

**EXPERIENCES AND NEEDS OF RURAL FAMILIES WITH A CHILD WITH
CANCER: THE FAMILIES' PERSPECTIVE**

by

Shannon Scott-Findlay

A Thesis

**Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements for the Degree of
MASTER OF NURSING**

Faculty of Nursing

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**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree
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MASTER OF NURSING

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Our health is a voyage and every illness is an adventure story

Margiad Evans

DEDICATION

This work is dedicated to my grandfather - Donald James Scott (1922-1988). The strength, determination and courage he epitomized throughout his life, particularly with his experience with cancer, gave me the confidence to pursue my dreams, the determination to reach for the stars, and the compassion to help others less fortunate than myself. Thank you Grandpa.

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ABSTRACT

Childhood cancer is the second most common cause of death for children. Canada is among the countries reporting the highest incidence of pediatric cancer, and the incidence of childhood cancer is gradually increasing in this country. Survival rates have dramatically improved due to advances in the treatment of childhood malignancies. Subsequently, the experience for the family has changed from living with their child's imminent death to now experiencing chronic uncertainty. The diagnosis of pediatric cancer affects the entire family. The treatment and care for children with cancer are usually located within a large tertiary health care facility and often families live a great distance from the treatment centre. The focus of this study was to explore the needs of rural families, experiencing childhood cancer, who live a considerable distance from the centralized pediatric cancer treatment centre. A review of the literature suggested a lack of research examining rural families with a child with cancer. A qualitative research study, using an ethnographic methodology and integrating family systems theory as the conceptual framework was used to explore the needs of these families. Ten family interviews were conducted; in total twenty-five family members participated. The interviews were tape recorded and later transcribed. Purposeful sampling was used to drive the selection of families for this study. Data were collected using a semi-structured interview guide specifically developed for the study.

Data collection and analysis proceeded concurrently. Analysis revealed eight themes which were significant in the overall experiences of rural families with a child with cancer. Some of the themes were 'digging up the pain - the diagnosis story,' 'living at a

distance from our hope,' 'life is now different and life goes on,' and 'the wind beneath our wings.' Findings highlighted that persistently the experiences of these families were filled with additional stresses due to living at a distance from the treatment centre and living away from home during treatment. Some of the stressors unique to rural families were the added expenses of travelling and accommodations, travelling in poor weather, trust with the local health care providers, and the family unit being separated during inpatient periods. It was evident that the entire family was affected by the diagnosis as they tried to 'make a place' for cancer in their family life. Overall, most rural families felt they received enormous support from their family, friends, and local community in assisting them to cope with the diagnosis. Families also suggested several recommendations to enhance the current delivery of pediatric oncology services in Manitoba in order to take into account the unique challenges that rural families face.

Implications for nursing practice, education, research, and policy are discussed.

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Chapter 1

Statement of Problem

Introduction

Cancer is the second leading cause of death in children after infancy and below the age of 20 years (Aitken & Hathaway, 1993; Foley, Fochtman, & Mooney, 1993; Health Canada, 1996; McCourt, Chu, Desmeules, 1993). Canada is among the countries of the world reporting the highest rates of childhood cancers (Canadian Council of Cancer Registries, 1993; Health Canada, 1996); this can partly be explained by the completeness of cancer registration in Canada. The incidence of cancer in children in Canada has been gradually increasing (Canadian Council of Cancer Registries, 1993; National Cancer Institute of Canada, 1995). Each year, approximately 1,300 Canadian children under the age of 20 will develop cancer (Gibbons & Levy, 1993; Health Canada, 1996) and approximately 240 will die of it (Health Canada, 1996). Cancer occurs in approximately 16 out of every 100,000 Canadian children and teens each year (Health Canada, 1996). Within the province of Manitoba approximately 30-40 children are inflicted with cancer yearly (Manitoba Cancer Foundation, 1995). Annually, in Canada there are approximately 5000 hospital admissions and 50,000 days spent in hospital due to pediatric cancers (McCourt, et al., 1993).

The diagnosis of childhood cancer is a crisis for the entire family (Adams & Deveau, 1988; Aitken & Hathaway, 1993; Bain, 1995; Tringali, 1986) and evokes many strong emotions and images, such as uncertainty, fear, helplessness, anger, pain, and certain death (Hockenberry, Coody, & Bennett, 1990; Thomas, 1984; Thorn, 1985;

Tringali, 1986). Danielson, Hamel-Bissell and Winstead-Fry (1994) assert that for the family, coping with cancer, “ [it] is as much an emotional battle as a physical one” (p. 355). When a child who has everything to live for is diagnosed with cancer, the dreams and ideals of the future are suddenly destroyed (Peterson & Peterson, 1977). Children with cancer are frequently sick, feeling unwell, and often irritable. The specific problems experienced by these children are often related to their developmental stage and their stage in the cancer trajectory (i.e. diagnosis, treatment, remission, etc.).

Families of children with cancer experience many life changes and have to deal with several new challenges, including doctors’ appointments, painful cancer treatments, dealing with the range of emotions experienced by the ill child and siblings, disciplining the ill child, and increasing financial demands. Activities that the family once treasured and looked forward to are often replaced by appointments, diagnostic tests, and treatments. All aspects of the families’ lives appear to be encroached upon by cancer (Adams & Deveau, 1988).

Recent advances in the treatment of childhood malignancies have dramatically improved survival rates, and thus, have changed the nature of the experience for the family from one of living with their child’s imminent death to now one of chronic uncertainty (Koocher & O’Malley, 1981; Martinson & Cohen, 1989; Martinson, Colaizzo, Freeman, Bosser, 1990). Health Canada (1996) reports that most of the time, treating cancer in children is more successful than treating malignancies in adults. It has been suggested that by the year 2000, between 1 in 900 and 1 in 1000 young adults, aged 16 years to 34 years, will have survived childhood cancer (Health Canada, 1996; Meadows, Krejmas, &

Belasco, 1980).

The majority of pediatric oncology care takes place at tertiary medical centres which are located in metropolitan areas, and often a large percentage of children receiving treatment for childhood cancer live a great distance from the centre (Aitken & Hathaway, 1993). Within the province of Manitoba, specialized pediatric cancer care and treatment is delivered only at one site, located in Winnipeg, its provincial capital. Manitoba has a unique population distribution, in which approximately 60% of the province resides in Winnipeg, and the other 40% is scattered throughout the vast province. The centralization of specialized pediatric cancer services, has a unique and major impact on the rural families affected by this life-threatening, yet chronic illness (Aitken & Hathaway, 1993). Often these families are separated from their family and friends for many weeks at a time; they experience financial difficulties, parental stress, and employment problems (Aitken & Hathaway, 1993; Barbarin & Chesler, 1986; Health Canada, 1996; Lansky, Cairns, & Clark, 1979; Spinetta, 1982).

Problem Statement

The purpose of this study was to explore and describe the experiences and needs of rural families experiencing childhood cancer. The emotional, financial, family, information, and social needs of these families were explored. The central question guiding the study was, “what are the experiences and needs of rural families with a child with cancer?”

Purpose of the Study

The goal of this study was to develop an understanding of the unique experiences

and needs of this group of families. Through identification of the experiences and needs of these families, health care professionals will be able to more thoroughly understand the unique challenges and demands with which rural families experiencing childhood cancer live. Descriptions of rural families' experiences of having a child with cancer were collected through in-depth semi-structured interviews conducted with the families.

The Research Questions

More specifically, the data collection process was guided by the following questions:

1. How do families with a child with cancer describe their experience?
2. How are the families' lives affected and altered due to their child's cancer?
3. How do families perceive the social supports and medical expertise in their home community?
4. How do rural families perceive their cancer experience? Do they think their experience is different from families who live within the city of Winnipeg?
5. How do rural families perceive their social supports, finances, and coping skills in order to deal with the inpatient and outpatient treatment periods and follow up appointments in the city?
6. What are some suggestions for possible resources and programs that would be beneficial to these families?

Significance of the Study

The study contributes to our understanding of the cancer experiences and needs of rural families with a child with cancer. Postl (1995) in his report "The Health of

Manitoba's Children" recommended an improvement, specifically in rural areas, in home care and family support services to families with a child with cancer. Once the findings of this study are disseminated, they may assist health care agencies and government to ensure health services are provided to meet the particular needs of these unique rural families (Adams, 1992; Aitken & Hathaway, 1993). Additionally, the findings of this study will be of benefit to health care professionals who work with rural pediatric oncology families during inpatient periods to organize discharge planning and teaching, respective of the resources and supports in the families' local communities.

Conceptual Framework

Conceptual frameworks and theories provide the basis for generating and refining the research problem and purpose and link them to the relevant theoretical knowledge in nursing or related fields (Burns & Grove, 1993). The research study was guided by family systems theory.

Family Systems Theory

The family systems theory has been frequently applied by health professionals when studying families (Wright & Leahey, 1994). This theory is based on the general system theory introduced by von Bertalanffy in the 1950s (Hazzard, 1971) and includes integration from theories in nursing, systems, cybernetics, and family therapy (Wright & Leahey, 1990). This conceptual framework was introduced to nursing when Fawcett (1975) combined the general systems theory with nurse theorist, Martha Rogers' framework (Mercer, 1989). The systems approach allows the family to be viewed as a complex interacting unit (Ackerman, 1984; Danielson, Hamel-Bissell & Winstead-Fry,

1994) and enables observation of the interaction among family members rather than studying family members individually (Wright & Leahey, 1994). This particular theory was chosen because of its flexibility which is required when dealing with a diagnosis of cancer that demands ongoing family adjustment and adaptation (Danielson et al, 1994). This theory suggests that families are open systems that are constantly exchanging energy and information with the environment (McPhee, 1995). An excellent analogy that illustrates the concepts of the systems theory as applied to families was portrayed by Allmond, Buckman, and Gofman (1979). This particular analogy also is beneficial in illustrating the effect of the diagnosis of childhood cancer on the entire family:

Visualize a mobile with four or five pieces suspended from the ceiling, gently moving in the air. The whole is in balance, steady yet moving. Some pieces are moving rapidly; others are almost stationary. Some are heavier and appear to carry more weight in the ultimate direction of the mobile's movement; others seem to go along for the ride. A breeze catching only one segment of the mobile immediately influences movement of every piece, some more than others, and the pace picks up with some pieces unbalancing themselves and moving chaotically about for a time. Gradually the whole exerts its influence in the errant part(s) and balance is reestablished but not before a decided change in direction of the whole may have taken place. You will also notice the changeability regarding closeness and distance among pieces, the impact of actual contact one with another, and the importance of vertical hierarchy. Coalitions of movement

may be observed between two pieces. Or one piece may persistently appear isolated from the others; yet its position of isolation is essential to the balancing of the entire system (p.16).

As the above analogy suggests, the family is a complex interacting system. When one member of the family is affected by illness, for example, the entire family is affected and must compensate for the ill member (Johnson, Craft, Titler, Halm, Kleiber, Montgomery, Megivern, Nicholson & Buckwater, 1995). A benefit of this approach is that it advocates for families to identify their own needs and meet these needs through methods they deem as helpful (McPhee, 1995). Using this approach, families will feel empowered, the ultimate goal of the family systems approach (McPhee, 1995).

The family systems theory acted as a guide to understanding the effect a diagnosis of cancer has on all of the members in the family unit. The theory was also useful in understanding how the dynamics within a family unit change when the family is dealing with a crisis such as cancer.

The most important axioms or tenets of the family systems theory integrated as theoretical foundations for this study are discussed. The first tenet is that a family system is a part of a larger supra system and is also composed of many subsystems (Wright & Leahey, 1994). Central to this idea, a family is composed of subsystems of individuals, and these individuals are very complex systems also composed of various subsystems, for example physical or psychological subsystems. In order to actualize this concept, the researcher asked the primary caregiver to identify and invite any person(s) he/she feels is a member of their family to attend the interview. The control of who was included in the

family interview was delegated to the primary caregiver. The rationale for this decision is discussed later in Chapter 3.

Secondly, the family as a whole is greater than the sum of its parts (von Bertalanffy, 1965; Miller & Winstead-Fry, 1982; Ackerman, 1984; Wright & Leahey, 1994). This tenet emphasizes that the family's "wholeness" is more than simply the addition of each family member (Ackerman, 1984). This concept illustrates the necessity of observing the interaction among family members, which often more clearly explains an individual family member's function or role. The researcher integrated this component of the theory by having an open invitation to all family members. This concept is the rationale for the decision by the researcher to have the interviews ideally held in the families' homes. By locating the interviews in their homes, the families had a greater potential to feel comfortable and the researcher was given the opportunity to see the emergence of various family members' beliefs and roles.

The third tenet used to frame the study, is that a change in one family member affects all family members. The principle of the entire family being affected by chronic and life threatening illnesses is frequently mentioned in the literature. For instance, Thomas (1984) stated that the entire family is disrupted by a child with a chronic illness, such as cancer. Roles and routines must be altered to accommodate a family member who differs from expectations. The analogy of the mobile illustrated this tenet (Allmond, Buckman, & Gofman, 1979; Wright & Leahey, 1994). This tenet essentially guided the study as the researcher based the study on the hypothesis, as supported in the relevant literature, that the entire family is affected by childhood cancer.

The creation of a balance between change and stability within the family is the fourth tenet. This essentially means, when a change occurs in a family, the family reorganizes in a way that is different from any previous organization (Wright & Leahey, 1994). Koocher and O'Malley (1981) in their research examining families with a child with cancer found that shifts in roles, household tasks and responsibilities were usually required. The family's life is often changed by a diagnosis of cancer; routines are altered, and family members must take on different and additional roles. The interview guide used to elicit information about these families' experiences reflects the idea of a balance between change and stability. Family members were asked about the changes and the "things that have stayed with same" since the diagnosis of cancer was made.

The last tenet of family systems theory which was integrated into this study was that family members' behaviour is best understood from a view of circular rather than linear causality. This tenet suggests that each family member's behaviour has an effect on and influences the other family members (Wright & Leahey, 1994). This point is vital in examining the effect of a childhood cancer experience on a family as it is related to the third concept, a change in one family member affects the entire family.

The family systems theory is not without criticisms. The main criticism of the system theory found in the literature is the circular causality of interactions (Cottone & Greenwall, 1992; Nelson-Gardell, 1995) which consequently in the opinion of the previous authors, leads to discrimination against women. Cottone & Greenwall (1992) believes this is due to the fact that the limits of a patriarchal society have not been addressed. The circular causality of interactions relates specifically to the issue that using a systems theory

perspective, a victim of abuse may be responsible for her victimization (Nelson-Gardell, 1995). This is due to the fact that systems thinking does not support a cause-effect relationship. The researcher considered the benefits of the systems theory for this particular study outweighed its short comings and criticisms in the area of family violence.

Summary

In this chapter, the researcher outlined the problem statement and purpose of the study. The significance of the study in relation to potential benefits for health care professionals who work with children with cancer, and the government were proposed. The conceptual framework, family systems theory, which guided the study was discussed and critiqued.

Chapter II

REVIEW OF THE LITERATURE

A review of the literature spanning from the mid-1970s to the present revealed that the needs of rural families experiencing childhood cancer have not been adequately researched. There has been a substantial amount of literature examining the experiences of urban families with a child with cancer and families with a child with a chronic illness. A literature review was conducted using the CD- ROM databases of MEDLINE, CINHALL, HEALTHPLAN, CANCER; as well as manual literature searches from key articles. The following literature review is organized and critically reviewed according to the major categories identified in the literature: the definition of family, family issues with a child with chronic illness, family issues where an adult has cancer, family issues where a child has cancer, parents and sibling of a child with cancer, the patient (adult and child) with cancer, and the distance factor.

The Definition of Family

Prior to proceeding into presenting the literature related to pediatric cancer and chronic childhood illnesses and the family one must thoroughly examine the concept of family. Families are special subsets of social systems (Broderick, 1993), yet due to the trends in modern day society describing 'family' has become increasingly difficult. Increasing divorce and re-marriage statistics, as well as the increased popularity of living common-law contribute to this dilemma of developing a definition of family that meets everyone's situations. Broderick (1993) succinctly described the complexity of this concept; "everyone knows what a family is, yet no one seems to be able to find a definition

that is acceptable to everyone” (p. 51).

The writer has formally investigated this concept and completed a concept analysis (Scott-Findlay, 1996). For the purposes of this thesis, a summary of the findings are presented. It is imperative to mention that frequently the concept of family is not defined in nursing research publications (Stuart, 1991), thus complicating an already complex issue. Kristjanson (1992) in her examination of conceptual issues related to measurement in family research reiterates that a frequent problem in the literature is that there is confusion related to the definition of the term “family.” A narrow definition of family, as portrayed in the Webster dictionary (1996, p.489), is “all the people living in the same house; a social unit consisting of parents and the children they rear; the children of the same parents;” this definition was not utilized in this study. In this study of the experiences and needs of rural families with a child with cancer, a conceptualization was used that offered the families the freedom for them to decide who they considered to be a part of their family unit.

The family is one of the most fluid institutions in North American life with no other sphere of society seeing such rapid and significant changes (Staples, 1989). The family unit is always changing in structure, size, composition, and roles (Perch, 1987). Bala (1995) stated that questions surrounding what types of relationships constitute a family are some of the most controversial issues. The conceptualization of “family” has changed throughout history. Ancient family forms varied from those of the present but the functions of the family have remained more or less constant (Hanson & Boyd, 1996). Historically, the social and legal conception of family was based on heterosexual marriage

and the blood ties that arose from marital relationships or adoption. Over time, this conceptualization has changed reflecting the demographics of today's society.

'Family' has been defined differently reflecting the perspective of each discipline (i.e. nursing, legal, economic, medical, sociological) that identifies family as a phenomenon of study. Wright, Watson and Bell (1996) propose that each family member has a clear interpretation of their family and due to this there are "as many families as there are family members" (p. 46). In Canada, over the last few decades, there has been increased complexity in the types of familial relationships that are legally recognized. These changes reflect the developments in society such as rising divorce rates, increased numbers of women in the labour force, birth control methods, single parenthood, and sexuality (Bala, 1995; Davies, 1995; Hanson & Boyd, 1996).

It is unrealistic in today's times to narrowly view the family in nuclear family terms; one man and one woman with children in a life long, sexually exclusive marriage (Macklin, 1980). In the United States, the majority of households do not represent traditional nuclear families (Macklin, 1980). Given similar values and culture, a comparable picture regarding family structure may be drawn in Canada. It is important to mention that many of the definitions of family exclude homosexuals (Eliason, 1996), thus broad, encompassing conceptualizations are needed.

For the purposes of this study, family was conceptualized using the attributes previously uncovered by Stuart (1989) in her conceptual analysis. These attributes were also found by the writer in her analysis of the concept.

1. A social system or unit that is self-defined by its members and is not

a constant, that is change and development are inherent.

2. The members may or may not be related by birth, adoption, or marriage and may or may not live under one roof.
3. The unit may or may not contain dependent children.
4. There must be commitment and attachment among members that develop over time and have some notion of future obligation.
5. The unit carries out the relevant functions of care giving, that is, protection, nourishment, and socialization of its members, including providing the primary source for children to learn cultural values.

(p.33)

An additional attribute which was used to provide criteria for inclusion into the study involved viewing the family as a system that is open and functions in relation to its broader sociocultural life cycle. A description of family put forth by Wright, Watson and Bell (1996) also assisted in providing clarity surrounding the concept of family. Their description centred around one of their beliefs about families; “a family is a group of individuals who are bound by strong emotional ties, a sense of belonging, and a passion for being involved in one another’s lives” (p.45).

Family Issues with a Child with a Chronic Illness

Children with a chronic illness place unique demands on the family and may disrupt a well-functioning system (Austin, 1991; Gallo, 1991; Rolland, 1992; Thomas, 1984; Vidaver, 1991; Welch-McCaffrey, 1988; Whyte, 1992). Feelings of isolation from family and friends and inadequate access to supports and resources are frequently reported by

parents caring for chronically ill children (Gallo, 1991; Ray & Ritchie, 1993). Ray & Ritchie (1993) investigated the factors that influenced parents' coping with a chronically ill child and found that the parents' manners of coping with their child's illness were influenced by the burden of care giving and the availability of coping resources.

Chronic illness affects the individual, family, and community in multiple ways (Vidaver, 1991). Fear, uncertainty, isolation, grief, and role change are some of the feelings and challenges experienced by family members with a child with a chronic illness (Ray & Ritchie, 1993; Thomas, 1984; Vidaver, 1991). Sabbeth (1984) in her paper examining the impact of chronic childhood illness on families explained the difficulty of assessing the impact of illness on the family. She also indicated that much of the research is done on the effect of the illness on the mother, and little is known about the impact on the father.

Whyte (1992) studied the nursing contribution to the support of the family with a child who has a chronic illness. Through a longitudinal ethnographic study of the experience of four families with a child with cystic fibrosis, Whyte described the chronic burden of care felt by these families. The study demonstrated the well being of the parents and siblings were influenced by the health and illness of the child with cystic fibrosis. Although Whyte's study found comparable results on the effects of a chronically ill child in the family, it is important to mention, not all of the findings from this study are applicable to families experiencing childhood cancer. This is due to the different illness trajectories of these two different chronic, yet life-threatening diseases.

The siblings of the ill child are also affected by a diagnosis of a chronic illness

(Sabbeth, 1984). Siblings experience tremendous change in the interaction with their family, and often feel resentment and anger toward the ill child (Kramer, 1981). The siblings experience many different reactions, such as fear of catching the disease, feelings of envy due to the attention their ill brother or sister is getting, and feelings of embarrassment of their sibling (Sabbeth, 1984).

Callery (1997) conducted a qualitative study involving interviews with the parents of 24 children discharged post-operatively from a children's hospital in Britain. The purpose of his study was to gain an understanding of the parental costs for their involvement in the care of their hospitalized child. Callery discovered that the majority of the costs to parents are largely hidden, including travel costs, loss of earnings, and loss of privacy. He commented that because these costs are hidden they are given inadequate attention by health care professionals and health policy makers.

Horner, Rawlins & Giles (1987) stressed the importance of comparing the needs of rural parents with a chronically ill child with urban families in similar situations. Unfortunately, the majority of research has been completed in tertiary care centres often looking broadly at the families' experiences with a chronic illness. Most research studies to date, do not differentiate the experiences of urban families as compared to rural families, or families who must travel great distances in order to get specialized care and treatment. Although the majority of the articles and research conducted only reported on the negative effects on the family from the child's chronic condition, Rolland (1987) found that families who were coping with a chronic childhood illness often appeared to be more cohesive than families who were not experiencing a childhood chronic illness.

As some pediatric malignancies may be categorized as chronic illnesses due to improved life expectancy, parallels may be drawn between families with a child with cancer and families with a chronically ill child. This section highlighted some research studies which explored the effects of a chronically ill child on the family such as feelings of isolation, role change and financial burdens. The literature stressed that the entire family unit is intimately affected by the diagnosis of a pediatric chronic illness.

Family Issues Where an Adult has Cancer

As previously stated, the diagnosis of cancer is a crisis for the family system (Tringali, 1986). The family with a cancer patient is confronted with alterations in its circumstances that involve drastic changes of life style and threaten cherished hopes and values for all its members (Kaplan, 1982). Kristjanson and Ashcroft (1994) in their review of the literature related to the families' experiences with cancer reported that cancer is "a phenomenon experienced by the entire family" (p.1). Welch-McCaffrey (1988) introduced her research by explaining that health care professionals must perceive cancer as a "family disease." The following literature highlights some key studies which researched the needs of cancer patients (Bunston & Mings, 1995; Vachon, Lancee, Conway, & Adair, 1990), needs of family members (Hinds, 1985; Tringali, 1986), availability of resources (Buehler & Lee, 1992), coping strategies of both the cancer patient and family (Dodd, Dibble & Thomas, 1992) and the psychological impact of cancer (Frank-Stromborg, Wright, Segalla and Diekman, 1984).

The needs of families who cared for patients with cancer at home were explored by

Hinds (1985) in a descriptive study. Eighty-three family members participated in the study. Results indicated that the majority of the families' support came from within their immediate social network. Twenty-seven per cent of the families indicated they needed assistance with physical care. Families also indicated they needed assistance with psychological (53%), financial (16%), and respite (79%) needs. It was interesting to note that seldom did families seek help for social or emotional needs. Through the results of her study, Hinds (1985) suggested that families who provide care for patients with cancer at home are a group at risk. Buehler and Lee (1992) explored the availability and perceived adequacy of formal resources to assist family caregivers of rural persons with cancer. They discovered that formal health care resources are "woefully lacking for rural families" (p. 306). They found that care giving for a family member was laden with burden.

Research examining the needs of family members affected by cancer is lacking (Tringali, 1986). The needs of this population were explored by Tringali (1986) and she subsequently discovered two areas as important to family members affected by cancer. The identified needs were informational needs and general help with the problems the families were experiencing. Seventy-six percent of the needs identified by the families were cognitive and 24% were emotional needs. The use of understandable terms and honest answers were of most importance to the family. Tringali's study discovered important information, but the generalization of these findings is limited by the small, non-random sample, and the definition of family consisting of one person.

Silveira and Winstead-Fry (1997) explored the needs of adults experiencing cancer

and their caregivers in rural settings through a replication of a 1992 urban study by Longman, Atwood, Sherman, Benedict, and Shang. The results of the study by Longman et al. (1992) led to the development of scales to identify the needs of patients with cancer receiving care at home, in addition to the caregiver's needs (intercoder reliability of 99% and a coefficient alpha of 0.80 for both scales). Thirty patients completed the self-administered 104 item patient needs scale and 30 caregivers completed the 90 item caregiver needs scales. Both scales had subscales within them that measured involvement with health care, personal care, activity management, interpersonal interaction and finances. Results from the surveys indicated that patients reported a total of 56 needs with the majority of their needs in the areas of personal care, involvement with health care and interpersonal involvement. The patients reported that 5% of their needs were not met. Interestingly, caregivers reported that 14% of their needs were unmet. They identified a total of 48 needs in the same areas identified by the patients' scores with the addition of activity management. When compared with the previous study, the samples were demographically similar.

Dodd et al., (1992) studied cancer patients' and family members' concerns and coping strategies. They found both patients and family members were very concerned about disease-related physical health, yet were not active in managing their concerns. Dodd et al, also discovered that the family members reported more concerns than patients. This finding has important implications especially when considering rural families with a child with cancer. Often these families are forced apart at critical times due to the distances which separate them. Thus, the family members at home have decreased

exposure to the ill family member and health care professionals who could address their concerns.

It is well documented that cancer can be a life threatening illness. This study by Johnson, Craft, Titler, Halm, Kleiber, Montgomery, Megiven, Nicholson & Buckwalter (1995) explored the effects of hospitalization on family roles and responsibilities. They discovered that a critical care hospitalization placed additional burdens on all family members. The exploratory design used identified seven main themes: pulling together; fragmentation of families; increased dependence; increased interdependence; increased responsibilities; change in routine; and change in feelings. These findings can be extrapolated to understanding families with a child with cancer, as these families experience many critical hospitalization periods. It is important to mention that a limitation of this particular study was that most subjects (79%, N=41) were female, and it is well-known that females tend to do the majority of family care giving.

Vachon et al., (1990) examined the needs of adult patients (greater than 22 years of age) across Manitoba and subsequently identified multiple unmet needs. Their study identified more than 100 trips were made to Winnipeg for treatment and follow up for some rural patients, and the range of cost for transportation experienced by the family was from \$15 to \$20,000. Some of the unmet needs included literature related to their diagnosis, contact with their clergy, availability of mental health counsellors, and support groups in their community. Vachon et al., (1990) identified that the urban and rural patients' needs were not always similar and suggested that further research was needed to examine the needs of patients who live outside of Winnipeg. This study discovered

important data for enhancing the delivery of cancer care within the province of Manitoba. However, the findings of the study are not generalizable to the needs of families with a child with cancer as children tend to acquire different types of cancers, as well as demand different levels of care.

Family Issues Where a Child has Cancer

The following research suggests that the diagnosis of pediatric cancer puts a strain on all facets of family life including the foundational marital bond (Barbarin, Hughes & Chesler, 1985; Fife, 1980; Friedman, 1987), emotional life (Binger, Ablin, Feuerstein, Kushner, Zoger & Mikkelsen, 1969; Hockenberry, Coody & Bennett, 1990; Kaplan, 1982; Leventhal-Belfar, Bakker & Russon, 1993; Martinson & Cohen, 1988), and financial security (Bloom, Knorr & Evans, 1985). Some studies explored the impact of the diagnosis on the family (Adams, 1992; Friedman, 1987) and the challenges the diagnosis of cancer places on the family unit (Moore, Kramer & Rose, 1986). Researchers used a variety of methodological approaches to determine the impact of cancer on the family. For instance, some researchers used interviews (Barbarin et al., 1985; Binger et al., 1969; Crom, 1995), whereas others used more quantitative means (Cayse, 1994; Fife, Norton & Groom, 1987; Wright, 1993) to explore the impact of pediatric cancer on the family unit. Some studies identified variables that may lessen the strain of cancer or serve as a protective function such as positive coping skills (Shapiro & Shumaker, 1987) and education (Kramer & Perin, 1985).

The needs of Canadian parents with a child with cancer were explored by Adams (1992) through the use of a nationally circulated questionnaire. Some of the findings from

his study suggested that the problems encountered by parents included marital difficulties, financial problems, isolation from friends, changes in lifestyle, problems associated with child care outside of the home, completion of active treatment, relationships with grandparents, and alterations to employment.

Frequent hospitalizations and clinic visits required for the care and cure of children with cancer disrupt regular family life (Close, Burkey, Kazak, Danz & Lange, 1995). Contrary to common speculations, the completion of cancer therapy is faced with ambivalence by many families. During the treatment process the child is receiving anti-cancer drugs and a staff of people are continually monitoring the child's health (Lansky, 1985). It is evident through Lansky's research (1985) that families rely heavily on the medical centre for their expertise and judgement. This observation begs one to consider, how are rural families with a child with cancer affected by their remoteness from the treatment facility and what are their needs?

The diagnosis of cancer in a child alters family functioning and coping and may subsequently impact the family's quality of life. Some research has reported that family coping, and subsequent quality of life, remains constant over time or improves (Fife, Norton & Groom, 1987; Thoma, Hockenberry-Eaton & Kemp, 1993) whereas, other research suggests family coping and functioning are impaired (Kaplan, 1982; Magni, Carli, Leo, Tshilolo & Zanesco, 1986; Rolland, 1992). Research has indicated that coping with pediatric cancer is related to pre-diagnosis coping. For example, families who have difficulty coping with the diagnosis often have preexisting problems (Fife et al., 1987). An important point is that a change in family dynamics appears to occur four to six months

post diagnosis. Fife et al.(1987) attribute this to the reality of the cancer diagnosis setting.

Fife et al., (1987) examined the family's adaptation to childhood leukemia through studying 34 families. Four psychometric measures were used to measure the specific effects of the stress of the diagnosis on the family and its individual members. The results suggested that families' patterns of coping were relatively constant over time. For instance, "families with predominantly stable relationships and adequate support within the family unit were able to maintain their usual quality of life despite the onset of acute stress" (p.167).

Life change events and coping behaviours in families of children with cancer compared with a control group of families with physically healthy children were examined by Thoma et al. (1993). Twenty-one families completed a psychometric measure, the Family Inventory of Life Events and Changes. The results indicated that there were no significant differences in the coping behaviours of families with a child with cancer compared with families with physically healthy children. Families with a child with cancer had a significant number of more stressful life change events during the last 12 months than the control families. The life change events included marital strains, intra-family strains, and financial and business strains. Overall, the results suggested that families with a child with cancer experience an increased number of life change events when compared with families who have physically healthy children, yet they appeared to have sufficient coping skills.

Hockenberry, Coody, and Bennett (1990) examined the psychosocial concerns of families with a child with cancer and discovered the families' ability to adjust to the initial

diagnosis depended on the prognosis for the child, the nature of the disease, parental attitudes, adjustment of the child, and the effects cancer could have on the child's basic needs. Shapiro and Shumaker (1987) reported comparable findings which suggest that psychological and physical well being within the family is enhanced through open and frequent communication around the diagnosis

Quality of life is important to understand in relation to coping as it is stated in the literature that the child's adjustment to cancer depends "on the parents' ability to deal with their own anxiety" (p.139, Wright, 1993). Wright's (1993) results indicated that the cancer diagnosis significantly changed their quality of life with indications that the parents' quality of life was not as good as before their child was diagnosed with cancer. Similar to the point stated above that parental anxiety influences the child's adjustment to cancer is that the parental coping styles during treatment phases have important repercussions for the psychological and social functioning of both the child and parents after the completion of treatment (Overholser & Fritz, 1990).

Both clinical and research observations have indicated a disturbingly large number of families who face childhood cancer fail to cope adequately with the problems the disease poses (Kaplan, 1982). This finding contradicts the findings by Thoma et al. (1993) who reported families with a child with cancer have adequate coping skills. No rationale can be provided to explain this difference, except that each individual and family copes uniquely with their life situations. Kaplan's (1982) previous research suggests time should be spent by health care professionals assessing the family's ability to cope with the cancer diagnosis and providing additional support to the family if necessary. Rural families may

be at risk for inadequate coping because of the lack of formal support and resources in their local communities.

In another study, Koch (1985) interviewed the parents and siblings of 32 childhood cancer patients to understand their experiences with cancer. Five themes related to the diagnosis of cancer were extracted from the interviews. They were: “experience of increased negative effect, rules prohibiting emotional expression, health and behaviour problems following the diagnosis, role changes, and increased closeness” (p.65). These themes are consistent with findings in related studies. Koch used the findings to construct a model which illustrates family adaptation to pediatric cancer. The model highlights the importance of families dealing with pediatric oncology being flexible through allowing role changes and expression of emotions.

Relapsing illnesses, such as cancer, have a unconventional effect on the family unit and its functioning (Rolland, 1992). Relative to progressive or constant course illnesses, the episodic nature of cancer requires a flexibility that permits movement back and forth between two forms of family organization, from a form of “normalcy” to a form of reallocation of roles. This shifting back and forth is important to consider when looking at the coping strategies of families with a child with cancer.

Cancer has a serious impact on the family which produces strain on the family causing a shift in the roles and responsibilities (Friedman, 1987). Marital relationships are often affected and ties with extended family change due to the responsibilities associated with the care of a child with cancer. Friedman (1987) stated that “too much closeness between the mother and sick child often exists” (p.224). This has implications for the

development of the child in the future. Friedman (1987) identified that self-help and community groups are important in helping families cope with stressors that childhood cancer creates.

Rose (1987) explored methods of assessing families of school-aged children with cancer. She cited a study by Barbarin, Hughes & Chesler (1985) that focused on marital functioning in families with a child with cancer. Thirty-two families were interviewed regarding marital quality, spousal support, family cohesion. Results indicated that the majority of families (54%) displayed improved family and marital life. Yet, results demonstrated that as hospitalizations increased perceived marital quality and spousal support decreased. This factor would be especially important when examining rural families needs regarding their quality of family life as children with cancer are often hospitalized for periods of time, thus separating family members during these periods of time and possibly further increasing the strains on the family.

The results of the above study by Barbarin et al. (1985) are different from results suggested by Fife (1980) who proposed that there is considerable strain placed on marriages which are dealing with childhood cancer. Fife attributed this to parents who do not take the time to meet their own needs or the needs of the marriage because of their continual involvement in the care of their ill child.

A report of the psychosocial issues inherent with families experiencing childhood cancer was compiled by Health Canada in 1996. The reports cited that financial pressures on families with a child with cancer can become a source of stress although the hospitalization costs are the primary responsibilities of the provincial and territorial health

care systems. This can be attributed to costs related to accommodations, travel, food, and items not covered by health insurance such as certain drugs, limb prothesis. Additionally, one parent, in two parent families, may have to take a leave of absence from work to care for the ill child. In families where there is only one parent, the situation is often more complex and stressful. Health Canada (1996) documented the effect the diagnosis of cancer has on the child.

The costs of caring for a child with cancer disrupt a family's financial security. An American study conducted by Bloom et al. (1985) considered all medical charges, out-of-pocket expenses and wages lost through analyzing hospital records, submissions to insurance agencies, and family financial logs. They determined those family out-of-pocket expenses (for example, transportation, tutors, parking, etc.) added approximately 50% to the total cost of disease-related care and consumed 38% of gross annual family income. They discovered that more than one third of the families' gross annual income was spent on disease-related costs. This translates into significant changes in most families' standard of living and may have serious implications for how various members of the family cope with the diagnosis (i.e. siblings, patient). Due to the current structure of Canada's health care system, most medical charges would not be of grave concern to these families.

Parents of children with cancer often have fears about bringing their child home from the hospital (Martinson & Cohen, 1989). As well, they commonly experience dependency on the medical centre. Consequently, these families may begin to distrust the competence of their local physician. This study has implications for rural families as a lack of trust for the local physician could cause feelings of isolation and fear. Martinson and

Cohen also found the uncertainty of the child's status was a major source of stress for the family. Leventhal-Belfer, Bakker and Russon (1993) also discovered similar findings when studying parents of childhood cancer survivors. The parents' had pervasive concerns about their child's future health complications and feared the possibility of a relapse.

The diagnosis of pediatric cancer is a huge challenge to the family as they are faced with treatment plans and decisions which they know little about (Moore et al., 1986). Educational information is frequently cited in the literature as an essential need to families dealing with a child with cancer. The bulk of information regarding diagnosis and treatment is given to families shortly after diagnosis which is an extremely stressful time. The period after diagnosis is full of anxiety which makes it difficult to internalize the information. Kramer & Perin (1985) suggested the educational needs for families experiencing this diagnosis were based on the critical phases of childhood cancer (pre-diagnosis, diagnosis, maintenance phases, completion of treatment, relapse). Moore et al., (1986) suggested that information be provided to these families on a continual basis tailored to the needs and learning preferences of the family.

The Effect of Childhood Cancer on Individual Family Members

No family member appears to be left untouched from cancer. Several research studies have highlighted the effects of pediatric cancer on the sibling (Hymovich, 1995; Kramer, 1981; Spinetta, 1981; Walker, 1988), ill child (Hymovich, 1995), mother (Whiteley, 1996), and father (Cayse, 1994). Research studies have discovered that cancer does not always have negative effects on the family; sometimes there are positive benefits

(Kramer, 1981).

Siblings

Cancer affects the entire family; this is especially the case with siblings as their bonds are often intense and complex (Walker, 1990). Walker (1988) studied 26 siblings, aged 7 to 11 years, from 15 families in order to understand the cognitive and behavioural coping strategies used by siblings of childhood cancer patients. Data were obtained from open-ended parent interviews and psychosocial assessments and direct questions to the siblings. Results indicated that 69% (N=18) of the children displayed one or more types of stress response since the cancer diagnosis in their sibling. Qualitative data revealed three main themes of: loss, fear of death and change. Another important finding was that there was a 44% disagreement between what the children revealed as their coping strategies and what the parents thought their child's coping strategies were. This finding highlights the importance of including siblings whenever possible in family interventions so that their unique needs are known and subsequently met.

Spinetta (1981) studied 102 siblings in a three-year longitudinal study to understand the impact the cancer diagnosis has on the siblings. Results revealed the siblings overall adjusted more poorly than the child with cancer and they felt that their parents were emotionally distant from them. Spinetta's results revealed siblings' needs were being inadequately met. She also discovered some age-related differences. Four to six-year-old siblings had negative attitudes toward themselves and had significantly lower self-concept scores. The six to twelve-year-old siblings adapted poorly to the diagnosis, and experienced maladaptive responses, anxiety and depression. Results also indicated

that these children required more help when their ill sibling and parents were trying to return to periods of “normal” life, during periods of remission.

Martinson, Gilliss, Colaizzo, Freeman, and Bossert (1990) examined the impact of childhood cancer on the siblings. The siblings’ responses were grouped and analysed according to the status of their ill sibling (living or dead). Through their research, some of the concerns and needs of siblings were identified; the need for information, the feeling of being displaced and unimportant, and the need to be involved in the life of their ill sibling.

Research studies have indicated that there are positive benefits to having a sibling with cancer (Kramer, 1981). Kramer used qualitative research techniques to understand some of the potential positive benefits. Eleven siblings were involved in the study; the main findings were that siblings experienced increased sensitivity and empathy, there was increased family cohesion and the siblings matured through the experience. Negative consequences were also discovered through her research. These included: increased parental expectations, emotional deprivation and decreased parental tolerance for unacceptable behaviour.

Hymovich (1995) in her work examining the meaning of cancer to children also included some literature review and analysis on the meaning of cancer to siblings. She indicated that data on the cognitive meaning of cancer to siblings is quite sparse (Hymovich, 1995). Siblings of children with cancer report a different experience than their sibling with cancer. Cancer means a wide variety of feelings to the siblings. It may mean being isolated, deprived, or left alone. These children may also feel envious of the attention focused on their ill sibling or they may feel anger or remorse for the illness of

their sibling. Due to feelings that siblings may experience Hymovich (1995) recommended children should be included in the entire cancer process.

As these studies have shown, siblings of a child with cancer are affected by the diagnosis. They often experience a wide variety of emotions which may be quite traumatic.

Parents

The emotional impact of childhood leukemia on the patient and family was examined in a landmark study from the 1960s (Binger et al. 1969). They conducted a qualitative, retrospective study of families who had lost a child from acute leukemia. Initially, most parents experienced feelings of depression, self-blame and physical distress. These feelings later turned into acceptance. It was interesting to see the approaches and treatment used during this time period (1960s). At this time, families with a child with cancer were dealing with a terminal illness and they knew the outcome was death of the child. Today, the large majority of families with a child with cancer are dealing with a chronic illness that has achieved remarkable survivorship. Binger et al. (1969) concluded that everyone reacts to a childhood cancer diagnosis individually which parallels people's unique life experiences, and personality.

As previously mentioned, the diagnosis of pediatric cancer may have a profoundly negative impact on the parents and family (Kaplan, 1982; Magni et al. 1986). Magni et al., (1986) longitudinally examined the psychological distress in parents of children with acute lymphocytic leukemia or Hodgkin's disease. Forty-one parents completed the Symptom Distress Checklist at three intervals throughout their child's illness trajectory

(within the first few days post-diagnosis, 8 months post-diagnosis, and 20 months post-diagnosis). The results were compared with a control group of 25 similar subjects. Results verified high scores of psychological distress, specifically with sleep disturbances and depression subscales.

Fathers and mothers are greatly affected by pediatric cancer. Unfortunately, there are no studies which look specifically at the experience of rural fathers' and mothers' experiences with childhood cancer. Whiteley (1996) developed and tested an instrument to measure care needs of mothers of children with cancer. Her research also included exploring the extent to which the care needs of these mothers were met. She discovered that the overall needs scores for mothers who lived in Winnipeg were significantly lower than the needs scores for mothers who lived outside of Winnipeg. The distance a mother lived from Winnipeg did affect the extent to which her needs were met. Results indicated that mothers living from 101 to 240 km from Winnipeg had significantly higher needs-met scores than mothers living further than 240 km from Winnipeg. Her results demonstrated that rural families with a child with cancer could have significantly more unmet needs than families living close to the treatment centre.

Koocher & O'Malley, (1981) discovered that the majority of the mothers having a child with cancer reported that they coped by talking about it, whereas the fathers coped by hiding their feelings. Aitken & Hathaway (1993) found that effective communication is an essential element in the care of the child with cancer and the parents need reliable support systems to help them cope with the multiple problems this disease brings. Woods, Lewis, & Ellison (1989) suggested that families influence the adjustment of the person

with cancer, thus, effective coping patterns would be essential in ensuring positive adjustment of the inflicted child.

Cayse (1994) studied fathers of children with cancer to identify their stressors and coping strategies. Twenty-three fathers completed the Parental Perception Inventory questionnaire. The two most commonly reported coping strategies used by fathers were 'praying' and 'looking at the options'. 'Wondering what my child's future is likely to be' and 'my child's health' were the two most commonly reported stressors. This particular study pointed out the importance of having a family approach to assisting families with a child with cancer. As well, the study suggested implications for nursing that can help the father cope, such as accessing resources, and answering questions. The findings from this study may be extrapolated to the current study to hypothesize that rural fathers may experience increased stress due to the distance to the cancer treatment centre from their home. This may be explained by the fact rural fathers have less exposure to the cancer treatment centre due to the distance. Thus, they may have subsequently more unmet needs.

The Patient

The Adult with Cancer

In a study that examined the psychological impact of the diagnosis of cancer, Frank-Stromborg et al., (1984) developed a questionnaire to discover the activities of daily living and other areas of their lives that had been affected by the diagnosis. The questionnaire also included some questions that explored the feelings experienced by the patient after they received their diagnosis. The questionnaires were distributed using a

convenient, non-random sampling method in an ambulatory treatment centre or cancer self-help group. 340 questionnaires were returned completed. The largest number of participants (29%) indicated they experienced feelings of shock, fear and disbelief when informed of their cancer diagnosis. Contrary to expectations of the investigators, 27% of participants stated positive feelings and attitudes; they accepted their diagnosis and wanted to proceed with treatment. The third largest group of responses indicated the respondents felt angry, depressed, and/or hopeless about their current situation. It is important to mention that the reliability of the questionnaire instrument has not been assessed but content validity has been confirmed. This study verifies previous studies in that patients and families experience a wide variety of potential responses to a cancer diagnosis. Health care professionals must be sensitive to the wide array of emotional needs that may change during the cancer trajectory.

The psychosocial needs of individuals with cancer were investigated through the use of focus groups of patients and hospital caregivers (Bunston & Mings, 1995). Twenty-one categories of needs were discovered through content analysis of the individual patients' descriptions. They most frequently identified: fear of recurrence, fear of the unknown, concerns around treatment efficacy and side effects as their needs. The least frequently cited needs were pain control, information needs, and anger management. There was lack of congruence between the patients' descriptions of their needs and the health professionals perceived understanding of the patients' psychosocial needs. The health care professionals' perspectives most frequently identified the following as patient needs or concerns: finances, employment, fear of the unknown, family adjustment,

information needs, emotional responses and treatment concerns. Bunston and Mings' study emphasizes the importance of obtaining more than one perspective when gathering information.

The Child with Cancer

Health Canada (1996) suggested children with cancer often have difficulty achieving normal developmental milestones due to the issues facing them. Their report pointed to the child's age and developmental stage as some of the factors which affect a child's coping with their illness. For instance, pre-school children may revert back to behaviours of younger children and school-age children may become upset and angry as their lives are upset (i.e. attending school, being with their friends).

Certainly an important point to consider when looking at the issues faced by families with a child with cancer is overall function. Olson, Boyle, Evans, and Zug (1993) explored the overall function in rural-based childhood cancer survivors. Eight psychometric measures were used to evaluate social competence and emotional health in 20 rural cancer survivors (aged 6 to 16) and 40 age- and gender-matched peers. Results demonstrated that the cancer survivor portrayed poorer social competence, as noted by teachers and parents. Additionally, teachers and parents stressed poorer school performance and more behaviour problems, respectively, among this same group. The article stated there is a lack of information regarding the childhood cancer survivors' functioning in daily life and the long term effects of cancer treatment. On a more positive note, the results suggested that children who are survivors of cancer have good self-esteem and sense of control and they function normally in daily activities. As Olson et al.

(1993) suggested, “children surviving cancer bring certain strengths and limitations to this process” (p.340). The article highlighted the importance of dealing with both the physical problems and functioning in daily living in order for children dealing with cancer to be a total cure.

The meaning of cancer to the affected child was studied by Hymovich (1995). Her study was based on limited data available from a review of the literature and two data sets of unpublished interviews with children and parents. The meaning of cancer to children is an important aspect when considering family functioning and coping with illness.

Hymovich (1995) discovered that the meaning of cancer depends on several characteristics, including the child’s development and cognitive level, previous life experiences, the family member with cancer and family relationships. She ascertained that children with cancer perceived the illness differently at different development levels. For instance, she discovered that school-aged children were more concerned with the treatment and manifestations of the disease, whereas adolescents were threatened about the possibility of permanent disability. Due to the manifestations of their illness and their concerns and fears, the child with cancer should be an integral part of the treatment plan. Children with cancer develop their meaning of illness from others (Hymovich, 1995) and in order for children to thoroughly understand the meaning of cancer, they need information appropriate to their needs and developmental level. Thus, the argument can be made that the child with cancer should be included in the family interview as they will be able to contribute information about their needs and concerns. As well, it may be an opportunity for them to develop a more thorough understanding of their illness.

The Distance Factor

Rural Living and Health Care

According to the latest statistics, approximately 1 in 4 Canadians lives in a rural area (Bavington, 1994). An issue of particular importance in rural communities is access to health care (Knollmueller, 1994). Bavington (1994) suggests that rural communities are at risk as they are characterized by lower average total incomes, higher unemployment rates, lower education levels, and poorer housing. Curtiss (1993) examined the issues for cancer care in American rural communities, and discovered geographic location can have a profound impact on access to health care, use of resources necessary to maintain health, and availability of specialty consultation. She continues to suggest the needs to travel a long distance for care adds physical, financial, and emotional burden to an already stressed patient and family. Curtiss reported the psychosocial impact on patients and families being treated away from home is tremendous: people often report feeling isolated, abandoned and distanced from friends and family, thus further compounding the requirements for coping with cancer.

Horner, Ambrogne, Coleman, Hanson, Hodnicki, Lopez, Talmadge (1994) qualitatively explored the perceptions of American rural dwellers on health care issues. They concluded that the perceptions and preferences of rural consumers of health care have not been fully explored. Some of the participants in their study commented on the discomfort of driving in the "big city" to attend medical appointments. The participants felt they should be involved in planning health care delivery in their area and that further research was required.

Weinert and Long (1987) explored the health care needs of rural families and determined the health perceptions and health care preference of rural people have not been adequately explored. They discovered that the level of perceived social support was consistently higher for rural dwellers, and that rural dwellers relied less on formal sources of support, perhaps due to the fact that these sources of help are simply less available. Weinert and Long suggested that the health care services must be tailored to suit the preferences of rural persons, and the formal health care system needs to correspond to the informal helping system in the rural areas. This study, along with the two previous studies, is limited in the generalization of the findings to understand Canadian rural families because the study was American based and dealt solely with adults with cancer.

Adults with Cancer

The needs of urban and rural patients and caregivers were similar in several aspects in a study by Silveira and Winstead-Fry (1997). Yet, the participants reported some different areas as important. For instances, only the rural caregivers reported that interpersonal interactions were important. These differences have implications for practice. As Silveira and Winstead-Fry (1997) suggested, these findings are important as previously it was uncertain if urban research was generalizable to rural populations. They postulated that perhaps “differences [between urban and rural populations] arise in the appraisal or the strategy to meet the needs” (p.75). This study is important as it suggests that rural and urban patients and caregivers have similar basic needs yet differences may arise in their particular ways to meet the needs. In interpreting the results it is important to remember that the study did not include children as patients; as well, all rural patients

from this study were within one hour of their treatment facility.

Families with a Child with Cancer

The majority of research studies that have investigated families with a child with cancer are American based, quantitative and involve only the parents (Aitken and Hathaway, 1993; Binger, Ablin, Feuerstein, Kushner, Zoger & Mikkelsen, 1969). As well, few studies have specifically examined the effects of distance from the treatment centre in families experiencing pediatric cancer due to the distance from treatment centre (Aitken & Hathaway, 1993; Mercer, 1994; Mercer & Ritchie, 1997). The two most notable research studies that specifically examined the effect distance from the cancer centre the families' homes were by Aitken and Hathaway (1993) and Mercer (1994).

In the first study, Aitken and Hathaway (1993), examined the effect of remoteness had on parents of children with cancer. They utilized the Hymovich Parent Perception Inventory to assess the parents' concerns, feelings, and coping behaviours. The findings suggested the parents who travelled long distances for cancer care were living at a near-poverty level, were younger, and less educated than the parents who lived within 100 miles of the cancer centre. The families who travelled a great distance felt that they had to travel too far for cancer care and they believed they did not get enough information about their child's condition. The long distance group of parents also indicated that they used more ineffective coping strategies than the more proximal parents, and they identified friends as more supportive than the closer parents. The study reflected the overall need to recognize the special concerns of families who have to travel a great distance for cancer care and treatment for their child, and the importance of developing programs and

resources to address their unique needs.

This study also revealed that a long-distance relationship between the cancer centre and the affected family decreased the amount of contact and communication between the oncology team and the family and child, thus having implications for the child's care. Aitken and Hathaway (1993) also suggested that more research is needed to identify the specific issues surrounding the care of children who have cancer and their parents who live in rural versus urban areas. The study is limited as it is an American-based project which solely focused on the parents, not the siblings or the child with cancer. As well, some of the findings focused on the implications of paying for medical care, which is not an issue for discussion in the current Canadian health care system.

The second study was Canadian-based and explored the needs of parents whose children were undergoing cancer treatment to identify differences in needs between parents whose children received all of their care at a major tertiary centre and parents whose children received at least some of their care in the local community (Mercer, 1994; Mercer & Ritchie, 1997). This is the only Canadian study to date which has critically reviewed the challenges for rural families with a child with cancer. It is essential to state that this study was conducted in the Maritimes. There are different challenges, such as different weather patterns and unique transportation dilemmas, that must be considered when examining the illness experiences of families from the Canadian Prairies as compared to Atlantic Canada.

Mercer (1994) and Mercer and Ritchie (1997) indicated that there was no literature regarding the needs of families in areas outside the major tertiary centres and

most research on this target group has been conducted within the tertiary centre. Fifty-eight families completed a modified version of the Caregiver Needs Assessment Survey and 20 of these families participated in a semi-structured interview to assess their important needs. Mercer and Ritchie discovered that the most important met needs for these families related to care and treatment and the most important unmet needs dealt with financial support and personal needs. Overall, the highest percentage of needs listed were in the category of interpersonal interaction. There were no statistical differences between the needs of parents whose children received all of their care at a tertiary centre and those who received some part of the treatment at a community centre. Parents whose children received at least some of their care at the local community hospital reported more total needs and difficulties in seeking advice in their local area. Mercer and Ritchie (1997) concluded that there is an overall need to enhance the present system, specifically in the area of information, for Atlantic Canadian families with a child with cancer who is receiving some of his/her care outside of the tertiary care centre. As well, the local health care professionals do not have the opportunity to develop expertise in this area due to the low prevalence of pediatric cancer.

Families who travel from other countries to receive cancer treatment for their children may experience some similarities to the experiences of rural families. For instance, Crom (1995) conducted a phenomenological study to explore the experiences of South American mothers who brought their children to the United States for treatment of cancer. She reported that cancer had a devastating impact on the child and family. Language difficulties, continual preoccupation with the illness, and cultural challenges

were some of the greatest challenges experienced by these mothers. Some of these experiences could be similar to the feelings endured by rural families with a child with cancer receiving treatment in an urban setting. Rural families with a child with cancer undergo stressful situations, are located in unfamiliar environments and often, experience cultural differences.

Adams (1992) also found that parents frequently voiced the tremendous stress encountered by the distance travelled to treatment centres and the lack of services in their own communities. The parents in this study suggested that there should be increased contact by health care professionals with rural families such as improved communication systems for rural families and increased attention to forging links between the professionals and parent support groups. As well, research and evaluation should be directed to the additional problems that rural families encounter (Adams, 1992). Adams' research study was limited by the overall response rate of 7.2% and the small percentage of participants from the prairie and maritime provinces where long distances and lack of services specifically for rural families are a major problem.

Summary

There are varying opinions regarding the extent and time of the literature review in qualitative research proposals (Kuckelman Cobb & Hagemaster, 1987). For the purposes of micro ethnography, applicable literature was reviewed prior to data collection to identify the scope, range, intent, and type of research that has been done to date. As well, the literature review is an ongoing process from data collection through to data analysis and reporting the findings.

The review of the literature reflects the current state of knowledge regarding the family, families with a child with a chronic illness, families where an adult has cancer, families where a child has cancer, the effect of childhood cancer on individual family members, the patients and the effect of distance. Some of the critical findings in the review of the literature were that the entire family is affected with the diagnosis of cancer in a family member and support comes from the immediate social network. Thus, there are implications for rural families who are often separated from their support network during critical periods of time. The great majority of research in these areas focused on the experiences of white, middle class, urban families. Thus, understanding the cancer experience from the rural families' perspective becomes more challenging. The review of the literature indicated that there is a lack of literature examining the experiences and needs of rural families with a child with cancer. The cumulation of literature suggested that further research is required in the selected area of study due to the lack of specific literature examining this cohort of people with important and unique, often unmet, needs.

Chapter III

METHODOLOGY

In this chapter the methodology incorporated in this study is presented. A micro ethnographic approach was used to explore the experiences and needs of rural families with a child with cancer. The sample was obtained from the pediatric oncology clinic of a provincial cancer treatment centre through the pediatric oncology nurse clinician. Other avenues were implemented to recruit families such as sending posters to the Ronald McDonald House. The majority of the data were collected in the families' homes unless they chose another location. The investigator used a semi-structured interview guide to collect the data from the families. A demographic form was completed with the assistance of the researcher at the start of the interview. In addition, a sub-scale of the Family Assessment Device (FAD) was administered to each family member participating in the interview who was capable of understanding the measure. The FAD was utilized in order to obtain information about the participating sample's family functioning. Ethical considerations were upheld throughout the study.

It is important to mention that there were several conceptual and methodological complexities inherent within this study as it was designed as a family study. In other words, both the individual and family were the unit of analysis.

Family Research

It is important to discuss the implications of a family research study at the onset of the methodology section as these considerations influence the entire study's design. It has been documented that research with families introduces several complex conceptual and

methodological dilemmas (Gillis, 1983; Gillis, 1991; Knafl, Gallo, Zoeller, Breitmayer & Ayres, 1992; Moriarty, 1990; Moriarty & Cotroneo, 1992). Moriarty (1990) suggests that nurses have always been interested in families, yet research and theoretical interest in the family as a unit of analysis has been relatively recent. During the last two decades, there has been a trend toward a family perspective in research, as compared to an exclusive individual perspective to analysis (Feetham, 1984; Gillis, 1983, Murphy, 1986). Moriarty continues by suggesting that family research is complex because of the special challenges of working with more than one person. Gillis (1983,1991) agrees with Moriarty by saying that interest in family research is growing, yet the complexities of this type of research often impede its progress.

Feetham has tackled some of the conceptual and methodological issues of research involving families. She is well-known for her distinctions between family-related and family research (1984, 1988). These distinctions have been used frequently in the family research literature. Family-related research derives data from individuals to focus on relationships between family members, whereas, family research focuses on the family as the unit of analysis. Feetham (1988) has also delineated criteria for family research:

- 1) There is a conceptual or theoretical framework for the research, 2) there is an explicit conceptualization of the family, 3) there is a definition of the family that is consistent with the conceptualization, 4) the research adds to the knowledge of family functioning and family structure, 5) the research is relevant to nursing practice, 6) the conceptualization, measurement, and analysis aspects of the research all reflect the family as a unit of analysis,

and 7) the research adds to knowledge of the family system (p.36).

Robinson (1995) has started to challenge some of the previous literature on family research. She believes that the literature to date has separated the family and the individual, and subsequently “the part of person that is separate from family has often been omitted” (p.9). Simply, Robinson maintains that all of the attention is on the family and subsequently, the influence or uniqueness of the individual becomes vague and clouded. She believes this is due in part to the focus on the establishment of a separate, unique body of research and knowledge in family nursing and secondly, a misunderstanding of the interface between general systems theory (von Bertalanffy, 1968) and our conceptualization of the family which results in the individual being forgotten. Central to this misunderstanding of general systems theory is that one cannot understand wholes without understandings parts and their relationships. This is where previous family research has faltered because this research has solely focused on the ‘whole,’ the family, and has forgotten to look at the ‘parts,’ the individuals. Robinson believes that “to consider a whole without also considering its parts and their relations is a form of reductionism that is not consistent with systems theory” (p.12). She proposes that future research “simultaneously focus on two systems - that is, the person and the family.... this way, one never loses sight of the individual when focused on family and one never loses sight of the family when focused on the individual” (p.10). Robinson calls this form of research, nursing research of individual/family system. This form of research looks at both the individual and the family and suggests that because there are as many families as there are family members (Maturana & Varela, 1992) as many perspectives as possible should

be obtained from different family members because each outlook is likely to vary somewhat. The researcher through her critical examination of family research in the literature and her work with families, agreed with the arguments put forth by Robinson. Moving beyond the current dichotomy surrounding individual and family research was desired by the researcher; thus, Robinson's recommendations were adapted into this study's design.

The present study was an interface of research looking at both the family and individual. The researcher had previously conducted a conceptual analysis of family and presented the definition of the family that guided the study, as outlined in Chapter 2. The researcher considers she upheld all of the criteria set forth by Robinson (1995).

Moriarty (1990) describes family research as "research that considers the family unit as the unit of analysis and that involves data collection with at least two family members" (p.2). This premise draws forth other questions as who should or should not be included in the study? Uphold and Strickland (1989) claim that the number and type of participants for the study depends on the research question and the theoretical underpinnings of the study. They make an interesting and important comment by stating that more reliable and valid data is not guaranteed because several family members are used as respondents. In fact, the opposite may be true as the researcher may receive very different explanations of the families' experiences and needs. Uphold & Strickland (1989) also suggest that bias may be inherent within family studies because not all family members may agree to participate in the study. Woods & Lewis (1992) maintain that one way to deal with the complexities of producing a holistic family perspective is to consider

“multiple levels of family systems as sources of data” (p.408). They mean obtaining data from individuals, total family, dyads within the family, and perhaps the family network. In order to deal with these complexities, the writer decided to invite any person whom the family considered to be part of their family to participate in the interview, as well as the child experiencing cancer. This conceptualization was consistent with the definition of family given in Chapter 2 and it is appropriate when using family systems theory.

Cromwell & Olson (1975) concur with this statement as they believe multiple family members’ perspectives are required when working from a family systems perspective in order to grasp the complexity of the system. Inclusion of a child in a research study involves methodological and ethical dilemmas. Deatruck & Faux (1991) indicated through their research that children can be reliable, valid informants of their illness experiences. The researcher took extra ethical precautions for children who wanted to be involved in the study. These considerations will be discussed later in the chapter.

Research Design

There has been a longstanding relationship between families and qualitative methods of inquiry (Daly, 1992). Subsequently, a qualitative approach was used for this study. Qualitative data are flexible and sensitive enough in order to provide the multiple perspectives required for family research (Daly, 1992) and can produce thick descriptions of family experiences, beliefs, values, and culture. Gilgun (1992) suggests that qualitative family research is essentially “research with a focus on experiences within families as well as between families and outside systems” (p. 24). This conceptualization was fitting considering the theoretical underpinnings of family systems theory which guided the

research study.

In qualitative studies, the study design will unfold or change as the research study progresses and as fieldwork occurs (Patton, 1990). Patton (1990) continues by stating that:

There is both a science and an art to qualitative inquiry generally, and qualitative analysis specifically. The scientific part is systematic, analytical, rigorous, disciplined and critical in perspective. The artistic part is exploring, playful, metaphorical, insightful, and creative. (p.433)

A qualitative nature of inquiry permits the researcher to explore selected issues in detail and depth (Patton, 1990). Qualitative approaches increase the understanding of phenomena due to the wealth of description and detail about a small number of people or cases, as contrasted with the quantitative method which gives broad generalizable findings. The qualitative approach was chosen because of the rich descriptions and deep meanings that can be obtained from using this method. As Morse and Field (1995) so eloquently state “qualitative inquiry is used to describe how groups of people live or how people cope with their daily lives. Qualitative research provides the reader with understanding and enables others to make sense of reality” (p. 16).

Ethnography “is the work of describing culture” (Spradley, 1980, p.3).

Ethnography’s origin is in the field of cultural anthropology. The intent of ethnographic research is to obtain a holistic picture of the subjects’ everyday lives. This holistic picture reveals how people structure and describe their world (Creswell, 1994). Morse & Field (1995) state that “ethnography moves beyond description to reveal or explain aspects of

social patterns or observed conduct” (p. 27). Streubert & Carpenter (1995) state that the ultimate goal of ethnography is to understand the lives of individuals through research. They believe that central to ethnographic research are three characteristics: “researcher as instrument, fieldwork, and the cyclic nature of data collection and analysis” (p. 90). Researcher as instrument simply means that the researcher becomes immersed in the culture by means of observation and conversation and recording of these interactions. It is important to mention that the researcher will never fully understand the emic or native perspective as he/she is from outside the culture. The second characteristic of fieldwork involves going to the place where the culture of interest is. Lastly, the cyclic nature of data collection means that answering questions poses further questions; this is the rationale for data collection and analysis to be concurrent.

Morse (1987) states there is great diversity in “prescription and practice” (p. 258) among researchers doing ethnography. Hammersley and Atkinson (1983) suggest that “there is disagreement as to whether ethnography’s distinctive feature is the elicitation of cultural knowledge, the detailed investigation of patterns of social interaction, or holistic analysis of societies” (p.1). As Chalmers (1990) suggests there appears to be overlap among qualitative methodologies. By that, she means qualitative methods are not separate entities and various qualitative methodologies have been used concurrently in studies to meet the goals of the research. Others, such as Field and Morse (1985) and Spradley (1980) validate this premise.

Ethnography centres around the concept of culture (Sorrell & Redmond, 1995), but as Spradley (1979) suggests a culture is broader and more diverse than simply

exploring people of similar ethnic backgrounds; that is, “any group of people who share knowledge, customs, objects, events and activities is considered to be a culture” (p. 6). Thus, according to this definition, rural families experiencing childhood cancer are a unique culture themselves because of the similar event they are experiencing.

An ethnographic design was selected for this study for two reasons. First, there is a lack of studies exploring the experiences and needs of rural family experiencing childhood cancer. Second, the purpose of the study was to understand the lives and experiences of these families in order to appreciate their unique needs. Describing the experiences and needs of rural families experiencing childhood cancer was essential in order to fully understand their unique experiences and needs. Ethnography facilitated this knowledge development and understanding through the rich descriptions of the beliefs, meaning and values, in other words the culture, of these families.

For the purposes of this study, micro ethnography guided the study design. This particular design was chosen because of the narrow focus of the question and the small nature of the study (Streubert & Carpenter, 1995). The end result of choosing an ethnographic research design was that health care professionals and other caregivers will be able to more thoroughly comprehend and appreciate the unique experiences of these families through the results of the study. Through using an ethnographic approach, the information related to the families experiences and needs were accessed from the emic, or insider’s perspective, rather than the health care professionals, which is often the case. As well, the results of the study have added to, and perhaps, in the future, will challenge the body of literature on rural families experiencing illness.

A semi-structured interview format was utilized to collect information from the participants. Morse and Field (1995) consider that this method is effective “when the researcher knows most of the questions to ask but cannot predict the answers” (p. 94). When utilizing qualitative approaches, the researcher is the instrument (Patton, 1990). By this, one means that the researchers can greatly influence the rigor and subsequent results of the study through their skills, competence, and presence.

Sampling

The issue of sample size in qualitative research is complicated. Sandelowski (1995a) postulates that sample size in qualitative research is a matter of judgment and experience. Sample sizes depend on the type of research design. Sandelowski (1995a) suggests a downfall to not having exact criteria for sample size in qualitative studies may be that the sample number used maybe too small to have achieved theoretical saturation. Yet, preset sample size may force continued data collection and analysis long after saturation has been reached.

Purposeful sampling was used to obtain the sample. A purposive sampling approach within subjects was used to maximize variation within the data (Patton, 1980). Purposeful sampling is typically used in qualitative studies. Using this sampling method, people with particular characteristics are sought out because they are considered to be good sources of information (Sandelowski, 1995a). This suits the purpose of qualitative research which is to understand phenomena. Due to the fact that qualitative and quantitative research are striving for different end products, the rationale that guides sample selection is different. In comparison to qualitative research, quantitative studies

strive to be able to generalize results, thus an adequate sample size and a sample representative of the population is important. Patton (1990) believes that nothing captures the differences between qualitative and quantitative methodologies better than sampling issues.

Taking the above literature into consideration, the researcher speculated that a sample of approximately 10 to 15 families likely would be required to fulfill theoretical saturation. In fact, theoretical saturation was achieved after interviewing eight families. As the researcher was a novice in qualitative methodologies, there was a need to be certain that saturation had been achieved. Thus, the researcher conducted interviews with two additional families. Families involved in the study included children who are along the continuum of the cancer experience spectrum, for example, newly diagnosed, remission, recurrent disease, and advanced disease. No families currently experiencing a child with cancer in the palliative stage were included in the research study. The researcher waited until at least eight weeks after the initial diagnosis to contact the families. This was done in recognition that these families are especially vulnerable because of the overwhelming stress and life changes a diagnosis of cancer brings to the family unit. At the time of the family interview, the length of time since diagnosis varied from 3 - 36 months.

A potential limitation of the sampling approach was that the families who agreed to participate may be more open in their communication patterns. Therefore, to determine the level of communication and functioning within the family a sub-scale of the Family Assessment Device (FAD) (Miller, Epstein, Bishop & Keitner, 1985) was administered to all participating family members. It was important to find out about the communication

patterns of the sample to ensure that the study was not reporting findings based only upon families who are more open as opposed to families who tend not to discuss their experiences and emotions.

In family research sampling is a more complex process because of the dilemma surrounding sample composition (Moriarty, 1990). Another important factor related to sampling was the acknowledgement that families will vary in the amount of enculturation they have experienced with childhood cancer. Therefore, families were obtained from all areas of the cancer trajectory from diagnosis to palliation.

Morse (1986) and Morse and Field (1995) state that qualitative sampling is guided by the principles of appropriateness and adequacy. Appropriateness means seeking out participants who can meet the theoretical requirements of the study. This concept is especially important because in qualitative research the data collection process must be efficient because often the sample size is small and there are large amounts of data from each participant. Adequacy refers to the fact that enough data are collected so that no new interpretations will emerge if more participants were recruited and there are rich descriptions of the phenomena.

There were strengths and limitations inherent within the sample used for this study. A strength was that families believed that the study was important; therefore, they were willing to explicitly share their experiences with the researcher. The limitations of the study were that no one-parent families, and no families from Northern Manitoba were included in the study. As well, a further limitation was that the majority of families included in this study had a male child with cancer. These limitations may be explained by

the particular families who were at cancer clinic on the days where the pediatric oncology nurse clinician was actively recruiting families for the study. As well, families who may have been in crisis may not have been interested in receiving more information about this study.

Recruitment and Access

Recruitment of multiple family members is challenging because of the difficulty of scheduling interviews when all interested family members can attend (Moriarty, 1990), as well as the increased costs and time associated with explaining the project and interviewing more than one person. Moriarty (1990) suggests that researchers must explain the benefits of research in order for recruitment to be successful. One benefit is that family research gives the family members the opportunity to sit down together, talk about their experiences and learn more about other members' needs and experiences.

Inclusion criteria for the sample consisted of the following:

- 1) Able to speak, understand, read, write English. Exceptions were to be made for children, for instance, pre-school children who are not yet able to write yet would be able to participate in the family group interview.
- 2) Live outside of the perimeter of Winnipeg. In the literature it is apparent that the interpretation of "rural" has been an obstacle to researchers (Weinert & Boik, 1995). Consequently, due to the population distribution of the province of Manitoba, the researcher decided to label 'rural' as living outside of Winnipeg.
- 3) Be a member of a family (nuclear or extended) in a family experiencing childhood cancer (birth to 18 years) or be a child with cancer.

4) The child with cancer must be receiving treatment and/or follow up at the provincial cancer treatment centre.

The researcher attempted to recruit families for this study using two approaches. The primary method was through the pediatric oncology clinic at the provincial cancer treatment centre. After receiving access to the cancer treatment centre, the researcher (see letter for access, Appendix A) planned to ask the pediatric oncology team if she could be present during clinic days (Tuesdays and Fridays). Members of the pediatric oncology team would then approach families who met the study criteria, provide them with information about the project and ask them if they are interested in hearing more about the study (Appendix B). If the families were interested, the researcher would be present at the clinic to describe the study, answer any questions they might have had, and inquire if they were interested in participating. However, the pediatric oncology team felt this approach would not be effective because of the structure of the clinic visits. Thus, the pediatric oncology nurse clinician was responsible for recruiting families whose children met the study requirements and also fit the purposeful sampling criteria requested by the researcher.

The nurse clinician phoned the primary caregiver(s) of each family at home or spoke to them during cancer clinic and asked if they would be interested in hearing more about the research study and if they agreed to release their names and phone number to the researcher. Then researcher phoned the families to give them more information about the research study and to inquire if they had any questions (Appendix C). The families were then asked if they were interested in participating in the study, and if so, a time and

place for the interview were arranged. At this time, the researcher explained that all family members were invited to participate in the family interview and the choice of who was to be included in the interview was left with the primary caregivers of the child. This stipulation was put into place in order to give some control given to the primary caregivers with regards to inclusion of other family members in the study.

Another recruitment venue was through posters (Appendix D and E) advertising the study placed at Ronald McDonald House, a home located close to Children's Hospital where several rural families stay while their child/sibling is receiving treatment and/or follow-up. Unfortunately, no families were recruited through this venue. It is speculated this method was not popular because there was no human contact specifically reaching out to families with this method. As well, times when families stay at Ronald McDonald House tend to be filled with more anxiety as their child will most likely be receiving inpatient treatment if overnight accommodation is required. The researcher did not utilize admission periods to Children's Hospital as opportunities for recruitment into the study because often inpatient admissions are times of increased stress on the family.

Eleven family names were given to the researcher to phone and provide additional information and inquire if they were interested in participating in the study. Ten of the families participated in the study; the remaining family did not participate because they felt they were too busy with their ill child at the present time. Toward the end of the study, the pediatric oncology nurse clinician gave the researcher two additional names of families who were interested in the study. These families were not needed because theoretical saturation had already been achieved. The researcher subsequently phoned these families

to thank them for their interest in the study and inform them that their participation was not required at this time.

Data Collection

Data collection and analysis were carried out concurrently. The collection of data lasted six months. Data collection continued until no further information was required. Data was collected through family interviews, field notes, participant observation during the family interviews, information received during phone calls for clarification and verification of findings, and information from a demographic form and a sub-scale of the Family Assessment Device. A semi-structured interview guide was used to structure the family interviews. The semi-structured interview guide was developed, and subsequently revised, from a pilot study in 1995 of this proposed study. The guide was initially developed from literature describing research findings of related studies. Modifications have since been made to encompass the findings of the pilot work, to fit with the theoretical framework and to deal with the complexities of interviewing families. The goal of data collection was to capture the experiences of the family members related to living in a rural area and having a family with a child with cancer so that the researcher is able to describe their lives, community, and culture.

There was only one face-to-face interview per family. May (1986) concurs with this decision by stating that “one-time interviews may be best when access to informants is difficult” (p.189). She proceeds by making an observation that was originally proposed by Munhall & Oiler (1986), that most ethnographic and grounded theory research studies rely on one-time formal interviews with the more emphasis on participant observation and

informal methods of data collection. May continues by suggesting if one time only interviews are used, provisions should be put in place to contact informants for clarification of unclear points, and for validation of findings. Chalmers (1990) cited the work of Lofland and Lofland (1984) and West (1980) to emphasis that interviewing can be the major source of data in qualitative research, with participant observation supplementing this information.

The researcher contacted the families after the interview if she required any clarification about material discussed in the interview. In addition, the rationale for only one time interviews was based on the feasibility and cost of additional interviews. Driving to each families' homes for the interview took a great deal of time and money, thus in order to be efficient and to not stress the families, only one interview took place. The researcher drove more than 2100 km interviewing ten families (Appendix F). It is important to mention that it was easier to recruit families because they only had to participate in one face-to-face interview rather than more than one. This is a crucial point to emphasize as the researcher did not want to place an added burden on these families whose lives were already severely stressed.

The family was called the day prior to the scheduled interview in order to confirm the interview appointment. The telephone confirmation had the advantage of putting less stress on the family if they did not want to participate and saved needless driving for the researcher if the family did not want to participate. Moriarty and Controneo (1992) believe that collecting data in the home increases recruitment of families because of the convenience; as well, the home is seen as a safe, comfortable place for discussing sensitive

matters (Steinglass, 1980). Daly (1992) indicates a challenge for qualitative researchers is to enter the protected area of the families' experiences. She believes that a qualitative design allows for the opportunity to build a rapport between the family and the researcher, so hopefully these protected experiences will be uncovered and discussed. Relating this point to the beliefs of Moriarty and Controneo (1992), it appears that the home is an appropriate setting for the interview. Moriarty (1990) believes another advantage to having the interview completed in the families' homes is that it gives the researcher the opportunity to observe the family in its natural setting.

On the day of the interview, the researcher and the family met at the predetermined location. The researcher again explained the project to the participants and discussed consent (Appendix G) and assent (Appendix H) to participate in the study. The researcher then gave the family a handout describing the project in more detail (Appendix I). This handout was for the family to keep, as well, the families were instructed if they had any questions about the project after the researcher left to phone either the researcher or the thesis advisor at one of the numbers on the bottom of the handout. The researcher reiterated that their participation was entirely voluntary and they were under no obligation to participate. As well, the family members were reminded that they were free to withdraw from the project at any time and everything discussed would be kept confidential. Assent forms were utilized for any children, siblings and/or the child with cancer, who wanted to participate in the research study. The assent forms were designed to explain the project to the child in a way that they could understand. It is important to acknowledge that individual children may be capable of fully informed consent/refusal at

different ages (Tri-Council Working Group, 1996). Thus, the researcher and parents assessed if the child understood the assent process. Their parents or the researcher read the form to them. If they agreed, the child signed the form and one parent co-signed the form as well.

Once the consenting process was completed and the ground rules of the interview process were briefly discussed the interview recording began. The interview sometimes started by having the family complete the demographic form (Appendix J). At other times because the family was already speaking about the diagnosis of cancer and their experience with childhood cancer the interview proceeded immediately with the demographic form being completed at the end of the interview. The demographic form was constructed to collect information about the child with cancer's age, type of diagnosis, the age of the parents, and distance to the provincial cancer treatment centre, to name a few. This form was an easy task and helped build rapport between the researcher and families who were more quiet and reserved at the beginning. Once the demographic form was completed, a rapport had begun to develop between the family and researcher, thus making it easier for them to proceed into a research conversation. The interview began with a grand tour question, in other words, a broad question that asks the families to describe their experience with cancer. As Spradley (1979) suggests, broad descriptive questions encourage the participants to gain confidence by speaking openly, thus building rapport between the participants and researcher. The interview guide is outlined in Appendix K. As the interview progressed, the researcher began to ask more focused questions. Probes were used, as listed on the interview guide, to clarify the meaning of

responses and to ensure all information related to the topic was discussed. The interviewer did not always proceed in the order outlined on the interview guide; the interviewer allowed the family to assume control of the progress of the interview. At times, the researcher had to take control of the discussions in order to ensure that all relevant information had been discussed.

The General Functioning subscale of the Family Assessment Device (FAD) was completed by all participating family members, except for young children, after the interview. The FAD was originally constructed as a screening tool to collect information on various elements of the family system as a whole (Epstein, Baldwin & Bishop, 1983). The FAD (Appendix L), is 53-item, self-report scale, designed to assess family functioning (Miller, Bishop, Epstein, & Keitner, 1985). The Device is based on the McMaster Model of Family Functioning (Epstein, Bishop & Levin, 1978) which originally identified six dimensions of family functioning; problem solving, communication, roles, affective responsiveness, affective involvement, and behaviour control; a seventh dimension, general functioning, has been added to the scale to assess overall health/pathology (Miller et al., 1985). The FAD has a Likert scale design, with a four item scale ranging from 'strongly agree' to 'strongly disagree.' The seven scales within the instrument have a demonstrated internal consistency ranging from 0.72 to 0.92 (Miller et al, 1985) and test-retest estimates from 0.66 to 0.76. Each of the seven subscales has health/pathology cutoffs; these reference points have adequate levels of specificity and sensitivity (Miller et al., 1985).

For the purposes of this study, only one sub-scale, general functioning, was utilized. This sub-scale, 12 items, was used to assess overall family health pathology. The

FAD, especially the general functioning subscale, is short and easy to administer, as well, it has adequate test-retest estimates and internal consistency (Miller, Bishop, Epstein, & Keitner, 1985). The FAD has been utilized in a variety of research studies including studies relating to adolescents with a mother with breast cancer (Kristjanson, Chalmers, Taylor-Brown, Nelson, Woodgate, & Ramserran, 1997), families with a premature infant (Lanouette & St. Jacques, 1994), and children with a chronic condition (Gottlieb & Feeley, 1994). The general functioning sub scale of the FAD was used 'post hoc', that is, it was not being used to drive the selection of the sample. The primary purpose for the use of the FAD in this study was to describe the samples' family communication patterns as well as to ensure that a range of families are represented in the data. The findings the FAD will be discussed in the findings section of the study.

The interviews ended with an informal debriefing which included asking the family if they would like to contribute any other information, as well as asking the family if they had any questions or closing remarks. At this time, the researcher assessed and/or asked if the family needed immediate assistance due to the sensitive nature of the topic of the interview. If more information or support was required, the researcher would have given the family the phone number of the pediatric oncology social worker and/or the pediatric oncology nurse clinician for assistance with more complex issues. At the end of the interview, the researcher inquired if the family would agree to be phoned within the next few weeks if the researcher needed clarification of anything discussed during the interview. In addition, the researcher invited the primary caregivers to speak together privately if they wanted to. The purpose of this activity was to ensure that the primary

caregivers had the opportunity to 'speak their mind.' In the family interview the primary caregivers, in particular, may have felt that they should not truly speak their mind in order to protect their child. Actually, the researcher did not have to ask if the primary caregivers wanted to speak privately with her because it occurred naturally as the researcher was beginning to leave the interview setting. It was the researcher's experience that occasionally at the end of the interview when either she was leaving or the tape recorder was being turned off that the primary caregiver more openly discussed their experiences and feelings.

The interview guide used for this study was pilot tested on two rural families experiencing childhood cancer in the Fall of 1995 as part of Masters course work. The guide proved to be useful to elicit thick descriptions of the families' needs and experiences. The guide was flexible enough to enable the researcher to meet the goals of the pilot study and the families to discuss issues and events that were significant to them. As well, the interview guide was critiqued by six Master of Nursing student colleagues. As previously mentioned, some revisions had been made to the guide. True to qualitative inquiry, the format of the interview guide changed as the study progressed. For instance, in the last few interviews the researcher tested out some hypotheses that she had formulated to date during analysis. Thus, the interview covered the same information, but also included some closed ended questions to 'test out' some of the researcher's hypotheses and conceptualizations. Two areas that were added to the interview guide involved trying to get at the specific experiences of fathers and attempting to discern if rural families with a child with cancer felt as though they were the gatekeepers and the

local experts for their child's care.

During data collection, the interviewer remained "multidirectional partial" (Moriarty, 1990, p.10) so that family members were encouraged to present their own ideas, and experiences even if they are not congruent with other family members. The interviews were being tape recorded, with minimal note taking during the interview. During the interview the researcher documented any significant events such as family reactions, and body language during the interview. These notes documented the participant observation component which is a significant element of qualitative research. As Morse and Field (1995) indicate, "participant observation is the second most common approach to data collection" (p. 106). There was minimal note taking during the interview as it had the potential to alter the group process occurring. The notes, when took, were very brief, mere words and phrases. As Schatzman & Strauss (1973) suggest "the presence of a stranger in a natural human situation introduces some measure of disturbance in the scene" (p.53). This supported the decision for minimal recording during the interview.

Field notes were made by the researcher and tape recorded following the interview. Field notes were used to supplement interview data and included the researcher's impressions, further details about the setting, expressions in the interview, body language and other nonverbal communication. As well, the researcher included some possible hypothesis and relationships in the field notes. These field notes were later transcribed and were similar to the notes or 'memos' as described by other qualitative researchers (Schatzman & Strauss, 1973). Schatzman & Strauss (1973) believe that notes

“become vehicles for ordered creativity” (p.104). They suggest that there are three distinct types of notes, methodological, theoretical, and observational. Methodological notes are instructions or critiques by the researcher about the research process.

Theoretical notes are self-conscious attempts to derive meaning from the observational notes. Theoretical notes are where the researcher attempts to conceptualize, interpret and link concepts together. Finally, observational notes are statements which relate to events experienced through listening and watching. Each observational note is developed as a unit event. Morse and Field (1995) explain the importance of field notes and state that “detailed, accurate and extensive field notes are needed for a successful qualitative study” (p.112).

The researcher was aware of the disadvantages of conjoint or family interviews. One disadvantage in particular is that the researcher may characteristically provide counselling to “reconcile differences or to get at the ‘real truth’” (Morse, 1987, p. 134). The reason for the conjoint interviews was efficiency of time for the family and researcher, as well, this style of interviewing offered benefits to the family. The benefits to the family included the opportunity to ‘tell their stories’ to an attentive listener, in addition to the family members having the opportunity to learn about each other’s needs, experiences and feelings related to the illness.

Interviews

At the onset of the study, the researcher planned for the semi-structured interviews to ideally take place in the families’ local communities if they lived less than 3-4 hours from Winnipeg. All of the interviews except for two were conducted in the families

homes. The two remaining interviews were conducted in locations that the families requested, Ronald McDonald House and the Children's Hospital. In each case, arrangements were put in place to provide privacy for the families during the interviews.

The majority of the family interviews occurred in the evening, a time that seemed to be the most convenient in order to get the largest number of family members participating. Most of the interviews were conducted in the kitchen at the dinner table. This interested the researcher because it was seen by the family as a 'common ground' where the family was comfortable to sit down together and discuss sensitive issues. The number of family members participating ranged from two to five people. People participating included mothers, fathers, the child with cancer, siblings, and grandmothers. The interviews began with a grand tour question, "Can you tell me about your experience of having a child with cancer and living in a rural area." Often, families had difficulty with this question as they did not know where to begin. Normally, they started by telling their story, the story surrounding how they came to know their child was ill, the diagnosis phase, and treatment. During their stories there was frequently great emotion expressed, hurtful expressions on their faces, sobbing, wet eyes, and occasionally poor eye contact. None of the families wanted to stop and take a break; they wanted to continue to share their experiences. It was interesting to note, in the families where both parents were present, it was almost expected that the mother/wife would speak first, and in fact, in some cases the father/husband, would request for them to proceed. The researcher did not notice any great reluctance of the families to share their experiences. They spoke openly about their ordeals.

The interviews lasted from just over an hour to slightly more than two hours. The families tended to be vocal, requiring few probes to solicit more details about their experiences. This was especially the case with families who had been diagnosed for longer periods of time. The researcher found herself sharing personal stories with those families had some difficulty conveying their experiences. This technique is suggested by Sorrel & Redmond (1995); it was effective in building trust in the relationship between the family and the researcher. As well, the researcher felt that the families had little difficulty speaking with her because she is a health care professional and she grew up in rural Manitoba, thus she could associate with their lifestyle. The researcher tried to give the family as much control over the interview as possible. Sometimes the researcher had to get the interview back on track as the family was deviating from the focus of the interview. The families did not appear to have difficulty with the interviews being taped. They got over the initial hesitation within the first few minutes and by the end of the interview, most of the families said they forgot the tape recorder was running. The exception was with one family, when the tape recorder was turned off, the mother expressed some different viewpoints than she had previously expressed while being taped.

At the end of the interviews all of the families said that the interview had been beneficial, at times often cathartic, in some way for them. For instance, one family stated it was beneficial because they often don't have the time to sit down and discuss how everyone perceived their experiences. Robinson and Wright (1995) discovered physically bringing the family together to discuss their experiences was one of the interventions families living with chronic illnesses stated as effective in healing their family suffering.

On a couple of occasions, the researcher was accompanied out to her vehicle by the mother and sometimes significant information and feelings were expressed at this time. There is evidence of this practice being common in family therapy. Some of the possible reasons for this occurrence include the family/individual just starting to 'warm up', and not wanting the session to end. Perhaps, another reason was the mother wanted the opportunity to express her feelings away from the rest of the family. In conclusion, the interviews were a positive experience for both the researcher in obtaining rich data describing the experiences of rural families experiencing childhood cancer and for the family and its members because of the opportunity to share their experiences.

Data Analysis

Data collection and analysis proceeded concurrently in order that themes that emerged in preliminary analysis could be explored in subsequent interviews. Interviews were tape recorded and transcribed and data were subjected to a process of thematic content analysis. Initial analysis of data involved tentative coding of items of data under general headings.

The demographic and FAD forms were analyzed using SPSS/PC+ statistical software to determine the characteristics of the families utilized for this study. Specifically, the information from the FAD questionnaires was used to obtain the range of mean scores in order to assess if the families used in this study could be considered average in terms of family communication and functioning.

Immediately following the interview, the researcher listened to the interview on the drive home in order to get immersed in the data. During the drive back to the city the

researcher started to develop hypotheses about the interviews and preliminary themes that were evident in the interview. The drive back was an excellent time to get immersed in the data and reflect upon the interviews. Memos were then generated by the researcher once she reached her home. Then the interviews were transcribed verbatim. The researcher took provisions to protect the transcriber due to the sensitivity of the interview material, such as having debriefing sessions and preparing the transcriber for the termination of the research (Gregory, Russell & Phillip, 1997). The transcriber was also briefed about issues surrounding confidentiality. Once the transcription was completed, the researcher checked the transcript for accuracy against the tape. This was another method of becoming immersed in the data.

After each tape was transcribed and checked, data analysis began. The researcher consulted several qualitative sources for how to proceed with data analysis. As well the suggestions put forth by Burnard (1991) were closely followed. Originally, the researcher considered that she would utilize the Ethnograph program (Seidel, Kidseth & Seymour, 1988) throughout the data analysis process. Yet, after doing the initial coding, the researcher decided against this step. This decision was made because the researcher feared that implementation of a computer program may take her further away from the data. The fact that the data set was relatively small, 328 pages of transcriptions and several pages of field notes and memos, the researcher felt comfortable with this decision. Sandelowski (1995b) supports the researcher's decision by suggesting, only recently have scholars realized the adverse effects of computer technology, such as "transforming the look and feel of qualitative research" (p.205) and making qualitative inquiry appear more

like conventional research. It was felt that the benefits of the computer data management technique, such as streamlining the organization of the data and quick manipulation of the data were outweighed by the possibility of the researcher losing the 'look and feel' of qualitative research.

Analytic work included line by line analysis of the transcripts to do open coding and to identify conceptual categories. Content analysis guided the interpretation of the data. The data analysis approach was guided by the four principles outlined by Morse and Field (1995), "comprehending, synthesizing, theorizing and recontextualizing" (p.126). The researcher read the entire interview over several times in order to grasp an understanding of the interview (comprehending) then the interview was read again for the purpose of identifying important topics. The topics or general ideas present in the interview were coded and the topics broke the interview up into segments. The researcher was continually immersed in the data through reading and rereading the transcripts until she felt that the meaning of the interview was grasped by the codes (synthesizing). Categories were combined, if appropriate, to create general themes. This process continued for each transcript. Then the researcher looked across all transcripts to discover if the categories were full and if saturation has been reached. As had been stated earlier, the researcher felt that theoretical saturation had been reached after interviewing eight families; yet two additional families were interviewed, as she was a novice with qualitative methodology. At this time, again some categories were combined or renamed (theorizing). Then the researcher looked for patterns and relationships between the categories (recontextualizing).

The analytical process was flexible in order to deal with the complexities of family research. Both the individual and the family were the unit of analysis; thus, the researcher searched for patterns, trends and differences between and amongst families, family members, and individuals as well as looking for patterns between different family roles and genders. The researcher compared data within and across families; and within and between family members. As Murphy (1992) suggests, by making comparisons across families “one can see differences and similarities more clearly, gaining insight into meanings and experiences that may be common to several families or unique to one family. The analysis of each new families’ data illuminates the previous family’s data” (p. 155-156).

Verification of Findings

In order to ensure that the researcher interpreted the families’ experiences and needs correctly, the researcher contacted three families to verify results. The selection of the three families was based on criteria identified during the data analysis that appears to be affecting the families’ experiences, such as distance from the treatment centre. After the family interview, each family was informed that they may be contacted by phone within the next few months to assist in validating the study findings. When the researcher was ready to validate her findings she selectively contacted three families (Appendix M). At this time, the researcher asked if she could mail a copy of the summary of the findings to the family for the initial reactions and feedback. If they agreed, the summary (Appendix N and O) would be mailed to them and within the next two weeks the researcher contacted the family via phone to discuss their opinions and reactions to the summary of findings.

Prior to the process, the researcher asked the families to select a spokesperson to represent the views of their family as the discussions would be conducted over the phone. During the validation of the findings (Appendix P), the researcher took detailed notes of the conversations. When the family member and researcher spoke about the study, the current findings were presented. Then the researcher asked if the caregiver could identify with the findings from the study. Also at this time, the researcher asked if there is anything else that the informant wanted to contribute about the experiences and needs of rural families with a child with cancer.

Through the process of verifying the findings with the three families it was discovered overall that they concurred with the findings presented by the researcher. Two families had some difficulty with the fact that hundreds of pages of data were condensed into a one and a half page summary. The researcher elaborated on this point to these families and stated that only the basic findings were sent to the families and only a few select examples of each theme were given. The reason surrounding this decision was to not confuse the families, as well as, not burden the families by the enormity of categories and examples represented under each theme. At times, some further information about qualitative methodologies had to be presented to the families so that they could understand the research data. Overall, they felt that they could put the findings of the study into context of their own lives. The family members involved in the verification of the findings, all mothers, were especially interested in the suggestions put forth by other rural families experiencing childhood cancer.

Verification of the data with participants is recommended by Morse & Field

(1995). As this was the researcher's first experience working independently on a qualitative research study, a nurse researcher with expertise in qualitative methodologies did open coding of three interview transcripts. Similar codes were achieved. As well, the study findings were verified by the related literature, a further method suggested by Morse and Field (1995).

Rigor

Rigor in qualitative research is distinct from rigor in quantitative research. The assessment of rigor was guided by the four aspects of trustworthiness identified by Lincoln and Guba (1985). They believed that the following four aspects are relevant to both qualitative and quantitative data: truth value or credibility, applicability or fittingness, consistency, and neutrality or confirmability.

Credibility refers to the fact that the researcher is responsible for reporting the participants' perspectives honestly and as clearly as possible. A study of a qualitative nature would be considered credible when the interpretations of human experience generated by the researcher are recognizable by the humans living with the experience (Sandelowski, 1986). Credibility in this study was enhanced by checking out data and interpretations with study participants. Using this method, the participants determined if the researcher has captured the meaning of their experience.

Applicability relates to whether the results of the study can be applied to other groups, or in other contexts. A study meets applicability if the findings 'fit' the data (Sandelowski, 1986). Applicability was addressed in this study by the line by line analysis of the interview transcripts during the data analysis phase. As well, the preliminary

findings of this study were presented at an International Qualitative Health Research Conference in February, 1998. During the poster presentation, several researchers commented on the congruency of the findings from this study with findings from studies they had independently completed.

Consistency is related to the compatibility of qualitative findings. Consistency or auditability is present within a study if another investigator could follow the researcher's method and arrive at similar findings. The researcher enhanced consistency in this study through detailed accounts of the research process and the decisions made related to the study's method. As previously mentioned an experienced nurse researcher open coded three of the interview transcripts and arrived at similar findings.

Neutrality refers to a lack of bias in the study methodology and results (Sandelowski, 1986). Neutrality is achieved if the researcher strives, and is successful, in producing results that honestly capture the phenomenon under investigation. This may be achieved through prolonged contact, using long periods of observation and identification of the researcher's own biases. Morse and Field (1995) suggest that researchers should identify their own biases and record them. Neutrality was addressed by the researcher through the detailed recording of any biases the researcher may have had throughout the research process. The researcher deemed neutrality was maintained throughout the study. This was due to the fact that the researcher never previously cared for any of the families interviewed in this study, thus, she did not have any perceived ideas about their experiences. The researcher experienced a few instances of 'over immersion' in the data during the process of data analysis where she had vivid dreams regarding some of the

families she had interviewed. The researcher acknowledged this, and was careful to ensure this did not effect the data analysis process. In addition, neutrality is achieved in essence through the careful integration of the above three criteria for rigor, credibility, applicability, and consistency.

Researcher Protection

Due to the sensitive nature of the research, there was potential that the researcher may be psychologically and emotionally fatigued and drained by the fieldwork, interviews, and participant observation. In order to prevent this, the researcher did not conduct more than two interviews in one day, recorded her thoughts and feelings in her thesis journal and debriefed with her thesis committee when required. Dunn (1991) suggests that qualitative researchers should report their experiences, in addition to the participants, because these experiences will influence the data collection process and the interpretation of the data. Boyle (1994) would concur with Dunn as she acknowledges the reflexive nature of ethnographic work and how the researcher is part of the world she is studying as well as being affected by it.

Reflection and Reflexivity

True to qualitative inquiry, the researcher needs to openly state his/her experiences and feelings throughout the research process. The purpose is that the researcher's experiences influence the entire research process and understanding one's experience equates to an enhanced comprehension of the data. The processes of reflection and reflexivity stresses the importance of how earlier experiences effect present and future experiences. Reflection and reflexivity help to put the researcher's life in context in

relation to the research study. Due to the personal nature of this section it will be written in first person.

Throughout my life I have been affected by the devastating effects of cancer, both personally and professionally as a pediatric nurse. The most striking example of how my life has been affected by this disease was when I was growing up in rural Manitoba. My Grandpa whom I was very close to, was diagnosed with prostate and colon cancer. Throughout the journey of this research project, I began to re-live the suffering of losing my Grandpa - ten years later. I feel that this was due in part to the similarities in the experiences of the families I interviewed and the experiences that my family faced. Some of the congruencies between my experiences and the experiences of the families I interviewed were the feelings of fear, the struggle for normalcy, and the whole family being affected.

During the course of this study, I remember how alone I felt ten years ago seeing my Grandpa succumbing to a disease, something I could not see, only feel. Throughout his struggle with cancer my Grandpa tried very hard to maintain normalcy; he would still drive me to school, work in the fields - only taking breaks to go and get his treatment. I remember my whole family changing - especially when things got worse. My Mom would be helping my Grandma care for my Grandpa and my Dad would be working harder because my Grandpa was too ill to work; yet as a family we tried so hard to keep things 'normal.' At this time, I was a teenager - not a child, not an adult - I was 'in between' and minimal information about my Grandpa's condition was given to me. I remember feeling helpless at times because cancer seemed to be taking over our lives. I would hear stories

from my Grandma of my Grandpa being sick on the side of the road coming home from radiotherapy in Winnipeg - this absolutely crushed me. One of the most distinct memories that I have is the last time I saw him - lying in a hospital bed, his skin yellowy-brown, his large frame visible through his paper thin skin. He was wearing a blue hospital gown, I remember the gown matched his eyes - he looked so weak and tired. As I went to leave, I hugged him and he said "please do not remember me this way"; I knew that would be the last time I would see him, and I slowly left his room hoping to prolong our last few moments together.

This personal experience changed my life as it taught me about complexities of life and forced me to examine what I wanted to capture from life. What surprised me throughout collecting and analyzing data for this study was that my memories of my grandfather came back very vividly. The similarities between the families I was interviewing and my own experiences were more parallel than I expected. In order to maintain boundaries on my research study, I wrote my feelings about my Grandfather down, and discussed them with my family. I realized that my personal experiences have perhaps affected and enhanced the research data, as does any qualitative researcher influence the data collection and analysis. Throughout the study, I felt that I shared a similarity with the families I interviewed because we seemed to be connected by a common morbidity - cancer. I mentioned my experiences to the families I interviewed, and I felt that my experiences helped to build trust and rapport with these families as they knew I could understand their pain.

Ethical Issues

There were several ethical issues present within this study, specifically due to the fact that children had the opportunity to be involved. The Tri-Council Working Group's report on the (Draft) Code of Conduct for Research Involving Humans (1996) was consulted to assist in managing these concerns. As outlined in the report, there is: an obligation to encourage and pursue research involving children as research subjects in legitimate research protocols. This obligation is rooted in three principles:

- 1) harm could come to infants, children, and adolescents if research about them is not pursued;
- 2) it is unjust to these three young populations to exclude them from research that may be to their benefit; and
- 3) respect must be given to the rights and obligations of parents to ensure the well-being of their children

(p. 12-5 - 12-6).

This research study focused on the experiences of families with a child with cancer, thus it was vital to include children as they are members of the family and their experiences may be different from their parents. To the knowledge of the researcher, there has only been one study, American based, which specifically examines the needs of families experiencing childhood cancer who must travel large distances for care. This particular study was quantitative in nature and derived family data from only assessing the parents. Due to the lack of research in this area, the findings of this project have potential to identify family

needs not previously known. Thus, the results could be of benefit to children and the rest of the family.

Due to the fact that children may be involved, particular attention was given in obtaining participation assent. This procedure has been previously discussed in this chapter. The researcher made every attempt to make full disclosure of the proposed research project in an open and understandable manner to the child and family in agreement with the child's maturity (Tri-Council Working Group, 1996).

Informed consent of all participating members was secured by the researcher at the start of the interview. Children completed an assent form with the assistance of one of their parents/legal guardians. The researcher explained the nature of the research, the demands that will be placed on the participants, in addition to the benefits and risks to the participants at the start of the interview. At this time, the researcher answered any questions that the family members may have and informed them that any family member or members may withdraw from the study at any time.

The researcher made every effort to maintain confidentiality. All participants' names and phone numbers were locked up separately from the interviews and tapes. The data transcripts did not record any names; instead an initial was used rather than the full name. The transcripts were coded with a unique number and the same number placed on the corresponding tape. All research data will remain locked in secured areas for seven to ten years. Only the researcher has access to the codes and the participant's names, addresses and phone numbers. Only the researcher and the thesis committee (except for Dr. Yanofsky, who cares for these children and their families) will have access to the tapes

and transcripts.

In addition, as this study involved children, the researcher acknowledged that there is the potential to observe situations involving possible child abuse. If the situation arose, the researcher would have terminated the interview and informed the family that she is obligated to contact the proper authorities regarding her concern for the child. The authorities would then be contacted. The researcher would have mentioned to these families that they may maintain contact with her if they have any issues they need to discuss.

It is well-known that the diagnosis of cancer affects the entire family. In order to protect the child with cancer from feeling responsible for the changes within the family, if relevant, the researcher asked at the end of the interview, if the primary caregivers wanted to speak to the researcher alone for a few minutes. Normally, more private conversations occurred between the researcher and primary caregivers when the researcher was getting ready to leave the families' homes. Plans were also organized if excessive negative comments started to occur within the interview. The researcher would have asked for a "time out." At this time, she would have acknowledged the difficulties of the diagnosis, and asked that these comments be discussed with the researcher separately. Fortunately, negative comments did not occur during the family interviews, although disagreements between family members occurred.

As the interviews discussed sensitive issues, it was essential to have some ground rules prior to starting the interview. All family members agreed to the rules before starting the interview. As well, the families were given the option of making additional rules,

given that the rules do not infringe upon the objectives of the research project and they do not add any additional ethical implications. The first rule was that everyone had the opportunity to speak during the interview. The researcher made every attempt to ensure that one family member did not monopolize the conversation and she specifically directed questions to quieter family members to obtain their feelings. The second rule was that some issues raised during the interview may be new to other family members. If this was the case, the family members must respect the confidentiality of these issues and must not discuss these issues outside of this group.

Due to the sensitive nature of the interviews the interviewer had a debriefing session at the end of each interview. At this time, any questions were answered and time was given to discuss feelings.

The researcher acknowledged that due to the sensitive nature of the interview there was the possibility that the children involved may experience some anxiety. Special provisions were organized to deal with this possible occurrence. The provisions included speaking with the child independently to discover their level of distress and then referring them to the pediatric oncology social worker and/or pediatric nurse clinician. If the child was in agreement, the researcher would have phoned the social worker and/or nurse clinician to arrange a time for the child and professional to meet. The researcher would not have left the child if they required immediate assistance. The researcher only would have returned to complete the interview if the child indicated that it was okay. As well, the researcher would have referred any families requiring further assistance to the pediatric oncology social worker and/or nurse clinician upon their agreement of this referral. These

provisions were not required during the interviews. Throughout the interviews, children were quite transient, often times leaving when they did not feel like talking and coming back when they wanted to add something. At the conclusion of the interviews the researcher assessed whether families were in distress due to discussing this sensitive topic. Overall, the families were not distressed; at times families commented that it was beneficial that the family sat down together and discussed their experiences. At the end of one interview, the mother appeared distressed as her son had just recently relapsed. The researcher and mother spoke privately for a few minutes prior to the researcher leaving. The mother stated that she would be alright and she felt that it was therapeutic to have the opportunity to discuss her feelings and experiences with a health care professional.

Since the researcher is a registered nurse at the Winnipeg Children's Hospital, it is important to mention that the researcher did not work with these families clinically during the data collection process. For the last year the researcher has had limited clinical exposure to children with cancer. This decision was made so that during the period of data collection and analysis there would be distance between the researcher and potential research families.

Summary

In this chapter the methodology was outlined. The family research study was a qualitative, micro ethnography with a sample of 10 families who live outside of the study city. Recruitment was based out of the pediatric oncology clinic at the provincial cancer treatment centre with the pediatric oncology nurse clinician assisting with this process. Data was collected in a location chosen by the families; overall, the interviews were

conducted in the families' homes with the exception of two interviews. Data was collected from a demographic form, the general functioning subscale of the Family Assessment Device (FAD), field notes, one semi-structured interview, clarification telephone calls, and verification of findings phone calls. Data analysis proceeded concurrently with data collection. Content analysis guided the data analysis process. Data analysis and organization were conducted manually, without the implementation of computer software packages. Ethical considerations for the study were also discussed.

Chapter IV

FINDINGS

In this chapter the findings from the analysis of the data are presented. This chapter is organized according to the eight major themes identified from the data analysis. Each theme is composed of several categories which had been developed from the merger of more minor categories or codes. This section exclusively presents the eight themes and their respective categories that deal with the experience of having a child with cancer and living in a rural area. Prior to presenting the themes, some information about the informants is presented. The chapter concludes with the results from the Family Assessment Device completed by the study participants.

The Informants

Ten families participated in the interviews with 25 family members being involved. A demographic form completed by each family gleaned most of the basic information about the family and its members. The demographics data for the families are outlined in Tables (4.1, 4.2, 4.3) to facilitate easy access to information. Overall, the 'average' family interviewed had two children (one with cancer), the parents were 36 years old and it had been just over a year since diagnosis.

Table 4.1 - Family Demographics

	Range	Mean	Median	Other
Age of child with cancer	2-18 years	8.3 years	9.5 years	
# of siblings	0-2 siblings	1.3 siblings	1 sibling	
Age of siblings	4 months - 18 years	10.6 years	11.5 years	
Parents' age	21-49 years	36.2 years	39.5 years	
Time since diagnosis	3- 36 months	13.9 months	16 months	
Gender of children with cancer				2 - female 8 - male
Type of malignancy				ALL - 2 Brain - 2 Hodgkin's - 2 Wilms' - 2 AML - 1 Abdominal tumour -1 NHL -2

Table 4.2 - Occupations of Parents**Families interviewed (n=10), Parents (n=20)**

Occupation	Frequency
Teacher	3
Office Worker	2
Farmer/Self Employed	4
Homemaker	3
Railway/Seasonal Worker	3
Service Industry	5

Table 4.3 - The Distances Families Travelled for Cancer Care

	Range	Mean	Median	Other Information
Distance to tertiary centre (one way trip)	63 - 460 km	182.3 km	133 km	
Number of trips to tertiary treatment centre (at time of interview)	8 - 250 trips	61.4 trips	36.5 trips	
Number of kilometres driven (round trip) to tertiary centre since diagnosis (at time of interview)	3,510-27,000 km	14,281.4 km	9,252 km	
Total number of kilometres driven by the 10 families to the tertiary centre since diagnosis (at time of interview)				142,814 km
Length of time to drive to tertiary centre from the families' homes	1 - 4.5 hours	2 hours	1.5 hours	
Distance to nearest medical facility	5 - 96 km	18 km	14 km	

It is worth noting that the enormous number of kilometres driven by these ten families for

the treatment and follow up of their children is equivalent to three and a half times around the world at the equator.

Figure 4.1 - Presentation of themes and categories

- I Digging Up the Pain - The Diagnosis Story
 - Signs and symptoms - knowing something is wrong
 - Trying to be heard
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- II Treatment - Trying to Destroy the Enemy
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VII Our Wishes On Falling Stars...Our Wish List

The hospital experience
 Changing the 'big' system
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The themes and categories unearthed during data analysis will be presented. Examples from the data are cited to support the development of these themes and categories.

Digging Up the Pain - The Diagnosis Story

The first theme was readily apparent in all interviews. All families started the interview by 'telling their story' about the diagnosis of childhood cancer. When the families were describing their experiences it was readily apparent the diagnosis of cancer was very painful. Family members often gave very detailed accounts of the diagnosis phase and the time before diagnosis. Four categories were discovered under this general theme, 'signs and symptoms - knowing something is wrong,' 'trying to be heard,' 'waiting and watching for the unknown,' and 'hearing the news.'

The detailed accounts of the child's diagnosis frequently included graphic descriptions of the child's worsening medical condition. In all cases, the family knew that something was wrong with their child because of physiological cues, behaviour changes, or mental differences. This category was called "signs and symptoms - knowing something is wrong." All families who were interviewed knew something was wrong with their child well before diagnosis. They subsequently took their child to a physician. In no cases did a physician diagnose cancer before the family started to notice changes in the child.

In four families, the process of diagnosis involved a great length of time prior to diagnosis (greater than one month), misdiagnoses, and severe symptoms in the ill child. In one family, a teenage boy had been experiencing severe headaches, dizziness, weight loss,

and vomiting for over two months. The local physician could not find anything wrong and each day the boy would go to school taking graval and pain killers continually. The mother knew something was wrong and was very persistent:

M) But I go and um, and his questions well, is everything going O.K. at school, O.K. at home, and you known then, it is a nerve thing. He figured it was nerves and I didn't think it was that. I think there is something wrong here.....We mentioned C.T. scan, he sent, the doctor sent him for an ultrasound on his stomach. (Pause). And whenever we kept mentioning C.T. scan he'd say well that's an expensive test. We'll just you know eliminate all the others first.

I) Ya

M) Then finally Christmas we were, Christmas day was not a good day. On Boxing Day and then we took them down to the doctor. And that was the last time I was going to this doctor, I said one more time if he's not going to do anything we're going elsewhere. And he put him in the hospital. Well then the other doctors came to look at him and I guess I kind of pushed this guy to do something for B. They said there is something wrong here" (Interview 004, p. 10, 385-420).

In some of the families that waited under one month for a diagnosis, it still felt like an eternity for them. For these families, watching their child's medical condition getting worse without any explanation was very painful.

The next category, trying to be heard, centred around the experiences of families trying to be heard by health care professionals. Often times, these families had to be extremely persistent and were continually going to their local doctor, and having requests for diagnostic tests overlooked. One family tried relentlessly to be heard by their local health care professional:

M) And it was hard because I just started that new job and all of a sudden she was sick all the time and broke her leg and it's hard to find people to watch her when she's sick and I'm sick and I didn't know what was wrong. I'd bring her to the doctor sometimes three times a day. Like, something's wrong, do some tests and they wouldn't do any tests.

I) Were you getting frustrated?

M) Oh very frustrated because I'd call B and say that, like, I called him one time and he called me from his friend's house and he'd gone fishing. He called to say that he was on his way home and I said I think the doctors are giving me the run around (Interview 012, p.17, 713-726).

During the turbulent time before and at the time of diagnosis, families often endured a tremendous amount of stress while their child was going through diagnostic tests, and sometimes the symptoms of cancer were increasing significantly, causing the child great pain. The period of time before the family knew what was wrong with their

child was very distressing. During this time, families often times came into the city for consultations, and tests - frequently on an emergent basis. These experiences were captured under the category “waiting and watching the unknown.” The following example illustrates the stress some rural families experience before the diagnosis. The two year old boy had been spiking a fever of 106 -108 degrees for several days and he was very weak with a rash and bruises on his body. His mother had relentlessly taken him to the doctor for several days before a blood test was done:

M) And the doctor looked at him, and the doctor said ‘well I think what it is, is his internal organs, his white blood cells have gotten too high and they are turning on his internal organs and its not a big deal he’ll probably just go into the hospital for a couple of days.’ He sent us to the lab and said go home and we’ll call you if there is anything wrong. Well, probably an hour and a half later he phoned me back and said we think your son has leukemia, he told me right on the phone. He said I’m really sorry we didn’t find this out on Monday. Now it’s Wednesday. So his whole body was in systemic shock by this point....his body was shutting down. So we drove him into Winnipeg in the car because they said it will just be faster if you can drive in than get an ambulance or whatever.... He was almost unconscious when we got him in” (Interview 005, p.3 - 4, 115-138).

Hearing the diagnosis, the final category, was manifested in a wide variety of ways.

Some families felt almost relieved because they now knew what they were up against, whereas, other rural families were in shock. All of the families indicated that this time was extremely stressful for them as they were trying to get over the initial shock of the word, 'cancer.' No families had suspected that their child had cancer prior to the actual diagnosis. Families gave detailed accounts of what happened during the initial days following the diagnosis. The events included a lack of privacy, being overwhelmed by the amount of information being given to them and the large number of people involved in caring for their ill child. One mother recounts the memories at diagnosis:

M) Ya I was sitting in there and I couldn't stop my face from shaking
cause I was so scared and I couldn't stop my face from shaking so
I just had to get out of there.

I) Right

M) I went to the washroom, I washed my face cause ever since this
happened I have never let my son see me cry" (Interview 010, p.6,
228-235).

Treatment - Trying to Destroy the Enemy

Family members and the child with cancer talked very vividly and explicitly about the treatment of the cancer. The manner in which the cancer was discussed was as something that they needed to get rid of or kill so that their family could return to normal. All of the families interviewed had either undergone chemotherapy and/or radiation treatment for their child's cancer. Some families also experienced surgical intervention for their child's malignancy. Two categories supported this theme, the types of treatment and

the side effects. The children experienced a variety of side effects from treatment, including vomiting, hair loss, increased fatigue, weight loss, and changes in behaviour. These side effects were accentuated by the fact that these families often had to undergo long drives after receiving treatment which at times often increased the symptoms. This family had to drive over an hour and a half to get home from Winnipeg with their son vomiting:

Gm) Then they sent him home on time, (clears throat), I was kind of upset about that. He had just had his chemo and uh, he vomited all the way home.

I) Uhm

Gm) We stopped at OB and tried to get something to settle his stomach or something. He just couldn't keep anything down so we ended up going back the next day, didn't we? (Interview 003, p.3, 103-110).

The treatment of childhood cancer consists of several unique circumstances for rural families, including treatments being late because of poor weather, and long periods in the hospital without seeing family and friends due to the distance. It seems so paradoxical as during cancer treatment family support is essential. Yet, in with rural families, the family unit is forced to split apart because of the responsibilities and commitments of its members. Because of this, it appears that each family member suffers in some way. During treatment, these feelings appear to be heightened because the periods of time away from home are at the longest.

Away From Home

This theme, 'Away from home' signified the experiences of rural families with a child with cancer when they were outside of their own environment; in other words, when they were in the city for treatment and follow up for their child's malignancy. A large percentage of the interviews focused on the family members discussing the effects of being away from home. During the interviews, the viewpoints of different family members were discussed. Not just those who were away from home, but those family members who had to stay at home also vocalized how they perceived their experience. This theme accounted for the implications of travelling to get care such as experiencing poor weather and driving conditions, dealing with the distance, learning to adapt to the city, and living in the city. Four categories contributed to this theme, 'travelling to get care,' 'dealing with the distance,' 'urban health care,' and 'escaping the situation.'

Rural families with a child with cancer spent a substantial amount of time driving back and forth between their home and the tertiary care facility. As was previously stated, the ten families involved in this study drove a distance equal to three and a half times around the world, just for cancer treatment and follow up for their child. Rural driving is fraught with adversities, especially in a province such as Manitoba where the land is flat, with few trees, and the weather is of extremes, with winters being very cold, with large snow falls and heavy winds. On days when the child with cancer needed treatment or follow up, families stated that once they finally got into the city they felt as though their day was half over. In actuality, it had just begun.

The common oncology treatment modalities try to kill the cancerous cells, while at

the same time, they destroy healthy cells. This demands careful monitoring of the child's blood work in order to determine their degree of immunocompromise. In some cases, family members would drive into the city for cancer treatment, only to discover that the child's blood values were not high enough for treatment. Blood work was commonly done in the rural area and sometimes discrepancies occurred between blood values in the city and those done in the rural areas. There are two possible explanations for this, one could be explained by different procedures and equipment in the various labs or having the blood tests done in the rural area the day before the treatment. These discrepancies resulted in wasted trips for the families.

Travelling for care was one of the largest stresses for rural families with a child with cancer mentioned in the interviews. One mother felt that she could not handle both the stress of having a child with cancer and driving in the city:

M) I realized right at the very beginning I was very stressed and I just couldn't handle the traffic. Well, making decisions, where am I going to park or what lane am I going into? I just didn't want to - it was too much (Interview 009, p.9, 358-362).

Another family stressed the challenges of rural winter driving:

F) I remember the worst part was a lot of time, you know we'd drive, we'd leave here at five in the morning and get there for eight, we'd spend all day in the hospital and the clinic and then we'd leave about five, about five the suns starting to come down in the winter time. Then you are basically driving at night into snow and trying

to get back here, and it uh, you know there is a lot of snow. And you leave the city and its ok but then all of a sudden you hit P and there's no trees and all of a sudden it starts snowing and then it get blizzarding and then it gets worse (005, p.22, 917-925).

Dealing with the distance between the families' homes and the cancer treatment centre was difficult and often times equated into more responsibilities for the family in the care of their child. As well, because of the distance, families often times were not together, or they had to go to extreme lengths to try and be together. This one family tried to be together throughout some of their child's cancer treatment, however, it was a two and a half drive to the city from their home:

M) But it is, it's hard. Like this week we are going to drive in Monday, drive home Monday night because Dad has the day off and he wants to come with us and drive in Tuesday, stay somewhere Tuesday night come home Wednesday to have Thursday off, drive back out Friday and come home Friday night (Interview 005, p.21, 872-877).

The distance introduced additional complexities with respect trying to maintain a routine and a household during this stressful time. During long inpatient periods for treatment, families had to find family or friends to help care for other siblings, take care of pets and their home, and even do simple tasks such as pick up the mail. For a family dealing with the stress of having an ill child, the organization of these responsibilities was often times viewed as an additional burden. Some families had no supports to call on for

extra help to assist them, like this family:

- F) Well for a couple of weeks we both stayed [at the hospital], and then we started taking turns and she stayed there most of the time.
- M) I only left for one night but then I got sick.
- F) And after a few weeks like in there and once he was stabilized and O.K. then I had to drive back here because we just left the house that day.
- M) And we ran out of clothes
- F) Our clothes and our cat
- M) It was winter
- F) Our water pipes froze up here. So we would come in about once a week to shovel the drive way, to get pillows, to make sure everything was, like our water pipes didn't burst or something
(Interview 005, p.9, 348-360).

It is evident that life continued on while the family was going through this stressful time.

While away from home, the families spent a significant amount of time interacting with health care professionals at the children's hospital and at the provincial cancer treatment centre. The families overall had positive experiences with the urban health care professionals. They felt that the health care professionals met the majority of their needs. The rural families, at times, felt overwhelmed by the number of health care professionals involved in the care of their child, but they felt that the care they received was well coordinated and had a personal touch. However, two rural families thought that the urban

health care professionals did not understand the extra challenges that rural families with a child with cancer face. One family recounts this experience:

M) Dr. X told us that she's being admitted so and so forth so we packed up everything, cleaned the house, got somebody to move in for when we left, we came all the way up here (3 hours), B went up to Ronald MacDonald House to unpack and everything, I brought her in to see the Dr. and B met us there and he said, 'oh, I forgot to tell you, we have to wait for the test results on Thursday, so you don't have to be up here till Friday.' Like that kind of forgetful, I don't think they realize that it's not just as easy for us (Interview 012, p.27, 1108-1117).

The times that a child was admitted into the children's hospital for cancer treatment and management of symptoms were very stressful times for the family, especially for the family members staying with the child, in most cases, the mother. The children's hospital allowed one parent to stay overnight with their hospitalized child. Staying overnight in the hospital with their sick child was comforting for their child, yet at times was exhausting for the parent because of uncomfortable sleeping conditions, frequently being awoken for assessment of the child, and the stress of seeing other ill children. This situation was stressful for the parent because they do not seem to be able to leave and take a rest. Some families spoke of the benefits of escaping the situation in order to take refuge and reflect on everything:

M) Usually I would stay every night with S, but then I would come here for a

couple of hours during the afternoon.

- I) Right, just to get away.
- M) Ya, ya, just sit around and talk to the other parents and see what they've gone through and what I, you know, would have some idea of what to expect (Interview 002, p.10, 406-413).

This mother continued on by stating she would go and have a cigarette or go to Ronald MacDonald House to do laundry, just to take refuge from everything.

Living At A Distance From Our Hope

This theme, 'Living at a distance from our hope' encompassed the emotions and experiences families conveyed to the researcher about living in a rural area with a chronically ill child who was acutely ill at times. This theme captured the events, emotions, insecurities and dilemmas of rural families with a child with cancer while they are in their own homes and communities. This theme consisted of six integral pieces or categories, 'experts and gatekeepers for our children,' 'trust,' 'suspicion,' 'exploring our alternatives,' 'the rural experience,' and 'our home - our sacred place.'

The first category, 'experts and gatekeepers for our children' became evident as rural families had to take on significantly more responsibility than urban families for the care and coordination of their child's treatment. At times, the families thought that this was more than they should be expected to do. For instance, families were drawing blood off of their child's central line then transporting the sample to their local lab for analysis. One mother spoke of the fact that she gave her son chemotherapy in their home because the local nurses were not comfortable doing it:

M) We never once had a nurse come here. One time he was so sick from his Chemo that I, because I do some of his Chemo at home, I was starting to tell you that the nurses won't do some of his chemo out there, they're afraid to do it. Dr. Y was really annoyed. He said there is no reason why they shouldn't. Well, they won't. So I do it at home. I am not even a nurse.

I) Uhmm

M) Once I asked because he was so sick. I phoned to ask and see if I could get a nurse out here to do hydration for me.

I) Right.

M) There's none. They're not allowed to do it in X.

I) So what did you have to do then?

M) I just kept on, I just took care of him myself. (Interview 005, p.14,565-580).

In their own communities some families spoke about how they knew their child's condition and treatment better than the local health care professionals; thus they decided which health care professionals they would allow to care for their child, if any:

F) S was like that cause I brought him for a blood test and they didn't have the slightest clue what they were doing.

I) And how did you feel then?

F) Like I was wasting my time.

I) Uhmm. So you got angry more than worried?

F) Ya, why run around and go there when we can do it ourselves

(Interview 007, p.12, 460-467).

These families thought they had substantial responsibility for their child's care in addition to being parents and providing emotional support and reassurance at this critical time. Given how stressful the diagnosis of cancer is, especially in a child, it seems unreasonable that rural families have to take on additional roles, such as giving chemotherapy.

Trust was a big concern to these families. Rural families with a child with cancer have to build trust with several more people than urban families. They have to start building trust with local health care professionals and the pediatric health care professionals in the city, especially the pediatric oncology team. In most cases, there was already trust with the local professionals, but sometimes the expectations of the family changed because the health care professionals were caring for a child with cancer. There were differing levels of trust expressed by the families in regards to how they perceived their local health care services. All families except for one said if there were any side effects from treatment (i.e. neutropenia, fever, etc.) they would immediately call the pediatric oncology team in the city. The remaining family felt they had enough trust with their local physicians to contact them first.

Unfortunately, for some families, they had little trust with their local health care professionals, thus escalating their feelings of isolation. One family recounted the diagnosis of their child, who, at the time, was very ill. This family drove their acutely ill child into the city under the direction of the local physician.

M) We were told that he should have been air lifted into the city,

that's how sick he was.

I) Right, right

M) and now I find it very hard to trust anyone here in X, because I don't feel that they know, I know they don't know as much because they are not pediatric oncologist out here, so to me I find it very hard to put my trust into any of the doctors here. (Interview 005, p.6, 231-239).

Suspicion, at times, plagued the minds of these families because of unfortunate incidents in the past. In most cases, this dealt with the local health care professionals. The researcher hypothesized this suspicion begins prior to diagnosis and is intensified if the local health care professionals misdiagnose the child, or fail to refer the child to a specialist quickly. This one family had suspicions of the local health care provide because of the inconsistencies in the care between the local and urban settings:

M) No, he was really nice when I brought him in, when I brought him in he was very nice. But I mean when we've taken him in, the first time when we took him in and he had to do the blood work on him and we said oh wait, he didn't clean him, he has a central line.

I) Right

M) That he didn't clean the central line properly. He didn't wash his hands, he walked all the way from his office down to the lab, opened door, had an alcohol swab, dipped it into an alcohol bottle and one wipe on his line and injected his needle.

- I) Right
- F) He didn't wash his hands for 30 seconds
- I) For 30 seconds and
- F) and you take about 4 wipes
- M) and we tried to tell him that stuff how they, how we've been taught and stuff. He said I know what I am doing. I don't need you to tell me how to do it. I do it my way, you do it your way.
- I) So it sounds like there is a lack of trust, somewhat, like for you. You don't trust him?
- M) For me, I ...
- F) We try to keep a close eye on him, (Interview 005, p.7, 272-297).

Some families also expressed how they became suspicious of health care professionals in the city when there were inconsistencies in the care of the child. At times, some families were so upset and concerned at this that they would not leave their child's side. Again, these families were taking on another role - that of 'monitor.' During the interviews, families frequently gave critiques of the care certain health care professionals gave their child and compared it to previous care:

- F) When K was in hospital and he was hooked up to tubes and machines going through it and I remember there were so many objectives that I was really following it really closely. And I noticed the nurses making mistakes and I would say 'what are you doing? Are you sure that you know what you are doing? Are you

sure you know?’

- M) And most of them were very good.
- F) A couple of them would
- M) The good nurses would let you question it and say ‘good for you - you know what is going on.’ The ones that weren’t so good would
- I) Take it personally?
- M) Ya, well they would be like, ‘ you don’t need to ask any questions unless I ask you’ (Interview 005, p.8, 310-326).

It is essential to mention that the issues surrounding trust, mistrust, and inconsistencies in care are not exclusive to rural families. All families experiencing childhood cancer must build trust with the health care professionals caring for their child. Yet, the findings from this study indicate that rural families experience different implications from trust and mistrust with health care professionals due to the distance between their home and the cancer treatment centre.

Throughout their experience, families explored the alternatives they had for the care and treatment of their child. It appeared that they needed a balance between what worked for their family and getting the best treatment for their child. In the majority of cases, this involved having blood tests drawn in their home or local community, having the results faxed to Winnipeg, and then getting the treatment in the city. For some families, they said that some of their child’s treatment could have been done in their local community, but the families were not comfortable with that. Other families, had some minor chemotherapy done in their local area.

Living with a child with cancer in a rural area has its benefits and drawbacks.

Families, including the child with cancer, mentioned one of the benefits of living in a small community was that everyone knows you and understands what you, as a family, are going through:

- B) Everyone in town, I know most of the people. Well, most I guess but not all, and all of them seem to know me for some reason.
- M) Because you were on the front of the Free Press.
- B) But yah, I can't imagine being in the city in a school full of 400 kids.
- I) Uhmm
- B) Well more than that even like a 1000 kids maybe or something.
- I) So do you think you have a better experience because people know you and know what you're going through?
- B) Uhh, I don't know if they know what I'm going through but they (pause) express concerns and help me out with whatever I need you know.
- I) Right
- B) More understanding I guess. Like that would give me a sense of not being comfortable if I was in the city cause I wouldn't know what some kids thought of it. (Interview 004, p. 30, 1120-1238).

Yet, at times, this feeling that 'everyone knows what you are going through' was a disadvantage. This was because there appeared to be this understanding within small communities that everyone in the community needed to provide emotional support to the

family going through the crisis. These families in crisis were, at times, often overwhelmed by local people trying to be kind and give support to them. One family in particular discussed how they became further exhausted as found they had to give support back to the community in order for the community to cope with their crisis.

Living in rural areas also resulted in having fewer resources available to assist the family to cope. Two families described their experiences of seeking local professional psychosocial support in order to help them cope with having a child with cancer. In both cases, the experiences were not effective, thus further heightening the stress these families experienced:

- M) And I thought well, I got to talk to somebody, I'm just busting here, so I thought, okay, I'll phone and she agreed to see me. That was the worst mistake that I made. I went in there, this young gal says to me I'm sorry if I sounded 'curt' on the phone, but I have to be in PM by 1 o'clock. That was her first comment.
- I) O.K. so that sets the mood right there doesn't it?
- M) Yah, I thought, ohhh, O.K. - and she sat, now I know she was trying to look pleasant, now as miserable as I felt I could pick out all these vibes, I don't know how I did. But um, she did, she was trying to look pleasant but to me she had a stupid grin on her face the whole time I'm telling her this. And I'm thinking she doesn't even care. And then she couldn't offer any, like I know she couldn't take any of it away, but there was no words of wisdom, of like I don't know what I was expecting but there was

nothing (Interview 004, p.32, 1304-1321).

The last category related to this theme, was 'our home - our sacred place.'

Families spoke about how wonderful it was to get their child home from the hospital, yet, conversely, how they feared this event. The fear appeared to be related to the fact that while the child was in hospital, they were being monitored by so many 'extra sets of eyes,' whereas at home, the responsibility fell on the shoulders of the family to notice any changes. One family vocalized their feelings when they first brought their son home after being in the hospital for 6 weeks:

I) So when you first brought him home you were happy to have him at home?

F) Ya, I was happy to be back in the house

M) But it's scary (Interview 005, p.19, 803-806).

This theme illustrated the unique stresses and challenges that rural families with a child with cancer faced when living in their own community. The analysis discovered that being a distance from the cancer treatment centre could have both positive and negative experience for these rural families.

Life is Now Different and Life Goes On.....

This fifth theme, 'Life is now different and life goes on...,' related to how the families appeared to have accepted the diagnosis and tried to move their lives forward. Throughout the interviews families spoke of how their lives were changed because of cancer. Yet, they spoke of how they needed to come to terms with the diagnosis because life continues to progress. Six categories were related to this theme: 'normalcy - trying to

maintain status quo,' 'the price of cancer,' 'receiving bad news... sometimes it is part of the journey,' 'school - a connection to normalcy,' 'taking on new roles,' and 'the strains and stresses.'

Families described how they tried to maintain some normalcy in their family life. This appeared to be a coping strategy for some families. Some families tried to continue with the same family routines, discipline and activities as before the diagnosis; they felt it was essential for their survival as a family. Other families felt that nothing was the same because life changed so quickly and so immensely. One family describes how they tried to maintain status quo:

M) I try to keep it the same as it was before. You know the same house rules and you do the same things as we did before (Interview 002, p.20, 837-839).

The diagnosis of cancer places many additional burdens on the family and taxes them in many ways. Throughout the interviews, informants spoke of the sacrifices and suffering they have endured because of cancer. These sacrifices were financial, emotional, and physical. Financial costs were frequently reported by these informants. Due to the increased costs associated with living in a rural area with a child with cancer, many of these families experienced great financial hardships. The increased costs included money for transportation, accommodations, food, parking, and basically, as some families put it, 'we were maintaining two households.' The majority of these families also experienced loss of income as one parent either took a leave or quit their job. One family eloquently described the additional expenses encountered by rural families with a child with cancer:

- F) Well the biggest thing about living out here is the expense of it
- I) Right
- F) That extra expense, it's cost us a lot of money. In the last 12 months...
- I) Now what do you think... how has the extra money been spent? I have my own ideas of how it is spent, but I'd like you to say it for me, like parking and driving?
- F) There's parking and transportation in and out..
- M) Food..
- F) Then the extra food and accommodations and ...
- M) Sometimes like we're set up for two separate households
- (Interview 003, p.9, 384-397).

Some of these families spoke of having to spend their savings in order to survive during these difficult times. One family in particular stood out in the mind of the researcher; their son was recently diagnosed with Non Hodgkin's Lymphoma:

- M) I mean you've got so much to think about. You don't have time to worry about parking and where the money's gonna come from, and
- I) Uhmm
- M) Like I couldn't think of that the first week. I couldn't think of anything. I couldn't remember anything. But now, like I think a lot about like we're behind in all our bills.
- I) Has C provided you with some information about that?

M) I talked to her and I think it was the second week there and we were broke. I didn't have any money. I had enough gas to get there and that was it. So I think they gave me some money.

Gm) \$50 (Interview 010, p.14, 562-580).

It was not only the financial sacrifices that these families had to make that were difficult. Cancer also took a toll on the amount of time the family could spend together. At stressful times like this, the family needed to be together, not separated, which was frequently the case.

An element of the acceptance that 'life is now different' was the fact that receiving bad news and dealing with loss was part of the process. This dealt with receiving personal bad news, such as a relapse. One of the families who was interviewed, had recently discovered that their son had relapsed:

M) It's the same this time. Like B's, people know now. The word is out. It's almost like the same thing over again, only its worse.

I) Now why is it worse?

M) Because when he went in the first time he wasn't well. And we knew something had to be done right away and plus we were taken out of our home environment and put into (pause) a totally different environment but we were around people who were going through the same thing.

I) Right

M) And you didn't have to try and look strong.

- I) Right
- M) Nothing. Now you're out here, he looks fine and we know this is coming up and you have people coming up to you and its ahhhh.
- I) Yah, something you don't want to deal with I bet.
- M) And, and they all say well they don't understand and I'm thinking well ya you don't (Interview 004, p.14, 555-573).

The losses went beyond personal losses, to include the loss of friends with cancer. This was traumatic for the families. For example, a few families discussed the shock and grief they experienced when children known to them, through their personal situations of experiencing childhood cancer, died. One family stated that they felt the first death of a child from the cancer treatment centre was the hardest for them to cope with.

School is an essential part of the everyday routine for children. Thus, when a child with cancer returned to school it was initially welcomed by the family; yet, at the same time feared because the parents, especially the mother, were concerned about the ill child at school. The mothers' minds were plagued by thoughts such as: will they be okay, does anyone have a cold. Children with cancer often miss a lot of school. Families indicated that the rural teachers were very understanding and maintained good lines of communication between the family and the school with the progress of the ill child.

One intervention that helped both the school aged ill child and the sibling cope with the extra dilemmas faced by returning to school was a presentation by the pediatric oncology nurse clinician and one of the teachers from the Children's Hospital. These professionals discussed cancer and some of the changes the child with cancer was

experiencing. Families reported that these presentations helped alleviate some of the anxiety experienced by the child with cancer and his/her siblings, and alleviate some of the fears and myths the other children in the school had about cancer. Unfortunately, in some cases, these professionals were not allowed to give a presentation to all of the students in the school, only to the teachers. This was due to the decision of the principal and teaching staff at the respective schools.

Deeply rooted in the life changes experienced by rural families with a child with cancer were the acquisition of new roles which included taking on new tasks. All rural families interviewed were at some time responsible for different aspects of their child's care, whether it be heparinizing the central line, doing dressing changes, drawing blood, or giving chemotherapy.

F) So, but like I said I couldn't go back to work, I couldn't leave her. Even when we brought him home we were like giving him injections and at first S wasn't comfortable with it. She didn't want to give injections. Even changing the bandage we were worried about getting infections in there, giving needles that she didn't want to do it. Plus he needed medicine and pills and uh..... (Interview 005, 13, 551-558).

In order to take on these new roles, current roles and responsibilities often had to be shifted. For instance, the mother had to leave her job or take a leave of absence so that she could go to all of her child's medical appointments and be present for all of the inpatient periods. Mothers were not the only ones who experienced role shifts, some father expressed that they took leaves from work, used up all of their holidays or went on

disability so they could be with their family. Often times during inpatient stays in the city, one parent accompany with the child. The other parent would be left to care for the remaining children, maintain the household, and go to work. In most cases, the mother would go to the medical appointments, leaving the father at home to run the household. For some fathers this meant doing more around the house and subsequently learning new skills, such as doing laundry, and cooking. As previously mentioned, for some families these role changes were challenging because they had to be parents at this crucial time, and yet they also had to be 'caregivers':

M) I'm in tears any day when he's in pain, when he's sick, that kind of thing. I mean I'm a registered nurse, a midwife. I've done a lot of nursing in the Outback but nothing like seeing my son in pain.

That throws me every time (Interview 009, p.12, 483-487).

The strain and stresses of these families 'new' lives was graphically displayed throughout the discussions of their experiences. The stresses these rural families experienced were diverse in nature. Some of the stresses included lack of support, extra responsibilities and lack of understanding from their jobs, no support from family and friends while they were in the city, and feeling like they were an inconvenience to their local health care professionals. One family discussed the difference they perceived between urban families with a child with cancer, and rural families like themselves. They emphasized that they believed they had additional stresses to face, such as the extra stress of not having any support while they are at Children's Hospital for long periods of time while their daughter was getting treatment:

M) Ya, but there's a lot of families that just come in for the week of chemo and go home and have their child recuperating at home, which we can't do, for the simple fact that it's too far away if something happened. But blood transfusions, platelet transfusions are harder to get; whereas here they could get them the same day, where it takes 24 hours where we're from. So, just things like that, but... and it's probably nicer for them too if they have family here whereas we don't, they have family here. They can come and see you and stuff like that... (Interview 012, p.20, 819-829).

The Wind Beneath Our Wings

The sixth major theme, 'The wind beneath our wings,' referred to the integral facet of support in the experiences of rural families experiencing pediatric cancers. Support was essential for the use of positive coping mechanisms and acceptance of cancer in these families. The support of family, friends, and other families with similar experiences was the sustenance for these families.

'The ties that bind us together' was the first category related to this theme. This category signified the strong bonds and relationships that developed between and amongst other families with a child with cancer. These relationships developed through spending time together at the cancer clinic, Children's Hospital or Ronald MacDonald House. The relationships developed over time and some families maintained close contact by phoning each other frequently and visiting. The families stated that these relationships were essential in helping them to cope. For rural families, these relationships were more difficult

to maintain because of the costs associated with long distance phoning and driving long distances. Some families spoke very highly about the ties and relationships that they formed with other families; they felt as though they were a part of an extended family.

Most of the rural families interviewed received extensive support from family, friends, and their faith. Perhaps what was most remarkable was the support they received from their local communities, in terms of cooking, assistance with farm work, and money. Several communities hosted fundraisers for these families to assist them cope with the additional costs of having a child with cancer. Some of the families felt the main advantage of living in a rural community was the emotional support they received from their local community. They continued by saying the driving was worth it considering the amount of support they received from their community:

M) Ya, they did a lot of fund-raising for us. They had dances and socials. Um they had bowling tournaments, dart tournaments, they had raffles. They sold buttons of A to help with it. They raised probably close to 17, 18 thousand dollars for us, to help us out. So that all went into a fund for A and when we're up in Winnipeg we use that account to get by on everything and then for her drugs and stuff like that so it's been really helpful and they raised it to help with the bills seeing that I couldn't work anymore (Interview 012, p. 5, 177-186).

The next category was called, 'coping - trying to come to terms with cancer.' Each family had adopted different coping approaches to the diagnosis of

cancer. The methods that the families implemented appeared to be a support for them, thus it was included in this theme. Families spoke of how their philosophy on life had changed; for instance, some families reported that they tried to live each day as it comes. One father described the importance for their family of concentrating on the positive and living each day as it comes. This particular family had been told that their son had an approximate 70% chance of survival:

- F) We're assuming that he's in that 70% and if he's not, we'll worry about that later so we're just going to enjoy everyday for what it is
(Interview 009, p.11, 450-453).

Other families had not reached the stage of coming to terms with cancer yet and they felt uncomfortable with cancer.

The final category related to this theme was 'cancer has enhanced our lives.' The researcher did not predict discovering that some of these rural families would be able to see any benefit of their experience with this disease. Some of the families commented that because of the extra stress that cancer has brought to their lives their relationships are stronger, and the family has become closer. One mother expressed a touching explanation of how she felt their lives had somehow been enriched by the experience of having their young son diagnosed with a Wilm's tumour:

- M) Now, when I look out the window and see A so well, jumping up and down on the trampoline, it means so much to me. If cancer had not touched our lives, I probably wouldn't have appreciated seeing him so healthy and so happy as much (Interview 006, p.2,

64-70).

The Entire Mobile Swings - The Whole Family is Affected

This theme was commonplace throughout the interviews with families. It was evident that the diagnosis of pediatric cancer in rural families put tremendous stress on the family unit. It was evident that no one left the experience unscathed.

The price the children pay was the first category in this theme. This category deals with the changes both the child with cancer and the siblings underwent because of cancer. The child with cancer thought he or she had to grow up faster because of this disease. The siblings underwent many changes, in fact, they appeared at times to be the silent victims of cancer. This is because they experienced a gamut of emotions ranging from guilt of somehow causing the cancer to fear. Because these families lived in rural areas these children were often separated from their brother or sister and most often their mother for long periods of time while their sibling was receiving cancer treatment. Many of the siblings said that they wanted to be there for their brother or sister but could not be because of the distance. These children went for weeks at a time without seeing one of their parents and their ill brother or sister. Due to these long periods of separation, the siblings often had to do more around the house and subsequently became more independent. One child remembers his feelings when his brother was in the hospital for a long time and his mother was with his brother:

R) Well I felt kind of lonely because my little...but sometimes I would feel bad.... and then when he got shingles, I was, I was like, I didn't know but I was kind of sad....and then sometimes I felt

mad.....at the start I thought it was my fault and I didn't know if
like I could have made it happen (Interview 003, p.24, 1025-1076).

The next category was 'father's experience - I am there when I can be.' Fathers appeared to have had unique, yet turbulent experiences because most of the time they were expected to work, often times missing medical appointments and portions of inpatient treatment periods. Fathers painted very descriptive pictures of how they had difficulties concentrating at work because they wanted to be with their child and spouse at medical appointments. Some fathers felt as though they really missed out on the experience, such as the development of relationships with other families, and providing support to their child and spouse. Thus, they tried to create their own experience; some father did this by getting more involved with the 'hands on' care of their child at home. Other fathers seemed to become absorbed in their work - it almost appeared to be a coping strategy. In all cases, though, fathers took on different and new roles, such as more responsibility around the house and more child care. The following excerpt is a family discussing the stresses of the father not always being there in the city for medical appointments:

- F) I think, I think ya, I think I would have rather been there more, but
- M) Like I think sometimes you feel guilty
- F) I just can't. Not that you feel guilty, I just feel like I've missed a lot.
- M) Sometimes I feel mad. Like sometimes I feel mad because, miss a day of work and go with him and I'll go to work (Interview 008, p.

27, 1104 -1111).

Mothers had a complex role once their child was diagnosed with cancer. Even though in some families, both the mother and father went to all medical appointments, most of the care for the child fell on the shoulders of the mother. Mothers had their traditional maternal role to maintain, in addition to learning their new role of being a 'caregiver' for their child. This new role often forced mothers to quit or leave their job, learn to drive in the city, and learn some basic medical procedures (i.e. central line care). One mother describes how her life has changed:

M) For me, I quit everything. I quit my ministry, I quit my job, I quit my farm, put everything on hold and I accept the fact that it takes 11 months plus, waiting time... so.. I accept that, but I'm not.. I'm frustrated with the fact that he has to suffer. I don't mind the treatment, I find the suffering that he's going through too hard (Interview 009, 18, 756-762).

The marital relationship was affected because of the diagnosis of the pediatric malignancy. The researcher speculated that this finding is not unique to rural families, but perhaps, intensified because of the extra tolls involved in living in a rural area, such as the distance and the lengths of time some couples are separated due to cancer treatment and follow up. This category, 'changes in marital dynamics' describes some of the changes that informants experienced with respect to the relationships that bond them together. Some families found that their marriage was stronger because they discovered that they could make it through these difficult times together. In one family, the parents separated

for a period of time due to the stress that the diagnosis put on their relationship. This particular family said that the additional stress from their extended family and their unstable relationship before the diagnosis caused them to need the break to reflect on the diagnosis and their relationship. All families said that because of the illness and the large distances that they travelled for cancer care they did not see each other as often. This family depicts how their marriage was put on hold, especially early after the diagnosis of leukemia in their young son:

- M) Sometimes like for you, like I remember in the beginning what was really hard, this is getting really personal. I needed him to hold me or whatever, but like he couldn't.
- F) Ya
- M) He felt like it was taking away from him [the ill child], so you know there is different issues that as a couple you go through and there is different issues just dealing with, individually.
- F) Individually
- I) Like all your energy was focused on your son. So you noticed changes then in your marriage, like in your relationship?
- F) Oh ya
- M) Oh ya
- F) It was put on hold (Interview 005, p. 16, 665-681).

The last category pertaining to the effects on the whole family when a child has cancer was 'cancer, a new member of our family - making it a part of our lives.' Some

families spoke about accepting cancer, and they vocalized it as if cancer was a member of their family. This could be explained by the fact that cancer invades families' lives in such immense ways. Making cancer part of their lives meant different things to different families; for some families it meant accepting cancer, for others it signified a change in priorities. It is essential to mention that not all families felt this way. But for the few families who did, it was very significant because of the way in which they spoke about cancer and the changes it was forcing them to make. Again, this incident may not be unique to only rural families with a child with cancer, but the experience of achieving this sense of acceptance may be more difficult to realize in rural families due to the increased demands many face.

Our Wishes on Falling Stars...Our Wish List

The final major theme identified in the data analysis was 'Our wishes for falling stars...our wish list.' Throughout the interviews family members cited suggestions and 'wishes' they had for enhancing the current delivery of pediatric cancer services in the province of Manitoba. Suggestions were recommended for strengthening pediatric oncology services for rural families at the urban, rural and health policy levels.

Rural families thought that overall urban health care professionals went the 'extra mile' to attempt to coordinate treatment and care for their child. At times though, some families felt that health care professionals in the city did not understand and could not appreciate the additional stresses they, as rural families, face. As well, some families felt that some health care professionals were not aware of the local health care services and thus made inappropriate assumptions about the level of expertise in the rural setting (eg.

physiotherapy services).

Most families were happy with the current cancer services in the city. However, some felt that the outpatient cancer clinic could be more organized to facilitate the needs of rural families (i.e. decrease waiting times, have treatments organized prior). They understood that treatment was based on their child's blood values, but they commented that clinic days were often very long and stressful days. Some families said they would have liked to receive some treatment closer to home, but only if the local health care professionals received more information and training pertaining to pediatric oncology. Other families liked the current organization and liked coming to Winnipeg where "the experts are."

Overall, the hospital experience was a positive experience for most families. Two families thought it would be beneficial if hospital policies could be altered to allow more than one parent stay overnight with the child in hospital; thus necessitating larger rooms. Another hospital policy these families would like to see altered was the current emergency room policy. Rural families reported that after driving several hours into the Children's Hospital emergency room, they did not want to sit and wait in the ER. Waiting in the ER increased the families anxiety as there are many sick children in the ER, thus exposing their immunocompromised child to potential infections. These families felt that it would be beneficial if they could go directly to the pediatric oncology ward and wait to be examined by a physician; thus not being exposed to unwanted infections.

Financial implications were inherent in the suggestions that rural families had for improving the care in the city. Some families stated it would be very beneficial if there

were free parking areas close to the hospital for families who would be admitted for long periods of time for cancer treatment. One family thought that meal cards for rural families would be beneficial during inpatient periods, especially since they stay with their child all the time and can not go home for dinner. Due to the distance between their homes and the city, all rural families have to phone long distance when they have to ask a question of the pediatric oncology team. The costs incurred by some of these families related to calling Winnipeg for information were significant. They thought a toll free phone number would help them cope with the increased costs, as well as help them feel that it is 'okay' to phone and ask questions. One out of province family talked about the importance of developing policy partnerships between the provincial governments so the costs of outpatient drugs would be covered for families from out-of-province.

Rural families spoke of the benefits (i.e. gaining a sense of security) of rural health care professionals having more exposure to the care and treatment of pediatric cancer patients, in particular, working with central lines. Some families felt they would feel more secure knowing that someone nearby could understand what they were experiencing. Sometimes, they found themselves instructing their local health care professionals. Some families who lived close to a Community Cancer Program site felt it would be beneficial if they could receive extra supplies and medications from them. Occasionally, this was a problem for rural families because at the outpatient cancer clinic or at discharge from the Children's Hospital they are given the exact number of pills that their child needs. Unfortunately, sometimes their child vomits and thus they are short of medication. This often necessitates getting another prescription and having to pay for it independently.

At the policy level, rural families thought there should be more provisions for families in their situation. Some families felt that leaves of absence from their occupations were not long enough to “get life organized.” Others experienced financial hardship because there are delays in receiving unemployment insurance. Travel allowances supplied by the government were another suggestion put forth by the rural families. Rural families have several needs that are not being met by the current delivery of services. It is evident that our current health care, social and financial aid programs need to shift in order to encompass the diverse challenges and special circumstances these rural families with a child with cancer face.

The Family Assessment Device

The Family Assessment Device was given to all informants at the end of the interview. The device was not given to children approximately under the age of twelve because of the difficulties inherent with reading and comprehension. As was previously stated, the purpose of the device was to determine the general level of functioning of the families involved in the study. Only one subscale, the general functioning subscale was used. It is a 12 item subscale which assesses the overall health/pathology of the family. The informants read the short statements and check off one of four possible responses (strongly agree, agree, disagree, strongly disagree). The scores assigned to the responses range from one to four with one reflecting healthy functioning and four indicative of unhealthy functioning (Epstein, Baldwin & Bishop, 1983). A mean cut off score greater than two indicates that a greater number of unhealthy items were endorsed (Miller et al, 1985).

A total of 21 FADs were completed. The data was entered into the SPSS/PC+ computer software package and the data was analyzed. The mean total scores ranged from 1.33 to 2.33 with a mean of 1.81 and a median of 1.92. There were three mean total scores greater than the cut off point of two (2.08, 2.08, 2.33). The range of mean total scores indicate that a strength of this study was that a range of perceptions of family health from the informants was apparent. The researcher interpreted the results from the FAD to indicate that the family members that participated perceived their respective families to be healthy.

When looking at each of the statements separately, there were only two statements where no unhealthy choices were checked, 'in times of crisis we can turn to each other for support' and 'we are able to make decisions about how to solve problems.' All of the statements, except for three, only had one informant indicate an unhealthy response. The following statements had more than one informant indicating unhealthy responses 'we can express feelings to each other' (2 informants disagreed), 'planning family activities is difficult because we misunderstand each other' (3 informants agreed), and 'making decisions is a problem for our family' (3 informants agreed).

Summary

In this chapter the researcher presented the experiences of rural families with a child with cancer. The eight major themes and respective categories uncovered by the researcher were presented and elaborated on with examples from the raw data. Extra attention was taken to describe the situations that are unique for rural families experiencing childhood cancers in the themes, 'Away from home,' 'Living at a distance

from our hope,' 'Life is now different & life goes on....,' 'The wind beneath our wings,'
'The entire mobile swings - the whole family is affected,' and 'Our wishes for falling
stars.' In addition, the results from the demographic form and the FAD were discussed.

Chapter V

DISCUSSION

Introduction

This chapter presents a discussion of the research findings in relation to empirical and theoretical findings in the current literature. As well, methodological issues inherent in the study will be discussed. The final section of the chapter offers recommendations for nursing research, practice, education and health policy.

Methodological Issues

This section discusses the issues surrounding the research design and methodology. Both the strengths and limitations of the study's methodology will be discussed.

An important point that must be considered is that not all of the families involved in the research study experienced the same type of pediatric malignancy. All malignancies are treated differently, thus each family experienced events differently and had different treatment protocols. This is not a limitation of the study, but simply, a point that must be considered when reading the study. For instance, children with leukemia undergo a long maintenance phase in their treatment, thus requiring frequent visits to the cancer treatment centre. Families not experiencing pediatric leukemia may not have to make as many visits into the tertiary cancer centre.

Some of the strengths of this study's methodology included the good response rate to participating; rich, description data; and the achievement of theoretical saturation. As previously stated, 11 families were approached by the researcher to participate in the

study; ten families participated. The families who participated in the study provided very rich descriptions of their experiences living in a rural area and travelling long distances to get cancer treatment. Vivid examples of their experiences and perceptions were given by the families. Theoretical saturation was achieved by the researcher after completing eight family interviews. Two additional interviews were conducted; they further strengthened and emphasized the findings.

The limited amount of time set aside for data collection, a small purposive, relatively homogenous sample, and interviewing the family together are limitations of this study. The potential effects of these limitations on the findings of this study are examined. The data consisted of information gained from limited participant observation, one face-to-face interview, field notes, clarification phone call, and the verification of findings phone calls. Data collection took place over the span of six months and occurred primarily in the homes of the families' interviewed. It was a distinct advantage to the findings of the study that the researcher drove to eight of the ten families' homes. Although the data were collected over such a substantial period of time (six months), only one face-to-face interview occurred. Due to this methodology limitation, perhaps incomplete 'pictures' of the rural families' experiences were illuminated. The researcher deems further research on this unique population is required in order to fully grasp their experiences.

The second methodological issue concerns the small purposive sample which generated the data for this study. Due to the fact that only two-parent families participated in the study the applicability or relevance of the study findings are somewhat

restricted. The majority of the families who participated in this study were of similar cultural backgrounds; all of the families were Caucasian. The lack of cultural diversity is also a limitation. In addition, the applicability of the findings of the study are somewhat limited as the majority of the families who participated had a male child with cancer; only two families with a female child with cancer participated. Thus, in future studies the researcher recommends that one-parent rural families and families from diverse cultures be obtained in order to acquire information about their unique experiences.

The final limitation was the fact that the entire family was interviewed together. Interviewing the family together and then interviewing each family member individually would have been most useful. This is because perhaps family members did not want to bring up sensitive issues in front of the other members. At the end of the interview though, time was set aside for family members to speak to the researcher individually; on two occasions this happened.

Generalizability, although frequently associated with quantitative methodologies, has been utilized within the realms of qualitative research methodologies to describe the applicability or relevance of research findings (Johnson, 1997). Johnson (1997) cites Morse (1992) as arguing that “the generalizability of a study is facilitated when links are made with the work of others” (p. 201). Morse continues by stating that generalizability is enhanced when “support for one’s findings are located in existing theory” (p.201). Given this interpretation of applicability or generalizability, the findings from this study may be deemed as exemplifying characteristics of generalizability. This is because the findings from this study can be supported in the work of other related research studies.

It is important to mention that due to the diversity of the families interviewed, with respect to different types of malignancies and different stages in the cancer trajectory, it is difficult to identify the 'typical' rural family with a child with cancer. One point was common throughout all families; the distance was a great source of stress and strain for the entire family unit.

In summary, despite some limitations, the study findings provided vivid 'literary pictures' of the experiences of rural families with a child with cancer. The small purposive sample, which was homogenous in some aspects, provided constraints for this study.

Discussion of the Research Findings

In this section, the findings of this research study will be discussed in relation to the current research literature. The research findings that focus on the unique experiences of rural families with a child with cancer will be emphasized.

Digging Up the Pain - The Diagnosis Story

As previously mentioned, the 'diagnosis story' often monopolized the first part of the family interview. Family members described in detail the story of their experiences before diagnosis, during diagnosis, and after diagnosis experiences. Wright (personal communication, March 21, 1998) stated that she believes people tell stories of their illness in order to 'make sense of their suffering.' She also hypothesized that the telling of stories may be part of the healing process.

Frequently, families would say that they knew something was wrong and they had to tirelessly try to be heard in their local communities. Not all families, however, had a prolonged period of time before diagnosis. The current literature widely supports that the

time before diagnosis is a stressful time, full of uncertainty, for families with a child with a chronic or life-threatening illness (Clarke-Steffen, 1993; Cohen, 1993, 1995; Knafl, Ayres, Gallo, Zoeller, & Breitmayer, 1995; Moore, Kramer & Perin, 1986). Knafl et al. (1995) in their qualitative study examined the events in families' lives preceding the diagnosis of a serious illness in their child. They discovered that the time before diagnosis was a very stressful time for parents. They identified that parents took one of five major pathways to securing a diagnosis: direct, delay, detour, quest, or ordeal. The progression from the direct pathway of diagnosis to the ordeal pathway involved a great increase in time spent 'trying to be heard' by health care professionals. Their findings support the results from this study which discovered that some rural families tried endlessly to be heard by health care professionals, thus prolonging the length of time before diagnosis, and subsequently increasing the stress and strain for these families. Clarke-Steffen (1993) reinforces these findings with the results from her qualitative, longitudinal study of families with a child with cancer. She discovered that the uncertainty at diagnosis, or as she calls it, 'the waiting and not knowing,' was the worst part of their child's cancer.

Cohen (1993) suggests that the uncertainty pervades beyond the time before diagnosis to encompass the entire illness trajectory: "to live with a child who has a life-threatening, chronic illness is to live with sustained uncertainty" (p.84). Moore et al. (1986) concur with the current findings from this study, by suggesting that diagnosis is an extremely overwhelming time for the family. They suggest that diagnosis is not the time to provide families with a lot of information as they are not able to retain it; this study reinforced this as several families reported that they could not remember or comprehend

anything that was said at diagnosis.

The researcher believes that the information from this theme is not unique to rural families with a child with cancer. The literature supports that all families in this situation experience similar emotions. Yet, the results from this study indicated that rural families perceive they have more challenges and unique stressors compared to urban families with a child with cancer. As well, this study found that rural families may experience added stress due to the great distance from the specialists' care.

Treatment - Trying to Destroy The Enemy

Again, this theme is not unique to the experiences of rural families with a child with cancer. Yet, family descriptions of the treatment of their child's cancer indicated that it was a significant part of their experience. The implications of having to travel for treatment and cancer care will be discussed later on.

Away From Home

This theme captured the unique events that rural families experienced while away from their home for treatment or follow up for their child's cancer. Families expressed that times away from home were stressful and difficult. Some of the issues that were significant in relation to this theme included the travelling to get cancer care, dealing or coping with the distance, learning the urban 'system,' and trying to escape or take a break from the situation. Recently, the researcher discovered a new service offered at Children's Hospital. Free of charge massages to parents of children admitted to the hospital are being provided by Massage Therapy students. This service may prove to be helpful to some parents in decreasing their level of stress; this is provided that the availability of this

service is advertised to parents. It is not known whether this service is unique to this provincial children's hospital or is found in other Canadian children's hospitals.

The issues and challenges related to cancer care in rural areas have been discussed by Curtiss (1993). She believes that the psychosocial impact on the patients and families being treated away from their homes is profound. She continues by stating:

The losses imposed by a cancer diagnosis are profound. People often report feeling isolated, abandoned, and distanced from friends and families. Isolation for treatment at far away centres further compounds coping with cancer and therapy. Visits from family and friends may be infrequent because of geographic distance and the time it takes to travel. Difficult decisions may need to be made alone, without the support of family members, the touch of a loved one, or the sharing of tears with a friend (p.244).

The results from this research study are congruent with the ideas brought forth by Curtiss. Rural families with a child with cancer face extra stresses and dilemmas that urban families do not face, simply because of the closer proximity they have to the cancer centre.

Horner et al., (1994) agrees with the findings of this study through the discovery that rural people experienced extreme discomfort when they had to drive in the city because of traffic congestions and not being familiar with the area. Some of the families in this study felt that just getting to the cancer centres was half of the effort or strain involved. A few families experienced stress when city driving, thus they brought friends and family members with them to decrease their anxiety. City driving, finding the cancer

centre, and discovering 'where to park' were especially stressful events for some families. This could possibly be explained by the fact that these families were experiencing great stress as they were trying to deal with 'cancer' and they did not need any further stress. Coping with cancer in a child is enough stress, let alone the added stress of trying to understand and orient oneself to a new environment and culture.

Aitken and Hathaway (1993) discovered that parents who live a distance from the urban based cancer treatment centre believe they had to travel too far for their child's cancer care. The parents in their study also felt that poor weather could affect their child's treatment course. The rural families from the current study expressed a great amount of concern that poor weather and driving conditions could, and often times already had, affected their child's treatment regime. In the present study, not all rural families believed that they had to travel too far for treatment. Some of the rural families who lived close to the city felt that they had to travel just a little bit longer than urban families and they did not mind the extra distance as they felt they received more community support than urban families. Families who lived further away, though, felt that they had to travel great distances and they stated they would welcome pediatric oncology services closer to their home.

Living At a Distance From Our Hope

As previously indicated, this theme described the experiences of rural families with a child with cancer while they are at home in their local communities. The literature review demonstrated that there is not an abundant amount of research that explores the challenges faced by rural families with a child with a chronic, life-threatening illness. In

this study, a serendipitous finding was that the rural families perceived themselves to be the local experts and gatekeepers for their children. There is not a related or relevant body of existing research to support this newly discovered claim. Thus, future research is needed to explore the extent of this additional role of rural families with a child with cancer.

Trust with the local health care professionals was a concern for rural families experiencing childhood cancer. Moore et al. (1986) critically examined the diagnosis and early treatment phases for families with a child with cancer. They discovered through their literature search, Barbarin et al.'s (1985) study which noted that families experienced stress and worry when dealing with the local doctor and community hospital. These feelings were illustrated by parents questioning the abilities and competence of local hospitals and physicians. Rural families from this study cited similar examples of 'watching him closely' or feeling like their time was being wasted in their local hospital because, in their view, the rural health care professionals were unaware and unfamiliar with the care of children with cancer. As well, Hayes and Knox (1983) discovered that parental stress is affected by the amount of trust they have in the health care providers. They also found that parents became concerned about the continuity of care for the ill child when the care is delivered outside of the tertiary centre. The vivid descriptions of the 'rural experience' in rural families with a child with cancer from this study included examples of lack of knowledgeable resources, lack of counselling services, and lack of communication between urban and rural health care providers. Adams' (1992), Buehler and Lee's (1992) and Mercer and Ritchie's (1997) study findings are congruent with these

findings. Adams discovered in his national survey that all families experiencing childhood cancer sensed a lack of counselling outlets for them to discuss their experiences, needs, and fears. Buehler et al. found that the formal health care resources for rural families caring for a loved one with cancer are seriously lacking. The inadequate formal resources included respite services, child care, home health and physician care. They concluded that the entire experience of caring for a rural family member with cancer was fraught with caregiver burden and distress. Results from Mercer and Ritchie's study (1997) indicated that young rural families experiencing childhood cancer had greater financial and emotional support needs than urban based families. Their findings indicated that families had the most needs in the category of interpersonal interaction, specifically the need for further communication between parents and health care providers and parents and the child.

Life is Now Different and Life Goes On...

Rural families, over time, tried to accept cancer, admit life was different, and then move forward. All families shared that their lives were transformed because of cancer. Frank (1991) who wrote about his personal accounts of living with cancer, felt that no aspect of life was left untouched by his illness. Furthermore, he reflected that life did not revert back to normal after treatment ended. Thus, life is permanently changed and then the 'changed life' becomes a new normal.

The experiences rural informants highlighted to the researcher stressed that at first most families tried desperately to maintain normalcy, then they came to accept cancer and that life changes. However, other families continued to cling to achieving normalcy.

Findings from the research support a quest for normalcy (Robinson, 1993). Martinson and Cohen (1989) looked at the family reaction to childhood cancer and discovered that parents had a need to normalize family life and restore prediagnosis routines. Included in their interpretation of normalcy was maintaining regular discipline and trying to promote normal development for the child with cancer. The findings from this study were similar, as some families tried tirelessly to maintain status quo. It is interesting that Martinson and Cohen reported that normalizing was easier if families adopted a 'one-day-at-a-time' philosophy; many study families reported using this philosophy in their daily lives. Through this examination of the study findings with the research literature, a testable hypothesis became evident. This hypothesis is that those families who strive for pre-diagnosis normalcy experience increased stress and strain as compared to families who accept life has changed. Further research studies are needed to explore and challenge this hypothesis.

The process that some rural families experienced, that of trying to maintain normalcy, then shifting routines and goals, and the final acceptance of cancer and realization that life continues on parallels the work of McCubbin & McCubbin (1994). They developed the Resiliency Model of Family Stress, Adjustment and Adaptation. The premise of this model is that illness is a stressor that affects family life. At first, families struggle to make adjustments, then after sometime the family adapts to accepting the illness. The important point to stress is when families adapt they accept the illness as part of their lives.

Congruencies can also be found between the findings of this study and a different

model, the McCubbin and Patterson's Family Adaptation Model. Their model stresses the two phases that a family experiences in a stressful situation, first adjustment then adaptation (as cited in Gallo, 1991).

The rural informants in this study cited that they experienced many strains and stressors in their lives because of the burdensome situation they are in. The stresses associated with having a child with cancer are cited throughout the literature, yet the 'special' or unique stresses associated with travelling for pediatric cancer care have only been cited in one study by Aitken and Hathaway (1993). It is important to acknowledge that these rural families have many strains and stressors in their lives, but it is essential to point out that the needs, and therefore the stressors, of these families change over time (Heath, 1996a; Heath 1996b).

The costs of cancer were frequently recited during the interviews with the rural informants. The financial costs associated with having a child with a malignancy living in a rural area were emphasized and commonly prefaced with a statement indicating finances were often the mostly heavily affected aspect of rural families' lives. Bloom et al., (1985) and Lansky et al., (1983) have both explored the costs of caring for a child with cancer. Both studies, although non Canadian, indicated that families spent a significant portion of their budget on out-of-pocket expenses such as food, accommodations, and gas. Bloom et al., (1985) discovered that for those families in the "lowest income quartile, out-of-pocket costs were 47.9% of mean family income, while for families in the highest income quartile it was 31.8%. Wage loss, as a percent of total out-of-pocket costs, was greatest for those in the highest income quartile at 59.4% and ranged down to 26.4% for those in

the lowest income quartile” (p.2395). As indicated by Aitken and Hathaway (1993) in reviewing Chapter 2, families who lived great distances from the treatment centre tended to be young, less educated, and have lower incomes than families who lived closer to the treatment centre. Thus, the findings from Bloom’s study are significant. Lanksy et al. (1983) earlier reported that nonmedical expenses constituted 26% of the families budget. It is important to note that there were no differentiations reported between the costs for urban and rural families; thus one must keep in mind the financial costs to rural families would be higher because of the distances they are travelling.

The last category from this theme to be discussed is ‘receiving bad news...sometimes it is part of the journey.’ This category signifies the struggle that rural families experienced when ‘bad things happened.’ For instance, after periods of adjustment, most families came to accept cancer; for some families the adjustment did not end there. In some cases, cancer entered into the lives of other people that they knew or their child’s condition would worsen, thus, demanding further realignment and adjustment in their lives. For example, as previously mentioned, one family was recently experiencing a relapse in their child’s brain tumour. This was an exceptionally stressful time for the family. As the family expressed, relapse was worse than being diagnosed. Hinds, Birenbaum, Clarke-Steffen, Quargnenti, Kreissman, Kazak, Meyer, Mulhern, Pratt & Wilimas (1996) explored the responses of parents to the first recurrence of cancer in their child. They discovered the overriding construct for parents experiencing relapse was ‘coming to terms.’ Hinds et al. (1996) discovered that the families had to overcome the shock and basically accept the recurrence in order to move forward and discuss treatment.

There appears to be some similarities in acceptance of recurrence and acceptance of the initial diagnosis. The researcher does not predict that family response to recurrence is greatly different in rural families as compared to urban families. The differences could be perhaps explained by the rural families' experiences are compounded because of the distance and the implications inherent in recurrence (i.e. further treatment).

The Wind Beneath Our Wings

Rural families stressed that the support they received was important in their ability to cope with the illness. The researcher came to believe that coping with childhood cancer for rural families was as much an emotional battle as a physical one. The title of this theme is trying to signify how the support these rural families received from many different people 'carried' them over or through the difficult times. Those rural families who had limited support perceived their experiences to be more negative. Again, this experience of support is not distinct for rural families as compared to urban families. The essential point is that support is especially important in rural families experiencing childhood cancer because of the distance between their homes and the cancer treatment centre which subsequently leads to increased strain and stress for these families.

Families in this study cited several examples of the overwhelming support they received from their family, friends, other families in similar situations, their church, and local community. Rural people believing that they have exceptional social support is not a new concept; for instance, studies by Austin, Iverson, Muhlenkamp and Weinert (as cited in Weinert & Long, 1987) confirm that rural dwellers perceive they have greater social support than urban people. This feeling of social support provides a sense of security and

belonging. As well, Aitken and Hathaway (1993) discovered that parents of children with cancer who lived more than 100 miles away from the cancer treatment centre used the support of friends more frequently than families who lived closer.

An unexpected finding in this current study was that some families felt that cancer enhanced their lives in some way. This positive perspective of cancer takes time for the family to realize and appears to help the family cope with or come to terms with cancer. Some rural families felt that their families were closer, others felt that they appreciated life in a different way. These findings are reinforced in the literature. For instance, Barbarin et al., (1985) and Koch (1985) reported families (regardless of urban or rural) became closer as a result of pediatric cancer affecting their lives.

The Entire Mobile Swings - The Whole Family is Affected

The picture painted by rural families with a child with cancer highlighted that each family member was affected in distinctive ways by the diagnosis of this illness. No family member was left untouched and each family member adapted to the changes in their own unique way. There is a significant amount of literature which parallels this finding, stating that the entire family is affected when a child in the family is diagnosed with cancer or any serious illness (Barbarin et al, 1985; Birenbaum, 1990; Chesler et al., 1992; Fife, 1980; Heath, 1996a; Heath, 1996b; Magni et al., 1986; Magni et al., 1988; Martinson et al., 1990; Sterken, 1996). The stress on the family unit is complex and multifaceted. This is due in part to the static, yet, dynamic nature of families. This theme integrated the use of a metaphor of a mobile in its description because the action of touching one piece of a mobile causes all pieces to be effected. This is parallel to how cancer affects one family

member, yet touches the entire family. The use of the metaphor of a mobile to describe the families' experiences with life-threatening illnesses has been used previously (Allmond, Buckman & Gofman, 1979).

Children are greatly affected by childhood cancer, both the child with cancer and his or her siblings. Findings indicate that cancer often caused children to become more independent as siblings were separated from one parent and their sibling for long periods of time and they had to help out around the house more. For both the child with cancer and his or her siblings, it is perceived that the experience of cancer itself causes children to 'grow up faster.' Siblings in this study reported a diversity of emotions including missing their ill sibling, feeling sad and sorry for their brother or sister, and at times feeling jealous of the attention their sibling received. Research studies by Chesler et al., (1991) and Martinson et al. (1990) support this findings.

Rural fathers with a child with cancer had unique experiences. Most rural fathers expressed that they felt their experiences were different because they were unable to attend most of the medical appointments and inpatient treatments because often times they had to stay at home to work, and take care of the other children and responsibilities. For some fathers, this exclusion from the cancer experience at its most stressful times was not desired and caused them great stress. One father reported that while his common-law wife and daughter were in the city for chemotherapy, he was out in the bush working. He said the stress was so great that he ended up hurting his back. Other fathers tried to 'claim' their own experience in some other ways, for instance taking responsibility for the central line. There is little research related to exploring the paternal experiences of dealing with

pediatric cancers. Sterken (1996) studied the uncertainty and coping measures used by this population. He discovered that “the age of the father, age of the child, and the length of time since diagnosis showed direct correlation to paternal uncertainty and coping” (p.81). As stated, there is little research in this area; thus more research is required to more thoroughly understand the unique experiences of fathers, especially rural fathers, with a child with cancer.

Results from this study indicated that the mothers’ roles changed because of the additional roles they had to assume. Due to the additional roles they acquire, rural mothers may have more unmet needs. Whiteley (1996) discovered similar findings in her research of the care needs of mothers of children with cancer. Her results indicated that mothers living from 101 to 240 km from the urban treatment centre had significantly higher needs-met scores than mothers living further than 240 km from the city. In her research concerning families’ responses to chronic illness, Robinson (1994) reported that the mother has an important role in buffering or shielding the family from the impact of illness. The practice of protecting the family may result in the mother feeling alone and overwhelmed.

The marriage was also not left untouched throughout these experiences. Some families reported that they perceived their marriage was now stronger because of cancer, whereas other families felt that the diagnosis of cancer had a negative affect on their marriage. Congruent findings have been found in the literature (Barbarin et al, 1985; Fife, 1980).

Our wishes on falling stars...our wish list

This theme documented the wishes or ‘perceived needs and wants’ of rural families

with a child with cancer. Their wish lists included a variety of wishes ranging from financial wishes to wishes for changes in current policy. Adams (1992) conducted a needs assessment of Canadian parents of children with cancer. The needs identified are similar to many of the findings of this study. Although, he did not ask for the parents' wishes, he asked parents to identify their concerns. This information in turn, can be interpreted to understand their wishes and needs. Adams' reported that parents' concerns were in the areas of staffing, need for information, lack of support groups, lack of services in local communities, and the lack of counselling services. The two concerns from Adams' study which were apparent as findings in this study were the lack of services in the rural areas and lack of counselling services. Results from Adams' questionnaire also indicated that policy changes (i.e. tax deductions) would be welcomed by these families. It is essential to state that Adams' study looked at Canadian parents with a child with cancer and that the response rate was very poor, 7.2%, with only 1% of the respondents coming from Manitoba.

As previously mentioned in Chapter 4, some rural families thought a toll free number to members of the pediatric oncology team would help them to cope. Although there currently is not a toll free number to children's hospital, a new service is being provided by the local telephone system. Out of town parents of children who are admitted to children's hospital may receive phone cards. These cards allow families to make free long distance phone calls to family members and friends at home. This new service should assist families with the additional costs of long distance phoning and assist them in receiving support from their family and friends.

Aitken and Hathaway (1993) studied the differences in the stress and coping behaviours of parents living relatively close to the treatment centre and parents who lived a greater distance away. They suggested a toll free line to the treatment centre in their discussion of findings because of the fact that parents who lived a great distance from the treatment centre had more unmet information needs than parents who lived closer to the treatment centre. Aitken and Hathaway's suggestions were mirrored in this study.

Some of the families in this study 'wished' that some of the treatment could be closer to home. Close, Burkey, Kazak, Danz & Lange (1995) compared the medical costs, out-of-pocket expenses and quality of life for children with cancer between those who received chemotherapy in the hospital and those who received it at their home. They reported that selected chemotherapy at home resulted in decreased costs, better appetites in patients, more activity in the children with cancer, and more independence in the patients. They also realized that family life was able to proceed more normally with chemotherapy treatment at home and parents could spend more time together and with the rest of the family. These results indicate that other families share the 'wish' of the families from this study, and that this option can work and produces several benefits, including financial and emotional gains. Not all families in this study would like to have treatment closer to their home; these families felt secure in receiving all of the treatment and care for their child's cancer in the city.

In summary, the findings from this study were discussed and examined in conjunction with relevant current literature. Findings from this study paralleled findings from several other research studies. The congruency in results from this study with

findings from the current literature adds strength to this study.

Recommendations

Based on the findings presented from this research study, the following recommendations are offered for nursing research, education, practice and policy.

Recommendations for Research

There are two recommendations addressing nursing research. First, the author recommends that some of the hypotheses identified from this study be tested by means of further qualitative research. For instance, the perceived belief that some rural families with a child with cancer consider themselves experts of their child's care because they carry out more responsibility for their child's care, should be tested by means of further qualitative research studies specifically exploring this issue. Quantitative research methods could also be employed to test the hypotheses generated by this study. Second, due to the vivid pictures and descriptions of the rural families' experiences with childhood cancer, there is a need for research that specifically examines and compares the experiences of urban and rural families with a child with cancer.

Recommendations for Nursing Education

The results from this study have implications for nursing education. The researcher suggests that nursing students at all levels should be educated in regards to the unique experiences and challenges faced by rural families experiencing cancer and any other illness. This is especially important in a province like Manitoba where the majority of the population is urban and the tertiary care centres are located in Winnipeg. Health care professionals may lose sight of the unique needs of rural residents. As well, nursing

education should explicitly focus on how to care for the whole family when one family member is afflicted by a chronic, yet life threatening illness. The additional stress and strain experienced by these families demonstrates a need for increased attention to the mental health responses of family members in these types of situations in nursing education. For instance, this study suggested that nurses could focus more attention on the siblings and fathers of children with cancer from rural areas. In this study, these family members often felt 'left out' of the illness experience due to the long distances between home and the treatment centre leading to feelings of sadness and isolation. When nurses have contact with siblings and father, for example, they could spend time to assess if their needs for information and support are being met.

Recommendations for Nursing Practice

The findings from this research study are important to health care professionals involved in the care of rural pediatric oncology patients. The researcher strongly recommends that health care professionals take the time to consider the additional stresses and responsibilities that rural families with a child with cancer face. The researcher also suggests that one not lose sight of the special needs of these families, especially during crucial times, such as inpatient periods, patient/family teaching, and discharge planning. For instance, when organizing discharge planning for rural families with a child with cancer consider the local resources and the areas of expertise in the local health care professionals. Not considering the unique circumstances of these rural families could result in not providing high quality care which is sensitive to the challenges these families face.

The researcher plans to make presentations to the relevant health care professionals who care for these families in order to discuss the distinctive cancer experiences that rural families face.

Recommendations for Policy

There are three recommendations for changes in health policy from the findings of this study. First, it is recommended that the Government of Manitoba and the Government of Ontario work together to provide a pediatric oncology discharge drug program for families from Ontario who are treated in Winnipeg. It is not equitable that families from Ontario, who travel great distances for cancer treatment have to pay for their child's own oncology discharge medications when families from Manitoba receive discharge medications free of charge. The researcher acknowledges that health care is under provincial jurisdiction, yet Medicare is a national initiative. Rural families with a child with cancer spend significant amounts of money for travelling, accommodations, and food. They do not need to be burdened with the additional cost of discharge medications. There needs to be equity in our services.

Second, policies need to be developed at the provincial and national levels to further assist rural families with a child with cancer to implement travel allowances and further income tax deductions. These policies need to assist families financially to compensate them for the extra costs they incur.

Third, tertiary hospital policies should be re-examined to investigate if there are any ways to address the needs of rural families with a child with cancer during inpatient periods. Possibilities include realigning hospital policies so that more than one parent can

stay overnight, the development of hospital rooms so that both parents can comfortably stay overnight, and changing the emergency room policy for all pediatric oncology patients.

Family Systems Theory

The family systems theory was used as a conceptual model for this study. Utilization of this conceptual framework was beneficial because of its flexibility in studying families experiencing chronic, yet life-threatening illnesses. The analogy of the mobile previously utilized in describing the family system theory could also be used to explain the transformation in the lives of rural families with a child with cancer. Perhaps the two most important tenets of the family systems theory exemplified in this study were a change in one family member affects all family members and the balance between change and stability within the family. The first tenet was illustrated in the descriptions the rural families provided related to their experiences with childhood cancer. Numerous examples were cited by families describing how everyone was affected, and no one was left untouched by cancer. The second 'came to life' in this study through the creation of the theme 'life is now different and life goes on.' Basically, the families stated that they experienced periods of great change dispersed with periods of stability, yet they tried to move on. These families were adjusting their lives and trying to come to terms with cancer, in other words, accept cancer.

The integration of family systems theory in this study was a benefit. There were no negative effects noticed by the researcher for utilizing this theoretical framework.

Findings from this study illustrated congruencies with the theoretical underpinnings of family systems theory.

Conclusion

The purpose of this study was to describe the experiences and needs of rural families with a child with cancer. A qualitative methodology, ethnography, and the implementation of family systems theory, provided the structure for the design of the study. Data was collected from rural families using semi-structure interviews, participant observation, field notes, and clarification and verification of the findings through phone calls. Analysis of the data collected led to the generation of a literary picture of the unique experiences and needs of rural families with a child with cancer. Eight major themes were analyzed from the data. Not all of the themes identified are unique to rural families. For instance, the theme “the entire mobile swings - the whole family is affected” is not unique to rural families. The rural families’ experiences are intensified or further compounded, as compared to urban families experiencing childhood cancer. This is primarily due to the distance between the cancer treatment centre and the families’ homes.

The eight themes identified related to the diagnosis and treatment of their child’s cancer, the dilemmas of living away from the cancer centre, the effect that cancer has on the whole family, and the families’ wish list for enhancing pediatric oncology services for rural families. This research study provided a unique perspective by providing a Canadian focus on the experiences and needs of rural families with a child with cancer. The results of the study were discussed, as well as, the methodological issues intrinsic to this project and the applicability of family systems theory to the findings. Recommendations for

nursing research, education, practice and policy were offered and examined.

References

- Ackerman, N. (1984). A theory of family systems. New York: Gardner Press Inc.
- Adams, D. (1992). Parents of Children with Cancer Speak Out: Problems, Needs and Sources of Help. Toronto, ON: Candlelighters' Childhood Cancer Foundation of Canada.
- Adams, D. & Deveau, E. (1988). Coping with childhood cancer: Where do we go from here? (revised edition). Hamilton, ON: Kinbridge Publications.
- Aitken, T., & Hathaway, G. (1993). Long distance related stressors and coping behaviours in parents of children with cancer. Journal of Pediatric Oncology, 10(1), 3-12.
- Allmond, B. W., Buckman, W., & Gofman, H. F., (1979). The family is the patient. St. Louis: C.V. Mosby.
- Austin, J. (1991). Family adaptation to a child's chronic illness. In J. Fitzpatrick, R. Taunton, & A. Jacox, (Eds.), Annual Review of Nursing Research, 9, 103-120.
- Bain, L. (1995). A parent's guide to childhood cancer - The Children's Hospital of Philadelphia series. New York, NY: Dell Trade Paperback.
- Bala, N. (1995). The evolving definition of the family. Policy Options, 10(6), 3-6.
- Barbarin, O., & Chesler, M. The medical context of parental coping with childhood cancer. American Journal of Community Psychology, 14, 221-234.
- Barbarin, O., Hughes, D. & Chesler, M. (1985). Stress, coping, and marital functioning among parents of children with cancer. Journal of Marriage and the Family, 47, 473-480.
- Bavington, H. (1994). Rural public health. Canadian Journal of Public Health,

85(5), 295-299.

Binger, C., Ablin, A., Feuerstein, R., Kushner, J., Zoger, S., & Mikkelsen, C. (1969). Childhood leukemia: Emotional impact on patient and the family. The New England Journal of Medicine, 280(8), 414-418.

Birenbaum, L. (1990). Family coping with childhood cancer. The Hospice Journal 6(3), 17-41.

Bloom, B., Knorr, R., & Evans, A. (1985). The epidemiology of disease expenses. Journal of the American Medical Association, 253(16), 2393-2397.

Boyle, J. (1994). Style of ethnography. In J. Morse, (Ed.), Critical Issues in Qualitative Research Methods. Thousand Oaks, CA: Sage Publications, pp.159-185.

Broderick, C. (1993). Understanding Family Process: Basics of Family Systems Theory. Newbury Park, CA: Sage.

Buehler, J., & Lee, H. (1992). Exploration of home care resources for rural families with cancer. Cancer Nursing, 15(4), 299-308.

Bunston, T. & Mings, D. (1995). Identifying the psychosocial needs of individuals with cancer. Canadian Journal of Nursing Research, 27(2), 59-79.

Burnard, P. (1991). A method of analysing interview transcripts in qualitative research. Nurse Education Today, 11, 461-466.

Burns, N., & Grove, S. (1993). The practice of nursing research: Conduct, critique, and utilization (2nd ed.). Philadelphia, PA: W. B. Saunders Company.

Callery, P. (1997). Paying to participate: Financial, social and personal costs to parents of involvement in their children's care in hospital. Journal of Advanced Nursing,

25, 746-752.

Canadian Council of Cancer Registries (1993). The Making of the Canadian Cancer Registry. Ottawa, ON: Minister of Supply and Services Canada.

Cardwell, J. (1971). Social Psychology: A symbolic interaction perspective. Northbrook, IL: AHM Publishing Corp.

Cayse, L. (1994). Fathers of children with cancer: A descriptive study of their stressors and coping strategies. Journal of Pediatric Oncology Nursing, 11(3), 102-108.

Chalmers, K. (1990). Preventative Work With Families in the Community: A Qualitative Study of Health Visiting Practice. Unpublished doctoral dissertation.

Chesler, M., Allswede, J., & Barbarin, O. (1992). Voices from the margin of the family: Siblings of children with cancer. Journal of Psychosocial Oncology, 9(4), 19-39.

Clarke-Steffen, L. (1993). Waiting and not knowing: The diagnosis of cancer in a child. Journal of Pediatric Oncology, 10(4), 146-153.

Close, P., Burkey, E., Kazak, A., Danz, P., & Lange, B. (1995). A prospective, controlled evaluation of home chemotherapy for children with cancer. Pediatrics, 95(6), 896-900.

Cohen, M. (1993). The unknown and the unknowable - managing sustained uncertainty. Western Journal of Nursing Research, 15(1), 77-96.

Cohen, M. (1995). The stages of the prediagnostic period in chronic, life-threatening childhood illness: A process analysis. Research in Nursing and Health, 18, 39-48.

Cottone, R. & Greenwall, R. (1992). Beyond linearity and circularity:

Deconstructing social systems theory. Journal of Marital and Family Therapy, 18(2), 167-177.

Creswell, J. (1994). Research design: Qualitative and quantitative approaches. Thousand Oaks, Ca: Sage.

Crom, D. (1995). The experience of South American mothers who have a child being treated for malignancy in the United States. Journal of Pediatric Oncology Nursing, 12(3), 104-112.

Cromwell, R. & Olson, D. (1975) Power in Families. Beverly Hills, CA: Sage.

Curtiss, C. (1993). Trends and issues for cancer care in rural communities. Nursing Clinics of North America, 28(1), 241-251.

Daly, K. (1992). The fit between qualitative research and characteristics of families. In J. Gilgun, K. Daly & G. Handel, (Eds.), Qualitative Methods in Family Research. Newbury Park, CA: Sage, pp 3-11.

Danielson, C., Hamel-Bissell, B., & Winstead-Fry, P. (1994). Families, health & illness: Perspectives on coping and intervention. St. Louis, MI: Mosby.

Davies, B. (1995). Windows on the family. Canadian Nurse, 91(9), 37-41.

Deatrick, J. & Faux, S. (1991). Conducting qualitative studies with children and adolescents. In J. Morse, (Ed.), Qualitative Nursing Research: A Contemporary Dialogue (pp.203-233). Newbury Park, CA: Sage.

Dodd, M., Dibble, S., & Thomas, M. (1992). Outpatient chemotherapy. Public Health Nursing, 9(1), 37-44.

Dunn, L. (1991). Research alert! Qualitative research may be hazardous to your

health! Qualitative Health Research, 1(3), 388-392.

Eliason, M. (1996). Lesbian and gay family issues. Journal of Family Nursing, 2(1), 10-29.

Epstein, N., Bishop, D., & Levin, S. (1978). The McMaster Model of Family Functioning. Journal of Marriage and Family Counselling, 4, 19-31.

Epstein, N., Baldwin, L., & Bishop, D. (1983). The McMaster Family Assessment Device. Journal of Marital and Family Therapy, 9(2), 171-180.

Fawcett, J. (1975). The family as a living open system: An emerging conceptual framework for nursing. International Nursing Review, 22, 113-116.

Feetham, S. (1984). Family research: Issues and directions for nursing. In H. Werley & J.J. Fitzpatrick, (Eds.), Annual Review of Nursing Research (Vol.2, pp.3-25). New York, NY: Springer.

Feetham, S. (1990). Conceptual and methodological issues in research of families. In J. Bell, W. Watson, & L. Wright, (Eds.), The Cutting Edge of Family Nursing (pp. 35-47). Calgary, AB: Family Nursing Unit Publications.

Field, P. & Morse, J. (1985). Nursing Research: The Application of Qualitative Methods. London: Croom Helm.

Fife, B. (1980). Childhood cancer is a family crisis: A review. Journal of Psychiatric Nursing and Mental Health Services, 18(10), 29-34.

Fife, B., Norton, J. & Groom, G. (1987). The family's adaptation to childhood leukemia. Social Science Medicine, 24(2), 159-168.

Foley, G., Fochtman, D., & Mooney, K. (1993). Nursing care of the child with

cancer (2nd ed.). Philadelphia, PA: W. B. Saunders.

Frank, A. (1991). At the will of the body. Boston, MA: Houghton Mifflin Company

Frank-Stromborg, M., Wright, P., Segalla, M. & Dickman, J. (1984).

Psychological impact of the cancer diagnosis. Oncology Nurses Forum, 11(3), 16 - 22.

Friedman, M. (1987). Intervening with families of school-aged children with cancer. In M. Leahey and L. Wright (Eds.). Families and life-threatening illness. Philadelphia, PA: F. A. Davis.

Gallo, A. (1991). Family adaptation in childhood chronic illness: a case report. Journal of Pediatric Health Care, 5, 78-85.

Gibbons, L. & Levy, I. (1994). Summary report of the Canadian childhood cancer control strategy development consensus conference. Chronic Illness in Canada, 15(2), 77-82.

Gillis, C. (1983). The family as a unit of analysis: Strategies for the nurse researcher. Advances in Nursing Science, 5(3), 50-59.

Gillis, C. (1991). The family as a unit of analysis: Strategies for the nurse researcher. In A. Whall & J. Fawcett, (Eds.), Family Theory Development in Nursing: State of the Science and Art. Philadelphia, PA: F. A. Davis Co.

Gregory, D., Russell, C., & Phillips, L. (1997). Beyond textual perfection: Transcribers as vulnerable persons. Qualitative Health Research, 7(2), 294-300.

Gilgun, J. (1992). Definitions methodologies and methods in qualitative family research. In J. Gilgun, K. Daly & G. Handel, (Eds.), Qualitative Methods in Family

Research. Newbury Park, CA: Sage, pp 22-39.

Gottlieb, L. & Feeley, N. (1994). The McGill Model of Nursing and children with a chronic condition: 'who benefits and why?' Canadian Journal of Nursing Research, 28(3), 29-48.

Hammersley, M & Atkinson (1983). Ethnography: Principles in Practice. New York, NY: Tavistock Publications.

Hanson, S. (1987). Family nursing and chronic illness. In L.Wright, & M. Leahey (Eds.), Families and chronic illness. Springhouse, PA: Springhouse.

Hanson, S. & Boyd, S. (1996). Family health nursing: Theory, practice and research. Philadelphia, PA: F. A. Davis Co.

Hayes, V. & Knox, J. (1983). Reducing hospital-related stress in parents of children with cancer. Cancer Nursing, 10, 24-28.

Hazzard, M. (1971). An overview of systems theory. Nursing Clinics of North America, 6(3), 385-393.

Health Canada (1996). This battle which I must fight: Cancer in Canada's children and teenagers. Ottawa, ON: Author.

Heath, S. (1996). Childhood cancer - a family crisis, 1: The impact of diagnosis. British Journal of Nursing, 5(12), 744-748.

Heath, S. (1996). Childhood cancer - a family crisis, 2: Coping with diagnosis. British Journal of Nursing, 5(13), 790-793.

Hinds, C. (1985). The needs of families who care for patients with cancer at home: are we meeting them? Journal of Advanced Nursing, 10, 575-581.

Hinds, P., Birenbaum, L., Clarke-Steffen, L., Quargnenti, A., Kreissman, S., Kazak, A., Meyer, W., Mulhern, R., Pratt, C. & Wilimas, J. (1996). Coming to terms: Parents' response to a first cancer recurrence in their child. Nursing Research, 45(3), 148-153.

Hockenberry, M., Coody, D., & Bennett, B. (1990). Childhood cancers: Incidence, etiology, diagnosis, and treatment. Pediatric Nursing, 16(3), 239-246.

Horner, M.M., Rawlings, P., & Giles (1987). How parents of children with chronic conditions perceive their own needs. Maternal Child Nursing, 12, 40-43.

Horner, S., Ambrogne, J., Coleman, M., Hanson, C., Hodnicki, D., Lopez, S., & Talmadge, M. (1994). Travelling for care: Factors influencing health care access for rural dwellers. Public Health Nursing, 11(3), 145-149.

Hymovich, D. (1995). The meaning of cancer to children. Seminars in Oncology Nurses, 11(1), 51-58.

Johnson, J. (1997). Generalizability of qualitative research: Excavating the discourse. In J. Morse (Ed.), Completing a qualitative project: Details and dialogue. Thousand Oaks, CA: Sage Publications.

Johnson, S., Craft, M., Titler, M., Halm, M., Kleiber, C., Montgomery, L., Megivern, K., Nicholson, A., & Buckwater, K. (1995). Perceived changes in adult family members' roles and responsibilities during critical illness. Image - Journal of Nursing Scholarship, 27(3), 238-243.

Kaplan, D. (1982). Intervention strategies for families. In J. Cohen, J. Cullen, & L. Martin (Eds.), Psychosocial Aspects of Cancer. New York: Raven Press, (pp.221-

233).

Knafl, K., Ayres, L., Gallo, A., Zoeler, L., & Breitmayer, B. (1995). Learning from stories: Parents' accounts of the pathway to diagnosis. Pediatric Nursing, 21(5), 411-415.

Knafl, K., Gallo, A., Zoeller, L., Breitmayer, B. & Ayres, L. (1992). One approach to conceptualizing family response to illness. In S. Feetham, S. Meister, J. Bell & C. Gillis, (Eds.), The Nursing of Families: Theory/Research/Education/Practice. Newbury Park, CA: Sage.

Knollmueller, R. (1994). Rural health care and health care reform. Public Health Nursing, 11(3), 143-144.

Koch, A. (1985). "If only it could be me": The families of pediatric cancer patients. Family Relations, 34, 63-70.

Koocher, G., & O'Malley, J., (1981). The Damocles Syndrome: Psychological consequences of surviving childhood cancer. New York, NY: McGraw-Hill Book Company.

Kramer, R. (1981). Impact of childhood cancer on healthy siblings. Issues in Comprehensive Pediatric Nursing, 5, 155-165.

Kramer, R. & Perin, G. (1985). Patient education and pediatric oncology. Nursing Clinics of North America, 20(1), 31-47.

Kristjanson, L. (1992). Conceptual issues related to measurement in family research. The Canadian Journal of Nursing Research 24(3), 37-52.

Kristjanson, L. & Ashcroft, T. (1994). The family's cancer journey: A literature

review. Cancer Nursing, 17(1), 1-17.

Kristjanson, L., Chalmers, K., Taylor-Brown, J., Nelson, F., Woodgate, R., & Ramserran, S. (1997). Information and support needs of adolescent children of women with breast cancer. Unpublished Research Report. University of Manitoba, Winnipeg, Canada.

Kuckelman Cobb, A., & Hagemaster, J. (1987). Ten criteria for evaluating qualitative research proposals. Journal of Nursing Education, 26(4), 138-143.

Lanouette, M. & St. Jacques, A. (1994). Premature infants and their families. Canadian Nurse, 90(9), 36-39.

Lansky, S., Cairns, N., & Clark, G. (1979). Childhood cancer: non-medical costs of the illness. Cancer, 43, 416-431.

Lansky, S., (1985). Management of stressful periods in childhood cancer. Pediatric Clinics of North America, 32(3), 625-631.

Leventhal-Belfer, L., Bakker, A., & Russo, C., (1993). Parents of childhood cancer survivors: a descriptive look at their concerns and needs. Journal of Psychosocial Oncology, 11(2), 19-41.

Lincoln, Y. & Guba, E. (1985). Naturalistic inquiry. Beverly Hills, CA: Sage.

Longman, A., Atwood, J., Sherman, J. & Bendict, J. & Shang, T. (1992). Care needs of home-based cancer patients and their caregivers. Cancer Nursing, 15(3), 182-190.

Macklin, E. (1980). Nontraditional family forms: A decade of research. Journal of Marriage and the Family, 42, 905-922.

Magni, G., Carli, M., Leo, D., Tshilol, M., & Zanesco, L. (1986). Longitudinal evaluations of psychological distress in parents of children with malignancies. Acta Paediatric Scandinavia, 75, 283-288.

Manitoba Cancer Registry (1995). Pediatric Oncology Statistics. Unpublished raw data.

Martinson, I., & Cohen, M., (1989). Themes from a longitudinal study of family reaction to childhood cancer. Journal of Psychosocial Oncology, 6(3/4), 81-98.

Martinson, I., Colaizzo, D., Freeman, M., Bossert, E. (1990). Impact of childhood cancer on healthy school-age siblings. Cancer Nursing, 13(3), 183-190.

Maturana, H. & Varela, F. (1992). The tree of knowledge: The biological roots of human understanding (rev. ed.). Boston: Shambhala.

May, K. (1995). Interview techniques in qualitative research: Concerns and challenges. In J. Morse & P. Field (Eds.) Qualitative Research Methods for Health Professionals (2nd ed.), pp 188-201. Thousand Oaks, CA: Sage.

McCourt, C., Chu, D., Desmeules, M (1993). Youth and cancer: The challenges for Canada. Chronic Disease in Canada, 14(2), 53-56.

McCubbin, M. & McCubbin, H. (1994). Families coping with illness: The resiliency model of family stress, adjustment and adaptation. In C. Danielson, B. Hamel-Bissell, & P. Winstead-Fry (Eds.). Families, health & illness: Perspectives on coping and intervention. St. Louis, MI: Mosby.

McPhee, M. (1995). The family systems approach and pediatric nursing care. Pediatric Nursing, 21(5), 417-423.

Meadows, A.T., Krejmas, N.L. & Belasco, J.B. (1980). The medical cost of cure: Sequelae in survivors of childhood cancer. In J. Van Eys & M.P. Sullivan, (Eds.), Status of the curability of childhood cancer. New York: Raven Press, pp. 263-276.

Mercer, M. (1994). The perceived needs of parents of children with cancer. Unpublished thesis. University of Dalhousie.

Mercer, M. & Ritchie, J. (1997). Home community cancer care: Parents' perspectives. Journal of Pediatric Nursing, 12(3), 133-141.

Mercer, R. (1989). Theoretical perspectives on the family. In C. Gillis, B. Highley, B. Roberts & I. Martinson (Eds.). Toward a science of family nursing. Menlo Park, CA: F. A. Davis.

Miller, I., Epstein, N., Bishop, D., & Keitner, G. (1985). The McMaster Family Assessment Device: Reliability and validity. Journal of Marital and Family Therapy, 11(4), 345-356.

Miller, S. & Winstead-Fry, P. (1982). Family systems theory in nursing practice. Reston, VA: Reston Publishing Company.

Moore, I., Kramer, R., & Perin, G. (1986). Care of the family with a child with cancer: Diagnosis and early stages of treatment. Oncology Nursing Forum, 13(5), 60-66.

Moriarty, H. (1990). Key issues in the family research process: Strategies for nurse researchers. Advances in Nursing Science, 12(3), 1-14.

Moriarty, H. & Cotroneo, M. (1992). Sampling issues and family research: Recruitment and sampling strategies. In S. Feetham, S. Meister, J. Bell, & C. Gillis, (Eds.), The nursing of families: Theory/research/education/practice. Newbury Park, CA:

Sage.

Morse, J. (1986). Quantitative and qualitative research: Issues in sampling. In P. Chinn, (Ed.), Nursing research methodology: Issues and implementation. Rockville, MD: Aspen Publications, pp. 181-192.

Morse, J. (1987). Qualitative nursing research: A contemporary dialogue. London: Croom Helm.

Morse, J. & Field, P. (1995). Qualitative research methods for health professionals (2nd ed.). Thousand Oaks, CA: Sage.

Munhall, P. & Oiler, C. (1986). Nursing research: A qualitative perspective. Norwalk, CT: Appleton-Century Crofts.

Murphy, S. (1986). Family study and nursing research. Image, 18(4), 170-174.

Murphy, S. (1992). Using multiple forms of family data. In J. Gilgun, K., Daly & G. Handel, (Eds.), Qualitative methods in family research. Newbury Park, CA: Sage, pp 146-169.

National Cancer Institute of Canada (1995). Canadian cancer statistics. Toronto, ON: Author.

Nelson-Gardell, D. (1995). Feminism and family social work. Journal of Family Social Work, 1(1), 77-95.

Olson, A., Boyle, W., Evans, Zug, L. (1993). Overall function in rural childhood cancer survivors. Clinical Pediatrics 32(6), 334-342.

Overholser, J., & Fritz, G. (1990). The impact of childhood cancer on the family. Journal of Psychosocial Oncology, 8(4), 71-85.

Patton, M. (1980). Qualitative evaluation methods. Beverley Hills, CA: Sage Pubs.

Patton, M. (1990). Qualitative evaluation and research methods (2nd ed.). Newbury Park, CA: Sage.

Perch, K. (1987). The economics of changing household composition and family roles. Family Community Health, 9(4), 1-8.

Peterson, G., & Peterson, D. (1977). The expectations, hopes, and fears of parents. In J. Van Eys, (Ed.), The truly cured child. Baltimore, MD: University Park Press. (pp. 99-104).

Postl, B. (1995). The Health of Manitoba's Children. Winnipeg, MB: Manitoba Health.

Ray, L. & Ritchie, J. (1993). Caring for chronically ill children at home: Factors that influence parents' coping. Journal of Pediatric Nursing, 8(4), 217-225.

Robinson, C. (1993). Managing life with a chronic condition: The story of normalization. Qualitative Health Research, 3(1), 6-28.

Robinson, C. (1994). Women, families, chronic illness and nursing interventions: From burden to balance. Unpublished doctoral dissertation, University of Calgary, Alberta, Canada.

Robinson, C. (1995). Unifying distinctions for nursing research with persons and families. Journal of Family Nursing 1(1), 8-29.

Robinson, C., & Wright, L. (1995). Family nursing interventions: What families say makes a difference. Journal of Family Nursing, 1(3), 327-345.

Rolland, J. (1987). Chronic illness and the family: An overview. In L. Wright & M. Leahey, (Eds.), Families and chronic illness. Springhouse, PA: Springhouse.

Rose, D. (1987). Assessing families of school-aged children with cancer. In M. Leahey & L. Wright (Eds.). Families and life-threatening illness. Philadelphia, PA: F. A. Davis.

Sabbeth, B. (1984). Understanding the impact of chronic childhood illness on families. Pediatric Clinics of North America, 31(1), 47-57.

Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8(3), 27-37.

Sandelowski, M. (1995a). Sample size in qualitative research. Research in Nursing & Health, 18, 179-183.

Sandelowski, M. (1995b). On the aesthetics of qualitative research. Image, 27(3), 205-209.

Schatzman, L. & Strauss, A. (1973). Field research: Strategies for a natural sociology. Englewood Cliffs, NJ: Prentice-Hall Inc.

Scott-Findlay, S. (1996). Concept analysis of family. Unpublished presentation, University of Manitoba.

Seidel, J., Kidseth, R., & Seymour, E. (1988). The Ethnograph. Littleton, OR: Qualis Research Associates.

Shapiro, J. & Shumaker, S. (1987). Differences in emotional well-being and communication styles between mothers and fathers of pediatric cancer patients. Journal of Psychosocial Oncology, 5(3), 121-131.

Silveira, J. & Winstead-Fry, P. (1997). The needs of patients with cancer and their caregivers in rural areas. Oncology Nursing Forum, 24(1), 71-75.

Sorrell, J. & Redmond, G. (1995). Interviews in qualitative nursing research: Differing approaches for ethnographic and phenomenological studies. Journal of Advanced Nursing, 21, 1117-1122.

Spradley, J. (1979). The ethnographic interview. New York, NY: Holt, Rinehart & Winston.

Spradley (1980). Participant observation. New York, NY: Holt, Rinehart and Winston.

Spinetta, J. (1982). Impact of cancer on the family. Frontiers of Radiation Therapy Oncology, 16, 167-176.

Spinetta, J. (1981). The siblings of the child with cancer. In J. Spinetta & P. Deasy-Spinetta (Eds.) Living with Childhood cancer. St. Louis, MI: The C. V. Mosby Company, pp. 133-142.

Staples, R. (1989). Family life in the 21st century. In C. Gillis, B. Hidley, B. Roberts & I. Martinson (Eds.) Toward a science in family nursing, pp 156-169. Menlo Park, CA: F. A. Davis.

Steinglass, P. (1980). Assessing families in their own homes. American Journal of Psychiatry, 137 (12), 1523-1529.

Streubert, H. & Carpenter, D. (1995). Qualitative Research in Nursing: Advancing the Humanistic Imperative. Philadelphia, PA: J. B. Lippincott Co.

Stuart, M. (1991). An analysis of the concept of family. In A. Whall & J. Fawcett

(Eds.) Family theory development in nursing: State of the science and art. Philadelphia, PA: F. A. Davis.

Thoma, M., Hockenberry-Eaton, M., Kemp, V (1993). Life change events and coping behaviors in families of children with cancer. Journal of Pediatric Oncology, 10(3), 105-111.

Thomas, R. (1984). Nursing assessment of childhood chronic conditions. Issues in Comprehensive Pediatric Nursing, 7, 165-176.

Thorn, S. (1985). The family cancer experience. Cancer Nursing, 8(5), 285-291.

Tri-Council Working Group (1996). Code of Conduct for Research Involving Humans (draft document). Ottawa, ON: Medical Research Council of Canada.

Tringali, C. (1986). The needs of family members of cancer patients. Oncology Nursing Forum, 13(4), 65-70.

Uphold, C. & Strickland, O. (1989). Issues related to the unit of analysis in family nursing research. Western Journal of Nursing Research, 11(4), 405-417.

Vachon, M, Lancee, W., Conway, B., & Adair, W. (1990). Final report on the needs of persons living with cancer in Manitoba. Manitoba Division of the Canadian Cancer Society.

Vidaver, V. (1991). Concepts in chronic illness and home care. In C. Helvie (Ed.), Community Health Nursing: Theory and Practice (pp.271-285). New York: Springer Publishing Company.

von Bertalanffy, L. (1968). General systems theory. New York: George Barziller.

Walker, C. (1988). Stress and coping in siblings of childhood cancer patients.

Nursing Research, 37(4), 208-212.

Walker, C. (1990). Siblings of children with cancer. Oncology Nurses Forum, 17(3), 355-360.

Weinert, C. & Boik, R. (1995). MSU Rurality Index: Development and evaluation. Research in Nursing and Health, 18, 453-464.

Weinert, C., & Long, K. (1987). Understanding the health care needs of rural families. Family Relations, 36(4), 450-456.

Welch-McCaffrey, D. (1988). Family issues in cancer care: Current dilemmas and future directions. Journal of Psychosocial Oncology, 6(½), 199-211.

Whiteley, M. (1996). Reliability and validity of the FIN-PED: An instrument to measure care needs of mothers of children with cancer. Unpublished thesis, University of Manitoba.

Whyte, K. (1992). Family nursing approach to the care of a child with a chronic illness. Journal of Advanced Nursing, 17, 317-324.

Woods, N., Lewis, F., & Ellison, E. (1982). Living with cancer: family experiences. Cancer Nursing 12(1), 28-33.

Woods, N. & Lewis, F. (1992). Design and measurement challenges in family research. Western Journal of Nursing Research, 14(3), 397-403.

Wright, L. & Leahey, M. (1984). Nurses and families: A guide to family assessment and intervention. Philadelphia, PA: F. A. Davis Co.

Wright, L. & Leahey, M. (1990). Trends in nursing of families. Journal of Advanced Nursing, 15, 148-154.

- Wright, L. & Leahey, M. (1994). Nurses and Families (2nd ed.) Philadelphia, PA: F.A. Davis.
- Wright, L., Watson, W. & Bell, J. (1996). Beliefs: The heart of healing in families and illness. New York, NY: Basic Books.
- Wright, P. (1993). Parents' perceptions of their quality of life. Journal of Pediatric Oncology Nursing, 10(4), 139-145.

Appendix A
LETTER TO THE PROVINCIAL CANCER TREATMENT CENTRE FOR
ACCESS

June 20, 1997

Dear John Farber, Chair, Access Committee,

I am a graduate student in the Master of Nursing Program at the University of Manitoba. Currently, I am doing my thesis work which explores the experiences and needs of rural families with a child with cancer. The study is utilizing a qualitative method of inquiry. The purpose of the project is to more thoroughly understand the unique needs and experiences of rural families living with childhood cancer. The methodology for the study includes a family interview of approximately one and a half hours which explores the experiences of these families living with childhood cancer. Through this study, I hope that health care professionals working with these families will become more knowledgeable about the changes which occur with rural families experiencing childhood cancer.

I have spoken with Dr. Sarah Israels, head of Pediatric Oncology at the Foundation, and she has verbally supported the project and has agreed to assist with recruitment of families for the study. As well I met with the Pediatric Oncology Team on June 17th to describe my study in further detail and to answer any questions; Dr. Rochelle Yanofsky is planning to join my thesis committee as an additional external member. The study is pending approval from the Ethical Review Committee of the Faculty of Nursing. The purpose of this letter is to simply inform you and the research committee at the Foundation regarding this research study taking place at the Manitoba Cancer Treatment and Research Foundation.

Please do not hesitate to contact myself if you have any questions or concerns about this project.

I can be reached at _____ or you may contact my thesis chairperson, Dr. Karen Chalmers at 474-7318.

Sincerely,

Shannon Scott-Findlay, RN, BN
Master of Nursing, student

Appendix B
EXPLANATION FOR RECRUITERS
(Members of Pediatric Oncology Team)

A project is being conducted on the experiences and needs of rural families with a child who has cancer. This project is being conducted by Shannon Scott-Findlay, a Masters in Nursing student at the University of Manitoba. I thought that you might be interested in hearing about this project. If you agree to release your name and phone number, Shannon will phone you and provide you with some more information about her study and answer any of your questions about the study.

Would you like to hear more about the project? You can decide whether or not you want to participate when you speak with Shannon. The interview will take approximately one and a half hours, and will be similar to an informal conversation. May I release your name and phone number to Shannon? If you agree Shannon will be contacting you within the week or two Thank-you.

Appendix C
EXPLANATION AT THE CANCER TREATMENT CENTRE AND/OR ON THE PHONE

Hello, my name is Shannon Scott-Findlay. Thank-you for allowing me to meet with you (or phone you). Is now a good time to talk? As was previously mentioned by (member of the pediatric oncology team), I am a student in the Masters in Nursing program at the University of Manitoba. I am also a registered nurse working part-time at Children's Hospital. The purpose of this project is to examine the unique experiences and needs of rural families with a child who has cancer. This project is to fulfill the thesis requirements of the Master of Nursing Degree.

If you agree to participate in this project, I will set up an interview at a location of your choice, and at a time that is convenient for you. The interview will be approximately one and a half hours in length. The purpose of the study is to examine the experiences and needs of rural families with a child who has cancer from a family perspective. You are free to invite other family members, including children, who you feel have been affected by your child's illness. The interview will involve discussing your experience with your child's illness, your feelings at the time of the cancer diagnosis, and the effects the diagnosis has had on your lives. I would like to tape record the interview so that I will not have to take detailed notes. There are also two short forms to complete and I may take a few notes during the interview. The information from the interview will be transcribed and analyzed with information from other rural families with a child with cancer. I may need to call you again to clarify any details from the interview. When the project is written up the information will be grouped in such a way that it will not be possible to identify you.

No one other than my thesis committee, Dr. Karen Chalmers (Faculty of Nursing, University of Manitoba), Dr. Wanda Chernomas, (Faculty of Nursing, University of Manitoba), Ms. Jill Taylor-Brown, a social worker from St. Boniface General Hospital, and myself will listen to the tapes or read the transcripts. Dr. Yanofsky will have access to only grouped data. You are free to withdraw from the project at any time. Your participation is entirely voluntary, and you are under no obligation to participate in this project.

Do you have any questions?

Are you interested in participating in this project?

Can we set up an interview time?

Thank you for your interest in this project, I look forward to meeting you.

Appendix D**Poster*****Rural Families Experiencing Childhood Cancer***

Shannon Scott-Findlay, a registered nurse at the Winnipeg Children's Hospital, is conducting a study on rural families experiencing childhood cancer. The purpose of the study is to examine the unique experiences and needs of rural families with a child with cancer. The study is part of her Master of Nursing degree at the University of Manitoba.

The study involves an interview with your family, approximately one and a half hours in length which focuses on your family's experiences with cancer, the effects the diagnosis has had on your lives and the support and resources in your local community. There are also two short forms to complete. The interview will occur at a place and time that is convenient for you and your family.

All information discussed during the interview will be kept confidential. No specific information from the interview will be shared with your child's health care providers and your child's care will not be altered in any way. The study has been approved by the Ethical Review Committee of the Faculty of Nursing, University of Manitoba and by the Pediatric Oncologists at the Manitoba Cancer Treatment and Research Foundation.

If you have a child with cancer (up to 18 years old) and live in a rural area (outside of Winnipeg) and are interested in receiving more information about the study please contact Shannon at ***-****, please leave a message if no one is home.

Thank you for your interest!

Appendix E

LETTER TO PLACE POSTERS AT RONALD MCDONALD HOUSE

June 28, 1997

Dear Ms. Kerri Mushumanski, Manager, Ronald McDonald House,

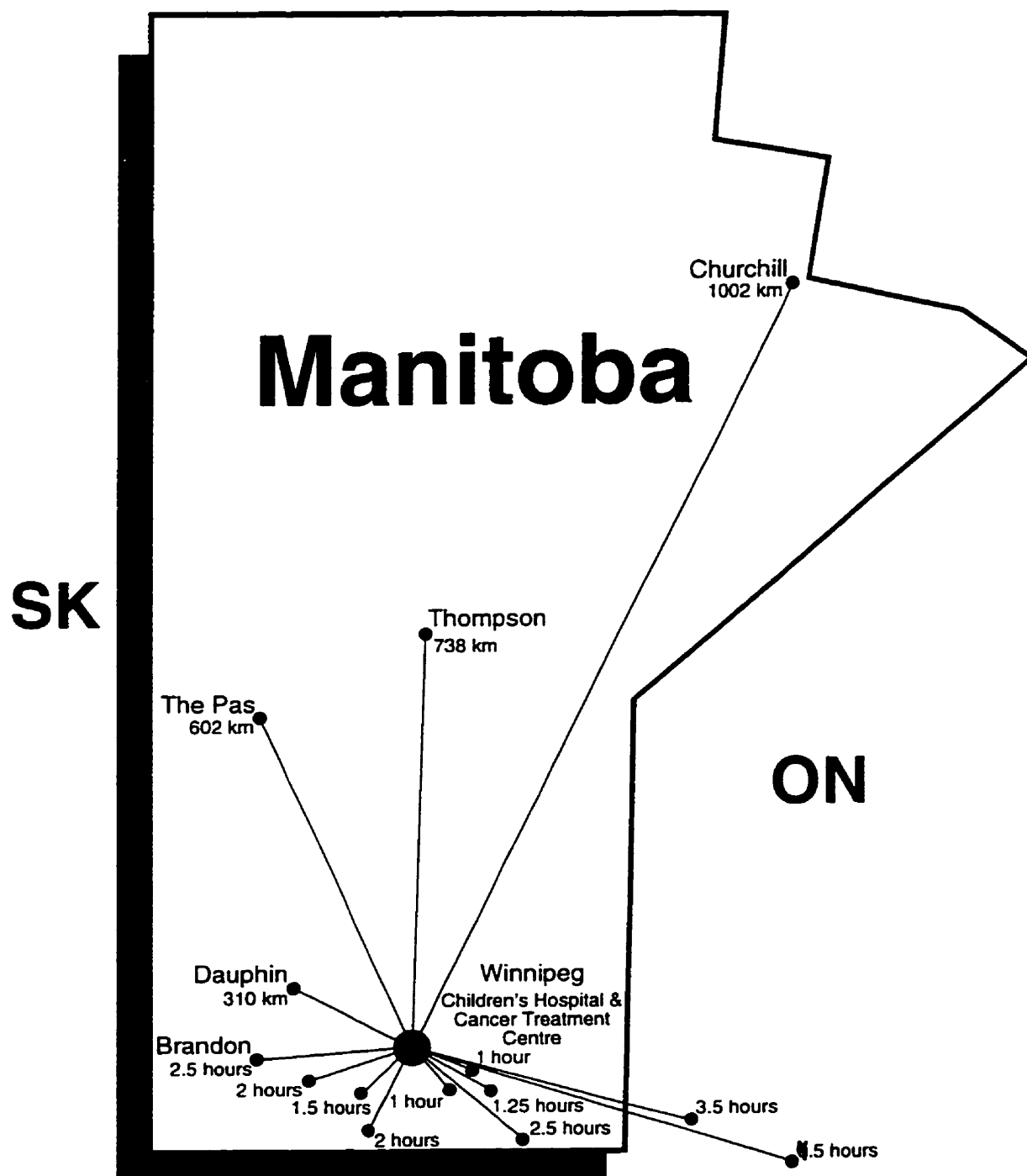
The purpose of this letter is to request permission to post the enclosed posters within the Ronald McDonald House. I am a registered nurse at the Winnipeg Children's Hospital, as well as a graduate student in the Master of Nursing Program at the University of Manitoba. I am currently doing a study which explores the experiences and needs of rural families with a child with cancer. The purpose of the project is to more thoroughly understand the unique needs and experiences of rural families living with childhood cancer. Through this study, I hope that health care professionals working with these families will become more knowledgeable about the changes which occur with rural families experiencing childhood cancer.

The study has been approved by the Ethical Review Committee of the Faculty of Nursing at the University of Manitoba and by the pediatric oncologists at the Manitoba Cancer Treatment and Research Foundation/Children's Hospital. I have asked for your assistance in placing this posters at the Ronald McDonald House because of the frequency with which rural families with a child with cancer stay at your accommodations. I would sincerely appreciate your assistance by posting these notices in visible areas of the House. Please feel free to photocopy these notices if you and/or other parents would like a copy. Again, I thank for your assistance. Please contact me (***-****) if you have any questions or concerns.

Sincerely,

Shannon Scott-Findlay, RN, BN
Master of Nursing student

Appendix F MAP OF PROVINCE



The researcher drove to the sites on the map where only the length of time to drive to the city is listed. The other towns and cities listed on the map are to give some perspective of the vastness of the province.

Appendix G CONSENT FORM

I, _____, agree to participate in this project examining the needs of rural families with a child with cancer conducted by Shannon Scott-Findlay, Masters in Nursing student, Faculty of Graduate Studies, University of Manitoba. I understand that I will participate in an interview of approximately one and a half hours. Shannon will ask me questions regarding my experiences of living within a family experiencing childhood cancer. The questions will focus on: our family's experience with our child's cancer, our feelings at the diagnosis, and the effects the diagnosis has had on our lives. The interview will be tape recorded and the information recorded later transcribed. There are also two short forms to complete and Shannon may take some brief notes during the interview. Shannon may later phone me to clarify any details, if necessary, prior to analyzing the data. This information will be analyzed along with information from other rural families with a child with cancer. When the project is written up, the information will be grouped in such a way that it will not be possible to identify me. Additionally, Shannon will be selecting a few families to initially share the findings of her study with in order to ensure her analysis accurately reflects the experiences of rural families experiencing childhood cancer.

Also, no one other than Shannon, her thesis committee (Dr. Karen Chalmers, Faculty of Nursing; Dr. Wanda Chernomas, Faculty of Nursing; Ms. Jill Taylor-Brown, Department of Psychosocial Oncology, urban General Hospital) and a typist who will transcribe the interview, will listen to the tapes or read the transcripts. Dr. Yanofsky will only have access to grouped data. I also understand that I am free to withdraw from the study at any time. My participation is entirely voluntary. I am under no obligation to participate in this project. All information discussed during the interview will be kept confidential. No specific information from the interview will be shared with my child's health care providers and my child's care will not be altered in any way. The study has been approved by the Ethical Review Committee of the Faculty of Nursing, University of Manitoba. I am free to contact Shannon (***-***-****) or her thesis committee chair, Dr. Karen Chalmers (204-474-7318) at any time if I have any questions about the study.

My signature below indicates my willingness to participate.

_____ (Family Member's signature) _____ (Date)

_____ (Researcher)

Would you like to receive a summary of the findings from this study once it is completed?

___ Yes

___ No

If yes, please write your name and address below for the purposes of mailing. You can expect the results in approximately four to six months.

Appendix H

ASSENT FORM FOR CHILDREN

I, _____, agree to take part in this project looking at rural families with a child with cancer conducted by Shannon Scott-Findlay, Masters in Nursing student, Faculty of Graduate Studies, University of Manitoba. Shannon will ask me questions regarding my experiences of living within a family experiencing childhood cancer. The questions will be about: our family's experience with childhood cancer, our feelings at the diagnosis, and the effects the diagnosis has had on our lives. The interview will be take about one and a half hours and will be tape recorded. There are also two short forms to complete.

When the project is written up, it will not be possible to identify me or my family.

Also, no one other than Shannon, her thesis committee (Dr. Karen Chalmers, Faculty of Nursing; Dr. Wanda Chernomas, Faculty of Nursing; and Ms. Jill Taylor-Brown, Department of Psychosocial Oncology, urban General Hospital) and the typist will listen to the tapes or read the transcripts. Dr. Yanofsky will only have access to grouped data. I can quit the study at any time. My participation is entirely voluntary. I do not have to participate in this project. Everything talked about will not be discussed with any one else. No information from the interview will be shared with our health care providers and our family's care will not be altered in any way. The study has been approved by the Ethical Review Committee of the Faculty of Nursing, University of Manitoba. I am free to contact Shannon (***.***.****) or her thesis committee chair, Dr. Karen Chalmers (204-474-7318) at any time if I have any questions about the study.

My signature below indicates my willingness to participate.

_____ (Child's signature)

_____ (Parent's signature)

_____ (Researcher)

_____ (Date)

Appendix I HANDOUT TO FAMILIES

I am conducting a project that examines the experiences and needs of rural families who have a child with cancer. The purpose of this project is to examine the unique experiences and needs of rural families with a child with cancer. This project is to fulfill the thesis requirements of the Master of Nursing Degree at the University of Manitoba. My interest in this topic has grown from my experience as a pediatric nurse at a children's hospital and my experience growing up in rural Manitoba.

I am working under the supervision of Dr. Karen Chalmers, of the Faculty of Nursing, University of Manitoba (474-7318), Dr. Wanda Chernomas (Faculty of Nursing), Dr. Rochelle Yanofsky (Children's Hospital and the provincial cancer treatment centre) and Ms. Jill Taylor-Brown (Department of Psychosocial Oncology, urban General Hospital). Families from rural areas with a child who has cancer are being approached for this project.

If you agree to participate, I would like to talk with you and your family (family members may decide to participate or not) about your experience with your child's illness. Your child would also be invited to participate if that is agreeable to you and your child. The questions will focus on: your family's experience since learning a child has cancer, your feelings at the time of the cancer diagnosis, the effects the diagnosis has had on your lives, and the supports and resources in your local community. The interview will take approximately one and a half hours, and will take place at a time and place that is convenient for you. I would also like to tape record the interviews. This would allow me to listen more carefully to you without having to take detailed notes. There are also two short forms to complete. During the interview, I may make some brief notes from my observations and about the information being discussed in the interview.

At a later date, I will be transcribing the tapes and the information will be analyzed. I may request to do a follow-up phone call to clarify any details from the transcripts, if necessary, prior to analyzing the data. All the information will be kept confidential; you may withdraw from the study at any time. The information will be grouped along with the information from all other parents. When the project is written up, the information will be grouped in such a way that it will not be possible to identify any individual children or families. As well, I will be selecting a few families to initially share the findings of my study with in order to ensure that my analysis accurately reflects the experiences of rural families experiencing childhood cancer. This meeting would take approximately 20 - 30 minutes and would take place in person in Winnipeg after one of your child's medical appointments or arrangements could be made to discuss these issues on the phone. You could choose later to participate or not to participate in this second interview.

No specific information from the interview will be shared with your child's health care providers but a summary of the findings of all my interviews may be given to the Pediatric Oncology Staff at the provincial cancer treatment centre. The study has been approved by the Faculty of Nursing Ethical Review Committee. You are under no obligation to participate; you may withdraw from the study at any time. If you would like any further information, please contact me at:

--**** - home

204-474-8202 - general office, Faculty of Nursing

Thank you for your interest in this project.

Shannon Scott-Findlay RN, MN student, Faculty of Nursing - University of Manitoba

Appendix J -DEMOGRAPHIC FORM

Age of child with cancer _____

Child's diagnosis _____

Date of diagnosis _____

Age at diagnosis _____

Child's current grade in school _____

Do you have other children?

___ Yes

___ No

If yes, what are their ages?

What is your age? _____

Your partner's age (if relevant)? _____

What is your occupation? _____ ☐ Full Time ☐ Part Time

What is your partner's occupation (if relevant)? _____ ☐ FT ☐ PT

Distance to nearest medical facility _____

Distance to MCTRF/Children's Hospital _____

Can you please indicate the approximate date for the last time you were in Winnipeg for an appointment or treatment related to your child's diagnosis. _____

Approximately how many times have you gone to Winnipeg for Drs.' appointments, treatment, and other services related to your child's diagnosis? _____

Is your child currently receiving active treatment?

___ Yes

___ No

How would you describe your child's current health condition? _____

Appendix K

INTERVIEW GUIDE

Thank-you for agreeing to meet with me. I would like to ask you a few questions about your child and family.

I also want to inform you that you do not have to answer a question if it makes you uncomfortable. I understand that it may be difficult for you to discuss your experiences with cancer. At anytime, we can turn the tape recorder off to “take a break”, if you would like to. No specific information from the interview will be shared with your child’s health care providers. All information will be kept confidential and you may withdraw from the study at any time.

1. Tell me about your experience with childhood cancer?
 Probe for:
 - referral process
 - experience at Cancer Foundation and Children’s Hospital
 - what has helped you to cope with the diagnosis and its treatment?
 - overall effect of diagnosis on the family
 - isolation related to distance from treatment centre?

2. How have your lives been affected since the diagnosis of cancer?
 Probe for:
 - which problem has been the most difficult and how did you resolve it?
 - what is your primary stress?
 - what have been the stabilities or “things that have stayed the same within your family?”
 - impact on family situation
 - amount of time spent together as a family
 - financial - change in employment?
 - family supports
 - family structure
 - siblings
 - disciplining children
 - feelings of being in the city for treatment (i.e., availability of social supports, driving in the city, different parental roles during in-patient treatment)
 - what have the strengths been in your family in order for you to deal with the diagnosis?

3. Since diagnosis, how many times have you had to go to Winnipeg for appointments and follow-up appointments? What has your experience been with receiving cancer care in Winnipeg? How do you feel about the distance between you and the treatment centre?
 Probe for: -distance to Winnipeg
 -implications of receiving treatment in Winnipeg
4. Tell me about the cancer treatment. Is your child's family physician (local doctor prior to diagnosis) aware of the diagnosis? Who do you first contact when your child with cancer is feeling unwell?(ie side effects of treatment, nausea, etc.)?
 Probe for: -details of treatment, location of treatment
 -is any treatment given in local community?
5. Can you tell about your situation of living in a rural community with a child with cancer? Probe for: do you think that families living in urban area have a different experience than your family from a rural area? If yes, how?
6. Tell me about the support that you as a family have received to assist you cope with childhood cancer.
 Probe for: -are the supports adequate:
 -local supports available for example, to help your child with the transition back to school, does your family have access to counselling services if required, etc.
7. Are there any services and supports that you wish that you had access to your home community?
8. Are you part of a support group for parents/families with a child with cancer. If yes, do you feel this is helpful (how so). If no, do you think that the support of other parents would be beneficial?
9. When looking back at the initial diagnosis and treatment, do you have any suggestions for health care professionals in planning care for children with cancer from rural areas?
 -approaching the school regarding the diagnosis
10. Is there anything else that you want to add that we have not discussed yet with respect to your child's condition and your needs as a family dealing with a cancer diagnosis and treatment?

11. Do you have any questions for me?

Thank you for giving me the opportunity to meet with you to discuss your experiences as a family with childhood cancer.

I may contact you by telephone within the next few weeks to clarify any information from the interview. Is this okay? As well, I will be selecting a few families to initially share the findings of my study with over the phone or in Winnipeg if you are in the city for an appointment. The purpose of this step is to ensure my findings from the analysis accurately reflect the experiences of rural families experiencing childhood cancer. Would this be okay for me to call you? You could decide then if you want to meet/talk with me.

Appendix L

FAMILY ASSESSMENT DEVICE

This questionnaire contains a number of statements about families. Please read each statement carefully, and decide how well it describes your own family. You should answer according to how you see your family. For each statement, there are four (4) possible responses: Strongly Agree, Agree, Disagree or Strongly Disagree. Try not to spend too much time thinking about each statement, but response as quickly and honestly as you can. If you have trouble with one, answer with your first reaction. Please be sure to answer every statement and mark all answers in the space provided below each statement.

1. In times of crisis we can turn to each other for support.
☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree
2. Individuals are accepted for what they are.
☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree
3. We can express feelings to each other.
☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree
4. We feel accepted for what we are.
☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree
5. We are able to make decisions about how to solve problems.
☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree
6. We confide in each other.
☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree
7. Planning family activities is difficult because we misunderstand each other.
☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

8. We cannot talk to each other about the sadness we feel.
___ Strongly Agree ___ Agree ___ Disagree ___ Strongly Disagree
9. We avoid discussing our fears and concerns.
___ Strongly Agree ___ Agree ___ Disagree ___ Strongly Disagree
10. There are lots of bad feelings in the family.
___ Strongly Agree ___ Agree ___ Disagree ___ Strongly Disagree
11. Making decisions is a problem for our family.
___ Strongly Agree ___ Agree ___ Disagree ___ Strongly Disagree
12. We don't get along well together.
___ Strongly Agree ___ Agree . ___ Disagree ___ Strongly Disagree

Appendix M

Script for requesting families for verification of findings

Hello, this is Shannon Scott-Findlay, I am a graduate student within the Master of Nursing Program at the University of Manitoba. I met with you and your family a few months ago to discuss your experiences with regard to living with childhood cancer. Is now a good time to talk? The purpose of this call is to inquire if you would be interested in assisting me for to verify or confirm the findings of my research study. When I met with you and your family, at the end of the interview I inquired if you might be interested in meeting with me. The purpose of this process is to ensure that my analysis accurately captures what it means to be in a rural family experiencing childhood cancer. If you agree, I will mail you a summary outlining the themes/categories I have seen within the data. I ask that you read this summary and discuss it amongst your family. Then, I will call you by phone. What I suggest is that you appoint someone in your family to act as the spokesperson for your family; thereby communicating the thoughts and suggestions from the family. This should be more simpler because we will not be meeting in person. Throughout our short conversations on the phone, I will be taking detailed notes about your reactions and opinions about the findings of the study. I want to reiterate that confidentiality will be maintained. Data has been grouped so as to protect anyone being identifiable. Your child's care will not be altered by your decision. Would you be willing to participate in this process?

Thank you very much, I look forward to speaking with you. I will mail a copy of the summary to you today.

Appendix N Summary of Findings

Summary of Findings - The needs and experiences of rural families with a child with cancer: A family perspective

I conducted a qualitative study. Simply speaking, the purpose of a qualitative study is to break the interview and observational data down into themes and categories which will be able to highlight the main points discovered.

A theme which was vividly apparent in all interviews was the description of the process of diagnosis. I called this theme *"Digging up the pain - the diagnosis story."* When families were describing their experience it was readily apparent the diagnosis of cancer in their child was very painful. Some important points I discovered related to this theme were the signs and symptoms, knowing something is wrong, trying to be heard, watching the unknown and hearing the news.

The second theme which was apparent in the interviews related to the treatment of cancer. Families talked very vividly and explicitly about the treatment of their child's cancer, thus I called this theme *"Treatment - trying to destroy the enemy."* Included in this theme were descriptions about both treatment and side effects.

The remaining six themes I discovered related specifically to living in a rural area with a child with cancer. A lot of the interviews focused on being away from home during treatment and follow up for their child. Thus, two themes were readily evident in the data, *"Away from home,"* and *"Living at a distance from our hope."* The first theme includes the implications of travelling to get care such as experiencing poor weather and driving conditions and dealing with the distance. The second theme was attempting to encompass the emotions and experiences relayed to me about living in a rural area with an acutely ill child. Some important points I heard families telling me included families feeling as though they were the local experts for their child's condition and having differing levels of trust with local health care and the care given in Winnipeg.

As we all know, cancer greatly affects the entire family, this was very explicit in our interviews. Two themes were assigned related to this point, *"Life is now different and life goes on"* was one theme I discovered from thoroughly analyzing our interviews. This included the financial costs of cancer, talking on new roles (i.e. heparinizing central lines, drawing blood from central lines, etc.) and the extra strains and stresses in your lives (i.e. hassles from work, no support in the city). The next theme, *"The entire mobile swings - the whole family is affected"* was organized to include points that indicated that each family member is affected (i.e. mother often has to quit her job or take a leave of absence, father can not go to all medical appointments).

Another important issue discussed in our interviews related to your experience having a child with cancer was the support that you had as a family. I entitled this theme "*The wind beneath our wings.*" I felt this captured the points reported by families such as the different types of support (family, friends, God, the community, etc.), and the important relationships that you have formed because of this experience (i.e. with other families going through a similar situation, developing relationships at Ronald McDonald House).

The final theme apparent from my data related to the excellent suggestions you, as families, gave me for enhancing the current delivery of cancer care for children from rural areas. I entitled this theme, "*Our wishes on falling stars... our wish list.*" This includes suggestions for enhancing pediatric oncology services at the rural level, in the city and for reforming the overall health care structure.

This was a very challenging task trying to streamline all of our interviews into themes and categories. But I hope that you will agree with me, that grouping the data gives your experiences a voice and a strength that would not be evident otherwise.

Thank you for your input - and I look forward to speaking with you in the near future.

Appendix O

LETTER TO FAMILIES FOR VERIFICATION OF FINDINGS

February 16, 1998

Dear

Thank you for agreeing to look at the findings of my research study, "Experiences and needs of rural families with a child with cancer: A Families' perspective." You are one of three families I have selected to review my findings of the study. You have a very important role in helping me identify if my interpretations for our interviews match your experiences.

Please read over the summary of the research findings which I have included. The summary explains the major themes I discovered when analyzing the data I obtained from all of the interviews I conducted with rural families with a child with cancer, like yourself. This summary is the compilation of over 320 pages of typed our interviews.

Within the next week, I will contact you by phone to discuss the findings of the study. This phone call should be no longer than 15 minutes in length. As well, please keep in mind that perhaps the themes presented in their entirety may not exactly match the experience of your family. This is due to the different situations that families experience as well as the supports and influences in their lives. So please keep this in mind when looking at my findings. Confidentiality of our conversations will be maintained. Data from our conversation will be grouped so as to protect anyone from being identifiable. Your participating in this phase of the study is entirely voluntary and you are free to withdraw at any time. No specific information from the interview will be shared with your child's health care providers and your child's care will not be altered in any way.

I look forward to speaking with you again. If you have any questions prior to me calling you in the next week please call me collect at ***-***-****. Thank you for your continued assistance.

Sincerely,

Shannon Scott-Findlay, RN, BN
Master of Nursing student
Principle Investigator

Appendix P

Script for verification of findings

Thank you for agreeing to speak with me. I want to take a few seconds to quickly review the consent process. You are free to withdraw from the study at any time. Your participation is entirely voluntary. You are under no obligation to participate in this project. All information discussed during the interview will be kept confidential. No specific information from the interview will be shared with your child's health care providers and your child's care will not be altered in any way. The study has been approved by the Ethical Review Committee of the Faculty of Nursing, University of Manitoba. I will be taking detailed notes throughout are conversation.

The study has proceeded along well. To date, I have interviewed 10 families and analyzed the data. In my opinion these are the categories/themes that are starting to emerge from the data.

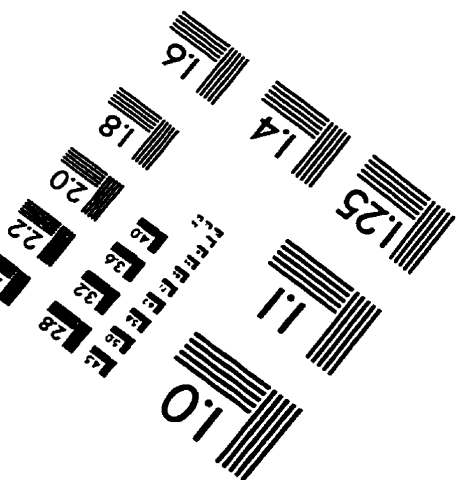
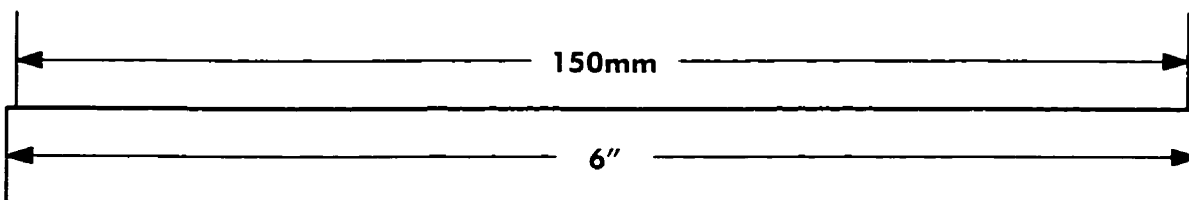
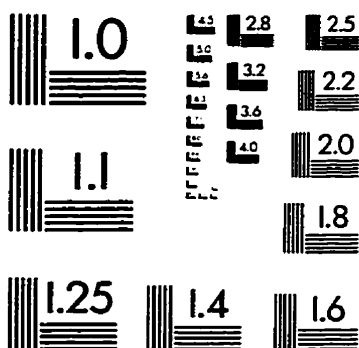
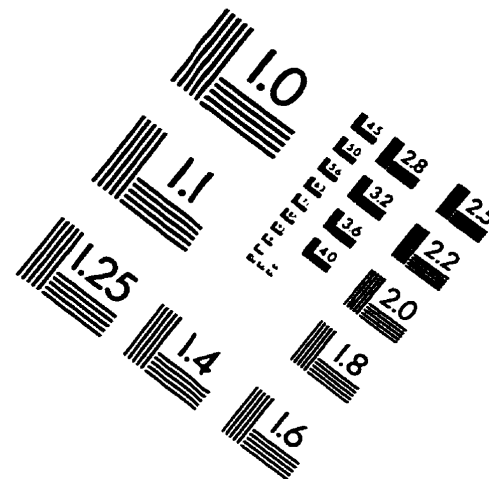
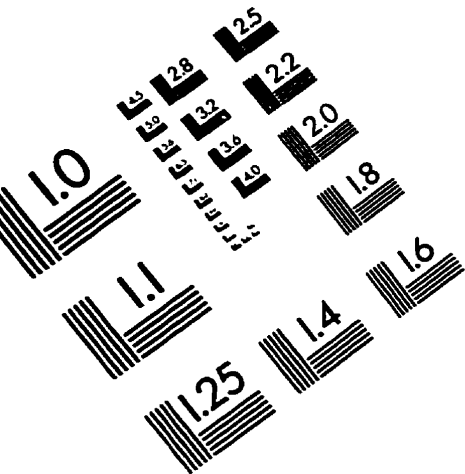
Can you and your family associate or relate to these categories? If not, do you know of other families experiencing childhood cancer that could related to these?

Do you feel that your experience and needs are captured by these categories?

Do you have anything else that you would like to add?

Thank you very much. Your assistance has been very helpful. I will be forwarding a copy of the research findings to you within the next one to two months.

IMAGE EVALUATION TEST TARGET (QA-3)



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