physical needs; child's emotional and

communication needs; need for growth and development information; and death and dying issues.

According to Diehl et al. (1991), the intensity of the care needed for these children impacted all levels of family relations and all family members. Under family issues, the lack of respite care surfaced repeatedly. The studies included children with both chronic illnesses and progressive life-threatening illnesses, and thus the general findings could apply to both groups of families.

In a separate study, Walker et al. (1989) mailed questionnaires on perceived needs of families to parents with children who have chronic health conditions. Results 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" (Walker et al., 1989, p.201). When asked about the importance of services, 47% of the respondents indicated that respite services were very important to them, 16% indicated that respite services were somewhat important, and 37% said they were not important. In interpreting these results, two points must be noted: firstly, illnesses such as hearing disorders and diabetes (which likely do not precipitate a need for respite services) were included in this study; and of the 16 categories of illnesses addressed by this study, only one (CF) is considered a progressive life-threatening illness. Secondly, the study sample was predominantly white, middle class, and well educated. The results of this study therefore are limited in generalizing about the importance of respite care to parents of children with progressive life-threatening illnesses. It is still noteworthy, however, that

almost half of the respondents viewed respite care as a very important service.

Parents' Perceptions of Critical Periods

Clements et al. (1990) examined parents' perceptions of specific periods frequently viewed as difficult in caring daily for a chronically ill child. The authors interviewed 30 families of children who had diabetes, cancer, or CF (i.e. sample consisted of families of children with both chronic illness and progressive life-threatening illness). Using grounded theory methods, the authors developed a model describing these critical times within a nuclear family. It was concluded that "the family of a chronically ill child develops specific ways of coping in an attempt to meet the needs of all of its members" (Clements et al., 1990, p.158), and that when emotional and physical support is available to meet these needs, equilibrium is achieved. When individual needs increase dramatically or sources of support change, however, a state of disequilibrium exists. These periods of family disequilibrium were identified as "critical times". Critical times were created by the following increases in individual needs: the initial impact of diagnosis, and times of increased physical symptoms in the ill child. They were also created by changes in support structure, such as relocation of the child, parental absence, or developmental changes. It was argued that through predicting these critical times, the health care team is able to optimize and maximize the effectiveness of their interventions.

These findings may be very important to families of children with progressive life-threatening illnesses. For example, all children with progressive life-threatening

illnesses will experience increased physical symptoms as their disease progresses, which may precipitate a "critical time". Understanding this possibility could lead to anticipatory health care guidance for these families. Also, since the findings suggest that emotional and physical support assists parents in meeting their needs and maintaining equilibrium, (thus preventing a "critical time"), it is important to explore whether respite care is perceived by parents as a useful form of this type of support.

Adaptive Tasks

Many authors who write about effective family coping in the face of a chronic illness focus on certain adaptive tasks which must be accomplished (Canam, 1987; Mailick, 1979; Futterman & Hoffman, 1974; Hymovich, 1976). Hymovich (1976) claims that whenever a child becomes ill, stress is created within that child's family. She states that all parents have certain basic needs when their family is stressed by a child's illness, regardless of the child's age, type of illness or therapy. Furthermore, in order for parents to recover from the crisis presented by their child's illness, they are called upon to accomplish three main tasks: to understand and manage their child's illness; to assist their child in understanding and coping with the illness; and to meet the needs of family members as well as those of the ill child. According to Hymovich, then, the proposed tasks apply to parents of children with both chronic illnesses and progressive life-threatening illnesses. It can be argued, though, that there may be slightly different or additional needs of the latter group of parents, so that components of the tasks may differ. For example, the task of "managing their child's illness" may

include "preparing a child and family members for the death of that child", or "adapting to the changing physical needs as a result of the progressive nature of the illness". It has been shown that parents often need support in caring for a child with a progressive life-threatening illness (Diehl et al., 1991; Woolley et al., 1989). It can therefore be suggested that parents may need assistance and support in accomplishing these tasks.

Normalization

Normalization is "an ongoing process of actively accommodating the child's evolving physical, emotional, and social needs" (Deatrick, Knafl and Walsh, 1988, p.15). In a study of families of children with long-term medical problems, Anderson (1981) concluded that "...one of the strongest notions evident among parents who presented themselves as coping well with their child's sickness was the phenomenon of normalization" (p.428). In an 1982 study, Anderson and Chung follow up on this concept of normalization, maintaining that one parent's decision to withhold information about the terminal nature of her child's illness was part of the normalization process: "Our data suggest that the decision not to divulge the nature of the sickness was a way of sustaining some semblance of normal life..." (Anderson & Chung, 1982b, p. 260).

According to these studies, normalization is important to parents' ability to cope with their child's illness. It would be beneficial to learn if this concept is important to parents of children who are living with a complex chronic condition as part of a progressive life-threatening illness. If so, then how can health professionals assist parents with this process?

Children's Hospice

Since the concept of children's hospice is relatively new, few research studies have been put forth to date, and most of these studies have examined issues in a British context. Even though British culture is comparable to that of Canada, Britain does have a different health care system and this may have implications for applying British findings to a Canadian population. Still, the findings of these studies are useful in presenting certain needs and perceptions of parents who care for children with progressive life-threatening illnesses.

Woolley et al. (1989) completed a retrospective study of 25 families attending Helen House (a children's hospice in Britain). Using a semi-structured questionnaire to interview parents, they found that the impact of the illnesses on the families studied was substantial, and that marital stress, financial and employment problems, and emotional difficulties for both the ill child and his/her siblings, were concerns. The need for respite care emerged as a common theme, and indeed the need for a sitter/child minder for their ill child was the most frequently mentioned concern. According to 60% of the parents, the difficulties in obtaining child minders limited their lives to a substantial degree. The parents also experienced high levels of psychological difficulties, with the mothers carrying much of the burden of the emotional problems. "These problems, which are largely unremitting, are especially worrying in view of the length of the children's illnesses (Woolley et al., 1989, p.701).

Families who were attending the hospice for respite care were able to draw

support from other families there. This was seen as important, since these families often face a long, isolating, uphill struggle typical of many degenerative conditions (Woolley et al., 1989). The authors concluded that children's hospices should be able to address certain issues, including the provision of flexible care and support for the whole family, continuity of support after the death of the child, help with anxiety over symptoms, and help with the physical problems of daily living.

A previous study done by Woolley, Stein, Forrest, and Baum (but published subsequently, 1991) asked parents of children with life-threatening illnesses whom (if anyone) they saw as being a "cornerstone carer" for their child (also called "case manager" and "care coordinator"), and which components of care they valued most. They found that these parents most valued: mutual respect and compatibility; availability; acceptance of parents' distress; understanding the illness; knowledge of available services; continuity of care through illness and bereavement; and a sense of humour. Continuity of care through illness and bereavement was especially important because many of the children suffered long, slow deterioration. These parents frequently emphasized the difficulty in identifying sources of help. Furthermore, they "described the complex task... of obtaining and orchestrating help in a way that still left them feeling in control of their own lives; lives already complicated and stressed by the impending loss of a child" (Woolley et al., 1991, p.221).

These studies provide insight into parents' general experiences, needs and perceptions of hospice care, but further research is required to develop this knowledge.

For example, many of the components of care identified in the study done by Woolley et al. (1991) could be studied in greater depth: what kind of support do parents require at different times, and/or what form of help might parents need with their child's activities of daily living?

Several authors have also advocated on behalf of children's hospice. Crenshaw-Cutchins and Mease state that "if service professionals...are to offer a holistic program of services to families with terminally ill children, they must provide the necessary emotional support, as well as tangible ways to relieve parents from the continuous 24-hour care of the child" (1985, p.87). In the first year at Helen House, most children were admitted for some form of relief care which included relief care on a planned basis or to enable the family to cope with some crisis (Burne, Dominica, & Baum, 1984). Dominica (1990) supports the need for respite care for families of children with life-threatening illnesses as one of the many services required by these families. "The keynote to paediatric care must be flexibility....for the needs of each family and each day are different" (Dominica, 1990, p.5).

Home Care

Most authors agree that home care of children with progressive life-threatening illnesses is optimal. Athreya and McCormick state that "it is obvious that community-based care and home care will make it easier for these families and cause less disruption to the normal lives of the children" (1987, p.124). Eng and Davies assert that "a major challenge for providing health care to children with progressive life-threatening illnesses

is to create a flexible and responsive continuum of care.... [to] allow children to remain in the customary setting of their home for as long as possible" (1992, p.18). However, as Anderson affirms, "...too often health care professionals take for granted that these movements are in the best interests of all of their clients and fail to recognize the complex factors that influence people's management of illness in daily life" (1990, p.72). Although families are willing to assume the caretaking role, adequate support is not provided for those who must take on this responsibility: "the services fall short of easing some of the hardships, both economic and emotional, that are part and parcel of caretaking" (Anderson, 1990, p.75). Care should be based on needs that are identified by parents, recognizing the complex factors that influence parents' management of their child's illness in daily life.

Summary

Much of the research describing various aspects of caring for a chronically ill child does not distinguish between chronically ill children and children with a progressive life-threatening illness. Some of the issues important to these two types of families may overlap. To this extent, these studies add valuable information about what it is like for parents who care for a child with a long-term illness.

From these studies, it has been shown that huge demands are placed on parents when their child requires complex care, and that these parents have a myriad of concerns and needs. The intensity of care needed for these children impact all levels of family relations and all family members. The need for respite care was identified, but

needs to be further explored within this study's sample population. The concept of normalization was perceived as being important to some families' abilities to cope. Also, the achievement of parental "tasks" was advocated to help families cope with their child's illness, but again this needs to be described for parents of children with progressive life-threatening illness. Finally, when emotional and physical support is made available to families of children with complex care needs, equilibrium is achieved. Within the child's illness, it was discovered that certain events place a family at risk for disequilibrium, and that with this knowledge health care professionals can anticipate and plan for appropriate support measures to offset these "critical periods".

Children's hospice literature is emerging to address that population of children with progressive life-threatening illnesses, and their families. What is noteworthy in the hospice literature is the overwhelming stress faced by parents as a result of the progressive and terminal nature of their child's illness, and the need for flexibility and continuity in the care provided to their family. With illnesses that may last for years, parents face an uphill battle against a long and slow deterioration.

While the studies done to date provide relevant data about parents' experiences, they have been done in Britain and it would be useful to gain parents' perspectives within British Columbia. With a children's hospice due to open in B.C. in 1994, this study is timely and will add to an emerging body of literature, as well as focus on a different cultural population than previous hospice studies.

CHAPTER THREE: METHODOLOGY

Introduction

This chapter describes the methods utilized to study the experience of parents who care for a child with a progressive life-threatening illness during the complex chronic phase. Because phenomenology is concerned with understanding human experience as it is lived (Oiler, 1982), this naturalistic research design was deemed the most suitable for exploring the research question.

This chapter will describe the chosen methodology, the sampling process, inclusion criteria for selection of study participants, participant recruitment, description of the participants, data collection and analysis, methods of determining reliability and validity, and measures taken for protection of human rights.

Overview of Phenomenology

Phenomenology was the method of choice in this research study. The phenomenological method is an inductive, descriptive research method, the goal of which is to describe the total systematic structure of lived experience, including the meanings that these experiences have for the individuals (Omery, 1983). During this process, the researcher moves back and forth between the subjective data and theoretical abstraction until he or she has an understanding of the meaning of the experience to the participants. This perspective allowed the investigator to find out from parents what caring for their child with a progressive illness meant to them within the context of their every day lives.

Sample Selection and Selection Criteria

Sampling was executed on the basis of individuals' ability to speak to the phenomenon of study. The researcher should "maximize opportunities to obtain the most insightful data possible, ideally selecting informants according to their knowledge base and receptivity" (Morse, 1987, p.183). To ensure appropriateness of the sample, or representation of information, the investigator chose participants who could facilitate understanding and insight into the phenomena of study (that is, any parent who cared for a child with a progressive life-threatening illness during the complex chronic phase).

Theoretical sampling was utilized to obtain participants for this study. In qualitative research, sample size is based upon theoretical saturation of the data (Sandelowski, 1986). Sample size was therefore difficult to determine a priori, although it had been suggested that six to eight subjects would be an adequate number for a masters thesis utilizing phenomenological methods. The final sample size was eight, as it was at this point that themes were recurrent and the conceptualization of the experience developed by the researcher was validated by the participants.

Parents of children between 2 and 17 years of age were sought as study participants. Canuck Place will serve children up to 17 years of age, hence this age was chosen as the upper limit. Parents with a child under two years of age may not have had extensive experience in caring for that child, and may not have been able to provide the researcher with insight into the research question. Diagnosis (or suspected diagnosis) of the illness must have occurred at least 12 months prior to participation in

the study, again so that all participants possessed adequate experience as a basis for their responses to the research questions. The perspectives of both parents would have been optimal, since gender differences do occur in terms of response to illness (Lynam, 1987; Mahon, 1992; and Stevens, 1989). The majority of volunteers, however, were mothers (the child's primary caregiver), which was acceptable and consistent with research into caregiving experiences done by others (Anderson & Elfert, 1989; Bridges & Lynam, 1993). It was required that the parents speak English fluently and reside in the lower mainland; therefore, some families who would otherwise be eligible may not have been included in this study. The affected child could not be in the terminal phase of illness since it was anticipated that parents' experience would be significantly different. Also, the affected child had to be at a certain point in his/her illness trajectory, such that he/she lived with a "complex chronic condition" and required "specialized and time-consuming care" as defined in this study.

Participant Recruitment

Participants were recruited through the local branch of the Muscular Dystrophy Association of Canada (MDAC), North Shore Health Department, and Boundary Health Unit. An appropriate contact person from each organization sent an introductory letter (Appendix A) describing the study to parents who met the study criteria. After receiving this introductory letter, parents who were interested in becoming study participants then contacted the researcher who provided them with additional information about the study. A representative from the MDAC sent out 14 introductory letters.

Five participants subsequently contacted the researcher. A representative from a community health unit gave the introductory letter to two families who subsequently volunteered for the study. As the data were being collected and analyzed, it was decided that the experiences of an additional participant was required. A representative from a second community health unit then gave the introductory letter to a family who agreed to participate in the study. The data gathered from this participant enabled the researcher to ensure saturation of the conceptual categories.

Description of the Participants

A total of 11 parents (five mothers and three couples) volunteered for this study. Participants lived in various communities throughout the lower mainland of British Columbia. Demographic data were collected to provide a description of the study participants (Appendix B). The mothers' ages ranged from 30 to 49 years, while the age range for the three fathers was 31 to 37 years (the fathers' age range in general was 31 to 51 years; that is, including those who did not participate). Two of the parents had one child each. All other parents had two or three children in total. One mother was divorced, and she lived alone with her two children. All other participants were married. All of the fathers were employed full time. One mother was employed full time (the single parent), four were employed part time, and three of the mothers did not work outside the home. Four of the families owned their home (of which one was inherited), one family rented their house, and three families each rented a townhouse, of which two were co-op units that were adapted for a disabled person. All families were

members of the At Home Program, which enabled them to receive full health benefits coverage, equipment and assistive devices at no charge, and money to be utilized for respite care.

The children with progressive life-threatening illnesses ranged in age from 26 months to 16 years. Each child had one of the following progressive life-threatening illnesses: Duchennes Muscular Dystrophy (MD); Spinal Muscular Atrophy (SMA), Type II; Metachromatic Leukodystrophy (MLD); Retts Syndrome; and Cerebral Palsy with Microcephaly and respiratory distress. All children lived at home, and two of the children had been hospitalized for more than one week in the year preceding the study.

Data Collection Procedures

Data were collected via audiotaped interviews conducted in the participants' homes. In all cases, home was the parents' location of choice for the interviews. Participants also chose the date and time of interviews. This factor was extremely important and, indeed, was probably the only way in which participation was feasible for most of the parents. Their daily lives were very busy. As one mother aptly expressed: "forty-five minutes or an hour may not seem like much to you, but to me, it means that I have to make that time, I have to rearrange things to make that time". One family cancelled their interview on three occasions before they could commit to the time required. Despite the scarcity of available time, all parents were very keen to participate in the study. Parents sacrificed their time out of a desire to help other families who may be going through a similar experience.

Interviews lasted from 35 minutes to two hours, and first interviews were almost always longer than second interviews. Initial interviews were unstructured and in-depth, in accordance with the chosen methods. The researcher used a set of trigger questions in the first interviews to focus the interview on the research question and to facilitate participant reflection on their experiences (Appendix C). In some instances, the list of trigger questions was unnecessary, as after the first question parents related their experiences with little prompting. Second interviews were semi-structured, and served the purpose of clarifying information from initial interviews, and validating findings. Questions for second interviews were thus developed from preliminary analysis of initial interviews. Examples of questions developed for a second interview are:

- 1.) "A", you described how, because of your son's young age at this time, the gap between what you experience and what "the rest of them" experience is quite small, but that it will widen. Can you elaborate on that thought?
- 2.) At the end of our last interview, you spoke about a boy who had passed away, and how the terminal nature of your son's condition is always somewhere in the back of your mind. Do you think this affects the way you live your life or the way you manage your child's condition? If so, how?
- 3.) You mentioned that in some instances you have had to "fight the system" to get services which you felt were in the best interest of your daughter, and you described a few situations. How did you learn to do this, and do you think this is an important skill? If so, why?

Interviews were transcribed verbatim and became the data for analysis. Due to time constraints, the researcher utilized the services of a transcriber for one half of the interviews. The researcher specifically chose to transcribe several interviews because the process of transcription helped to relive the interviews, and assisted her to capture the essence of the parents' lived experience. In one instance, the researcher followed the parents' recommendation that she view a movie about a similar family's experience. The movie emphasized the pain and grief that parents lived with daily, and also their fierce determination to provide a high quality of life for their child. Based on a true story, the movie was described by the family in this study as being very descriptive of their experience, and thus added poignant insight.

Sampling and data collection ceased when saturation of the data occurred. First interviews were completed with all parents. Second interviews were completed with five participants (two families were unable to grant second interviews due to time constraints, and one family was approached later in the study, so that it was useful to combine first and second interviews).

The Interview Process

Anderson (1991) states that the intersubjective construction of meaning is at the heart of phenomenological inquiry. Meaning is not merely investigated, but "is constructed by phenomenologist and informant through active and reciprocal relationships and the dialectical processes of interaction" (Anderson, 1991, p.116). The interview process is thus crucial to phenomenological methods. In this study, the

delicate subject matter needed to be handled sensitively by the researcher, and the "construction of meaning" between the researcher and participant(s) necessitated a certain amount of personal emotional investment on the part of the researcher. This was especially important to demonstrate the sincerity of the researcher in examining very personal and emotional areas of parents' lives, and to establish (as much as possible) a trusting environment in which parents felt free to "open up" and describe their experiences. Many of the interviews were emotionally charged, and the investigator attempted to take in and experience these emotions in order to understand the essence of parents' experiences. For example, the researcher noted an overwhelming feeling of loss underlying many of the interviews. The strong emotions associated with each interview often left the investigator feeling drained afterwards. When Oakley describes this type of process, she states that "...in most cases, the goal of finding out about people through interviewing is best achieved...when the interviewer is prepared to invest his or her own personal identity in the relationship" (1981, p.41).

Substantial reflection was required by the researcher both before and after each interview. Reflection before an interview allowed the researcher to build and focus her energy on the interview process. Subsequent reflection uncovered new meanings constructed in the interview, and allowed the researcher to regain personal energy.

Field Notes

The investigator also recorded field notes following each interview to record the context of the interview, especially those aspects which may have been missed on

audiotapes. For example, four of the eight initial interviews were interrupted at least three times each to enable parents to attend to their child's care needs. All parents had attempted to make alternate arrangements for their children, to facilitate the interview process. However, two families could not find a trained babysitter, one family had a nurse present but was still interrupted by their second child who was also affected with a progressive condition, and the fourth family had requested privacy from their teenager, but he required assistance in entering/leaving the house and toileting.

Field notes describing the context of the situation also indicated the number of times a family postponed the interview due to a hectic schedule, and the difficulty in scheduling interviews. It was not uncommon for a parent to express some variation of the following: "Monday is out, he (child) has a full day booked. Tuesday is a possibility if his physiotherapy is cancelled, which apparently it might be for this week. If so, you'd have to come between 2:00 and 4:00 because he has a doctor's appointment at noon, and speech therapy at 4:30". Field notes emphasized the great amount of time and effort required of parents to care for their children.

Data Analysis

The data were analyzed using Giorgi's (as outlined by Omery, 1983) steps for data analysis, and Anderson's (1992) recommendations for phenomenological data analysis:

Step One: The audiotape of the interview was transcribed verbatim. For interviews in which a transcriber was used, audiotapes were fully reviewed, and any errors or

omissions in the transcripts were corrected. Next, the transcript was read through completely to get a sense of the whole and to correct any errors.

Step Two: The transcript was read through again completely to reflect on the interview process. The investigator questioned and noted areas not clear or not understood. For example, one mother brought up the idea that in one respect, the flow of their life was easy, but in another respect, it was difficult. It was not clear from the transcript which areas of her life she was describing, and a note was made to clarify this thought. A note was also made of any areas not sufficiently explored and/or needing further exploration. For example, one set of parents described how they viewed their son's condition as a disability, and not a progressive, life-threatening illness. They stated that this affected the way they raised him, and provided a few examples, such as trying to live as "normal" a life as possible. Further exploration was sought as to how raising their son would have been different if the parents viewed his condition as a progressive life-threatening illness.

Step Three: The interview was read through again very slowly. The investigator started to code the data by delineating each time a transition in meaning was perceived. This preliminary analysis involved assigning meaning units or in vivo codes. All codes came from the data and everything was coded; if something was not understood, the investigator put a question-mark by the meaning unit and clarified it in the next interview. Examples of in vivo codes in this study are: philosophy regarding child's condition; direct and indirect care of the child; stressors; various emotions (for example:

sorrow/grief, guilt, optimism, anxiety, anger, frustration, discouragement, feeling fortunate, and feeling overwhelmed); loss; gaining strength; being an advocate for child; looking ahead; changes; balancing family life with health regime; wheelchair accessibility; sense of humour; and views of health care system. In all, there were 87 in vivo codes.

Step Four: The researcher reflected on meaning units and then began their transformation from concrete language to broader conceptual categories. Examples of initial conceptual categories were: learning to manage complex physical care, and managing change. Data from all other transcriptions were compared and similarities and differences were noted. For example, it was noted that all families viewed/defined their child's condition in a certain way. Although some of these views were similar and some were quite different, all helped to create a context in which the child was raised.

Step Five: The insights were integrated and synthesized into a developing indepth description.

Step Six: The investigator returned to participants for a second interview to clarify what was not understood, and elaborate on areas needing further investigation. This step also involved verification of some aspects of the participant's first interview and the emerging conceptual findings. For one participant who was approached late in the study, one interview combined the steps from the first and second interviews.

Step Seven: Steps one to four were repeated with the second interviews. The first interview was compared to the second interview. Redundancies in meaning units were

identified and eliminated (it was not uncommon for parents to repeat a description from the first interview). The remaining meaning units were related to each other and to the whole until conceptual categories were saturated. Examples of final conceptual categories were: managing change; creating a context to raise a child with a progressive condition; help seeking behaviours; learning to manage complex physical care; building a relationship with the health care system; and living with loss. In all, there were nine conceptual categories.

Step Eight: Additional insights were reflected upon, and were then integrated and synthesized into the major theme, which was "facing adversity".

The major theme was verified with three study participants to ensure congruency between the researcher's interpretations of the data and the parents' accounts.

Means of Establishing Reliability and Validity

Truth Value and Applicability

Credibility is the criterion against which the truth value of this study was evaluated (Sandelowski, 1986). To enhance credibility, the investigator kept a journal of her own behaviour and experiences in relation to the behaviour and experiences of participants. The investigator kept her perspectives grounded through meetings with thesis committee members. To keep truth subject-oriented and not researcher-defined (Sandelowski, 1986), the investigator attempted to "bracket" or control any preconceived ideas or bias about the parents' experiences. Allowing for quiet time before each interview assisted in building up energy to focus and attend to the emotionally charged

and sensitive descriptions given by study participants.

Fittingness is the criterion against which the applicability of this study was evaluated (Sandelowski, 1986). "A study meets the criterion of fittingness when its 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). The investigator checked for the representativeness of the data through validation from the participants as well as from a community health nurse with extensive experience working with parents of children with progressive life-threatening illnesses.

Consistency and Neutrality

Auditability is the criterion against which consistency was evaluated (Sandelowski, 1986). Findings are auditable if another researcher can clearly follow the "decision trail" used by the investigator. To ensure auditability, the researcher described and justified what was done in the study.

Confirmability is the criterion against which neutrality was evaluated in this study (Sandelowski, 1986). "Confirmability is achieved when auditability, truth value, and applicability are established" (Sandelowski, 1986, p.33).

Protection of Human Rights and Ethical Considerations

Approval for this research was obtained from the Ethics Review Committee of the University of British Columbia before commencement of the study (Appendix D). Ethical approval was also obtained from all associations (Muscular Dystrophy

Association of Canada, North Shore Health Department, and Boundary Health Unit) prior to making contact with potential study participants. Informed and voluntary consent to participate in the study (Appendix E) was secured from all participants. All participants were informed that they could withdraw from the study at any time without penalty, and that participation in the study would in no way affect care or services received. Consent was also obtained to audiotape the interviews. To maintain participant confidentiality, interviews were transcribed using code numbers and/or pseudonyms, and tapes were destroyed after completion of the study. Parents maintained the right to request that certain parts of tapes be erased or not transcribed, and may have refused to answer any questions or discuss any topics, with no effect on future care. However, no such requests were made in this study. Parents were informed that if they had any questions during the study, they could contact the investigator or a member of the thesis committee. All parents requested and will receive a summary of the completed study.

Summary

This chapter described the methods utilized to study the experience of parents caring for a child with a progressive life-threatening illness during the complex chronic phase. The naturalistic research design of phenomenology was deemed the most suitable for exploring the research question. Theoretical sampling was utilized, and inclusion criteria for selection of study participants were outlined. Means of participant recruitment and description of the participants were presented. The method of data

collection and analysis were then described, including the interview process and the purpose of field notes. Finally, methods of determining reliability and validity, and measures taken for protection of human rights were presented.

CHAPTER 4: PRESENTATION OF THE FINDINGS

Introduction

The goal of this study was to gain deeper insight into the day-to-day experiences of parents caring at home for a child with a progressive, life-threatening illness at a certain point in that child's illness trajectory. This point was when the child was living with a complex chronic condition (as previously defined), requiring specialized and time-consuming care. As parents' perspectives were elicited and transcribed, thereby becoming the data for analysis, a description of their experiences began to emerge. The study's findings describe parents' perceptions of their experience as understood and conceptualized by the researcher.

In this chapter, the study's findings will be presented. This will begin with a description of the context in which the study's findings are based. Next, the central theme that emerged from parents' descriptions, **FACING ADVERSITY**, will be introduced. This will be followed by an indepth description of the two components that comprise the central theme: "Defining Adversity" and "Managing Adversity". Finally, the role of the health care system in assisting parents with the process of facing adversity will be presented.

The Child's Illness Trajectory

Parents' experience of caring for a child with a progressive, life-threatening illness is an evolving one. The child's progressive illness is conceptualized as an illness trajectory: it begins with diagnosis of the condition, or the time when minor physical

symptoms are present; it then follows a course of progression until such a time that the condition becomes a complex chronic condition; eventually, the child enters the end-stages of his/her incurable condition which is followed by the death of the child (see Figure 1). The findings for this study are based on parents' experiences describing a specific time frame of their child's illness trajectory: the time that their child lives with a complex chronic condition.

Figure 1. Conceptualization of the child's illness trajectory

The amount of time spent at any one point or span of time during this illness trajectory may vary from child to child, depending on a great many factors (not the least of which is the individual disease or condition itself). What is important here is that all of the children represented by this study can expect to live with a complex chronic condition for many years. Thus, the findings represent parents' experiences over a long period of time, during which their child's condition continues to deteriorate.

Parents' experiences are evolving. These experiences do not occur in isolation from one another, and parents bring unique histories to their experiences during this time span. Furthermore, parents' experiences of caring for a child with a progressive illness are occurring within the natural evolution of their individual family life.

The Central Theme: Facing Adversity

The central theme that was conceptualized from parents' descriptions was one of FACING ADVERSITY. At the root of this theme is the successive hardships and challenges faced by parents while their child lives with a complex chronic condition, and the deep sense of commitment to doing what is best for their child. In other words, (a) the progressive nature of their child's condition has specific and significant implications for parents; and (b) without parents' love and strong commitment to their child, these challenges and hardships would not hold the same meaning for them.

Facing adversity is conceptualized as a set of horizontally linked spirals, extending across that section of the child's illness trajectory during which he/she lives with a complex chronic condition (see Figure 2). The spirals briefly overlap in either

direction across imaginary lines representing the different time spans of the illness trajectory. This is to demonstrate that although this theme describes a specific time frame, parents' experiences evolve over time.

Facing adversity is conceptualized as a process, comprised of two distinct yet closely connected components that combine to form successive spirals (see Figure 3). The two components, DEFINING ADVERSITY and MANAGING ADVERSITY are each made up of a complex arrangement of characteristics that connect to form each spiral. Amongst the hardships and challenges, parents construct a picture of their situation; they "define" their adversity. This definition is as unique as the family itself. The process does not stop here, of course, as parents must also learn how to live with their child's progressive illness; how to manage the illness within the day-to-day family life. Parents must learn to "manage" their adversity. Due to the progressive nature of their child's condition, parents experience a myriad of changes that impact on all levels of their family. These changes occur within the evolution of the family life cycle. Parents' then must redefine adversity, and in turn manage it. This succession of spirals has definite implications for parents: while it means they can learn from past experiences and/or bring previously learned coping and problem solving skills to new situations, it also means that certain events and experiences are cumulative (such as burden of care, and losses), which may over time increase the risk of parental exhaustion and inability to manage. The desired outcome is a balance in the spirals, demonstrating that as parents face each new form of adversity, they define it and

subsequently manage it. A tightening coil or wound up spiral (that is, little or no space between each loop) signals potential imbalance due to insufficient time or resources for parents to define and/or manage the adversity.

Figure 2. "Facing Adversity" in context

Figure 3. Components of "Facing Adversity"

The components of Facing Adversity, "Defining Adversity" and "Managing Adversity", will now be presented, described, and illustrated with examples from parents' descriptions of their lived experiences.

Defining Adversity

The first component of FACING ADVERSITY is "defining adversity". As each family was unique, their experience of adversity was individually defined. Defining adversity was shaped by characteristics of (a) the individual condition and (b) the

individual family, as well as the magnitude of impact of each situation that led to a new form of adversity.

The Individual Condition

Various characteristics regarding their child's condition contributed to the way in which parents defined their adversity. These characteristics were largely out of parents' control and mostly determined by the individual disease process. They included: how extensively affected the child was by the condition; the speed of progression; the number of affected children in the family; and the age and developmental stage of the affected child.

Extensiveness of Condition.

All children lived with a complex chronic condition, as this was a study criteria. Consequently, all children were physically debilitated and required complete assistance with activities of daily living (ADL's), such as bathing, toileting, feeding, and dressing. There were also children whose condition was more severely involved: those who were intellectually as well as physically disabled; and those whose physical level of care extended beyond total assistance with ADL's.

Parents of children whose disability was solely physical in nature expressed relief and gratitude that their child's mind was "intact": "Some people have it worse off...we're lucky because he's so bright - it [condition] doesn't affect his mind at all". Meanwhile, parents whose child had suffered intellectual and physical deterioration spoke of the extent of their stress:

(F)...one thing that is known of this disease is that they are ornery children, which does not make it easy. And [daughter], having been one of the most fun-loving children, a happy kid when she was normal, to one of the most ornery children....she can just let it rip, boy - and we don't know what's wrong or even if anything's wrong because she can't communicate...it's so very stressful.

The extent of physical involvement also varied in that some children required more intensive care such as suctioning, gastrostomy tube feeding, seizure precautions and the administration of medications via a nebulizer. Since parents' care and judgement of these children's conditions had potential life-threatening implications, they assumed an enormous responsibility. Accountability for such specialized skills had at one time been a completely foreign notion to them - one that, in their minds, was assumed by appropriate health care providers. For example, one mother spoke of the initial terror she felt upon learning that her son would eventually require a home respirator to assist with breathing during the night. These parents' definition of adversity included this substantial responsibility.

Speed of Progression.

The speed of progression also contributed to parents' definition of adversity. A quickly progressive condition allowed parents little time to make sense of their situation, before more changes were upon them. One set of parents described the speed with which their child's condition progressed:

(M)...really, from April right through the summer, you could just rapidly see her [daughter] losing, day by day.

(F) By August she wasn't walking. By December she didn't talk.

(M) She lost her sight around January, February.

(F) So, all within one year. It goes very quickly.

This father later reiterated: "...how rapidly they deteriorate, from what is perceived as being normal to visible deterioration. I mean, it just goes. You cannot believe how quickly a child can lose their functions, but they do". These parents barely had time to react to changes, let alone prepare for them. Their definition of adversity was constantly and quickly changing, which left them with a sense of being out of control. With reference to the conceptualization of FACING ADVERSITY, this family's experience would be illustrated by a tightly wound set of spirals, with little space between spirals. The rapid progression in condition contributed to an inability to define or manage their child's condition.

Other conditions progress quite slowly. Under these circumstances, parents have more time to define their situation and develop management strategies. A mother whose son had a slowly progressive condition stated, "It was almost like a gradual transition. Like, it wasn't all of a sudden...a gradual thing and I think that's what happened. It didn't just happen over night". This mother explained that because the condition progressed so slowly, there was more time for her family (and her son) to get used to the changes and adapt to his losses in physical ability. Conceptually, this example of FACING ADVERSITY was illustrated by a balanced set of spirals with large spaces in-between each spiral, representing the time between each change. That is, these parents were successfully facing adversity, and the slow progression of their child's condition was an enabling factor.

Age and Developmental Stage of Child.

Parents' definition of adversity was partially shaped by the age and developmental stage of their child. For example, parents of a three and-a-half year old boy described how, in some ways, it was easier for them because they perceived that the care they were providing for their toddler was not drastically different from the care provided for other children at that age. This father acknowledged that as their son got older, the impact would be magnified:

(F) It's easier to do a lot of things for him now. It seems more, more normal, 'cause that's what you do for infants, you have to take care of them all the time. When he's older, it will become more noticeable...because his peers will be getting their own hamburgers at McDonalds...and then the gap between what we experience and what the rest of them experience will widen, but right now it's quite small.

When asked to elaborate on this thought during a second interview, the parents disclosed that the gap had already widened:

(F) Well since our last interview we've experienced a widening...

(M)in terms of the gap widening, when you're caring for a small child, there's a lot of work any how. When they get older you expect that they'll feed themselves, toilet train and amuse themselves...with [son] it's becoming more work, for instance we're trying to teach him to be...toilet trained...it is presenting itself as a challenge...

Caring for a small three year old boy was also physically easier for these parents than it was for the parents of a 16 year old boy who weighed approximately 200 pounds.

Passing through developmental milestones was often difficult. For example, when their daughter (who was wheelchair-dependent) started school, her parents worried that she would not fit in: "I remember when she first went to kindergarten, all the kids

would just take off and play. And so then she'd ask the teacher to come out and play....we were very worried in the beginning." Another mother remarked on the challenges of toilet training her disabled three-and-a-half year old: "...we have a [special] potty chair for him, I'm just trying to figure out toilet training. I'm lost there!". Another mother described a very lonely and difficult summer before her son started high school. She related how suddenly his friends had all "taken off", as this was a time that boys his age were becoming more independent, and her son could not physically keep up. Yet another mother recalled anticipating September, when her son would start high school, with both excitement and anxiety. She felt fortunate that the local high school was wheelchair accessible, and that her son would not have to be "different" and go to an outside district school like he did for elementary school. Another mother had begun dealing with issues related to her son's evolving sexuality. She recalled being shocked upon finding her son kissing a girl in his bedroom after school one day. After giving the matter some thought and discussing it with her husband, she decided that:

(M)...I mean, we were all 16, 17 years old, and if you wanted to neck up a storm you'd find some place to do it, but in [son's] case, I feel like I'll give him the benefit of the doubt, with his [lack of wheelchair] accessibility....[laughs] I'll be okay, you know - little shocked, little shocked [laughs].

Number of Children with Condition.

Since most of the progressive conditions were hereditary, some families had more than one affected child. In one family, two children were affected. It was more difficult for this family to paint a picture of a "normal family". Their two affected

children had such extensive care needs that parents lost the picture, or definition, they had previously constructed of their family: "There we were, a few years ago...a completely normal family with three beautiful children, and then POW!...we have not one, but two disabled children!". This father expressed his frustration with other people's lack of understanding of his family's adversity:

(F) ...We don't have a paraplegic, and we don't have a quadriplegic, we don't have any type of child that's handicapped [physically] but can [still] understand, we don't have a handicapped child that's happy, we don't have a handicapped child that can even move, and most of all, we don't have a handicapped child - we have two!!

The Individual Family

Various characteristics of individual families also contributed to the way in which parents defined their adversity. These included the way in which parents perceived their child's illness, parents' acceptance of their child's illness, learning to live with loss, and gaining strength from their adversity.

Viewing their Child's Condition.

The ways in which parents perceived their child's illness profoundly shaped their definition of adversity. Many parents described their child as having a "condition" rather than an "illness". Even the title of this study offended some parents, and thereafter, the child's illness was consistently referred to as a "condition". One mother said that she liked the way the term "condition" was used:

(M)...there, I'm using the word "condition". That's one of the questions you asked me about...I was thinking about that...well that's actually what I think, I think of it as being a condition rather than describing it as a disease or illness.

Contrasting examples were provided by two sets of parents whose children had identical conditions. One couple viewed their daughter's condition as a progressive illness for which little could ultimately be done. They therefore did not see the point of getting involved with a host of services which they felt would not be beneficial in the larger scheme of things. When their daughter's physiotherapy sessions were stopped (when she entered the school system), they initially panicked because they felt "now, nothing was being done" for their daughter. They soon realized, however, that "to tell you the truth...the physio. thing, they really weren't doing much, you know". When asked about health services for their daughter, they replied:

(M) Well nothing's come up so far, that [we could be doing]-

(F) See, it's such a rare disease, they say, and there's so little that can be done about it, so I don't know how much [can be done], you know...there's really nothing that can be done.

This contrasted sharply with the views of another couple who were very clear on how they defined the condition, and how this definition influenced the way it was managed:

(M) We look at it as a disability, definitely, - I think to look at it as a life-threatening progressive illness, that really affects the way that you handle a child, the way you integrate a child into your family life, your friends, your social activities, and both [husband] and I have talked a lot about what normalization means, and so, the point when [son] was first diagnosed, we, it was of course very traumatic, but we decided that we weren't really going to change a whole lot of our lives....

When elaborating on this thought in a second interview, this mother commented that:

"raising a child with a progressive life-threatening illness means the whole focus is on being sick rather than on being well...he is a healthy child". The father illustrated how their definition of their son's condition guided their management of his care:

(F) ...an example...is stretching exercises for his legs. Muscles tend to contract if not exercised and stretched, so what can happen is the legs become somewhat contracted and they can't be straightened out all the way, so we do some regular physio. and stretching to avoid that. A comment I remember from an orthopedic surgeon was "well...is that really a concern, because he's not going to be walking; it won't really matter"... and I think that is an example of our attitude...because we continue on with the stretching and physiotherapy anyway...

Acceptance.

All parents claimed they had unconditionally accepted their child's condition, with all of its accompanying implications. Acceptance, however, was not always immediate for parents, and this characteristic influenced each family's definition of their adversity. It took one mother many years before admitting "we have a problem that we need to address". She described the time before she came to accept her child's condition as "the dark years", and that once she came to a point of acceptance, "everything changed for the better...everything was just brighter just like the sun shining through...". After this, she could look at her son as a whole person and at her family as a complete family again.

Overall descriptions of their children attested to the fact that these parents saw the child as a whole; that is, the focus was not on the illness or subsequent disability:

(M) Last summer, ourselves and one other couple and their two children went to XXX for a vacation together...the kids all played together and went to the beach together...[child] comes shopping with me, [husband] takes him to the Science Centre, we go to Maplewood Farm, or out for walks...he has birthday parties just like everyone else...

(F) [child] is very creative - she loves to draw.

(M) Yeah, her art work is everywhere [motions to walls around house].

(F) She loves to swim - that's her all-time favourite activity!

(M) Yes, and [husband] also takes her horseback riding.

(M) A typical day would be getting him up in the morning, bathing him, dressing him, making his breakfast for him. He can still feed himself. Um, nothing drastically different from anyone else, you know - getting his lunch ready for school, packing his bags, and then waiting for the school bus to come and pick him up and take him away to school.

One father aptly summarized the parents' views regarding acceptance of their child, along with his/her condition: "If the water well is half a mile away from the house, you walk half a mile to the water; there's no point thinking about that, or worrying about that at all". His wife reiterated: "...we don't spend a whole lot of time dwelling on it. It is what it is".

Living with Loss.

Loss was an integral part of defining adversity. Almost all new situations or challenges to which parents had to adapt (that is, each new spiral) represented some form of loss - losses related not only to their child but also to parents themselves.

Progression in their child's condition led to decreased abilities and increased care needs, which required adjustments by both the child and parents. Loss prompted parents to feel sorrow and grief. The extent of adjustment depended on the nature and severity of functions lost. As one mother said:

I don't know, it's always sort of discouraging when you come to another, sort of, level, when you know that he's gradually getting worse...it's difficult when you think "oh my gosh, we've reached, you know, another one towards the end".

In some families, the children had progressed through normal developmental milestones such as walking and playing independently, but subsequently the progression

of their condition eventually left them with total care needs. These parents described an especially painful loss, since their children were previously developing as healthy children. Another especially painful loss was when investigational or other treatments failed, after showing early signs of success.

Periods of progression in their child's condition sometimes led parents to introspection and thoughts of "what if":

(M) It's very sad going up to the school.

(F) School's a killer - don't go near the school.

(M) Seeing the children, and knowing that is the way they should have been at that age. And they're not. And they're beautiful girls.

From another mother: "I look at him watching the kids and think what it would have been like if he was there, you know, out there doing that [playing baseball]". For one family with two affected children, losses were compounded: "Another stressful thing is the emotional stress of watching [second child] go down. She wasn't suppose to...so, having to go through it all a second time...it's so painful".

Other parental losses resulted from their child's increased care needs, and included loss of time spent with each other, with their other children, and alone. One mother recounted how she had to give up a very good job in order to stay home and care for her daughter, whose care needs had become overwhelming. Another father described his losses: "I find it's generally a lot of work in terms of, she has less independence, she's dependent, we all lost our independence.... because she needs constant care".

Gaining Strength.

Many parents spoke of the personal changes that occurred. Facing challenges around the progression of their child's condition and subsequent increase in care needs often left them stronger and more resilient: (F) "When something like this happens to your family, it can devastate you, or it can have a positive effect...and I think overall it's had a positive effect...we've broadened our horizons". Another mother stated: "It's made me a much stronger person, a much more caring person...[I have] a better understanding of what other people are going through, a better understanding of life, I guess".

Characteristics of the individual child also helped parents to remain strong:

(M)...I think he's been the helper for me. Like, as long as he's accepted [it] - and he's accepted it I think, more than myself or my husband, or even his sister. It's just like, I don't know, I don't know, it's like a - I don't know if it's like a teaching, or, he's helping us be strong for some reason.

(M)...[She's] all smiley and sociable. This kid is almost dying and she's still smiling! It's incredible! And I think that's what gets me through it...I'm really fortunate that way.

(M)...Even though the disease is [progressing and] he is becoming more disabled, um,...with the maturity [he is] becoming more independent...it's a strange one, this [name of condition]. Like I say it is getting worse but I really feel that, in our case...in many ways, things are getting better.

Magnitude of Impact

Some situations or events leading to a new form of adversity had stronger impact than others. The magnitude of impact influenced parents' definition of adversity.

For example, a child's transition from walking to requiring a wheelchair had a

profound impact on the entire family. For most parents, this was a time of moving to a level house or renovating an existing dwelling, purchasing a van, ramp/lift and "tie-downs", trips to seating clinics, accessing new services regarding design and funding for the power wheelchair, and entering a partially accessible world. The issue of accessibility alone was staggering, as parents were required to carefully plan any trip outside of the house by first ensuring accessibility. Frequently visited stores, homes, and for some children, schools, were suddenly off limits.

In defining this form of adversity, parents described mixed emotions: it was a time of sorrow and loss, as the reality of their child's disability could no longer be denied, and it was a time of optimism and success, as their child had his/her first taste of independence:

(F) Two weeks ago we received his power chair, his power wheelchair...obviously now when we go out, we're with a child who obviously has a disability, there's no doubt about that whatsoever...the power chair definitely makes it a clean break, and that took a little bit of getting used to...we've, sort of come out of the closet now as it were.

This father continued by describing the positive aspects of the transition: "the fact that he is mobile now and he has the control". Another family recounted their experience:

(F) That was probably the biggest transition, when she got her chair. That was, it was pretty low...at the same time she became independent, so it was really positive. When we first got the wheelchair, I thought "oh my God, a wheelchair", you know, it's really sinking home, this is a wheelchair, this is serious. But then, finally when we got the wheelchair...she was suddenly mobile, you know. We were calling her over to us, that's a real God-send, you know, we'd never called her over to us.

Managing Adversity

The second component of FACING ADVERSITY is "Managing Adversity". This is characterized by parents managing changes related to the child's condition and, subsequently, the caregiving role. One mother explained: "...there's always change - things to change...because of his condition, and the difficulties that come up...it makes an emotional impact...we have to adjust...there's always adjustments".

The caregiving role was divided into direct and indirect care. Direct care was "hands-on care" and included any caregiving that directly assisted their child. Examples included assisting a child with ADL's, administering a medication, and suctioning. Indirect care was described as "hands-off care", and included any care for their child that did not involve direct interaction with the child. Examples included negotiating with a health professional to provide a service, arranging wheelchair transportation, learning how a new piece of equipment worked to assist the child, and coordinating the child's day with regard to doctors appointments and other health services.

The strategies involved in managing these changes were: seeking information; negotiating; planning/preparing; and utilizing resources. Each of these strategies was applied to managing change as related to both direct and indirect caregiving. Successful management of change (when preceded by the ability to define their adversity) was conceptually illustrated by a balanced set of spirals (within the process of FACING ADVERSITY).

Seeking Information

Gaining knowledge or information was empowering for parents. Parents sought information regarding the physical progression of their child's condition, how to provide various types of care for their child, how to operate various assistive devices and pieces of equipment, what services were available and how to access them, and how to be heard as parents. In short, parents sought information on how to meet the needs of their child and family.

Information Related to Direct Care of Child.

As one mother said: "So, O.K., I researched, I'm the researcher type. I'll research and try to look for everything on it, and learn everything about it". Another set of parents expressed their frustration at the lack of information upon diagnosis of their daughters' conditions:

(F) They had to blow the dust off the books for this one.

(M) ...we said we needed to know more about the disease. He didn't know where to start looking for more information, so he got a student to start looking up in the library, get some articles, and contact the author.

By the time their child's condition had become complex, parents were well informed about the actual disease and its course; however, new information needs repeatedly surfaced. Parents looked to different sources for information. Some parents looked to health professionals and others looked to families of children with similar conditions. One mother explained: "...there's other moms...[with] a wealth of experience...and that's where you really find out your information. That's how you find out the things that really work".

Information Related to Indirect Care of Child.

Gaining information about health care services was also empowering for parents, however the extent of information sought varied widely between parents. For some parents it was very important to learn about the "system", and the allocation and provision of health care services for their child. One mother described how her work in an organization that assesses health care delivery helped her:

(M)...it gives me information, and one of my big frustrations is that I didn't know how the supersystem worked...[information] is extremely important, because one of the things that really decreases your anxiety is knowing what's going to happen in the next step, how my son's going to be looked after in the school system, how do the protocol's work, what are the gaps in services that I'll have to be proactive about? How can I make sure everything is in place...?

Other families did not want such indepth information on how health care was being delivered in their community.

Planning/Preparing

All parents looked ahead to some degree, to prepare themselves for the future. The incurable nature of their child's condition prompted some parents to "live one day at a time" and to therefore not dwell on the future or plan too far in advance. For those parents to whom planning was very important, the concerns were mainly around their child's ever-changing care needs and how to ensure they would be met smoothly.

Preparing Related to Direct Care.

Planning too far into the future with regard to their child's actual condition was often overwhelming for parents. One mother described her initial terror when she learned her son would eventually need a night time respirator at home for breathing.

A few mothers spoke of facing the death of their child: "...I think when it's a terminal illness, it means you always have in the back of your mind 'I'm going to lose him eventually', and, you know, wondering how you're going to cope with that...". One physician told parents that their daughter might not live past her second birthday. Understandably, parents were devastated: (M) "That was it." (F) "Game over." (M) "Life just stopped." At a later time, however, parents met two teenagers with the same condition as their daughter, and the mother described her reaction: "It was, like, wow, there is [hope], you know, life does go on, and she will be able to do these things...". Another mother preferred to speak with other parents in order to prepare herself:

(M) ...it is parents who have [children with the] same condition that I enjoy the best because...if they had older sons, then I would sort of know what steps were coming up ahead of time...knowing what's ahead, what I have to prepare for, sort of helping me to mentally prepare for it.

Preparing Related to Indirect Care.

Changes in indirect care needs were anticipated in terms of both the equipment and the health care services that would (or in parents' eyes, should) become available to their child. Several parents were very astute in their planning, as the following quotes suggest:

(M) I'm very active in the [organization], and right now, we are involved with something very exciting...we're currently working together to identify what the problems are with service delivery in [certain area], and then developing some strategies to help solve that.

(M) Going from infant development which goes to age three, getting into the preschool system which is three to five is a horrendous transition period because of the gap in services...once they go into the school system, it's horrendous...we will lose our physio....so, [physio.] who has been with us since the beginning,

who has been his primary service provider, she's solved all our problems, who's absolutely wonderful, we'll lose her.

(M) I'll get a good start on those obstacles so I know what I'm up against, well most of it, but there will be some surprises, and so you better prepare yourself for those transition periods because they're not very nice.

(M) ...what are the gaps in services that I'm likely to have to be proactive about? How can I make sure everything is in place, because part of normalization is not having a scuffle around your schooling [for example], it's having all those pieces in place before you get there...we are very, very proactive...

(F) Well, yeah, we need to plan a few years in advance, really, all the time...

Other parents decided to deal with the issues of equipment and services as they came up: "I'll just deal with today, mostly with today, and those other bits...like the respirator...will always be in the back of my mind...".

Negotiating

As their child's care needs increased, time became a precious commodity for parents. One important aspect of negotiation related to the great amount of time required of the caregiving role. Negotiating for services was seen as necessary but often stressful. All parents gave examples of when they had to "fight the system" for what they felt was in their child's best interests.

Negotiating Related to Direct Care.

Mothers were the primary caregivers. The role of the caregiver necessitated negotiation within a family. Time was precious, and often the extent of their child's care needs left little room for other essential things. As a result, fatigue had a significant impact on mothers' lives. Fatigue was related to the increased care needs of

their child, and to the fact that their child awakened at least once per night, requiring repositioning:

(M) Yes, it [sleep] is [an issue]. I don't seem to have enough. I have trouble getting enough sleep because I have to get up early in the morning to look after [son]...and then of course I'm usually up during the night as well.

Other mothers validated this thought: "Sleep? What's sleep?!"; and "I'm exhausted!"; and "sometimes..I think oh my gosh, I feel like I could sleep forever!"; and "...[I] get horribly, horribly tired [where] it hurts to move...I get really, really tired". Mothers also maintained that their fatigue was not only physical, but also emotional and intellectual.

The ever-increasing burden of care was also an issue for parents. The extent to which fathers were involved with the caregiving role varied from none to very much. In the single-parent family (in which the mother had full custody of her children), the father's involvement in his child's care was infrequent and erratic. All fathers were employed full time and their caregiver roles were thus excluded to after work hours. Sometimes, the caregiver role was shared with someone in addition to the father. For example, one mother employed a nanny to care for her toddler three days a week while she worked. Interestingly, mothers who shared the burden of direct care did not always report a decrease in fatigue since so much time and energy was still required for other illness-related activities (for example, negotiating services).

Mothers rearranged their daily lives in order to care for their children, and the amount and significance of change was greater for them than for the fathers. For

example, many mothers relinquished jobs to care for their child. Two mothers of school-aged children gave up employment even though their children attended school every day because there was no one to assist the children in the mornings, and their employment did not offer flexible hours. One mother was forced to accept a lower paying job because it offered flexible hours. She had very high praise for her employer, who was flexible around the needs of this mother and her affected child: "[My boss] knows he [son] comes first".

Negotiating Related to Indirect Care.

Changes in the child's condition often meant a change (or addition) in service, resulting in new bureaucracy, paperwork, service providers, equipment, and funding sources. In dealing with new services or service providers, parents often had to fight or negotiate for what they perceived to be in their child's best interests. One mother suggested that every parent of a disabled child should be taught the skill of negotiation. Negotiating also included forming relationships with health care professionals and learning how to access the health care system.

Unfortunately, most parents felt that without negotiating skills, the needs of their child would not be fully met. One mother described how her two daughters' increasing care needs had become overwhelming, and yet she could not get someone to assist her in the mornings with her children, nor could she find more respite care:

(M) I did fight and fight and fight with [service] to say that I could not do all three children [two disabled and one able-bodied] on my own in the mornings...we get 24 hours a week [of respite care], so I stretch that into four 4-

hour shifts, and one 8-hour shift. And I tried to get more, I mean I pushed and pushed and pushed...

Another parent stated: "...probably the thing I find the most stressful is trying to get services, and having to fight the system or the bureaucracy. It's so exhausting and that's what wears me out the most".

Utilizing Resources

Utilizing resources was closely connected to seeking information, planning and preparing, and negotiating. Resources considered most valuable were respite care, equipment and assistive devices, a government organization to fund the equipment (the At Home Program), support systems, and community education about children with disabilities.

Utilizing Resources Related to Direct Care.

One of parents' most valuable resources related to their child's direct care needs, was respite care. Parents were at different points of requiring and utilizing respite care. For example, at the time of their first interview one set of parents described an emerging, but not pressing, need for respite care. Up until that point, the parents had managed their daughter's total care needs, with occasional assistance from grandparents and an aunt. Then, these parents had another child. They admitted they were adjusting to parenthood again and they expected life to be busy and unsettled. Still, they were beginning to feel the need for breaks. Three months later, at the time of their second interview, the father described how the need for respite was becoming more and more pressing:

(F) It's almost like two babies that you have to look after. One's big and one's little. And to leave them with somebody, like my mother...I think that it would be too much...and we wouldn't really relax and feel like we had a break...we're starting to feel a little trapped...it would definitely be nice to have a qualified, trained babysitter that you can call on.

Another mother felt she should be available to give most of her son's care, and she relied on service providers assessing her need for breaks:

(M)...I know the social worker was saying that she would try and bring someone to come in and help care for [son] a couple of times a week, so I could have a bit of a break. Well, I might have thought that this would be nice, but I wouldn't make the effort to do it, because I sort of would feel, well, I should continue to be the one to do it. But, she said "oh no, you need the help"...I think I wouldn't ask perhaps for as much help as what I'm offered...I guess I'm not aggressive enough to go out and say "I want this", but I am very grateful.

Another mother described her growing realization of changing respite needs. Her daughter was requiring increasingly specialized care, and she became more and more uncomfortable with the idea of lay people watching her daughter:

(M)...initially...I had a girl who was coming over. I had to go to work that morning and she just looked at me and said "you know I don't think [daughter] looks that great"...and she kind of panicked...and I just felt that to have somebody reliable, competent, dependable, who could handle it, you know...I was worried about this. I need somebody that I can be sure of. And that I don't have to worry about, that they're doing the right thing. And that's when we got nursing respite.

Utilizing Resources Related to Indirect Care.

To a certain extent, parents could choose the types and number of services involved with their child. The extensive involvement of their child's condition, however, often necessitated a plethora of service providers. Utilizing these resources meant parents had to learn to form relationships with health care providers, and get used to

telling and re-telling their story to countless new faces. It also meant discovering duplication of, and gaps in, services, and engaging in endless paperwork and bureaucracy. A mother described her experience with changes in services for her daughters:

(M) There's usually a doctor's appointment, the children are involved in so many different organizations. [Second daughter] is involved with [A] Hospital. And so she goes through [two different services], she deals mostly at [A] Hospital. Now, next week, I have a whole week locked up because she's going for a neuromotor assessment at [B] Hospital. She will then become registered at [B] Hospital. She's just about reached the point now where she's done so well from the [investigational treatment], we'll have to continue going for bloodwork just so they can monitor her, but she's pretty well finished with [A] Hospital. And, she's now, because of her disease, she's more into the [B] Hospital program. So, she's just on the verge of switching over. [First daughter] was always at [B] Hospital, she never went for [investigational treatment], or, other than [names a service specialty and several medical tests], that I have to take [first daughter] to at [A] Hospital, she's mostly for seating, at [B] Hospital, seating for her wheelchair, or her tilt chair, or whatever.

Another resource utilized by parents was both formal and informal support systems. Support systems assisted parents to manage the many changes by giving them a different perspective, a boost of energy, new information, and the comforting knowledge that they were not alone.

Several mothers identified their spouse as their biggest support. Mothers described how their husbands helped them to manage changes related to their child's condition by problem solving, providing a different perspective, providing emotional support and encouragement, and assuming increased care giving responsibilities. Several parents also emphasized the support they received from friends. This ranged from acceptance and empathy of their situation to tangible favours, such as assisting

parents with health care paperwork and baby sitting children.

In terms of services and organizations, parents' perceptions varied of what was supportive and to what degree. While one mother stated "we're lucky, we've had a lot of services...that are willing to help", another mother felt anxious and frustrated about being "over-serviced".

Several mothers had praise for support groups. One mother realized she "did not have a lot of support at home" and felt very comfortable seeking support from a support group:

(M) I really enjoyed it. I liked being around those people because you can feel safe, I guess, saying whatever, and knowing that they're going to accept it. Whereas the ordinary person might not...[but] they'll [support group] accept it...they can laugh about it even.

Unfortunately, all mothers who had used support groups were forced to stop for various reasons. One support group had dissolved and was eventually relocated to another geographical area. The new location was too far away, making it difficult for one mother to find someone to care for her daughter (whose care needs had intensified). Another mother gave up participation in her support group when she was forced to work afternoon, instead of day, shifts because there was nobody to care for her son during the day. She valued the support group:

(M) ...Just to talk to other parents who are just starting to go through it, who are at [son's] age, and the ones who are older than [son], talking about what they are going through now. And just, listening and getting ideas, and helping them out with anything...just knowing that they have the same feelings as you, they're going through more or less the same emotions that you're going through and that it's O.K. to feel these emotions...

By the time their child reached a point of requiring specialized and time-consuming care, parents had accumulated a plethora of equipment for their child. Equipment included power and manual wheelchairs, wheelchair ramps for the house and van, lifts for the van and inside the house, commode, urinal, bath seat, suction, tube feed equipment (pump, bags, tubing, adapters, syringes, formula), hospital bed, special mattress, ankle-foot orthotics (AFO's), back brace, standing frame, adapted potty, and compressor with nebulizer (for the administration of inhaled medications).

Parents were required to deal with bureaucracy with regard to funding and supplying the equipment, to learn about each piece of equipment (including how the parts and the whole operated, and how to determine sources of problems), to take time to get their child fitted with the equipment, to access new services and health professionals in relation to the equipment, and to develop patience. One mother described the transitions associated with the changes in equipment:

(M) Well, every time he gets something new, we have to adjust. When we got this new chair, it's marvellous but we had to get different tie-downs for the van because the tie-downs that we had wouldn't fit, because where we used to put it there's a bar, and at the front where they used to put this bar, they, when they adjusted the chair they put something in the way of the bar so then we had to get new tie-downs. So there's always things that we have to adjust to. We keep getting new things which are marvellous, but there's always adjustments.

This mother went on to explain how, furthermore, her son's new and improved wheelchair was too heavy for the lifts at school, and that as a result her son would have to change schools!

Parents unanimously agreed with the government funding that covers the cost of

equipment for such children. Equipment costs were extremely expensive, and most parents were not able to cover these costs.

Several parents spoke with optimism about changes in British Columbian and Canadian society with regard to attitudes towards the disabled:

(F) I've got a very optimistic view about it all. The attitudes of people on the outside with respect to accepting disabled children is something that's improving all the time...the improvements in wheelchair technology and all that, that's improving all the time...and the same thing with genetics...so, the only complaint would be we'd like things faster. But everything's going in absolutely the right direction.

One mother spoke about how her son progressed from walking to being in a wheelchair around the same time that Rick Hansen was completing his wheelchair marathon across Canada, and the positive influence this had on her son: "...I think it helped him, it made him feel a bit better about that transition, going from walking to being in a wheelchair."

Although a few parents remembered times of prejudice or cruelty towards their child, parents agreed that raising a disabled child today is far easier than twenty years ago, due to increased interest in and acceptance by able-bodied people, improved wheelchair accessibility, and increased technology (especially computerization).

The Role of the Health Care System

The extent to which parents expected the health care system to provide resources varied. Parents had strong feelings regarding their experiences with the health care system. On the positive side, parents felt that, at least in theory, there were enough services to meet the needs of their child, and that respite care was an especially helpful and valuable service. In addition, many parents identified key individual service

providers whose assistance was especially valued. On the negative side, parents were overwhelmingly frustrated and angry towards the bureaucracy involved and the method of service allocation. Furthermore, although respite care was crucial for parents, existing respite care services did not meet the respite needs of all parents.

Parental Expectations

Parental expectations regarding the extent of services that the government should provide to these children differed. Some parents viewed health care as a privilege. As one mother expressed "...it's not the government's fault that [son] has [condition]". She elaborated:

(M)...I think it's more of a privilege and I'm pleased that it's there because...well, looking at it this way, it's cheaper for them to provide the services for us and have us look after [son], then, say, if I say well I can't look after him, he has to go into an institution, and it would cost the government more that way. So dollars and cents it makes more sense for them to help us out, but I don't consider it a right 'cause it's not.

Another father stated:

(F) I think the government's role is to provide I'll call them the expert care givers, as much as possible to provide everything in the home to children, and providing the monies for the necessary machinery. And then the parents apart from that, do what parents are normally suppose to do...In providing the necessary therapists ...it's also the school's responsibility.

One mother put it in these terms:

(M) I think the government could be asked to be a bottomless pit of funding and so I think you have to look at each child's holistic needs and...[ask] what do we need to try to equalize the playing field for this child?

Another mother felt it was the responsibility of the government to discover gaps in services and ways of filling them, while maintaining an "economic conscience". She

suggested a central clearing house for used equipment. She viewed that their son's equipment was "on loan" to them until such a time as it no longer served its purpose.

Obtaining Services

Negotiating services led to fatigue, frustration, and anger. As one father put it: "...there are a lot of services...you have to say yeah, there is help...and, while there are a lot of services, I will say...[the] frustrating thing is when they start putting in their petty little bureaucratic rules". Families who expressed the least amount of frustration were those who chose to minimize the services they accessed. Parents experienced several frustrations: trying to find trained, competent, trustworthy care givers who could establish rapport with their child; lack of continuity in services; duplication of services; having to fight for services; bureaucracy of services; lack of wheelchair accessibility; and gaps in services. Various parents described their frustrations with services:

(M) I guess an easier day is a day when we don't have any appointments...when it's just he and I, and I close the door to the outside world, and that's when it feels the most normal, 'cause this is my reality...and so there were no specialists, there was nobody intruding, there was nothing; nobody coming to "help" [laughs], we were just left alone, and that makes it an easier day.

(F) There are a few "cows" I call them, who sit in their little government positions and say "well this doesn't fall under our program". Well, too bad!...she [service provider] said we didn't need nursing help, and we described what we had to do with [daughter]... and this woman still sat there with her nice little government job, with her little budget that she has to allocate out to and said "I don't think you need a nurse". You know, you're ready to just let her have it.

Yet another mother described the frustration she felt at her inability to access an

occupational therapist for her child:

(M)...it took us about nine months to finally get some services from the [service organization] - that was another battle. I couldn't get an occupational therapist, and I had to work at it for about six to nine months, and it was really frustrating because I knew he [child] had some seating and toileting issues coming up, and we wanted to deal with some issues around modifications of toys...

Increases in the child's indirect care needs were overwhelming for some parents:

(M) I find there's a lot of people involved in our life. Sometimes it seems like everybody's here at once, or everybody's calling at once...sometimes I just feel overwhelmed, I start losing it...I start thinking, you know, geez everything I do..it's like a business...sometimes that gets overwhelming and it gets to be too much. It's another [job] to deal with, you know. Some days I feel like I'm a secretary for [daughter] because there's always scheduling of appointments, getting there, and arranging for people to get her there if I'm working...

Another mother described how an increase in services meant more new faces to remember and deal with:

(M) You know, you just get to know somebody and then they change, [and then there's] the next, "oh hi, I'm your new client services person"...you're on the phone so much...you can't put a name to a face...it seemed to me everybody I talked to was named "MMM" for about four years there, and I'm [thinking] "which MMM is this?"!

Parents of two affected children were completely overwhelmed by their daughters' care needs, and desperately looked to service providers for help. Their children's conditions had progressed very rapidly to the extent that one child lived in a vegetative state while the other was still mobile but requiring increasing care:

(M) [eldest daughter] is a one on one...basically, you can say that it takes from 7:00 until 9:00 to get her up [and care needs met]...[second daughter] is requiring more and more care...you have to watch her constantly or she wanders off and could hurt herself...Sleep?? What's sleep?!

Due to two affected children in this family, the rapid progression of their disease, and

the extensive involvement of their conditions, these parents were unable to manage their adversity without a great deal of assistance. The respite services that were offered to assist them, however, did not actually provide support to the degree allocated on paper. This was due to both a lack of back-up respite coverage (when a regularly scheduled caregiver was unavailable due to illness, for example) and the provision of respite care for one of their affected daughters only when she was able to attend school.

Unfortunately, the disease had left her in a state that frequently caused disruption to her class, even to the point of her being sent home. This required her mother to be able to take over her care at a moment's notice. The following quotes illustrate how the lack of follow-through by service providers led to parents' inability to manage their adversity, and an increasingly tight (and, eventually, out-of-control) spiral within the conceptualization of FACING ADVERSITY:

(F) We had a week where [nurse] cancelled, [other nurse] was sick, and it ended up that [wife] had [daughter] full blown for a whole week. And you can't do it. I think it was at the end of that week that we finally put her [daughter] in hospital. We finally put her in the hospital for respite, because [wife] was also sick during that week. And, you can't do it. Nobody could do it!

(M) And even one day I sent her to school and there was no nurse there and they phoned me up and said "Mrs. X, you'd better come and take [daughter] home". The nurse had no intention of showing up and thought we all knew.

(F) She called up one day and said "I'm feeling stressed".

(M) ...of course she finds [daughter] difficult to handle. Well, if you are stressed and you find it difficult to handle, well I have to handle her every day. Can you imagine how I feel if you don't show up???

(M) I wrote it in the book this week... "I'VE HAD IT! I'M EXHAUSTED! I'VE HAD IT!" This is not what I've been put on this life for.

As these parents became more overwhelmed and exhausted with caring for their

children, they became more discouraged as well:

(F) It's hard to understand - two years ago we wouldn't even think of putting [eldest daughter] anywhere [i.e., a care facility], but as you get into what's required to deal with her...

(M) And you live with that day after day after day - there is no end to it...I am giving 24 hours per day, seven days a week to it....because of a love of my children, obviously, and because it hurts me to think that I would put them in an institution, but two years into it, you have to say, as much as I love them...

Acquiring Equipment

As it was with the provision of services, frustration also became part and parcel of acquiring new equipment for their child:

(M) When did we start [the process of acquiring] the standing frame?

(F) That's a few years work!

(M) It was close to nine months, so it's like a gestation period!

(F) Yeah, we could have had another child in the time we spent getting that!

(M) It was so complex!

(F) It was custom-made, and we were going back and forth, back and forth. Part of [the reason why] it took so long to do it [was] that he was growing and getting larger [and] by the time they went back...he had to cut something else apart and fit something else together, which meant another bunch of trips.

Another mother waited four to five weeks for her son's power chair to be fixed: "[son] hates to [be without] his power chair because it takes away his independence or it takes away his legs...". When asked what helpful services health professionals could offer her family, one mother answered without hesitation: "provision of equipment in the least bureaucratic way related to the child's needs in a very timely fashion".

On the positive side, although acquiring equipment was sometimes frustrating for parents, they considered it a positive experience since most equipment aided their child in becoming either more comfortable and/or more independent. In many cases, it also

relieved parents of some otherwise time-consuming tasks. For example, when it took one mother up to two hours to feed her daughter, the doctor recommended a gastrostomy tube (G-tube) for her daughter. Although the mother needed to learn how to care for the tube, operate and maintain the necessary equipment (electric feeding pump, feeding bag, tubing and formula), and access three different services for purchasing supplies and formula, and obtaining funding, it was still much easier than trying to feed her daughter by mouth, and in this way was construed as a positive change.

Parents praised the advent of computerization as a form of acquired technology. All children were learning about or utilizing computers at age appropriate levels. Computers assisted children in becoming more independent in both school work and leisure activities, and parents were excited about this.

Respite Care

All parents valued some type of respite care to help maintain the balance between meeting the child's care needs and fulfilling other family roles such as parent, spouse or employee. In other words, the provision of respite care provided caregivers with a valuable resource (time) to define and manage their adversity.

The amount and type of respite care parents valued and required varied greatly depending upon the number of roles the parent fulfilled in the family, and the amount of direct care and the level of care required by the child. For example, a single mother who was both the primary care giver and the wage earner in the family asserted that

respite care on weekdays and at least three week nights was necessary in order for her to maintain her job. In other words, this mother required a trained care giver (a nurse, in this case) to care for her daughter while she was at work five days a week, and, optimally, on Sunday, Tuesday and Thursday nights (that way, as this mother explained, she could count on getting three "good" nights of sleep per week). Without the night nursing coverage, this mother maintained that she would be too exhausted to hold down a full time job.

An additional factor was the amount of care. For one mother, the sheer number of direct care needs of her two daughters was staggering, and this did not include care of her third healthy daughter. Within this mother's definition of adversity was two children with rapidly progressive conditions and extensive care needs. This mother had given up her career in order to care for her children at home, and even still, respite care was crucial for her. The service provider's assessment of "enough" respite care conflicted with the mother's views. The mother felt totally overwhelmed with her daughters' care needs even with the allocation of respite hours that she had at the time. She admitted, however, that her frustration stemmed mostly from the inconsistency of actual respite coverage (rather than the amount that was theoretically allocated to her).

The level of respite care required by the child also impacted on parents' experience. Finding a highly specialized care giver such as a nurse, or nursing aide was often difficult. Even qualifying for nursing respite care, which has strict program admission criteria, did not ensure actual respite care since nursing agencies were

sometimes unable to find enough nurses. The care needs of many children were not sufficiently specialized as to qualify for nursing respite, yet they were specialized enough to require a trained care giver. It was very frustrating for parents to find a lay person who could be taught certain ADL techniques such as lifting and toileting. As one mother verbalized: "It's very difficult training a teenager, finding a teenager who is appropriate to do this kind of care. We're very, very fortunate to have [name of teenager]".

Parents' perceptions of their child's condition influenced the type of respite they valued. For example, parents who strongly believed in the concept of normalization for their child, articulated these thoughts:

(F) Respite. They've got a wonderful program...the government wants to encourage parents to raise these disabled children in their own house, rather than putting them in institutions...

(M) ...we do have some excellent teenage sitters...but I prefer to use [nanny] when I can...that is ideal...I would never take him to [hospital A] or [hospital B] or anywhere else...we made that really clear that we would not use that for respite. That's not normal. I just, I repeat, that really, really upsets me thinking about it.

Many parents changed the form of respite care they valued either as their child grew older or as their condition progressed. For the mother of a teenager with a progressive condition, the discovery of a respite house on Vancouver Island was very exciting: "[Son] loves it over there - it's given him a great sense of independence...it's a really comfortable place". This mother wouldn't have been as comfortable, however, with her child being at a respite house when he was a young boy. Another mother recounted how she managed for a long time with lay people watching her daughter

before she [her daughter] started to require more intensive care, and this was when her mother looked to nursing respite.

Individual Health Professionals

Parents had praise for many individual service providers. Several parents were very grateful to those whom they perceived as key service providers, who assisted them to manage adversity. One family spoke highly of their community health nurse, whom they called their case manager:

(M) She gives us advice and recommendations, and ...tells us what plans are available for us...she is our resource person...she's the most important person...if we didn't have [nurse], we would be lost...she just, either gets it done, or will coordinate it, or will, you know, tell us to see the right people or whatever...she's a great support person to me...

Another mother singled out her son's physiotherapist: "The physio has been, she's almost functioned like a case manager for me. In a way, she's the main person that we turn to. She's, she's been wonderful". Another mother stressed the importance of having a health professional to serve as a type of supplemental case manager (to the mother):

(M) ...that's critical! It's critical for parents. It takes so much pressure off. Instead of "who do I call?" and being bounced "oh, try so-and-so", and "try so-and-so"...and...oh, another one. And now here I go having to give my story again...and some of them say "have you already tried this and tried that?", and it gets to the point where you just want to scream "of course I've tried this!"...it's just that you go through so much that another helpful suggestion is basically the last thing you need. And so when you have somebody who's that, that key focal point, they know everything that you've tried, and so they're with you...

A father praised the actions of a community health nurse in anticipating his daughter's need for a nurse at school: "...by the beginning of the third year [daughter] required a

nurse. And, see, at the end of the second year, we didn't know this, but three months later - boom! you know, and she needs a nurse". The actions of the nurse demonstrated foresight in defining a new form of adversity for these parents, and addressing its management before it became an issue. These parents provided another example of how their nurse foresaw adversity and acted to facilitate its management:

(F)...and she came with the forms, ...she said "I know this is premature, but I want you on the [program]"...

(M) Yes, by the time all the paper work had been done, and been through to Victoria and red tape, etc., we were needing it! And, she knew that.

It is for these service providers that parents expressed the utmost gratitude and respect.

Summary

In this chapter, the study's findings were presented. The experience of caring for a child with a progressive, life-threatening illness who requires specialized and time-consuming care was conceptualized as the process FACING ADVERSITY. At the core of this theme was the successive hardships and challenges faced by parents while their child lived with a complex chronic condition, and the deep sense of commitment to doing what was best for their child. This process was contextualized within a specific time span of the child's illness trajectory: the time when the chronic condition had become complex. FACING ADVERSITY was conceptualized as a set of horizontally linked spirals; each spiral was made up of two interconnected components: DEFINING ADVERSITY and MANAGING ADVERSITY. The goal of this process was a balanced spiral, indicating that parents were able to define and manage successive forms of adversity. Defining Adversity and Managing Adversity were described in depth, and

were illustrated with actual descriptions of parents' lived experiences. Finally, the role of the health care system was identified as assisting parents to manage their adversity; that is, to promote and maintain a balanced set of spirals, and to help loosen a tightly wound or out-of-control set of spirals. The role of health care services (especially respite care), service providers, and equipment in assisting parents with Facing Adversity was described.

CHAPTER 5: DISCUSSION OF THE FINDINGS

Introduction

This chapter will present an indepth discussion of the findings detailed in Chapter Four. Parents' experience of caring for a child with a progressive illness during the complex chronic phase was described as the process FACING ADVERSITY. This process was composed of DEFINING ADVERSITY and MANAGING ADVERSITY. Chapter Five will further explore parents' involvement in these two components of Facing Adversity. Attention will be placed on how the findings support and/or refute certain literature introduced in Chapter Two as well as additional theories and concepts selected in light of the findings.

In defining their adversity, two major concepts emerged for parents: normalization and loss. Normalization influenced how parents defined their adversity, and became increasingly challenging as their child's condition progressed. Loss characterized almost every new form of adversity, and parents' response to loss also influenced how parents defined adversity.

Managing Adversity was largely the responsibility of the primary caregiver, which was consistently the mother. The hardships faced by caregivers support literature about the demands of informal caregiving, as well as recent concerns raised by authors regarding the role of women as caretakers.

The amount of change faced by parents (and especially the primary caregiver) was substantial. Each new spiral of adversity signalled change of fairly significant

proportions. The kinds of change experienced by parents in managing adversity was best explained from a transitions perspective.

What follows is a discussion of the concepts "normalization" and "loss", and how they enhance understanding of DEFINING ADVERSITY. This is succeeded by a discussion of "women as caregivers", and "transitions", and how these perspectives enhance understanding of MANAGING ADVERSITY.

Defining Adversity

Defining adversity was very important to the overall process of Facing Adversity. The ability to define their adversity - to identify the changes and assess their impact on the family - was necessary in order for parents to determine management strategies.

Normalization

In defining their adversity, parents painted a picture of their family in light of the challenges resulting from the progressive nature of their child's condition. This definition was influenced by many characteristics of both the child's condition and the family itself. What became clear was that all parents defined their situation in terms of a "norm". Several parents described their determination and efforts to maintain normalcy in the face of adversity. Their goal was to maintain a normal family life, and subsequent management strategies reflected this goal. Anderson (1981) found in her study that "indeed the emphasis was on deconstructing the disease label, and emphasizing the normality of the child" (p.428). Other parents, however, described

their situation in terms of how far away they were from this norm. While they wanted normalcy, they did not see their situation as conducive to this ("this is not a normal family"). An exploration of normalization promotes a better understanding of parents' experiences in defining and managing adversity.

Normalization has been described as a concept, philosophy, phenomenon and management style (Anderson, 1981; Anderson & Chung, 1982a, 1982b; Deatrick & Knafl, 1986, 1990; Deatrick, Knafl, & Walsh, 1988; and Krulik, 1980). Deatrick, Knafl and Walsh described normalization as "the constant process of actively accommodating the changing physical and emotional needs of the child or adolescent" (1988, p.17). The goal of this process is to integrate the child into the family rather than making him or her a "special nucleus".

All parents chose to view their child's condition in a unique way. For example, one set of parents stated that they fully understood the implications of their son's progressive, life-threatening condition, however they chose to view it as a disability. If they were to view their son's condition as a progressive life-threatening illness, the whole focus would be on illness, instead of health; this would influence the way they raised their son. By viewing it as a disability, these parents could look at their son as an essentially healthy child with special physical needs. With this view, they could treat him as they would any other child.

In light of the philosophy of normalization, these parents' view of their son's illness can be construed as a means of normalizing their situation, rather than a denial of

reality. Anderson and Chung (1982b) found that parents of a child with a life-threatening illness chose not to openly discuss the terminal nature of the sickness. This was not viewed by the authors as denial; rather, "it was seen as a way of managing their everyday lives in a manner congruent with the parents' belief that it was the child's right to have as normal a life as possible" (Anderson & Chung, 1982b, p.261).

Treating their son as they would an able-bodied child required effort on the parent's part to minimize the disability. The mother referred to this as "equalizing the playing field". Both parents provided examples, such as sending their child to play-school with a dry diaper on to avoid a diaper change at school (and the possibility of other children discovering that the child wore diapers), and choosing a play-school with wheelchair accessibility so that their son could "just go straight in like all the other kids". The father described how he ensured wheelchair accessibility before an outing, and later stated: "...his normalization is about what we do for him, it's called 'seeless' - it's invisible....it's having all those pieces in place before you get there". Other examples provided by these parents included having their child play with other able-bodied children, and having birthday parties for their child ("just like any other family").

This family's experience corresponds with Deatrick and Knaf's (1986) suggestions that normalization entails both acknowledgment of the abnormality and denial of its social significance. It also fits the following criteria for normalization as a management style: (a) acknowledgement of the impairment; (b) normal definition of

family life; (c) assignment of minimal social significance to the impairment; and (d) the management behaviours used to demonstrate normality.

Upon closer examination of the conceptualization DEFINING ADVERSITY, several of the characteristics that influenced parents' definition of adversity also influenced parents' belief in and/or ability to subscribe to normalization. For example, one set of parents maintained that their attempts at normalization were enhanced by their child's young age, the fact that his disability was solely physical in nature, and because he was their first child which precluded any comparison to an able-bodied sibling. Authors have recognized the fact that the child's age and severity of symptoms influence the family's ability to achieve normalcy (Deatrick & Knafl, 1986).

Societal attitudes and services impacted on parents' abilities to carry through with their belief in normalization. For example, one mother argued that her child had unnecessarily been made to feel segregated by having to attend a different elementary school than his friends, because of a lack of wheelchair accessibility. She was relieved that not only was their local high school wheelchair accessible, it also offered computers and adapted sports activities which would enable her son to "do what all the other kids were doing".

Discussion in one lower mainland community about terminating the mainstreaming of children with disabilities left another mother very upset:

(M)...That's taking us back 10, 20 years! We're having to address and fight for some of the issues that have already been addressed! The emotional component to that, of thinking that my child might not be mainstreamed, might be put in a segregated class, with everything that we as parents are doing for him, that the

school system, in their power, might undo it??? I think you can begin to see that this just drives me insane! I'd hate to see the gains that we've made be taken away.

Darling and Darling (1982) agree that a limitation in services may hinder families' attempts to achieve normalization.

Other parents referred to the word "normal" when describing what they had lost as a result of their children's conditions: a normal family life. Parents of two affected children (whose condition had progressed very rapidly to a point of severe mental and physical impairment) had great difficulties in normalizing their situation. Deatrick and Knafl (1986) explained that the nature and severity of the affected child's condition influenced the family's ability to normalize their situation. Furthermore, Roskies (1972) found that parents were more likely to view the child as normal if they could identify signs of progress in the child's general development and specific condition. This point helps to explain the difficulty these parents experienced in attempting to view their children as normal.

Another mother found that although her son's physical condition was deteriorating, his increasing emotional independence enabled their family to maintain a sense of normalcy. For example, this adolescent travelled unaccompanied on the ferry (in his power wheelchair) to Vancouver Island, asking for assistance from ferry workers and the public. In contrast, another teenager of the same age was afraid to be assisted by anyone other than his family or aide. This frame of mind greatly reduced his potential scope of activities, and the family's efforts at normalization. This may suggest

that as a child gets older, he/she plays an increasingly important role in normalization.

Normalization may become increasingly difficult for parents to maintain as their child's illness progresses. This is due to two reasons: first, the severity of the condition may impede with normalization efforts, and secondly, normalization requires accommodation to change, which is more difficult when the changes are successive, great in number, and unrelenting in their demands.

Loss

Included in parents' definitions of adversity was their responses to a multitude of losses. Parents experienced successive losses which resulted from their child's progressive, life-threatening condition. Loss can be defined as "the state of being deprived of or being without a valued object" (Peretz, 1970, in Bozett, 1987, p.11). Grief is the intense emotional suffering a person experiences as a result of a significant loss (Simos, 1979). As compared with the grief experienced after a loved one dies, which hopefully progresses to some sort of closure, Werner-Beland describes the losses resulting from a chronic illness as creating "a state of chronic grieving" (1980, p.3).

Most changes that led to a new form of adversity were characterized by loss. For example, when a child lost some measure of functional ability, this resulted in increased care giving demands. The caregiver grieved the further loss of their child's abilities, as well as the losses associated with the increased burden of care: time, energy, perhaps a job, a career, a beloved home or neighbourhood. There was no remittance from these losses, only the awareness that more were to come.

One approach to examining parents' response to loss is via a grief framework. Typically, these frameworks outline predictable, identifiable stages one must go through to regain equilibrium after a significant loss, recognizing that each individual will proceed through the stages at a different pace and intensity. For example, Kubler-Ross (1969) identified five stages of the grief process: denial and isolation, anger, bargaining, depression, and acceptance. While such a grief framework adds insight to parents' responses, the successive cycles of adversity make application of the stages confusing. By the time their child lived with a complex chronic condition, parents were likely to be experiencing any or all of the five stages!

Chronic Sorrow

The concept of chronic sorrow more clearly describes parents' response to loss. Olshansky (1962) first used this concept to describe a natural response to a tragic event. He used the term chronic sorrow to describe the unending feelings of grief, loss, and fear experienced by parents of mentally retarded children.

Olshansky (1962) maintains that chronic sorrow varies in intensity and time, but to some degree it continuously pervades the lives of these parents. That is, parents can accept the child for who he/she is, acknowledge their child's illness and long-term consequences, and have adequate coping strategies in place in order to manage periods of crisis, however chronic sorrow is "manifested throughout the lifespan of the parent-child interaction" (Clubb, 1991, p.462). Olshansky suggests that feelings of guilt are never eliminated, and that parents never completely recover from the impact stage of the

child's illness. The intensity of this sorrow varies for the same person, from situation to situation and from one set of parents to another (Fraley, 1990).

Further research discovered that certain stressor events lead to times of increased sorrow (Wikler, 1981), grief and loss (Leahey & Wright, 1985), and anxiety and disequilibrium (Clements, Copeland, & Loftus, 1990). Such times included certain developmental milestones unreachable for the child with a chronic condition, as well as events or crises directly related to the chronic condition. These authors suggest that a peak in chronic sorrow could therefore be anticipated to some degree by families and health professionals.

Chronic sorrow describes the response to loss that parents experienced as part of the process Facing Adversity. As a new form of adversity evolved, this triggered a period of sorrow which became part of the redefining of their adversity. Unlike acute grief, chronic sorrow was recurrent; several parents described it as a wave. This concept cautions health care providers against placing a time limit on parents' grief. Furthermore, the magnitude of the most recent loss did not always reflect the current degree of sorrow felt. For example, one mother described a situation in which her child's wheelchair broke down to which she reacted with intense feelings of despair. Her explanation for this was that she was actually responding to a cumulation of events. This example demonstrates that for cumulative losses, such as those experienced by parents of children with progressive conditions, responses may be especially intense and exhausting over time.

To summarize, an understanding of DEFINING ADVERSITY is enhanced by literature that describes the concepts "normalization", and "chronic sorrow". All parents wanted normalcy in their family life, however not all parents could define their situation as normal. The term chronic sorrow described the waves of grief experienced by parents in response to the successive losses resulting from their child's progressive condition. Each new form of adversity had the potential to trigger sorrow for parents.

Managing Adversity

Managing adversity was a substantial undertaking. Due to the progressive nature of the child's condition, time was a factor; an inability to manage adversity within a certain time frame meant that parents could face a new form of adversity (or spiral) before a previous one was managed. A tight or out-of-control spiral could signal a crisis for a family.

Women as Caregivers

As the primary caregiver for their child, mothers assumed major responsibility for Managing Adversity. That is, these mothers were confronted with many changes related to their child's condition, and subsequent changes in their caregiver role. Changes were related not only to increased direct caregiving responsibilities, but also to an increased need for services. This perception of the caregiver role was also found by Anderson and Elfert (1989). In their study, several mothers viewed themselves as being responsible not only for the child's ongoing care, but also for the overall coordination of the child's health care.

The fact that all of the mothers were primary caregivers parallels other studies which examine various caregiving issues (Anderson & Elfert, 1989; Anderson, 1990; Lindsey-Davis, 1992; Marcenko & Meyers, 1991; O'Neill & Ross, 1991; and Turner-Henson, Holaday, & Swan, 1992).

Mothers initially assumed the caregiving role as a natural extension of their mothering role. During the time that their child was relatively free from symptoms, the caregiving role demanded little (outside of regular parenting demands). As their child's condition progressed to a point of requiring specialized and time-consuming care, most mothers took on this greatly expanded role out of a sense of moral obligation and commitment to their child. A few mothers admitted that, in their eyes, there were no other choices but to assume the role.

Two broad issues were thus raised concerning the caregiving role: first were the issues of societal expectations regarding women as informal carers. To this, emerging literature has begun to challenge ideologies that make assumptions about the role of women as caretakers. Secondly, mothers came up against numerous challenges in their caregiving role that greatly increased their risk of exhaustion and burnout.

Those mothers reporting the least amount of stress associated with the caregiving role were both willing and able to share this role. One mother had assumed almost total responsibility for her teenager's extensive care and although she was becoming increasingly exhausted, she felt that it was her responsibility to continue. Her hesitancy in requesting assistance may have been a reflection of society's expectations regarding

women and the caregiving role. O'Neill and Ross (1991) contend that women's motivation to care is considered a natural extension of the nurturant role associated with being a woman. Anderson and Elfert reiterate that as families take more responsibility for the care of the chronically ill, "...women are expected to be the caretakers; this is a societal ideology that is internalized by them and recreated in their everyday lives" (1989, p.740).

Several mothers who had been willing to share the caregiving role could not locate appropriate resources to do so. As a result, these mothers were forced to either quit their job or change to a lower paying job that offered greater flexibility to their caregiving role. In other words, these mothers either gave up a position in the paid workforce or moved downward to a less valued position (both in terms of money and prestige) for a role that is categorized as unpaid domestic work - a role in which women have been historically undervalued (Lupri, 1983).

Mothers who had not assumed their role out of choice, but rather a lack of viable alternatives, became frustrated and resentful. As one mother said:

(M)...there is no end to it...I am giving 24 hours per day, seven days a week to it...because of a love of my children, obviously, and because it hurts me to think that I would put them in an institution, but two years into it...I've had it! I'm exhausted! This is not what I've been put in this life for!

Furthermore, although the concept of family is emphasized by health professionals, it is the woman and not the family as a unit that takes on the role of primary caregiver (Anderson & Elfert, 1989). One father stated: "...I will be very frank - I do very little with the kids, very little...[wife] does it all...men don't have the

patience - I don't". Anderson and Elfert argue that the term family "glosses over the work that women actually do in caretaking, and the contribution that they make to the health care system. This work often goes unnoticed and unrecognized in society"

(1989, p.736). The sacrifices women make also often go unrecognized, as one mother pointed out:

(M) We're ambitious people. We knew what we wanted and we were going to get it...I had a career until two years ago. And I've always worked, all my life. As a career, I was an [names profession], a really good job, and I had to give up my career to care for the children. I don't think I'll ever be able to go back, and I wonder - is that the way it should be? The Ministry of Health - their goal is to encourage families to keep children at home. Well, that's all very nice, but they don't pay me to do it. They haven't paid me, the fact that I stopped work to care for these children, and that I am giving 24 hours per day, seven days a week to it...

Several authors advocate the need to focus on a broader context: the environment that contributes to the constitution of the caregivers' roles. Bridges and Lynam (1993) state:

...the literature has largely failed to examine the environment that has engineered the assumptions about family care and women's care; to determine how forces within the environment can be acted on to ensure that the caring role is taken on out of choice, not obligation; and to take steps to ensure that conditions that constitute systematic discrimination against carers are recognized and altered (p.35).

Anderson and Elfert agree that health professionals must become aware of the macro forces that influence the delivery of health care and "recognize the extent to which these forces influence the expectations they place on women" (1989, p.742).

The caregiving role was a demanding undertaking for all mothers, which intensified as the burden of care increased. The meaning of caregiving changed for

mothers as they moved through the various stages of caring, prompted by both the child's illness trajectory and the family life cycle. Burns, Archbold, Stewart, and Shelton (1993) described a new nursing diagnosis which they maintain can be measured and predicted: caregiver role strain. They describe "caregiver role strain" as a family-oriented nursing diagnosis that occurs when the caregiver feels difficulty performing the family caregiver role. It is measured via a framework developed by Archbold and Stewart (1986, in Burns, Archbold, Stewart, & Shelton, 1993) which provides measures for 10 categories of caregiver role strain. These include: strain from direct care, lack of resources, worry, role conflict, economic burden, mismatched caregiving role expectations, increased tension and feelings of being manipulated, communication problems, and managed care. They emphasize the importance of a complex assessment of caregiver role strain. The framework takes in to account the various sources of strain for mothers. Another strength lies in its ability to guide nurses in foreseeing or predicting potential caregiver role strain.

Transitions

Managing Adversity meant managing a multitude of changes related to the child's progressive condition. Parents described the changes as meaningful, stressful, challenging, and as having both negative and positive connotations. Parents were required to utilize certain skills in order to manage the changes, which often resulted in growth - perhaps becoming stronger, or developing a new way of looking at things, or learning a new coping mechanism. Parents described these changes according to a time

element; current changes were compared to previous changes, and changes in general were described as they impacted a certain point of time in that family's life.

Several parents referred to the changes as transitions. Parents described transitions in terms of their child's condition ("the transition from her being able to walk, to needing a wheelchair - that was the worst"); in terms of services ("going from infant development, which goes to age three, into the preschool system, which is three to five, is a horrendous transition period because of the gap in services"); in terms of equipment ("she went from wearing braces, to a scooter, to a wheelchair"); and in terms of development ("we were nervous when she started kindergarten because of the wheelchair").

Upon further examination, parents' experience of change indeed supported a transitions perspective. Change occurred along the child's illness trajectory in conjunction with their family life cycle. Mercer, Nichols, and Doyle (1989) maintain that transitions are embedded in trajectories (paths, progressions, or lines of development) that give them meaning. Transitions represent "a period of disequilibrium or flux for the individual who must adapt to a new situation, new roles, or responsibilities" (Mercer, Nichols, & Doyle, 1989, p.3).

Parents experienced transitions as part of the process Facing Adversity. Management strategies for adapting to these transitions included seeking information, planning/preparing, negotiating, and utilizing resources. It was not always the event itself, but a complex mix of factors that influenced parents' adaptation to transitions:

some parents adapted with relative ease, while others suffered severe strain. Mercer, Nichols and Doyle (1989) claim that feelings of inadequacy and lack of self-confidence are predominant during transitions because of the changes that are occurring.

Schlossberg (1981) developed a model which analyzes human adaptation to transitions. Her goal was to "elaborate a theory which describes the extraordinarily complex reality that accompanies and defines the capacity of human beings to cope with change in their lives" (Schlossberg, 1981, p.5). Exploring Schlossberg's model offers a way of viewing the role parents played in adapting to transitions, and Managing Adversity.

Transition was defined in the model as "an event or non-event that results in a change in assumptions about oneself and the world and thus requires a corresponding change in one's behaviour and relationships" (Schlossberg, 1981, p.5). The author purports that a transition is not so much a matter of change as of the individual's perception of change: "a transition is a transition if it is so defined by the person experiencing it" (Schlossberg, 1981, p.7). This view explains why similar changes resulted in different reactions by parents. It also supports a qualitative approach to investigating and describing parents' experience of transitions. Furthermore, it discourages rigid expectations of health professionals towards parents who are experiencing transitions.

In this model, it is not the transition itself that is of primary importance, but rather how that transition fits with an individual's stage, situation and style at the time of

the transition. The model postulated three major sets of factors that influence adaptation to transitions: (i) characteristics of transition; (ii) characteristics of pretransition and posttransition environments; and (iii) characteristics of the individual. All three sets of factors interact in a complex manner to produce the outcome: adaptation or failure to adapt.

Under (i) characteristics of transition is included: role change (gain or loss); affect (positive or negative); source (internal or external); timing (on-time or off-time); onset (gradual or sudden); duration (permanent or temporary); and degree of stress. Under (ii) characteristics of pretransition and posttransition environment is included: interpersonal support systems; institutional supports; and physical setting. Under (iii) characteristics of the individual is included: psychosocial competence; sex; age (and life stages); state of health; race-ethnicity; socioeconomic status; value orientation; and previous experience with a transition of a similar nature.

Parents identified many of the influencing factors from the model in their own lives. A child's transition from walking to requiring a wheelchair was a major transition by all accounts. Although this framework is very complex, applying the first factor (characteristics of transition) very generally to one family's experience with their daughter's transition to a wheelchair illustrates a few of the components that worked together to promote and hinder adaptation to the transition.

When her daughter required a wheelchair, the mother's role (as primary caregiver) was greatly expanded. Her child had already become increasingly physically

dependent, however the wheelchair signalled almost total dependence. The mother learned the mechanics of the wheelchair, how to drive a van and operate its wheelchair lift, and the complexities of planning accessible routes. The affect associated with the transition to a power chair was initially negative, but eventually became more positive when the parents realized that it signalled some form of independence for their child. The source of this transition was external, meaning parents had no control over it. They were, however, somewhat prepared for it (it was "on-time" for someone with that particular progressive condition). The onset was gradual which parents acknowledged assisted them in adaptation. The duration was permanent: their child would always require a wheelchair, which led to a considerable amount of stress. The impact of this transition was substantial. In time, the parents felt they adapted well. Although only one of three major sections of the model was applied here, it demonstrates the complexity of human response to change.

This framework accounts for the complexity of influencing factors on the ways in which transitions were described, experienced and managed by parents in this study. Furthermore, it describes them as dynamic and changing, thereby explaining why parents may have managed transitions differently as their child's illness progressed.

Summary

This chapter presented a discussion of the findings which were presented in Chapter Four. Parents' experience of FACING ADVERSITY was discussed in terms of its two components: DEFINING ADVERSITY and MANAGING ADVERSITY. Two

concepts which profoundly influenced parents' definition of adversity were "normalization" and "loss". Mothers assumed the most responsibility in managing adversity, and their role as the primary caregiver was discussed. Finally, parents' management of the multitude of changes (as part of their role in managing adversity) was discussed from a transitions perspective.

CHAPTER 6: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

This chapter will present a summary of the study, followed by conclusions based on the study's findings. Implications for nursing practice, education and research will then be suggested.

Summary

This study explored and described the experiences of parents caring for a child with a progressive illness during the complex chronic phase. The child's illness was conceptualized as occurring along an illness trajectory. The focus for this study was the time frame along this illness trajectory during which these children lived with a "complex chronic condition", meaning that they required specialized and time-consuming care (i.e., extensive care that required special training from a health care provider).

Improving health care has extended the lifespan of these children and, subsequently, the time they will live with a complex chronic condition (Mullins et al., 1991; Tucker & Roberts, 1990). It was therefore important to learn, from parents' perspectives, how they were managing during this extended period of time. Furthermore, a literature review disclosed a recent trend of grouping all types of chronic illnesses together (i.e., "progressive" and "non-progressive" illnesses). It was argued here that parents of children with progressive illnesses may face unique challenges due to the ever-changing and increasing care demands.

A further search of the literature revealed that children's hospice care focuses on

families of children with progressive, life-threatening illnesses. Furthermore, plans were under way for North America's first freestanding children's hospice to be opened in Vancouver, B.C. Its goals for service include respite care, palliative care, and bereavement care; that is, care is planned for the entire family of a child with a progressive illness, not only during the palliative stage, but also during the time that the child lived with a complex chronic condition. This provided further impetus to explore parents' experiences during this time frame.

The purpose of this study was to gain insight into the day-to-day experiences of parents caring at home for a child with a progressive illness, during the time that the child lived with a complex chronic condition. The phenomenological approach was used to elicit an understanding of parents' experiences. Three couples and five mothers volunteered to participate in this study. Each participant (or set of participants) had either one or two children affected with one of the following progressive illnesses: Duchennes Muscular Dystrophy, Spinal Muscular Atrophy (Type II), Metachromatic Leukodystrophy, Retts Syndrome, and Cerebral Palsy with Microcephaly and respiratory distress. Children were between the ages of 26 months and 16 years. Guidelines for protection of human rights and ethical considerations were adhered to.

All interviews were audio-taped and transcribed verbatim. These transcripts (plus field notes) became the data used for analysis. The data were analyzed using Giorgi's (as outlined by Omery, 1983) steps for data analysis, and Anderson's (1992) recommendations for phenomenological data analysis.

One major theme, conceptualized as FACING ADVERSITY, constituted the research findings. At the root of this theme was the successive hardships and challenges faced by parents while their child lived with a complex chronic condition, and the deep sense of commitment to doing what was best for the child.

Facing adversity was conceptualized as a set of horizontally linked spirals, extending across that section of time (in the child's illness trajectory) during which he/she lived with a complex chronic condition. Each spiral was made up of two distinct yet closely connected components, DEFINING ADVERSITY and MANAGING ADVERSITY. Each of these components was further made up of a complex arrangement of characteristics. With each significant change, parents' redefined adversity, and in turn managed it. This created a succession of spirals which had definite implications for parents: while it meant they could learn from past experiences and/or bring previously learned coping and problem solving skills to new situations, it also meant that certain events and experiences were cumulative (such as burden of care, and losses), which may over time increase the risk of parental exhaustion and inability to manage.

The desired outcome was a balance in the spirals, demonstrating that as parents faced each new form of adversity, they defined it and subsequently managed it. Defining adversity was shaped by characteristics of (a) the individual condition and (b) the individual family, as well as the magnitude of impact of each situation that led to a new form of adversity (some situations or events leading to a new form of adversity had

stronger impact than others). Characteristics of the individual condition were largely out of parents' control and mostly determined by the individual disease process. They included: how extensively affected the child was by the condition; the speed of progression; the number of affected children in the family; and the age and developmental stage of the affected child. Characteristics of individual families that contributed to the way in which parents defined their adversity included the way in which parents perceived their child's illness, parents' acceptance of their child's illness, learning to live with loss, and gaining strength from their adversity.

In defining their adversity, two major concepts emerged for parents: normalization and loss. Normalization influenced how parents defined their adversity, and became increasingly challenging as their child's condition progressed. Loss characterized almost every new form of adversity and parents' response to loss was described by the concept chronic sorrow.

Managing Adversity was characterized by parents managing changes related to the child's condition and, subsequently, the caregiving role. The skills involved in managing these changes were: seeking information; negotiating; planning/preparing; and utilizing resources. Each of these skills was applied to managing change as related to both direct and indirect caregiving.

Managing Adversity was largely the responsibility of the primary caregiver, which was consistently the mother. The hardships faced by caregivers support literature about the demands of informal caregiving, as well as recent concerns raised by authors

regarding the role of women as caretakers.

The amount of change faced by parents (and especially the primary caregiver) was substantial. Each new spiral of adversity signalled change of fairly significant proportions. The kinds of change experienced by parents in managing adversity was best explained from a transitions perspective.

The extent to which parents expected the health care system to provide resources varied. Parents had strong feelings regarding their experiences with the health care system. On the positive side, parents felt that, at least in theory, there were enough services to meet the needs of their child, and that respite care was an especially helpful and valuable service. In addition, many parents identified key individual service providers whose assistance was especially valued. On the negative side, parents were overwhelmingly frustrated and angry towards the bureaucracy involved and the method of service allocation. Furthermore, although respite care was crucial for parents, existing services did not meet the respite needs of all parents.

Conclusions

The research findings lead to several conclusions about the participants' experiences in caring for a child during the complex chronic phase of a progressive illness:

- 1.) Parents' experiences were evolving; the illness progressed along an illness trajectory and within that family's life cycle.
- 2.) Parents faced successive hardships and changes of a significant proportion during

the time their child lived with a complex chronic condition.

- 3.) Most changes signalled some form of loss.
- 4.) For every significant change, parents had to redefine their situation, and then learn to manage again; this process was conceptualized as FACING ADVERSITY.
- 5.) In defining their adversity, parents referred to a "norm"; that is, they described their situation in terms of how well they were or were not achieving normalcy in their lives. Normalcy was important to parents.
- 6.) The progressive nature of their child's condition had specific and significant implications for parents:
 - (i) certain events and experiences were cumulative, such as burden of care, and losses, which, over time, increased the risk of parental exhaustion and inability to manage;
 - (ii) parents could bring past coping and problem solving skills to new situations.
- 7.) Parents relied on both personal (informal) and formal resources to assist them in facing adversity.
- 8.) The health care system had the potential to either assist with, or exacerbate, parents' adaptation to some forms of adversity. Indeed, the health care system was at the root of some forms of adversity.
- 9.) All primary caregivers were mothers, who took on this role out of a sense of

love and responsibility to their child; some, however, did not take this role out of choice, but instead due to a lack of options.

- 10.) Mothers as primary caregivers faced certain hardships which were reflective of societal expectations regarding women as caretakers.
- 11.) Caregivers were at risk for strain, exhaustion and burnout over time.
- 12.) Parents valued continuity and flexibility in health care services.
- 13.) Respite care was crucial for these parents; however, existing services only partially addressed their needs.
- 14.) Bureaucracy and service allocation were immense sources of frustration for parents.
- 15.) Parents valued key service providers whom they trusted as "being there for them".

Implications For Nursing

Based on this study's findings and its discussion, several suggestions for nursing practice, education and research can be suggested. The following section offers these recommendations.

Implications for Nursing Practice

Understanding the experiences of these parents assists nurses in becoming more empathetic and individual in their care. The conceptualization of FACING ADVERSITY provides nurses with a new level of understanding from which suggestions for practice can be put forth. The findings advocate a thorough nursing assessment to

determine how parents define and manage their adversity. The nurse must learn how parents take in and integrate new information into their family life to "redefine their adversity". Are there certain characteristics that place parents at risk for a tightening spiral (which could signal a crisis)? The nurse must also assess how well parents are implementing the skills necessary to manage their adversity. How can the nurse assist parents to maintain, or regain, a balanced set of spirals? Nurses must be constantly alert and responsive to the changing needs of families.

Nurses should use their knowledge of the child's illness trajectory to anticipate the likelihood that certain needs may arise. This knowledge can be used to gently guide parents in their planning/preparing, and the nurse in his/her own planning of nursing interventions.

Mothers need to be supported whether or not they choose to assume the primary caregiver role. They should not be forced to pursue this role because of a lack of alternatives. Nurses must ensure that they are not perpetuating the idea that the woman must be the primary caregiver (they could inadvertently be doing this, for example, by always assuming the mother is the primary caregiver). For mothers who do choose this role, nursing interventions should be aimed towards them. The benefits of respite care and providing mothers with support in coordinating services will be discussed. These interventions can decrease the stresses of role strain, and allow mothers to experience positive aspects of the primary caregiver role.

Two disturbing areas in the study's findings were the lack of comprehensive

respite care available to meet the needs of families in diverse situations, and the overwhelming parental frustration with the responsibilities of complex service orchestration, especially the bureaucracy involved. Implications for nursing practice will address these areas by presenting (a) the attributes of a comprehensive respite care service, and (b) the merits of community based case management for these parents.

Respite Care Service

Respite care was crucial to these parents. At some point in their child's illness trajectory, all parents required respite care. Because of changing individual and family needs, one form of respite care would not meet the needs of all families. A comprehensive respite care service should address at least the following five areas:

(i) Level of Care.

Not all children required nursing respite care, and this was agreed on and understood by parents. All children, however, required trained caregivers, and their scarcity was repeatedly a source of frustration for parents. In order for parents to truly get a break from caregiving demands, they require caregivers whom they trust have been trained to care for their child and his/her unique health needs. As one parent stated, "I need somebody that I can be sure of...who is reliable, competent, dependable...and that I don't have to worry about.."

The nature of some illnesses are such that different levels of care are required depending upon the stage that the child is at along the illness trajectory. A child may initially require a trained caregiver, but eventually may require nursing care.

(ii) Who Finds the Caregiver?

Since very few families would be able to find their own respite nurse, this is mainly an issue for those children requiring trained caregivers. In the present system, the At Home Program may allocate a certain amount of money for families to use for respite care per year, depending on that family's income level (Ministry of Social Services & Housing and Ministry of Health, 1989). Parents are responsible for finding their own caregiver. While a few families valued finding their own trained caregiver because they felt this was "more normal", most parents lacked knowledge of how to find their own caregiver, or simply were unable to do so. These parents valued an agency from which they could call upon a trained caregiver, who could then be further instructed as to the individual needs of their family. In response to this need, an agency was developed in the lower mainland which provided trained caregivers for children requiring non-nursing respite. Parents could pay for this service with money allocated from the At Home Program. At the time of this study, however, there was an insufficient number of caregivers on hand to offer respite care to every family who had requested the service (R. Caya, personal communication, February, 1993). Several parents stated that they had "respite money" left over at the end of the year because they simply could not find enough trained caregivers. Furthermore, they were worried that the government would view this left-over money as a sign that it was not required!

Characteristics of the individual respite care provider were also important to parents. Several parents stated that, optimally, the respite care should be beneficial to

the child as well as providing parents with a break.

(iii) Institution vs. Home-based Respite.

The availability of both institution- and home-based respite care is necessary for families. Most parents advocated home-based respite because it was least disruptive to their family and promoted normalization. In certain circumstances, however, institution-based respite was desirable. For example, in order for parents to get away for a few days it was almost impossible to orchestrate 24 hour respite coverage in the home, whereas an institution offers 24 hour-a-day respite coverage. Also, the opening of respite homes, such as the one located on Vancouver Island, was described as "wonderful". In the eyes of one mother, this home promoted her adolescent's independence while providing his parents with respite at the same time.

(iv) Timing.

Timing is very important with regard to the provision of respite care. It should be provided in a timely manner in order to prevent parental exhaustion and burn-out, and not in response to a crisis that has been precipitated by years of assuming total responsibility for round-the-clock care. Timing is determined partially by the nature of the progressive condition. To the extent that many conditions follow a known projected course, respite care should be anticipated to a certain degree. This is especially important since an extended period of time may be necessary to finalize authorization for the service.

(v) Flexibility.

Flexibility is absolutely crucial in a respite care program. Not only are there many forms of progressive illnesses, each with different needs, but families are unique in their needs as well. Furthermore, the needs of families change over time and a respite care service needs to be responsive to this.

Parents may require all forms of respite care at various times throughout their child's illness trajectory, and this requires flexibility and ongoing assessment. There may be times when parents require emergency, extended or back-up respite care. Parents need to be able to depend on a respite service.

In summary, parents need a comprehensive respite care program that is flexible and responsive to their changing needs. Parents also need a health professional who can anticipate the changing care needs of a child, and recommend an appropriate level of respite care on a timely basis. Since various forms of respite care are based out of different agencies, there must be effective communication between and among the service agencies in order to avoid gaps in service.

Canuck Place plans to offer in-house respite care (with or without family present), in a home-like setting. This service should add to the comprehensiveness of respite care services in the lower mainland by addressing the need for emergency respite, and respite that enables families to go on a vacation. Furthermore, by offering respite care to this population, the hospice can become involved with the family long before the child reaches a palliative stage. Families in turn may then feel more

comfortable and supported by a familiar environment when death is imminent. Canuck Place also plans to mobilize existing respite care services, which hopefully will increase awareness of and communication amongst the various respite care services.

Case Management

Most families were involved with numerous health care services. In trying to orchestrate services, parents encountered fragmentation of care, duplication of services, and gaps in services; all were exceedingly frustrating for parents. Several parents praised individual health professionals who provided parents with information regarding such areas as allocation and provision of services, and sources of funding. For these families, the implication of a community based case management model would address the problems posed by fragmentation, duplication and gaps in services.

A study done by Marcenko and Smith (1992) to determine the efficacy of a case management program found that "mothers...identified greater access to services, assistance with financing of services, opportunities to network with other families, emotional support from other families and staff, information about care of the child, and the development of advocacy skills" (p.95). Case management would assist parents in accessing, coordinating, and monitoring services, which is especially important for parents whose child's care needs are changing over time. Indeed, Moxley (1989, in Marcenko & Smith, 1992) states that "the initial goal of case management services is to identify and fulfill a spectrum of family needs, and over time to respond to the changing and emerging needs of families" (p.89). Ideally, case management would be

implemented at a community health level by a nurse who is prepared to assess the family's holistic needs and determine appropriate services. Furthermore, the nurse should assess the degree to which a parent wishes to assume the role of case manager, and support the parent in this role as desired.

Implications for Nursing Education

Nurses working with families of children with progressive conditions require education about the individual disease process, as well as issues, theories and concepts in caring for a child with a long-term progressive condition. These include burden of care, the role of women as caretakers, transition theory, loss, and chronic sorrow. For example, knowledge of the concept chronic sorrow aids understanding of a parent's reaction to certain changes around their child's condition and their role as caregiver.

Nurses must be educated about the role of women as caretakers in our society. Awareness must be raised about the forces that keep women in these roles against their wishes. Health care providers need to answer the question of how much responsibility informal caregivers should be accountable for, and at what cost. Educating nurses in this area may lead to supportive measures for these women.

Nurses should be educated about the complex mix of characteristics that make up each family's adversity and influence how they manage it. Nurses must learn how to build trust with these families, by being responsive to their unique needs, and empathetic to their adversity.

Implications for Nursing Research

The findings of this study have raised questions for further areas of study.

Longitudinal studies are needed to learn how families successfully integrate long-term caregiving activities into the various stages and phases of family life. Especially important are the transitions in which a child's condition progresses from one major phase of the illness trajectory to the next (i.e., from diagnosis, to managing mild symptoms, to requiring specialized and time-consuming care, to palliative care and death). How do the needs of parents differ during the various stages of the illness trajectory? How can parents build on previously learned coping skills to assist them as they pass through the various phases of caring for their child? How does chronic sorrow manifest itself in these parents, and what does it mean to them? What are women's perceptions of their caregiving role over time?

Future research could examine the ability of these families to achieve normalization over the course of their child's illness trajectory. What factors help/hinder families' attempts at normalization in this population?

Studies are also required to evaluate the usefulness of specific interventions for caregivers. For example, evaluative studies are needed to determine the efficacy of present respite care services.

This study has described the experience of eight parents (or sets of parents) in caring for their child who has a progressive, life-threatening illness, during the complex chronic phase of that illness. Its findings contribute to a knowledge base for nurses and

health professionals who work with these families. Timing has been important, as plans for a children's hospice to open in Vancouver are well under way; this hospice will serve families of children with progressive, life-threatening illnesses.

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APPENDIX A: LETTER OF INFORMATION FOR PARENTS

LETTER OF INFORMATION FOR PARENTS

Title of Study: "Caring for a Child with a Progressive Illness During the Complex Chronic Phase".

Dear Parent,

My name is Anna Fundy and I am a pediatric Registered Nurse who is currently pursuing a Master of Science in Nursing degree from the University of British Columbia. I am working on my Master's thesis which explores parents' experience of caring for a child with a progressive life-threatening illness who requires specialized and time-consuming care.

In order to carry out my study, I need to speak with parents of children with progressive life-threatening illnesses. For parents who agree to take part in the study, there will be two to three interviews of approximately one hour in length. The interviews will be tape recorded. An example of questions that might be asked are: "Describe a typical day in caring for your child"; or "When I say the word "relief" to you, what comes to mind?". The tapes will not identify you by name, and will be destroyed at the end of the study. All information obtained will remain completely confidential. **Your participation in this study is totally voluntary, and you can withdraw at any time with no effect on your child's present or future medical or nursing care.**

I highly value your input, for you can increase awareness for other families and health professionals of what it like to care for a child with a progressive life-threatening illness. Your participation is timely, since a children's hospice (Canuck Place) is scheduled to open next year in Vancouver, with plans to assist families of children with progressive life-threatening illnesses.

I would like to speak with both you and your spouse (if applicable), however meeting with even one parent (the main caregiver) would be appreciated. Upon completion of the study, a summary of the findings will be made available to you.

If you would like more information about participation in this study, kindly call me at my home number (738-8707) and I will be happy to answer any questions you may have.

You are under no obligation to take part in this study; however your participation would be greatly appreciated.

Thank you for your time.

Sincerely,

Anna M. Fundy

APPENDIX B: DEMOGRAPHIC DATA SHEET

DEMOGRAPHIC DATA SHEET

Code No. _____

Title: Caring for a Child with a Progressive Illness During the Complex Chronic Phase.

Parents:	Age	Mar. Status	Occupation
Mother	_____	_____	_____
Father	_____	_____	_____

Child with condition: _____ Age: _____

Diagnosis: _____ Diagnosis made at age: _____

No. of days child in hospital in last year: _____

Siblings:	Sex	Age
	_____	_____
	_____	_____
	_____	_____

Services presently utilized:

Services used in the past:

APPENDIX C: TRIGGER QUESTIONS

TRIGGER QUESTIONS FOR FIRST INTERVIEW

Title: Caring for a Child with a Progressive Illness During the Complex Chronic Phase.

- 1.) Can you tell me a little about your son/daughter's condition and what kind of care is involved?
- 2.) Please describe a typical day in caring for your child.
- 3.) Can you tell me what it is like for you, within your family, to care for a child with a progressive condition?
- 4.) Does anyone else besides yourself participate in your child's care? How are care demands met? How do you manage this with other responsibilities?
- 5.) What are some of the most important issues to you, in caring for your child with a progressive condition? (eg.: Do you feel you get enough support? From whom? What kinds of breaks have you been able to take in the last six months - year? Are you satisfied with the time you have with your other family members? Do you feel you have enough energy? Is sleep an issue?)
- 6.) When I say the word "relief" to you (as in "I give you relief" or "I give you a break"), what comes to mind? Have you ever had these experiences that you've just described? What had to happen in order for you to have these experiences?
- 7.) Is there anything that would be very helpful for you in caring for your child?
- 8.) Is there anything else you would like to say that we haven't already touched upon?

**APPENDIX D: THE UNIVERSITY OF BRITISH COLUMBIA CERTIFICATE OF
APPROVAL**

Certificate of Approval

PRINCIPAL INVESTIGATOR Lynam, M.J.	DEPARTMENT Nursing	NUMBER B93-0067		
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT				
CO-INVESTIGATORS: Fundy, A.L., Nursing				
SPONSORING AGENCIES				
TITLE: Parents' experience of caring for a child with a progressive life-threatening illness who requires specialized and time-consuming care				
APPROVAL DATE FEB 24 1993	TERM (YEARS) 3	AMENDED:		
CERTIFICATION: <p>The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.</p> <table><tr><td> Dr. R. Corteen <i>or</i> Dr. I. Franks, Associate Chairs</td><td> Dr. R. D. Spratley Director, Research Services</td></tr></table> <p>This Certificate of Approval is valid for three years provided there is no change in the experimental procedures</p>			Dr. R. Corteen <i>or</i> Dr. I. Franks, Associate Chairs	Dr. R. D. Spratley Director, Research Services
Dr. R. Corteen <i>or</i> Dr. I. Franks, Associate Chairs	Dr. R. D. Spratley Director, Research Services			

APPENDIX E: PARTICIPANT CONSENT FORM

PARTICIPANT CONSENT FORM

Title of Study: Caring for a Child with a Progressive Illness During the Complex Chronic Phase.

Investigator: ANNA FUNDY, RN, BScN, MSN student.

Supervisory Committee Members: Judith Lynam, RN, MSN, Assistant Professor.
Betty Davies, RN, PhD, Professor.

The purpose of this study is to gain deeper insight into the day-to-day experiences of parents caring at home for a child with a progressive life-threatening illness who requires specialized and time-consuming care. The study will involve interviewing parents about their experience of caring for their child with a progressive life-threatening illness.

As a participant in this study, I understand that:

- participation in the study is entirely voluntary and **refusal to participate will in no way affect the present or future medical or nursing care that my child receives.**
- I can withdraw from the study at any time or refuse to answer any questions or discuss any topic, with no effect on my child's present or future medical or nursing care.
- there will be a maximum of three interviews of approximately one hour each; these will take place in my home or at another location mutually agreed upon.
- the interviews will be tape recorded and I can request erasure of any tape or portion of tape at any time during the study.
- the tapes will be transcribed (typed) and any information identifying me personally as a participant will be removed from the transcription. No names will appear on the data sheets; only code numbers will be used.
- the tapes will be destroyed at the end of the study.
- participation involves no known personal risks or discomforts, or direct benefits, for me or other family members.
- if I have any questions at any time during the study, I may contact Anna Fundy or a member of her supervisory committee.

I acknowledge receipt of a copy of the participants' information letter and consent form.
I consent to participate in this study.

Signature: _____ Date: _____

Witness: _____