

Caring for the Child who has Completed Treatment for Cancer: The Lived Experience of Parents
who do not Live Near Their Child's Tertiary Cancer Centre

By

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ABSTRACT

Caring for children with cancer involves caring for the entire family. Treatment for childhood cancer is centralized in major centres. A phenomenological study was conducted to elicit the lived experience of parents caring for a child who had completed treatment for cancer who do not live near their child's cancer treatment centre. Interviews with five parents exploring their recollections of parenting their child with cancer during and after treatment were conducted. Data analysis revealed the essence of the parents' lived experience as a journey within a journey. Four themes characterized the essence of parents' lived experience: (1) travelling for care, (2) learning to navigate their journey with healthcare providers, (3) coping with change, and (4) giving back. Similarities and differences between the findings from this study and other studies of families with childhood cancer are presented. Recommendations relating to nursing practice, education, research and healthcare policy are provided.

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CHAPTER ONE: INTRODUCTION

Statement of the Problem

Childhood cancer is diagnosed in approximately 1300 Canadian children under the age of 20 years every year (Canadian Cancer Society [CCS], 2009). Although once synonymous with death, childhood cancer is no longer considered a fatal disease. Rates of survival have increased from less than 50% prior to 1970 to greater than 80% (National Cancer Institute [NCI], 2008). Currently in Canada, depending on the diagnosis and treatment regimen, five-year survival rates are 82%, an 11% increase since the last reported five-year survival rate ten years ago (Ellison, Pogany & Mery, 2007). Survival rates of approximately 80% are comparable to those reported in the United States (NCI) and in Europe (Ellison et al.). Although childhood cancer is rare, attributing for less than one per cent of all cancer diagnoses in Canada (CCS, 2008), the potential lifelong effects of the diagnosis and treatment may affect the child and the family for a lifetime.

Improved survival rates for childhood cancer can be attributed to the advances associated with treatment. This includes treating children in tertiary centres that specialize in pediatric oncology (Aitken & Hathaway, 1993; Bensink et al., 2007; Kisker et al., 1980; Klein-Geltink, Pogany, Barr, Greenberg, & Mery, 2005; Scott-Findlay & Chalmers, 2001). The centralization of treatment provides the child and the family with care from the experts in the field that is based on study protocols developed through international collaboration among pediatric oncology healthcare providers. As a result of the improvements in treatments for childhood cancer, it is now seen as a chronic disease that continues to affect the life of the child and his or her family.

When a child is diagnosed with cancer, the entire family is affected (Ljungman et al., 2003; Pai, Greenley, Lewandowski, Drotar, Youngstrom, & Peterson, 2007; Patterson, Holm, & Gurney, 2003; Wilkins & Woodgate, 2005; Woodgate, 2001, 2006a, 2006b). Upon initial

diagnosis and throughout the cancer trajectory, the family may experience a variety of emotions such as devastation, helplessness, loss of control, fear, grief, and uncertainty about the disease and what it means for the child and the family (Patterson et al.). Along with the emotional aspects of a childhood cancer diagnosis, the child and the family are thrust into a new pattern of daily living that includes appointments to the clinic or inpatient unit for diagnostic tests and treatments (Clarke-Steffen, 1993; Woodgate, 2001). The family's life as they knew it is changed dramatically (Ljungman et al; Patterson et al.; Woodgate, 2001, 2006b; Woodgate & Degner, 2003a).

Children with cancer experience many transitions along the cancer trajectory. For example, Woodgate and Degner (2004) describe transition in childhood cancer in relation to the symptoms the children experience and the effects of those symptoms on the child and the family as a whole. Family members changed roles and responsibilities as the child's symptom transition periods changed. As such, their healthcare needs change with each phase and each challenge they incur along the way (Woodgate, 2001).

The dynamic nature of the childhood cancer experience is not exclusive to the periods of diagnosis and treatment but instead extends into the period when children have completed their treatment and are in remission. In short, for the children and their families, the cancer experience never ends (Woodgate, 2006b). For the child and family, the transition period as children complete treatment for cancer has been described as a time of celebration and hope coupled with fear (Haase & Rostad, 1994), of change (Labay, Mayans & Harris, 2004), of crisis that creates anxiety (Arnold, 1999) and of uncertainty (Arnold, 1999; Haase & Rostad, 1994; Labay et al.). New challenges surface for children and their families.

Children who complete treatment for childhood cancer are at risk for late or long-term effects from either the cancer itself or its treatment (CCS, 2008; Mehta, 2008). These effects include problems related to cardiopulmonary, endocrine, hepatic, musculoskeletal, gastrointestinal, renal or pulmonary dysfunction, neurocognitive impairments and the development of second cancers (CCS, 2008; Elson & Mehta, 2008). Long-term follow-up is necessary for these children in order to monitor late and long-term effects (CCS, 2008; Meadows, 2006). Most families must learn to live with the uncertainty of possible relapse of the child's cancer or of long-term or late effects of the treatment the child has received (Duffey-Lind, O'Holleran, Healey, Vettesse, Diller, & Park, 2006; Labay et al., 2004).

Although much has been learned about the transitions families must undergo at diagnosis and during the treatment period, relatively little has been done to explore the experience of families following the completion of treatment for cancer (Maurice-Stam, Oort, Last, & Grootenhuis, 2007; Van Dongen-Melman, Van Zuuren, & Verhulst, 1998). This is especially the case for children who have completed treatment for cancer and their families who live at a distance from the cancer treatment centre. Only two studies were located that look specifically at rural children who have survived cancer and these studies were focused on the evaluation of academic and social abilities of childhood cancer survivors (Olson, Boyle, Evans, & Zug, 1993; Samardakiewicz & Kowalczyk, 2007).

What remain unknown are the experiences of children and their families who live at a distance from the tertiary cancer centre after the completion of treatment for childhood cancer. More specifically, how do these children and their parents experience the transition period immediately after the completion of treatment? Are there factors in their location that affect their experiences? These are all important questions to answer, considering these families may be far

from healthcare providers who are familiar with their child's diagnosis, treatment, and subsequent follow-up requirements after treatment for childhood cancer from a tertiary centre is complete. For nurses to provide adequate care and support to patients during this critical time we must learn about how and what they experience caring for their child after treatment for childhood cancer is completed.

Purpose of the Study

Little is known about the subjective meanings that parents assign to their experience of transitioning to a time when their child has completed treatment for cancer. Accordingly, the purpose of this qualitative, phenomenological research study was to arrive at an understanding of the lived experiences of parents who live outside the city containing their child's cancer treatment centre as they transition to a time when their child has completed treatment for cancer. The questions guiding this study were:

1. What characterizes the lived experience of parents who live at a distance from the tertiary cancer centre as they transition through a time when their child has completed his/her cancer treatment?
2. What characterizes the day-to-day-living of parents who do not live near the cancer treatment centre as they transition through a time when their child has completed his/her cancer treatment?
3. What meaning do parents who live at a distance from the cancer treatment centre assign to the experience?
4. What recommendations do parents who do not live near the tertiary cancer centre have about how nurses and other health professionals can best support families as they transition through a time when their child has completed his/her cancer treatment?

In answering the overall research purpose and questions, attention was given to addressing how daily life changed from the period when parents were living with the challenges of caring for a child who was receiving treatment for cancer to a time when their child no longer requires treatment but nonetheless has unique care needs. The changing needs of the parents and their children are detailed.

Assumptions

My experience as a pediatric oncology nurse has provided me with an understanding of what it is like to care for children undergoing treatment for cancer and their families. The needs and priorities of families with a child with cancer change as they progress from diagnosis through treatment and beyond. As such, nurses and other healthcare providers must be able to adapt the care provided accordingly. After treatment for childhood cancer is complete, nurses may make the assumption that the parents are relieved to be able to return home and stay away from the tertiary treatment centre. While this may be true to some extent, there are other issues on the families' mind. While caring for children at the end of their treatment for cancer, some parents shared with me their feelings of fear and uncertainty about their child's future and about living so far away from the specialist healthcare providers. They felt a constant fear that something might be wrong with their child but they would not be able to identify it and have it managed in their local community. They worried that their assessment of their child might not be validated by their local healthcare provider. This was often thought to be due to the healthcare provider's lack of experience or exposure to children with cancer. Parents also stated feelings of isolation that they were far from anyone else who knows what they are experiencing, pediatric oncology specialists as well as other parents and children with cancer. As reinforced in the

literature, parents still continue to experience uncertainty, fear, and rough spots even after their child has successfully completed the cancer treatment (Woodgate, 2001, 2006b).

Definitions of Key Terms

For the purpose of this study, key concepts were defined as:

Childhood Cancer Trajectory

The trajectory of childhood cancer is composed of the time span that encompasses the diagnosis, active treatment, completion of treatment into survival or bereavement of childhood cancer.

Transition

Transition has been defined in nursing as a passage or movement from one state, condition or place to another (Chick & Meleis, 1986; Schumacher & Meleis, 1994). In the family context, a couple experiences a transition into parenthood with the arrival of their first child. In the context of childhood cancer transitions occur at diagnosis, during the course of treatment, and after the treatment is completed.

Meanings

Meanings are lived in that they refer to the way a person experiences and understands his or her world as real and meaningful (van Manen, 1990). Meanings attached to illness experiences and events may be positive, negative or neutral, and may change as changes occur in situations and relations (Woodgate, 2001).

Essence

The essence of the lived experience is a description of the phenomenon as a linguistic construction (van Manen, 1990).

Significance of the Study

This study contributes to the understanding of how parents who do not live near their child's tertiary cancer centre experience the survivorship of their child. At present, little is known about the parental experience after the completion of treatment while living at a distance from the cancer centre. The knowledge emerging from this study will help to inform clinicians, researchers, and policy makers about how to improve on the care of families of children who have been treated for childhood cancer. More specifically, the knowledge gained from this study may be used to develop and/or expand existing pediatric psychosocial programs that are focused on meeting the individual and collective needs of families experiencing childhood cancer. With supportive psychosocial programs, parents of children diagnosed with cancer will be helped not only through the difficulty and stress of active treatment but also during the period when children and families transition back to "normal" life once treatment is complete. Results from this study will provide nurses with a deeper understanding of the experiences and needs of parents who have children diagnosed with cancer. Nurses will be better able to anticipate the changing needs of parents as their children complete their cancer treatment.

Chapter Summary

This chapter has provided an outline of the problem statement and purpose of the study. The significance of the study is given in relation to the roles of clinicians, researchers, and policy makers in order to improve care provision for children with cancer and their families, during and after treatment. Terms of key importance are defined for the purpose of the study. The following chapter contains a review of the literature related to children with cancer and their families along the cancer trajectory as well as rural aspects of cancer treatment and follow-up.

CHAPTER TWO: LITERATURE REVIEW

Introduction

This chapter provides a review of the literature surrounding children with cancer and their families in order to provide the basis upon which this research project was developed. The literature review was conducted using PubMed (MEDLINE), Cumulative Index to Nursing & Allied Health Literature, and Scopus databases as well as manual searches from key articles.

A brief introduction about the incidence and prevalence of childhood cancer is given followed by an overview of how childhood cancer impacts the child and the family including transitions that the families experience along the cancer trajectory. Issues surrounding parenting and parenting a child with a chronic or life-threatening illness are discussed. The effects of living at a distance from the cancer treatment centre are identified based on literature about childhood and adult cancer. Survival rates are provided in respect to childhood cancer and consequences of survival for the child and the family are discussed. This literature review revealed that there is much to learn about childhood cancer survivors and their families who do not live near the tertiary cancer treatment centre and provides rationale for the current research project.

Childhood Cancer in Canada

Childhood cancer is diagnosed in approximately 1270 Canadian children under the age of 20 years old every year with about 200 children dying each year as a result of cancer (CCS, 2009). The diagnosis of cancer in children and adolescents is rare, accounting for less than 1% of new cancer diagnoses in Canada (CCS, 2008). However, for Canadian children younger than 20 years old, childhood cancer is the fourth leading cause of death (Ellison et al., 2007). Treatment for childhood cancer has improved significantly over the past four decades. Prior to that, a diagnosis of childhood cancer was synonymous with imminent death (Barnes, 2005). Currently

in Canada, depending on the diagnosis and treatment regimen, five-year survival rates are 82% which is an increase of 11% from the last reported rates over ten years ago (Ellison et al.). These survival rates of approximately 80% are comparable to those reported in the United States (NCI, 2008) and in Europe (Ellison et al.). Increasing survival rates translate into a huge increase in the number of childhood cancer survivors who may live for decades after their treatment.

Impact of Childhood Cancer on Child and Family

A cancer diagnosis in a child is a frightening and stressful time in a family's life that affects the entire family (Enskar, Carlsson, Golsater, Hamrin, & Kreuger, 1997; Ljungman et al., 2003; Pai et al., 2007; Patterson et al., 2003; Wilkins & Woodgate, 2005). The child, parents, and siblings of the child each have unique experiences of the cancer journey beginning at diagnosis and continuing through treatment and beyond. Each member of the family is confronted with new roles and responsibilities that change along the course of the child's treatment and beyond. Once the initial shock of the diagnosis diminishes, the realization of a long and challenging treatment regimen occurs.

When the family receives the news of the cancer diagnosis, there are a variety of emotions that may surface (Grootenhuis & Last, 1997). These may include devastation, helplessness, loss of control, fear, grief, and uncertainty about the disease and what it means for the child and the family (Patterson et al., 2003). Along with these emotions, the family's life is changed dramatically (Ljungman et al., 2003; Patterson et al.) due to the practical demands of the cancer treatment that alter their pattern of daily living (Woodgate, Degner, & Yanofsky, 2003). This includes appointments to the clinic or inpatient unit for diagnostic tests and treatments (Clarke-Steffen, 1993).

Parents are increasingly becoming the primary caregivers and thus are challenged to cope with multiple and complex problems and tasks (Patistea, 2004). Often, it is the mother that takes on this role of primary caregiver (Woodgate, 2006b). In doing so, the structure of the family changes as does the normality of their lives (Patterson et al., 2003). This change is “inevitable, as families now must undertake an uncertain and arduous journey” (Woodgate, 2006b, p. 1; Woodgate & Degner, 2002a). As Woodgate (2006b) uncovered, families described it as “life is never the same” after their child is diagnosed with cancer.

These changes cause the family of a child with cancer to have new and specific needs. For example, the child with cancer is often required to stay for long periods in the hospital in order to receive treatment such as surgery, chemotherapy or a bone marrow transplant. This forces the child to be away from school, friends, and other aspects of their regular lives. Siblings must learn to live with a sibling who is ill and also adapt to being without their ill sibling and the parent who often accompanies the sibling with cancer to the treatment centre (Harding, 1996). While these aspects are of incredible importance to the context of cancer within the family, the remainder of this section will address issues surrounding the parental changes.

The Role of Parent

Becoming a parent is an important milestone in a person’s life (Heath, 2009; McKellar, Pincombe, & Henderson, 2009). The transition to parenthood occurs with the arrival of the first child whether through birth or adoption, and may encompass feelings of excitement and anticipation (Medina, Lederhos, & Lillis, 2009). The transition to parenthood “is accompanied by the opportunities and demands for personal reorganisation and growth” (Heath, 2009, p. 119). This occurs as the parents learn to deal with the responsibilities of raising a child. Such responsibilities include social, moral, and legal aspects of the child’s care in order to keep the

child physically, emotionally, and intellectually safe, secure, and happy (Bridgeman, 2007).

Kaitz (2007) explains that the lives of new mothers are particularly affected by the transition to parenthood with concerns about “about their infant’s well-being, their ability to care for their infant, and the impact of life-changes on ‘who they are’, and on their close relationships” (p. 720). Parents must learn to care for their new child as well as learning who they are as parents together and individually. Although the actual arrival of the child is one moment in time, the transition to parenthood continues over a period of time as the parents learn to take on the responsibilities of taking care of a child.

Parenting a Child with a Chronic or Life-Threatening Illness

There is a parallel between becoming a parent and becoming a parent of a child with a chronic or life-threatening illness. The moment of diagnosis of the illness is one moment in time, but the parents learn over time what their child’s illness means for the entire family. This is their transition period as they learn how their child’s illness will affect their lives and their responsibilities. For parents of a chronically or life-threateningly ill child, their responsibility for their child is tested as they must relinquish aspects of the child’s care to the healthcare team as part of the treatment for the child’s condition (Heath, 2009). Decisions made in regards to their child’s treatment are often made in consultation with the healthcare providers (Bridgeman, 2007). It may be difficult for parents to feel any satisfaction about the decisions they make when they concurrently feel helpless and “ultimately responsible for their child’s life by having to make the right decision” (Woodgate & Yanofsky, 2010). In Woodgate and Yanofsky’s (2010) study about parents making decisions regarding participation in clinical trials, wanting what is best for the child was associated with making the ‘right decision’. Making the ‘right decision’ for the child was seen to be fulfilling the role of the ‘good parent’ for families of children with

cancer (Woodgate & Yanofsky, 2010). As a 'good parent,' there may be tension between the parent's duty to protect their child from harm and to treat the child's life-limiting or life-threatening condition. Having to watch their child endure painful procedures and uncomfortable treatments may leave them with a sense of helplessness even though they understand that their child's best interest is in mind (Kars, Duijnstee, Pool, van Delden, & Grypdonck, 2007; McGrath, 2001b).

Taking care of a chronically or life-threateningly ill child may introduce stress on the parents, the child and the siblings. Taking on the role of caregiver in addition to parent of the ill child may impact the other roles of the parent such as parenting the other children (Heath, 2009). For families, living with a child with a chronic or life-threatening illness means living with uncertainty (Bridgeman, 2007; Woodgate & Degner, 2002). There may be uncertainty for the parents about their child's needs and wellbeing (Bridgeman, 2007) and about prognosis, treatment, and follow-up issues (Woodgate & Degner, 2002). Parents stated that 'nothing is carved in stone' which identifies the uncertainty that they face every day once their child was diagnosed with cancer (Woodgate & Degner, 2002). In another study talking to families with children with cancer, Woodgate (2006b) found that during the course of treatment, the child's sense of self merged with the parents' sense of self. This was especially true for the mothers and seemed to follow the pattern of the child's symptoms worsening and being alleviated (Woodgate, 2006b). The mother and the ill child become one unit within the family unit with the mother's energy working towards caring for the child and protecting the family unit (Woodgate & Degner, 2004). The mother's time and energy is therefore limited for the rest of the family and while the father and sibling(s) may understand the importance of supporting the mother in this role, there is a sense of loss of their 'normal' way of life (Woodgate & Degner, 2004). This identifies the

changing roles of parents in families of children with chronic or life-threatening conditions. In short, having a child with a chronic or life-threatening illness impacts the entire family in a variety of ways.

Supportive Care Framework for Parents of Children with Cancer

In Ontario, Canada, a supportive care framework used in one cancer treatment centre has categorized supportive care needs of parents of children with cancer into six groups: informational, emotional, psychosocial, practical, spiritual, and physical (Kerr, Harrison, Medves, Tranmer, & Fitch, 2007; Kerr, Harrison, Medves, & Tranmer, 2004). These categories cover needs related to and independent of the child's cancer diagnosis.

Informational Needs

Kerr et al. (2007) found that parents spoke in detail about informational needs such as having information repeated during the time of diagnosis and treatment and the desire for an opportunity to talk to the physician or other health care professionals when their child was not present. The importance of informational needs about parents' seeking medical information is well documented (Goldbeck, 2001; Ljungman et al., 2003; Sawyer, Antoniou, Toogood, Rice & Baghurst, 2000; Shields et al., 1995; Yeh, 2002). Written information and details about the child's course of treatment was also important (Aitken & Hathaway, 1993; Santacroce, 2002; Shields et al., 1995). The level of involvement in decision-making with an understanding of potential risks and side effects was also identified as an informational need (Pyke-Grimm, Degner, Small, & Mueller, 1999). These are just a few of the documented informative care needs identified by parents.

Emotional Needs

It is not uncommon for family members to experience emotional instability (Patterson et al., 2003; Svavarsdottir, 2005; Sahler, Roghmann, Mulhern, Carpenter, Sargent, Copeland, et al., 1997; Sloper, 2000). The need for emotional support was highlighted and “receiving support professional and personally was essential for these mothers to cope with their child’s diagnosis of cancer” (Kerr et al., 2007, p. 288). According to Svavarsdottir (2005) and Sahler et al. (1997), there has been a lack of attention given to parents’ emotional well-being when they are caring for their child with cancer. Parental adjustment to childhood cancer has been studied but contradictory findings have been found. No significant psychosocial differences were found between parents of children with cancer one year after cancer diagnosis compared to parents of healthy children by Hoekstra-Weebers, Jaspers, Kamps, & Klip (1998) and Sawyer, Antoniou, Toogood, & Rice (1997). Grootenhuis and Last (1997) reported that when compared to healthy controls, parents of children with cancer experienced emotional problems in the same one year post-diagnosis time period. They also found that mothers of children with cancer were more likely to be overanxious and fathers more likely to be depressed (Grootenhuis & Last, 1997). In contrast, mothers of children with cancer were found to experience higher levels of depression, and anxiety than fathers in Yeh’s (2002) study. Svavarsdottir (2005) explains, “new research has shown that mothers and fathers of children with cancer not only experience the illness in their child differently, but also cope with it in a different way” (p. 532). These findings indicate a need for further research in gender differences of parents coping with a child with cancer.

Psychosocial Needs

Social support is an important psychosocial need (Dahlquist, Czyzewski, & Jones, 1996; Hoekstra-Weebers et al., 1998, 2000; Ljungman et al., 2003; Shields et al., 1995; Yeh, Lee, Chen, & Li, 2000). This support includes friends, family, healthcare providers, and other parents

whose child had cancer (Aitken & Hathaway, 1993; Shields et al.; Yeh et al., 2000). Lindahl Norberg and Boman (2007) reported that:

The availability of social support seems to be essential to the maintenance of psychological and physical well-being among parents of children with cancer [and that] subjectively perceived support seems to be a factor most strongly associated with well-being in various contexts. (p.295)

In general, parents of a child with cancer need a good, healthy support system to aid them in coping with the multiple problems (Aitken & Hathaway, 1993).

Practical Needs

Many families experience changes in their financial situation as a result of their child's diagnosis of cancer (Aitken & Hathaway, 1993; Ljungman et al., 2003; Shields et al., 1995; Sloper, 1996) that can become a major source of stress and concern for the families of children with cancer. This is due to the length of treatment, missed days from work, childcare for siblings, transportation to and from hospital stays and clinic visits (Aitken & Hathaway, 1993; Sloper, 2000). Many parents take time off work or quit their jobs entirely when their child is diagnosed with cancer (Goodenough, Foreman, Suneson, & Cohn, 2004; Heath, Lintuuran, Rigguto, Tikotlian & McCarthy, 2006; Limburg, Shaw & McBride, 2008). During treatment in the hospital, out-patient and in-patient, parents have to pay for parking, meals, and transportation. There are non-medical expenses related to transportation, accommodation, and meals while in the urban centre as well as for the family members at home (Goodenough et al.; Limburg et al.). Child care can be an issue because the siblings need to be cared for while one parent is in the hospital or at the clinic with the child with cancer and the other is at work (Aitken & Hathaway, 1993; Dockerty, Skegg, & Williams, 2003; Heath et al.). Completion of daily activities such as

cooking, childcare for siblings, laundry, and respite are also important practical needs (Kerr et al., 2004).

Spiritual Needs

Spiritual and religious support is important to certain families with a child with cancer (Kerr et al, 2004; Patterson et al., 2003). Parents of children with cancer and adults with cancer commonly report using prayer for specific health purposes on a regular basis (Post-White, 2006).

Physical Needs

Physical needs may include those of the child dealing with his or her physical symptoms of cancer and its treatment or of the parents dealing with their own physical symptoms such as dizziness, difficulty sleeping, headaches, and fatigue (Kerr et al, 2004; Patterson et al., 2003; Santacroce, 2002). More discussion on symptoms is provided in the transitions portion of this chapter.

There are a significant number of supportive care needs that are directly and indirectly related to the diagnosis of cancer in a child within a family. The importance of understanding the needs of the family from the parent's perspective relates to how the meeting of these needs will affect the functioning and adaptation of the child throughout the cancer trajectory.

Parents may experience “changes in family dynamics, financial drains, marital stress, employment difficulties, worry, lack of knowledge, dealing with the complex health care system” (Aitken & Hathaway, 1993, p. 4). These problems necessitate parental adaptation and coping. The way that parents adapt and cope to these changes can affect the child's functioning and ability to cope with his/her disease (Grootenhuis & Last, 1997; van Dongen-Melman et al., 1998). Suzuki and Kato (2003) explain that children's adjustment can be affected by their parents coping behaviours; good coping of parents and family members and level of family

support are associated with good coping among childhood cancer survivors and poor parental coping is associated with poor outcomes, especially in young patients. The way the child with cancer reacts emotionally and physically affects the parents' feelings and reactions (Enskar et al., 1997).

As such, their healthcare needs change with each phase and each challenge they incur along the way. As a result of the improvements in treatments for childhood cancer, it is now seen as a chronic disease that continues to affect the life of the child and his or her family. The cancer experience never ends for the children and their families (Woodgate, 2006b).

Transitions in Childhood Cancer

The concept of transition within the childhood cancer trajectory is not novel. In 1993, Clarke-Steffen developed a model of Family Transition to Living with Childhood Cancer. The initial transition begins when there is the "first clue" that the child has a more serious illness. It continues through the diagnostic phase when there is a "possibility of malignancy." At that point Clarke-Steffen (1993) describes the family as experiencing a "fracturing of reality" with the realization of the seriousness of the disease which leads the family to living in "limbo." While in "limbo" the family experiences emotional responses to the diagnosis that may include uncertainty, worry and preoccupation, vulnerability, and helplessness. The family is forced to "reconstruct their reality" by changing roles within the family, re-prioritizing aspects of family life, finding meaning in the diagnosis, looking forward to a different future, managing the amount of information, and accepting the therapeutic regimen. As the family's reality is reconstructed, they develop a "new normal" which is characterized by an altered daily routine, uncertainty, and a different world view (Clarke-Steffen, 1993). Each child and family is unique

and moves through these transitions at different speeds as the child experiences his or her own cancer reality.

Woodgate and Degner (2004) describe transition in childhood cancer in relation to the symptoms the children experience and the effects of those symptoms on the child and the family as a whole. It was identified that the children and their families' thoughts and feelings about cancer frequently corresponded to the change in symptoms (Woodgate & Degner, 2004). Family members changed roles and responsibilities as the child's symptom transition periods changed. The importance of the dynamic nature of the cancer experience is reinforced including recognition of the impacts of symptoms on the daily life of the child and family.

Rural Aspects of Cancer for Children and Their Families

Treatment for childhood cancer is often centralized in tertiary centres that specialize in pediatric oncology (Aitken & Hathaway, 1993; Bensink et al., 2007; Kisker et al., 1980; Klein-Geltink et al., 2005; Scott-Findlay & Chalmers, 2001). This provides the child and the family with care from the experts in the field that is based on study protocols developed through international collaboration among pediatric oncology healthcare providers. These tertiary centres may be near or far from the family's place of residence. When the tertiary centre is far from the family's home, there are several potential issues that may be raised as a result of the distance. These are aspects of the childhood cancer experience that may affect families in urban and rural settings but may be exacerbated due to long distances: financial issues, isolation, health care provider-family-child relationship, primary-tertiary link, distance and epidemiological issues.

Financial Issues

Financial issues have already been discussed in relation to families with children with cancer. While it is recognized that all families, regardless of whether they live in an urban or

rural setting will experience some effect on the family financial situation, there is reason to believe these may be exacerbated for families in rural settings. Many costs are incurred no matter how far the family is driving. Families are often discouraged from using public transportation due to the child's immune-compromised status forcing the family to drive to the hospital. In addition, access to public transportation may be limited depending on where the family lives.

However, the financial issues for rural families with a child with cancer are amplified because of the physical location of their home in relation to the treatment centre. This situation leads to multiple costs, expected and unexpected, incurred during the treatment. Parking, meals, and accommodation are the most frequently mentioned costs for parents of children with cancer in the city (Goodenough et al., 2004). Many families explain that they have to maintain two households, one at home and the other in the city, meaning they are buying food and paying for accommodation for two households. For some that home in the city is in the hospital, a hospice or home-away-from-home like Ronald McDonald House, and for others it is another type of accommodation like a hotel or apartment (Scott-Findlay & Chalmers, 2001). Meanwhile at home child care expenses may be increased for siblings while the parent who is not in the city must go to work (Aitken & Hathaway, 1993). Travel related costs such as gasoline and vehicle maintenance increase as the distance from the treatment centre increases. The parent and the ill child must travel to attend the tertiary centre frequently for treatment and monitoring while the other family members may be travelling in to visit them, thus doubling the travel related costs.

Loss or reduction of income is a common occurrence for families with a child with cancer (Aitken & Hathaway, 1993; Mercer & Ritchie, 1997; Scott-Findlay & Chalmers, 2001). This is generally due to the parent needing to be present for the treatment in the city and looking after the child while at home. Treatment for childhood cancer is intense, physically and

emotionally, especially immediately after diagnosis. Decisions often need to be made quickly and travel must occur as soon as possible so parents must take time off work on short notice and may not return for days or weeks at a time. Many employers are not able to be flexible to accommodate such needs and so the parent must quit or use sick time or vacation hours to get the desired amount of time off work (Aitken & Hathaway, 1993; Goodenough et al., 2004; Kerr et al., 2007; Scott-Findlay & Chalmers, 2001). These are short-term solutions for parents of a child with a chronic medical condition.

Isolation

Isolation may occur in families of children with cancer in a variety of ways and settings (Bensink et al, 2007; Nair, Goodenough, & Cohn, 2006). There is physical separation of the child with cancer and the parent from the rest of the family during treatment because usually only one parent is allowed to stay in the hospital when the child is admitted. There is the potential for emotional isolation that may arise from the diagnosis of a rare, life-threatening disease. These occur for families whether they live near or far from the treatment centre.

The isolation caused by the separation of the parent and child with cancer staying at the hospital may be tempered for urban families as visiting is likely more accessible for the remaining members of the family when compared to families who live in rural and remote locations. Not only are the child and the parent away from family, they are away from friends and other members of their community that may provide different forms of social support. Again, for rural families, this may interfere more often than for families living in the metropolitan centre where the treatment centre is located.

There is isolation for the family members that remains at home as well. Often the parent who stays at home wishes he or she could be present during treatment but is unable to because of

commitments at home such as work, other children, and household management (Scott-Findlay & Chalmers, 2001). The parent at home is isolated from the child, their partner, the treatment, the health care providers, and the support from other children and parents undergoing similar experiences (Aitken & Hathaway, 1993).

The sibling(s) of the child with cancer feel isolated from these aspects of care as well when they often must remain at home during treatment (Aitken & Hathaway, 1993). They are without a parent, often their mother, and their sibling, for long periods of time (Aitken & Hathaway, 1993; Scott-Findlay & Chalmers, 2001). This is difficult to experience and to adapt to for many children and adolescents.

The isolation caused by the separation of the parents is a source of much strain and stress on the parents and children involved (Aitken & Hathaway, 1993; Scott-Findlay & Chalmers, 2001). They are faced with a traumatic event and are forced to be apart sometimes for long periods at a time. They lose their physical support and the emotional support is difficult to maintain from a distance (Aitken & Hathaway, 1993).

Children with cancer and their families may feel isolated from others due to the diagnosis of childhood cancer (Kerr et al., 2007; Nair et al., 2006). Due to the rarity of the disease, few people know what it is like to live with and beyond this chronic condition. This is mediated by support offered at the tertiary centre while the child is admitted to the hospital most notably other children and parents in similar situations (Scott-Findlay & Chalmers, 2001). Conversely, when at home, there is also isolation from support, potential or actual, from centre-based support groups and from other children and their families who are in similar situations with whom they talk and spend time during their in-patient stays. This is reported to be an important source of support for families of children with cancer.

Provision of information and support from a variety of sources is integral for the families with a childhood cancer diagnosis. This may require counselling, written information, support groups with others with similar experiences, and on-going assessment of coping by all members of the family. There may be support programs that are accessible to urban families offered at the tertiary centre or through an urban charity. This provides opportunities for additional support, emotional and/or informational to children with cancer, their parents, and their siblings.

Rural families with a child with cancer may experience isolation from the specialist care that the child requires in order to care for his or her chronic condition (Aitken & Hathaway, 1993; Nair et al., 2006; Scott-Findlay & Chalmers, 2001). This type of isolation is related to the relationship between the child, the family, and the health care professionals.

Healthcare Provider – Parent – Child Relationship

The relationship between the health care provider, the parent(s), and the child is extremely important for the provision of care to the child during childhood cancer treatment (Romaniuk & Kristjanson, 1995). Most treatment protocols are long and intense, both physically and emotionally, for the families involved. This means that this relationship is long-term and develops into a partnership. Effective communication is an important part of this partnership throughout the cancer trajectory between the health care providers and the family. Aitken and Hathaway (1993) found that, “an open relationship with the health care team is important to promote healthy coping” (p. 5). This affects parents’ stress levels which affects how they are able to cope with the diagnosis and subsequent treatment.

Urban families have more immediate access to the oncology specialists therefore may experience a closer relationship with the health care providers. (Scott-Findlay & Chalmers, 2001). This may result from and in better communication between the child, the family, and the

health care team. When something alters the child's health status or a question arises, urban families are able to bring the child with cancer in to the tertiary centre and the specialist will be consulted or at least informed. Urban families may feel closer to the specialist due to the increased frequency of visits. This may result in better communication between the health care provider and the urban family.

According to Scott-Findlay and Chalmers (2001), many families explained that they had to “persevere with local health care professionals before their child was seen by a specialist” (p. 210). This caused a tremendous amount of stress and frustration prior to the childhood cancer diagnosis. This may have also made the families less satisfied with the competencies of the health care providers at the local level when they needed to return to them after the diagnosis. This may contribute to a sense of isolation. The families may experience insecurity when at home because they feel there is not a knowledgeable physician nearby to care for their child if he or she becomes ill suddenly (Kisker et al., 1980). This may reduce trust in the health care provider in the local community.

Some families felt that they understood their child's disease and treatment better than the local health care providers, which also may reduce the amount of trust and respect the family has for these important members of the health care team. It was important for the families to have trust in the local care team because of the long distance to the oncology specialists (Scott-Findlay & Chalmers, 2001). If there is a lack of trust, there is a lack of partnership among the child, the family, and the health care provider.

For families of children with cancer, there are a number of responsibilities for the care of their child that come with the diagnosis of childhood cancer. These responsibilities were increased in some cases when the parent had to perform medical tasks while at home or at the

local health care centre because the local health care professional was uncomfortable or unable to perform the task him or herself. This adds pressure and responsibility to the family. It may also reduce the amount of trust and respect the family has for the local health care professionals (Scott-Findlay & Chalmers, 2001) again affecting the partnership between the family and the health care team.

Even when receiving treatment in the city, families were not always happy with the care provided by health care professionals. Any inconsistencies in care provided by different professionals, made some of the family suspicious and some felt they could not leave their child's side in order to observe every aspect of care provided to the child. This added to the family's stress level significantly (Romaniuk & Kristjanson, 1995; Scott-Findlay & Chalmers, 2001). Some families felt that during the treatment the specialists in the tertiary centre failed to understand and take into account, their rural situation (Scott-Findlay & Chalmers, 2001). At the tertiary centre, there may be less familiarity between the specialist and the child when they are from rural area. A high level of communication may be hindered for rural families when compared to urban families due to long-distance phone calls that lack the face-to-face contact (Aitken & Hathaway, 1993).

Primary – Tertiary Link

Prior to and after a diagnosis of cancer, a child is usually under the care of a primary care provider such as a family physician, a pediatrician, or a nurse practitioner who is responsible for the health care of the child. When the child receives a diagnosis of cancer, the responsibility or care is transferred to a pediatric oncologist or hematologist depending on the diagnosis. The link between the specialist and the generalist is important for the health and satisfaction of care provided to the child and his or her family along the cancer trajectory and into survivorship.

Communication between the health care providers is important in order for the care to be coordinated. At the tertiary care centre, treatment for childhood cancer is provided by a multidisciplinary team (Arceci et al., 1998). This team often includes doctors, nurses, social workers, physical, occupational, and speech therapists, child psychologists, genetic counsellors, and others. The multidisciplinary team must be well-managed and coordinated. With this tremendous amount of expertise from a variety of sources, a continuity of care must be ensured in order for the care to become fragmented. This fragmentation may cause increased levels of stress and responsibility on the family.

The primary-tertiary link may be physically closer for urban families but that does not ensure that the communication is at the appropriate level. The interprofessional team must maintain the communication with the primary care provider. For urban families, access to the specialty services is increased. Appointments with the members of the interprofessional team may be able to be made as an out-patient which allows the child to remain at home. This reduces the interruption of their daily lives and keeps family members together more often.

For families living in rural areas, the access to the specialists at the tertiary centre may be reduced. This may occur for many reasons. The most obvious reason is that they are far removed from the tertiary centre and the service may not be offered in their rural location. They may not receive the service due to this or they may have to remain in the city either as an in-patient or in other accommodation in order to see the specialist. This puts added pressure on the family: if they stay in the city, they are away from family and friends for longer and incur higher expenses, if they return home, are they affecting the child's treatment and recovery by not obtaining all the services offered to them.

According to the position statement of the American Society of Pediatric Hematology/Oncology by Arceci et al. (1998), the overall coordination of care should be at the tertiary centre but the primary care provider remains important. They state that “in more rural areas, the need for this type of coordination of care and outreach services is further underscored” (Arceci et al., p. 102). Rural families have concerns about continuity of care when care is provided by local health care providers who may have no or very little experience in caring for a child with cancer. This may increase the child’s and the parents’ anxiety during a very stressful time in their lives.

Several methods to address the communication and coordination of care among the primary and tertiary care providers have been initiated in certain care centres for children with special health care needs. In certain areas of the United States of America, telemedicine programs that link the child, parent, primary care provider and the tertiary centre specialist have been established (Marcin, Ellis, Mawis, Nagrampa, Nesbitt, & Dimand, 2004). Many benefits are discovered using this method of communication including increased satisfaction of care from the physicians and the family’s perspectives. Two other centres implemented a program with a specialised nurse as the coordinator of services (Farmer, Clark, Sherman, Marien, & Sleva, 2005; Gordon, Colby, Bartlet, Jablonski, Krauthoefer, & Havens, 2007). These programs reported positive effects for the children and their families and decreases in hospitalisations and length of stays in the hospital (Farmer et al.; Gordon et al.). In Australia, a pilot study has been undertaken to test the cost-effectiveness of a videotelephone support service for rural paediatric oncology patients and their families (Bensink et al., 2008). All families expressed satisfaction with this service and combining videotelephone, home computers, and telephones proved to be more cost effective (Bensink et al., 2008). Overall, rural families of children with cancer have a “lack of

specialized health care resources, lack of counselling services, and a lack of communication between urban and rural health care providers” (Scott-Findlay & Chalmers, 2001, p. 214).

Distance

The distance from the family’s home to the tertiary centre may affect several aspects of care including how the child is transported to and from the treatment centre. Some families travel enormous distances for treatment such as children from Nunavut and northern Manitoba who travel more than 450 kilometres one way (Scott-Findlay & Chalmers, 2001). Personal vehicles are often used with one of the parents driving the child. Planes may be required for certain areas that are less easily accessed by land. Trains are an option in locations that are equipped with such services. Regardless of how the child travels to and from the treatment centre, issues surrounding weather, safety, and side effects may complicate the process. For example, in many parts of Canada, roads may be covered with snow or ice for many months of the year, increasing the danger of car crashes. Winds, rain, and snow can also cause delays in flights. Children with cancer are often dealing with symptoms of the disease itself or treatment side effects. As such, travel may exacerbate certain symptoms such as nausea or pain.

Epidemiological Issues

The search for the cause of childhood cancer is ongoing. When clusters of diagnoses for rare cancers occur in a specific area, research is conducted in order to understand why. Causal relationships between pesticides and childhood cancer have not been identified (Walker, Carozza, Cooper, & Elgethun, 2007).

There are two infectious hypotheses for the cause of childhood leukaemia: Greaves’ (2006) “delayed infection” and Kinlen’s (1995) “population-mixing” hypotheses (Chang, Metayer, Fear, Reinier, Yin, Urayama et al., 2007; Greaves, 2006). As Greaves (2006) explains,

“the body of epidemiological evidence now available is consistent with the view that many childhood leukaemias arise as a consequence of an abnormal immune response to common infection(s), but the mechanisms remain to be determined” (p. 194). Several studies were identified testing the immune system hypothesis (Chang et al., 2007; Clark, Ferketich, Fisher, Ruymann, Harris, & Wilkens III, 2007; Kinlen, Jiang, & Hemminki, 2002; Stiller, Kroll, Boyle, & Feng, 2008). All of these articles support the infectious hypothesis for the cause of childhood leukaemia.

Using the “population mixing” hypothesis, urban children are relatively resistant to epidemics (Kinlen et al., 2002) due to higher population density and higher prevalence of immune individuals (ie. herd immunity). Rural children, being around a higher prevalence of susceptible individuals, are more vulnerable to infective outbreaks, when exposed to infected individuals (Kinlen et al.).

For children with cancer in developing countries, abandonment is a serious threat to children’s survival when diagnosed with cancer (Arora, Eden, & Pizer, 2007). One of the associated links with abandonment in developing countries that has been uncovered is prolonged travel time. Although, this does not reportedly happen frequently in developed countries, it is important to note within the broader perspective of childhood cancer.

Rural Aspects of Cancer for Adults and Their Families

Regardless of which member of the family has been diagnosed with cancer, the family is separated while the patient is receiving treatment in the tertiary centre (McGrath, 1998). The family is faced with coping with the illness of one of its members in addition to the separation caused by the patient’s, and perhaps a young child or family caregiver’s, relocation to the metropolitan centre near the tertiary centre (McGrath, 1998). This means that the parent’s work

and/or the children's school may be interrupted, that someone must be available as a caregiver to the patient when required. Roles may need to be renegotiated with the reorganization of family life (Clavarino, Lowe, Carmont, & Balanda, 2002). Social support is disrupted as a result of being away from home for cancer treatment (Payne, Jarrett, & Jeffs, 2000). Travel to the treatment centre may be considered something as minor as an inconvenience to something as major as a barrier to treatment (Payne et al.).

Families with a member requiring specialist cancer treatment in a major tertiary centre far from their rural homes have reported many practical needs that remain unmet. In Australia, several studies have identified such practical needs as information deficits regarding treatment options, travel to and within the metropolitan centre, accommodation while receiving treatment, and the economic impact of travelling to the tertiary centre for treatment (Wilkes, White, Mohan, & Beale, 2006). Clavarino et al. (2002) found that both the rural patient and their caregiver have unmet needs in the psychological domain and the rural carers reported higher levels of unmet needs surrounding information and assistance with the health system in general. Financial concerns were highlighted in both these Australian studies (Clavarino et al., 2002; Wilkes et al.).

Survivorship in Childhood Cancer

The number of children living beyond their diagnosis of cancer is increasing at a dramatic rate. In Canada, the observed survivor proportions for all cancers at one year is 92%, at three years is 85%, and at five years is 82% (Ellison et al., 2007). This translates to a growing number of children and young adults who will live and contribute to society for many years as a survivor of childhood cancer. Along with the child, their entire family survives the cancer experience.

As treatment has improved the likelihood of survival, researchers have examined the experience of the family with a child with cancer from perspectives of the child, the parents, and

the siblings along the childhood cancer trajectory. Much has been learned about the initial transition the family must undergo at diagnosis and to the adjustment to long-term survivorship. However, relatively little has been done to explore the experience of families immediately following the completion of treatment for cancer (Maurice-Stam et al., 2007; Van Dongen-Melman et al., 1998). Research has concluded that support for patients and their families should not end with the completion of cancer treatment (Stam, Grootenhuis, Brons, Caron, & Last, 2006)

The transition period once treatment for cancer is finished is a time of change and uncertainty (Labay et al., 2004). Arnold (1999) described it as a time of crisis that creates anxiety and uncertainty. The anxiety may be related to the parents' ability to assess and respond to the child's physical and mental health needs (Labay et al.). Children who have had cancer and their families have been reported to experience symptoms of post-traumatic stress symptomatology/disorder (Kazak et al., 1997; Ozono, Saeki, Mantani, Ogata, Okamura, & Yamawaki, 2007). Haase and Rostad (1994) provide a description of children completing cancer treatment as a time of celebration and hope coupled with uncertainty and fear. The family returns back to their home and the child is no longer monitored as closely as they were at the tertiary centre during the treatment phase. There may be feelings of abandonment from the healthcare providers who focus more on the child in treatment than those who have completed it (Labay et al.). Not physically being at the tertiary centre, the families may lose means of practical, informational, and emotional support from the healthcare team, other children, and other families who share similar experiences (Labay et al.). Stam et al. (2006) suggest that the completion of treatment is one of the major transitions in pediatric oncology and as such, deserves special attention.

Late and Long-Term Effects of Childhood Cancer

Despite the increase in the number of children who complete treatment for childhood cancer, there are a large number of survivors who experience late or long-term effects from either the cancer itself or its treatment (CCS, 2008; Mehta, 2008). These effects include problems related to cardiopulmonary, endocrine, hepatic, musculoskeletal, gastrointestinal, renal or pulmonary dysfunction, neurocognitive impairments and the development of second cancers (CCS; Elson & Mehta, 2008). Long-term follow-up is necessary for these children in order to monitor late and long-term effects. A recent report indicates that nearly two thirds of childhood cancer survivors with have at least one chronic health condition, with over a quarter reporting a severe or life-threatening health condition (Oeffinger et. al., 2006). Most families must learn to live with the uncertainty of possible relapse of the child's cancer or of long-term or late effects of the treatment the child has received (Duffey-Lind et al., 2006; Labay et al., 2004).

Not only do the children who survive cancer experience late and long-term effects from the treatment, the child's family may also experience effects after the completion of treatment. Stam et al. (2006) measured the health related quality of life of the child and the parental emotional reactions within months of the completion of treatment for childhood cancer and compared them with the general population in the Netherlands. They report that both the patients and the parents experience worse well-being than the general population to a clinically relevant degree (Stam et al., 2006). Another Dutch study demonstrated that parents experience psychosocial consequences that continue for years after the completion of treatment without decreasing; uncertainty and loneliness were the most reported problems (van Dongen-Melman, Pruyn, De Groot, Koot, Hahlen, & Verhulst, 1995). These psychosocial problems increased when the parents were confronted with the child's medical late-effects and mothers experienced

more late psychosocial problems than fathers, in this particular study (van Dongen-Melman et al., 1995).

Both children who have survived cancer and their families have been reported to experience symptoms of post-traumatic stress symptomatology/disorder (PTSS/PTSD) (Kazak et al., 1997; Ozono et al., 2007). To date, findings are inconsistent in regards to PTSS and PTSD in children with cancer and their parents making it difficult to guide clinical practice (Bruce, 2006).

Long-term follow-up is required for children who have completed treatment for cancer in order to monitor late or long-term medical, psychological, and psychosocial effects. Follow-up should also include an assessment of the child's parents and siblings in order to ensure the family is coping as well as it can.

Rural Childhood Cancer Survivors and Their Families

There is a paucity of information about children who have completed treatment for cancer and their families who live in rural and remote locations. After the completion of treatment for childhood cancer from a tertiary centre, rural families are far from healthcare providers who are familiar with their child's diagnosis, treatment, and subsequent follow-up requirements.

Only two studies that look at rural children who have survived cancer were located. Both use quantitative methods to measure academic and social abilities (Olson et al., 1993; Samardakiewicz & Kowalczyk, 2007). The earlier study looked at 20 rural childhood cancer survivors and compared their social competence, emotional health, academic performance, and physical limitations to those of age and gender-matched peers (Olson et al.). Their rural survivors demonstrated strong self-esteem, normal social interaction, normal participation in group activities, poorer academic performance, more perceived absenteeism, more behavioural

problems, and poorer communication skills (Olson et al.). The more recent study evaluated the psychosocial and cognitive functioning of 29 rural childhood cancer survivors five years after the completion of cancer treatment (Samardakiewicz & Kowalczyk, 2007). Most of the rural childhood cancer survivors studied did not reveal difficulties with cognitive and psychosocial functioning however difficulties in verbal tasks were suggested and school absence remained a problem (Samardakiewicz & Kowalczyk, 2007).

These studies add to the understanding of how rural childhood cancer survivors live beyond completion of treatment. However, much remains unknown about rural children and their families' experiences of the completion of childhood cancer treatment and beyond. The transition experience from treatment to completion of treatment remains unknown for rural families. This gap in the literature is what prompted the development of this thesis project.

Canada has a large rural population and a vast expanse of land that spans great distances. As a result, about a third of pediatric cancer patients travel more than 100 km for treatment (Limburg et al., 2008). In Manitoba, a province in central Canada with an area of 649,947 square km (250,946 square miles) (Government of Manitoba, 2009), there is one tertiary centre in the capital city of Winnipeg. Approximately 55% of the population lives in Winnipeg leaving 45% to live in rural areas (City of Winnipeg, 2009). There are many rural children who have completed treatment for childhood cancer and their families residing in Manitoba and across Canada. This project will serve to learn about the lived experience of parents who have a child who has completed treatment for childhood cancer who live at a distance from the cancer treatment centre.

Chapter Summary

This chapter has provided a review of the literature surrounding children with cancer and their families during and after treatment. It contained rural aspects in addition to survivorship aspects of childhood cancer for the child and the family. This review provides the basis upon which this research project developed. The following chapter explains the method that was used in order to complete the thesis study.

CHAPTER THREE: METHODOLOGY AND METHOD

Introduction

The following chapter provides insight into the conceptual framework guiding the study and the research methodology and method that was used to address the study's purpose and research questions. The conceptual framework provided the structure for the chosen phenomenon to be studied. The relevance of the chosen framework for this study will be highlighted.

According to van Manen (1990), research methodology refers to the philosophic framework or theory supporting the method that includes directing what method should be used and for what reason. The method refers to the mode of inquiry using procedures and techniques to accomplish the research (van Manen, 1990). The methodology section will introduce the reader to the philosophical underpinnings of the qualitative approach of phenomenology. In the method section, the design, participation criteria, and the data collection and analysis methods are described. To conclude, measures of rigour, potential limitations of the study, and ethical considerations are discussed.

Conceptual Framework

Models and theories are integral to the profession of nursing because they serve to guide research, practice, education, and administration (McEwen & Wills, 2007). The Life Needs Model (King, Tucker, Baldwin, Lowry, LaPorta, & Martens, 2002) was chosen as the conceptual framework for this research study.

The Life Needs Model

King et al.'s (2002) Life Needs Model is a relatively new model that is both a conceptual framework and a model of service delivery (King et al., 2002). The key aim of the model is "to support children's participation in all areas of life, so that they thrive in their communities, rather

than simply function” (King et al., p. 58). The needs of the children, families, and community members are specified integrating a family-centred care approach. They provide programs that are structured to meet the children's age-specific needs while focusing on key transitions in the children's lives (King et al.). The nature of this model is community-based. The model is based on a holistic approach of enablement, empowerment, and is focused on needs and partnerships (King, Tucker, Baldwin, & LaPorta, 2006). The community focus is valuable for children with cancer and their families living in rural and remote locations. Support within the family's community is a critical aspect of coping with the child's diagnosis along the cancer trajectory (Scott-Findlay & Chalmers, 2001).

Within the Life Needs Model, life processes are recognised and services are organised to suit the child's age with special attention paid to transition points within the child's life when “concerns often arise for children and family” (King et al., 2002, p. 69). There is recognition of the importance of these transition points, such as starting school or completing high school, for the child and the family and that transitions are processes rather than one point in time (King et al.). For children with cancer there are the additional transition points of starting treatment, returning to school after diagnosis, completing treatment, and long-term follow-up. The Life Needs Model addresses the interaction of the child in his or her environment and aims to improve the child's participation and quality of life within his or her own community. Using a holistic view of the child, the model identifies “the child's physical, social, emotional, communication, and behavioural needs” (King et al., p.71). Services are provided based on these needs that involve and affect the child's health. Community is not only the environment in which the child lives, but also where the child participates. Members of the community are included in the model as the community's needs are evaluated and used to structure the provision of services.

The Life Needs Model names five types of commonly identified needs: the child's needs for foundational skills, the child's applied skill sets related to day-to-day function in the real world, the child's needs for support and information, the parents' and family members' needs for support, information, and skill development, and the community members' needs for information and education (King et al., 2002). This identification of needs as well as the recognition that transition points are time of changing needs is what makes this model so unique and so well suited for use with children with cancer from diagnosis through completion of treatment and beyond.

For this project, the research question focused on the experiences of parents living at a distance from the cancer treatment centre during the specific transition point when their child completes cancer treatment. Within the Life Needs Model, the parental needs for support, information, and education are one of the five commonly identified needs. The parent's explanations of their experiences should lead to a deeper understanding of their needs and may indicate how care can be improved by changing the level of support, information, and education that is provided to parents prior to, during, and after this transition period. The Life Needs Model also highlights the importance of transition points in children's lives that affect the entire family. Anticipation of the transition period is an important aspect of improving care for children and their families (King et al., 2002). This research question aimed to explore how parents feel their needs could have been better anticipated prior to the conclusion of their child's cancer treatment.

Method

Qualitative Research Overview

This study used a qualitative research design because little is known about the experience of parents living in rural and remote locations transitioning to a time when their children have

completed treatment for cancer. According to Creswell (2007), qualitative research designs are used to explore topics in order to arrive at a “complex, detailed understanding of the issue” (p. 40). The written account of the findings in this qualitative study includes “the voices of participants, the reflexivity of the researcher, and a complex description and interpretation of the problem” (Creswell, 2007, p. 37).

The purpose of this study was to explore the meaning that rural parents attribute to the transition period completion of their child’s cancer treatment. As such, it was a question about human experience that required an inquiry about a phenomenon experienced by an individual at a particular time in a particular setting. Phenomenology, the study of a phenomenon (van Manen, 1990), was chosen to study the phenomenon of completing treatment for childhood cancer while living in a rural location.

Phenomenology

The methodological approach of phenomenology is grounded within the worldview of social constructivism. Within this worldview, the focus is on the participant’s viewpoint in order to arrive at an understanding of the participant’s experience and the subjective meanings of their experience (Creswell, 2007). The researcher recognizes her own participation within the research process which is the interpretation of information provided by the participants. This interpretation is undertaken within the context of the researcher’s background and experience (Creswell, 2007). Inherent in the constructivist worldview is the assumption that there are multiple realities based on individual’s experiences.

Hermeneutic phenomenology is the study of persons in order to learn about the uniqueness of individual people experiencing the same phenomenon (van Manen, 1990). As van Manen (1990) explains, “phenomenology is the systematic attempt to uncover and describe the

structures, the internal meaning structures, of lived experience” (p. 10). The aim of hermeneutic phenomenology is to transform the lived experience into textual expressions of its essence making it fundamentally a writing activity (van Manen, 1990). The essence is the aspect of the phenomenon that if missing, the phenomenon would not exist (van Manen, 1990).

The current research project explored the unique experiences of each parent who has a child who has completed treatment for cancer and who lived in a rural or remote location. It is the parents’ meanings of their experience that were the ultimate answers to the research question. The study described and interpreted the transition experiences as recounted by the parents who participated in this project in order to uncover the essence of the lived experience of rural parents who live with children who have completed treatment for cancer. It was for this purpose that hermeneutic phenomenology was chosen for this thesis project.

The philosophical underpinning of phenomenology is based on writings of Husserl and Heidegger. This study uses Heideggerian phenomenology but both are described in order to provide context for the chosen approach.

Husserl. Edmund Husserl (1859-1938) was a German mathematician and philosopher who is credited as the founder of phenomenology (Zahavi, 2003). Intentionality is a central concept to Husserlian phenomenology. He explained that intentionality is the internal experience of being conscious of something (Moustakas, 1994). Husserl was interested in the “essential nature” and the “cognitive dimension of consciousness” (Zahavi, p. 13.) His aim was to describe how the world is experienced in a conscious manner without pre-conceptions or theorizing (van Manen, 1990) as provided using a first-person perspective (Zahavi). Husserl introduced the term “lifeworld” to describe “the original, pre-reflective, pre-theoretical attitude” (van Manen, 1990, p. 7) of everyday life. According to Husserl, bracketing is an important step in phenomenology

because it separates what is pre-conceived or understood by the researcher in order for the essence of the phenomena to emerge from the individual describing the phenomena (van Manen, 1990). Description of the phenomenon is made possible from descriptions provided by participants who have experienced the phenomenon of interest. These descriptions are analyzed and broken down into statements of meaning that provide a depiction of the essence of the phenomenon with no interpretation from the researcher. A description of the essence of the phenomenon is the goal of Husserlian phenomenology. Husserl's phenomenology is referred to as a transcendental type of phenomenology (van Manen, 1990).

Heidegger. Martin Heidegger (1889-1976) was a German philosopher who studied under Edmund Husserl. Heidegger expanded on Husserl's writings and defined phenomenology as ontology, or the study of "being in the world" as a human being (van Manen, 1990). The nature or meaning of the phenomenon is how its "being" is described by the participant (van Manen, 1990). This was the birth of hermeneutic phenomenology. As opposed to Husserl, Heidegger believed that phenomenology was a reciprocal activity that required not only the description of the experience of the phenomenon by the individual but also the interpretation of that description by the research (van Manen, 1990). The interpretation is accomplished by the researcher who uses his or her prior experience to uncover meanings in the descriptions provided by the participants of the study. In contrast to Husserl's requirement of bracketing, Heidegger advised researchers not only to explicitly identify their prior knowledge, preconceptions, and biases, but also to describe whether or not they affected the data collection and analysis (Annells, 1996). The goal is to produce a textual representation of the phenomenon described (Kleiman, 2004). Thus, Heidegger is associated with interpretive phenomenology.

This study uses van Manen's (1990) method of hermeneutic phenomenology which is based on Heidegger's method. As such, I have documented my assumptions in a previous chapter and will acknowledge them throughout the data analysis and findings. Van Manen (1990) provides a descriptive guide to conducting research on lived experience in order to produce "accounts of experienced time, space, body, and human relation as we live them [rather than] empirical or theoretical observations or accounts" (van Manen, 1990, p. 184). The participants provide the accounts that are interpreted by the researcher in order to provide a description of the lived experience of the phenomenon of interest.

Research Design

The qualitative research design of phenomenology was used in this study in order to answer the guiding question. In this project, the guiding question was "what is the lived experience of parents who do not live near their child's cancer treatment centre as they transition to a time when their child has completed treatment for cancer?" Hermeneutic phenomenology is a human science that studies individual people (van Manen, 1990). It is the study of the lifeworld, understanding meaning in everyday experiences as they are experienced (van Manen, 1990). This lifeworld is the natural everyday life of the individual before reflection or theorizing occurs (van Manen, 1990). The reflection occurs as the research occurs, bringing consciousness to the everyday experiences and the meanings found within. Therefore, human science research is a manner of being and becoming (van Manen, 1990).

Phenomenology seeks to capture the lived experience of a particular phenomenon by attending to the perceptions of those living the experience with the aim to identify and describe the essence of the experience (Streubert & Carpenter 1999, van Manen, 1990). The participants in phenomenological inquiry are persons who have experienced the phenomenon of interest, and

are able to articulate the meaning of their experience (Creswell, 2007). Van Manen (1990) describes that “the aim of phenomenology is to transform lived experience into a textual expression of its essence” (p. 36). Phenomenological reflection is retrospective because in order to reflect on an experience, an individual must recollect an experience that is already lived through (van Manen, 1990).

Table 3.1

Van Manen’s (1990) human science method for hermeneutic phenomenology: The research process

Van Manen’s (1990) Methodological Themes	Research Activities for this Study
Turning to a phenomenon which seriously interests and commits us to the world.	Literature review, proposal, recruitment of participants.
Investigating experience as others live it rather than as they conceptualize it	In-depth, semi-structured interviews
Reflecting on the essential themes which characterize the phenomenon	Analysis
Describing the phenomenon through the art of writing and rewriting	Interpretation of emerging themes, writing and re-writing themes
Maintaining a strong and oriented pedagogical (nursing) relation to the phenomenon	Refer to the research question and purpose, nursing experience and literature
Balancing the research context by considering parts and the whole	Movement from themes to the entire transcripts of individual interviews

Sample Selection Criteria

Using a phenomenological approach requires the participants to have experienced the phenomenon of interest and to be able to describe the meaning they attribute to that phenomenon in their lives (Creswell, 2007). Data is collected from individuals who have experienced the phenomenon by the inquirer who compiles it into a “description of the essence of the experience for all individuals (Creswell, 2007). As Moustakas (1994) explains, this is a description of “what” the individuals experience as well as “how” they experienced it. Individuals met the criteria for this study if they:

1. were male or female, and;
2. were aged 18 years or over, and;
3. were able to speak, read and write English, and;
4. were the primary caregiver (a parent/ legal guardian/caregiver) of a child (aged 0-18 years at diagnosis) who has completed treatment for childhood cancer at least three months ago but not more than five years ago, and;
5. lived outside the metropolitan centre containing the tertiary cancer centre at which the child was treated, with a travel time of at least an hour from their residence to the cancer centre, and;
6. were willing to participate in the study by providing written consent (Appendix E).

NB. Parent is a person in a parenting role regardless of biological associations with the child/children.

NB. The parents were asked if they would like to be interviewed together or separately. Their decision dictated whether they are interviewed as a couple or individually.

Participant Access

Ethical approval for research with humans was obtained from the University of Manitoba Education and Nursing Research Ethics Board (ENREB). Participant access was received from the CancerCare Manitoba Research Impact Committee.

Sample Recruitment

Parents of children who have completed treatment at least three months ago and not longer than five years ago living outside Winnipeg were recruited for this study. The purpose of the study was to learn what it is to be a parent of a child who has completed treatment for cancer living at a distance from the tertiary cancer centre. In order to achieve this, recruitment required the family's residence to live at least an hour's drive from the tertiary cancer centre. All families

recruited lived at least a two hour drive from the cancer treatment centre. The time frame of at least three months and no longer than five years from completion of treatment allowed the parents to commence their experience of the transition period between treatment and the completion of treatment without having too much time pass that the parents may not recollect the specific details of the transition experience.

A letter of invitation to participate in this study was sent from CancerCare Manitoba to parents of children who have completed treatment for cancer who were/are treated at CancerCare Manitoba (Appendix A). This letter included information about the investigator (her student status and affiliation with the university) as well as an overview of the purpose of the study was provided to potential participants. This letter was mailed to parents of a child who has completed treatment for cancer at least three months ago but not more than five years ago who lived outside Winnipeg. Contact information for the Principal Investigator was included in the letter.

Parents interested in taking part in the study were able to contact the investigator via phone, e-mail, or post. When potential participants contacted the Principal Researcher, a script was used to provide information about the study (Appendix B). Once the participants agreed to participate in the study, an appointment was scheduled to meet for an interview. The interview was scheduled at a time that mutually agreed upon by the participant and the Principal Researcher. The interviews were conducted at the participants' homes and in one hotel room. Prior to commencing the interview, a formal consent was signed and the participant was informed that he/she was free to leave the study at any time or to refuse to answer a question. Parents were told that confidentiality would be maintained and that none of their interviews will be shared with the physicians, nurses, and others responsible for the child's care at CancerCare Manitoba.

In addition to the invitation letter sent from CancerCare Manitoba to potential participants, a follow-up phone call from a research nurse at CancerCare Manitoba occurred approximately three weeks after the letter has been sent out. This research nurse was not affiliated with this study or with the Principal Investigator. This phone call served as a reminder of the study and prompted parents to contact the Principal Investigator.

Sample Size

There is no formula to determine appropriate sample size in phenomenology. All participants must have experienced the phenomenon in order to be considered for the study. One theorist suggests that five to 25 individuals should be interviewed for a phenomenological study (Polkinghorne, 1989). For this study, letters were sent to 22 parents from of children who have completed their cancer treatment. Two families were unable to be interviewed in English and so were ineligible for the study. Five parents consented to participate in the project.

Setting

Participants in this study were asked where they would prefer to be interviewed and a location suitable to both the participant and the researcher was chosen by the participant. Two of the initial interviews took place in the parent's home, one in a hotel room in which the parent and child were staying for the weekend, one in the parent's place of work, and one in a restaurant. The interviews at the homes and the place of work consisted only of the interviewer and the parent. During the interview in the hotel room, the child who had completed cancer treatment was present throughout and the child's cousin arrived near the end of the interview. The interview at the restaurant was with the parent in a quiet corner but a waitress was present for short periods of time during which the interview paused until she had left.

Assumptions

Guiding this research study were assumptions based on the philosophical beliefs of the qualitative research paradigm as well as the conceptual framework of the Life Needs Model.

These assumptions included:

1. There are multiple realities as everyone has his or her own individual experiences (van Manen, 1990).
2. The researcher and the participants interact during the study as data is obtained thereby changing both the researcher and the participant (van Manen, 1990).
3. Parents are the “experts on their child, their family, and their strengths, needs and values” (Rosenbaum, King, Law, King, & Evans, 1998).

Data Collection Methods

Data were collected using a demographic form (Appendix C), in-depth semi-structured interviews, and field notes.

Demographic Form

A demographic form (Appendix C) was developed that was completed by all participants. This form was completed at the beginning of the interview as an attempt to build rapport between the parent and the investigator. The demographic information provided a description of the individual participant as well as the population in this study.

In-Depth, Semi-Structured Interviews

The purpose of the interview in hermeneutic phenomenological human science is two-fold. The first is to explore and gather narratives that may be used to develop a multifaceted understanding of the phenomenon of interest (van Manen, 1990). The second purpose is to uncover the meaning of an experience through the conversational relationship with the interviewer and interviewee (van Manen, 1990). The use of a conversational interview does not

mean that there is no structure, rather that the process is disciplined “by the fundamental question that prompted the need for the interview in the first place” (van Manen, 1990, p. 66). The guiding question of the study focuses the hermeneutic interview and in doing so, often the participant begins to care more about the subject and the research question, subsequently becoming a co-investigator of the study (van Manen, 1990). All interviews were recorded and transcribed verbatim. Initial interviews ranged in length from approximately 45 minutes to an hour and a half.

An interview guide (Appendix D) was developed with questions and probes in order to start each conversation in a similar manner. However, the interview guide questions focussed on answering the study’s guiding question but did not restrict the investigator to only the guide questions. Parents were involved in open-ended qualitative interviews that helped to elicit detailed responses deemed significant to the study’s purpose, but were also afforded the opportunity to talk about what really matters to them (Morse & Field, 1995). The open-ended nature of the questions allowed the participant to answer the questions and to add further details of experiences as they chose. Restrictions based on closed-ended questions were therefore not applied to the interviews. Follow-up questions were based on information shared by the participant rather than on a strict list of questions that would be in a closed-ended questionnaire. Each parent who wished to participate in this study was interviewed individually at their own request. This was done in order to capture each person’s distinct experiences without the potential influence of the other parent (if applicable).

As the collaborative conversation continues, the participant is encouraged to reflect on their experience in order to uncover the meaning of their experience for him or herself (van Manen, 1990). One interview with each participant occurred with a possibility of a second that

provided time for reflection about what the participant said in the first interview. The follow-up collaborative hermeneutic interview uses information gathered in the previous conversation to interpret the significance of the themes on the guiding question of the study (van Manen, 1990). A list of general follow-up questions for all the parents was created as well as individualized questions based on each initial interview (Appendix F). This list was e-mailed to the participants as a second interview at the parents' consent as a means of follow-up. The participant was given the opportunity to clarify aspects of the initial interview that described his or her experience of the phenomenon. Two parents responded by answering some of the follow-up questions. This resulted in an additional five pages of transcripts.

Field Notes

Field notes were compiled after each interview and at each stage of the study as an additional source of data collection. They were recorded by the researcher to provide information about the process of the research including a description of the interview experience for the interviewer and include assumptions and pre-understandings about how parents who live at a distance from the cancer treatment centre experience the transition home upon completion of their child's cancer treatment prior to the first interview. Information included in field notes was thoughts, feelings, and insights of the researcher prior to, during and after each interview and analysis session. Descriptions of the location of the interview, the interaction between the interviewer and interviewee, and any other pertinent information about the data collection process were incorporated in the field notes. The organization of the field notes was done temporally, starting at the beginning of each activity and ending at the end (Emerson, Fretz, & Shaw, 1995). One advantage of the comprehensive approach is that the field notes will include all events including those that may have seemed unimportant at the time (Wolfinger, 2002).

Data Analysis

Data analysis occurred concurrently with data collection and as described by hermeneutic phenomenologist Max van Manen (1990). Van Manen's (1990) approach combines characteristics of descriptive and interpretive phenomenology with the aim of grasping the essence of the parents' experiences. This is accomplished through the reflective activity of writing as a means of conveying the essence of the lived experience (van Manen, 1990).

Following transcription of each interview, the recording was listened to and compared with its transcript in order to ensure accuracy. Phenomenological reflection, which involves conducting thematic analysis and determining essential themes, results in an understanding of the essential meaning of the experience (van Manen, 1990). Recordings and transcripts were reviewed repeatedly for significant statements in an attempt to find meaning and understanding through themes, which are the structures of experience (van Manen, 1990). Finding meaning and understanding occurred through a process of uncovering thematic aspects and isolating thematic statements (van Manen, 1990). Uncovering thematic aspects recognizes that a phenomenological theme describes one aspect of the experience but is unable to describe the entire lived experience on its own (van Manen, 1990). Thematic statements were isolated using van Manen's (1990) approaches: the wholistic approach, the selective or highlighting approach, and the detailed or line-by-line approach (p. 92-93). The wholistic approach views the text as a whole in order to determine the fundamental meaning. The highlighting approach draws attention to statements or phrases that seem to be essential in the description of the experience. Each sentence is examined to find what it reveals about the phenomenon of interest. It is not only a matter of putting the participants' words onto paper but is a dynamic process of interpretation of the findings by

means of a descriptive account. A creative process occurred as the essence of the lived experience is exposed in writing.

As this study is part of a Master of Nursing thesis project, collaborative analysis was used whereby my thesis advisor participated in discussions about themes and they were clarified, examined, and re-interpreted (van Manen, 1990). This resulted in the co-creation of the study's essence and themes by myself and my thesis advisor. Not only did this provide me with guidance and experience in thematic analysis, but it was a method of ensuring that my interpretation of the material is an appropriate representation of what the participants shared. Only the researcher and her advisor read the interviews and only the researcher had access to the data that is identifiable to each participant.

Measures of Rigour

Rigour is a means of bringing credibility to research. Creswell (2007) explains that rigour is established with extensive data collection occurs in the field or when multiple levels of abstraction is conducted by the researcher. In order to be rigorous, the researcher must also use at least one method of validation of the accuracy of the account (Creswell, 2007). In this study, participants were given the opportunity to validate their accounts during the second interview. In addition, my advisor was consulted as an external auditor of the account.

Rigour is often associated with reliability and validity. There is some debate within the qualitative research community about whether the terms reliability and validity are appropriate to evaluate qualitative research. In their seminal work, Guba and Lincoln (1981) presented the term "trustworthiness" in qualitative research as a parallel term for "rigour" in quantitative research. The criteria to ensure "trustworthiness" were described as credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Credibility refers to the believability

of the findings and is supported by data saturation (Lincoln & Guba, 1985). Transferability is the extent to which the findings in one qualitative study may be transferred to another with a similar population or context. The third criteria, dependability is the likelihood that similar findings or interpretations would be found if the study were repeated. Finally, confirmability refers to the extent to which the findings and interpretations can be confirmed by another person.

Morse, Barrett, Mayan, Olson, and Spiers (2002) suggest that the creation of new or parallel terms for reliability and validity causes confusion and may undermine qualitative research. They suggest that the terms reliability and validity should be maintained in qualitative inquiry (Morse et al., 2002). Strategies to ensure rigour must be initiated as the research project is conceived and must continue throughout (Morse et al.). Such strategies include investigator responsiveness, methodological coherence, appropriate sampling, concurrent data collection and analysis, theoretical thinking, and theory development (Morse et al.).

As a neophyte researcher, I followed the advice of Morse et al. (2002) because it was logical and provided straightforward methods to achieve rigour. As this project began, I intended on being open and flexible in order to respond to the study as it unfolded which contributed to investigator responsiveness. Methodological coherence was maintained by following van Manen's (1990) method of phenomenological research which was the most appropriate method to explore the guiding question. Appropriate sampling was ensured by adhering to the inclusion criteria and including only parents who have experienced the phenomenon. Concurrent data collection and analysis occurred as part of van Manen's (1990) approach to phenomenology. The interview guide changed depending on the extent to which the guiding question is being answered. This also contributed to investigator responsiveness. I was fortunate to have an

experienced qualitative researcher as my thesis advisor. This ensured not only that the essence of the parents' experiences was portrayed accurately but also that I used sound methodology.

Ethical Issues

Conducting research with humans requires that ethical principles are maintained throughout each project. For this project, ethical approval was obtained from the University of Manitoba ENREB. This body bases its decisions on the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada, 2005). The ethical principles included in this document are: respect for human dignity, respect for free and informed consent, respect for vulnerable persons, respect for privacy and confidentiality, respect for justice and inclusiveness, balancing harms and benefits, minimizing harm, and maximizing benefit (CIHR, NSERCC, SSHRCC, 2005).

Respect for human dignity is concerned with protecting all interests of the human subjects. Respect for free and informed consent ensures that the individual has the capacity to make their own decisions and those decisions will be respected. Vulnerable persons are considered those “with diminished competence and/or decision-making capacity” (CIHR, NSERCC, SSHRCC, 2005, p. i5) and are protected under this principle. Respect for privacy and confidentiality is accomplished by maintaining control over access and dissemination of personal information during all aspects of the study. The principle of justice covers fairness and equality (CIHR, NSERCC, SSHRCC) and inclusiveness ensures that anyone who may benefit from the research be included in the project. Balancing harms and benefits aims to minimize the possibility of harm arising from the research project and maximizing the possible benefits for the

individual as well as society that could be obtained from the research (CIHR, NSERCC, SSHRCC).

For this study, I upheld the ethical principles in the following ways. In order to uphold the principle of free and informed consent, I honoured each participant's right to choose to participate in the study and to change his or her mind at any time throughout the study. This was reinforced continually so that the participant was able to refuse to answer any question or stop the interview at any time, or withdraw from the study. I obtained written informed consent prior to collecting any data from the participants. This consent was preceded by an explanation of the study including its purpose and methods provided in written form for future reference. This explanation also included potential risks and benefits of participating in the study. Because the topic of the research study is potentially emotional for the participants and the investigator, I had an arrangement with health professionals in place if debriefing or counselling was required. The information obtained from this research project will likely not affect their child's care, the parents chose to participate in order to improve care for future children with cancer and their families. This demonstrates the principle of beneficence. The principle of justice was maintained as this population is currently understudied in Canada.

In order to maintain confidentiality and privacy, only my thesis advisor and I had access to the field notes and the recordings and transcripts of the interviews. Consent forms, transcripts, and field notes have been kept in separate locked cabinets after identifying information is removed. All documents will be kept for seven years after which, all data will be destroyed.

Chapter Summary

This chapter has presented an overview of the conceptual framework, the methodology, and the method used to plan this research project. Hermeneutic phenomenology was the

methodology chosen to answer the guiding questions. Data collection occurred concurrently with data analysis. I needed to be flexible in order to follow the emergent nature of this qualitative design. Ethical considerations and potential limitations were also discussed. The next chapter will provide the findings of this study.

CHAPTER FOUR: FINDINGS

Introduction

This chapter contains a description of the parents who participated in the study and the findings of this phenomenological study that investigated the lived experience of parents of children who have completed cancer treatment who live at a distance from the cancer treatment centre. Data analysis revealed the essence is a journey within a journey. The four themes that emerged from the interviews with parents were: These themes were: (1) travelling for care, (2) learning to navigate their journey with healthcare providers, (3) coping with change, and (4) giving back. The chapter concludes with parents' recommendations for health care professionals.

Participant Description

Five parents of children who have completed treatment for cancer in the past three months to five years prior to the commencement of the study were recruited. All of the participants live at least three hours away (>200 kilometres) from the cancer treatment centre. The length of travel ranged from three hours (200 km) to five hours (330 km). Of the five participants, four were mothers and one was a father. Their ages ranged from 34 to 50 years old. Four were married and one was divorced. All the parents currently work either part or full time. The distance to the nearest healthcare facility ranged from two to 14 km.

The children's ages at diagnosis ranged from seven to 15 years old and there were three girls and two boys. The time since diagnosis ranged from two and a half to five years. Diagnoses of the children included two solid tumours: brain and germ cell, and three haematological malignancies: one T-cell acute lymphoblastic leukemia, one Hodgkin lymphoma, and one T-cell lymphoma. All children had at least one sibling: two had one sibling, one each has two, three and four siblings.

Table 4.1
Participant demographics

Characteristic	Number (%)
<u>Age</u>	
Age Range	34 – 50 years
Median Age	41 years
<u>Sex</u>	
Female	4 (80%)
Male	1 (20%)
<u>Marital status</u>	
Married	4 (80%)
Divorced	1 (20%)
<u>Child's sex</u>	
Male	2 (40%)
Female	3 (60%)
<u>Child's age at diagnosis</u>	
5 – 10 years	2 (40%)
10-15 years	3 (60%)
<u>Child's diagnosis</u>	
Brain tumour	1 (20%)
Solid tumour	1 (20%)
Leukemia	1 (20%)
Lymphoma	2 (40%)
<u>Number of siblings</u>	
1	2 (40%)
> 1	3 (60%)
<u>Time since diagnosis (at time of interview)</u>	
2-3 years	1 (20%)
3-4 years	2 (40%)
4-5 years	2 (40%)
<u>Distance to tertiary cancer centre (one-way)</u>	
200-299 km	3 (60%)
300-399 km	2 (40%)
<u>Distance to nearest medical facility (one-way)</u>	
0-5 km	3 (60%)
6-10 km	1 (20%)
10-15 km	1 (20%)
<u>Parent most responsible for child's care</u>	
Mother	1 (20%)
Father	1 (20%)
Both	3 (60%)

Thematic Analysis

Participants in this study provided vivid descriptions of their child's cancer journey. This began before the child received a diagnosis of cancer and continued to the present day. Despite the fact that treatment had ended at least two and a half years ago and ranged up to five years, their child's cancer continued to be a part of their lives. Through the parents' descriptions of their experience of caring for their child through cancer diagnosis, treatment, and beyond while living at a distance from the cancer treatment centre, themes emerged that depict their experience and ultimately reveal the essence of their experience. In the next section, the essence of the phenomenon and the themes that communicate the essence will be presented.

The Essence: A Journey Within a Journey

For participants in this study, the essence of parents' lived experience of transitioning to a time when their child is no longer receiving treatment for childhood cancer at a distance from the family home is *a journey within a journey*. All the parents began the interview with a description of their child's diagnosis story providing specific details about the symptoms that led to them to discover that their child had cancer. From the point of diagnosis onward, parents embarked on a cancer journey that continues today. Within their cancer journey, they navigated a treatment journey that seemed to be the only course of action to take in order to make their child better. Parents struggled to move on with their child's cancer journey as it impacted their own lives as a parent of a child with cancer and the lives of their whole family. Throughout the treatment journey, parents learned about their child's cancer and what it meant to their family to have a child with cancer. For some families, there was questioning about why their child had cancer, for others there was a firm resolve that everything would work out for their child, but all were confronted with an unexpected challenge that introduced many stressors into their lives. Families

had to travel to the tertiary cancer centre for treatment where they met healthcare providers and other families experiencing childhood cancer. Alongside all these new people, parents continued along the treatment journey as part of their cancer journey. Once the treatment was complete, families were reunited at home and attempted to move on with their lives without cancer as the focus. Cancer did not however disappear from their lives rather it shifted out of the foreground of their daily routines. Their cancer journey embodied both positive and negative aspects of having a child with cancer. While many of facets of the treatment journey contained negative characteristics such as symptoms and side effects, the cancer journey included positive characteristics such as the relief and joy of their child's cancer being cured. Parents spoke about how their childhood cancer journey continues in their families' lives even though their treatment journey is complete and their child is currently healthy.

Parents sensed that even though some time had passed and the treatment journey had ended, their cancer journey would continue to influence the parents' thoughts and feelings. This was particularly true for one parent who felt that time proved helpful for herself and her family:

Now cancer isn't the center of our lives. Yeah, it happened but it's not the focus anymore. It comes up but it's just pretty nonchalant now and that's the stage we're at. It's good, I am glad that time can do that for us. (A3)

This mother talked at length about how all-consuming her child's cancer treatment journey was for her and her family and yet she felt that time had already helped them to move from all-consuming to nonchalant in the span of a couple of years. She was able to recognize the shift from cancer as the centre of the family's life to cancer no longer being the focus of their everyday life. However, her family's experience of her child's cancer was not gone entirely.

Another parent talked about how her child's cancer remains a part of her everyday life as she thinks about it and will continue to be concerned about her child's future and the possibility of the cancer returning. Cancer, for this parent would be a lifelong journey:

Yeah, you still think that even though the paper says he's in remission...it's never over, never...It won't ever go away. We just describe it as having a grey cloud over us all the time. Having said that, you think about it daily and you are concerned always. (A5)

Several of the parents stated that they imagined that their child's cancer would continue to be close at hand for as long as they could foresee. Parents could not imagine a time that they would not think about their child's cancer at some point in the day or when their lifelong cancer journey would be over. Similar to the parent whose child's cancer 'won't ever go away', some of the parents felt that it was the thought of their child's cancer recurring that kept cancer close by:

The worst would be like the anxiety...We still live with it – it's still there. It's not going to go away ever, probably. He could turn twenty, it will probably still be there. You're always going to worry "is it going to come back because it's cancer"...I don't think that that will ever go away. (A3)

But if she gets a bad headache you know, right away it's in the back of my head it's back...It's always in the back of my head though, that as soon as she gets sick or something, right away it's back... (A4)

The experience of having a child complete treatment for childhood cancer will stay with the parents as part of their lives forever. Even though the parents may not be able to forget their experience with their child's cancer, they are able to move on with their lives while taking it with them.

It impacts me every day...But, we do have to keep living, we do have to move on and we have to hold on to the good stuff. I'm not saying that it's easy. (A5)

For families with cancer, the cancer journey is comprised of many highs and lows from which families learn to move on. There are many types of moving forward and moving on throughout the cancer trajectory. Moving forward sometimes means learning new things and

sometimes means letting go of things when families are introduced to new challenges along the way. Regardless of how families moved on with their lives, their childhood cancer journey would always be present in their lives.

As the parents moved on from their treatment journey, along their cancer journey, a shared experience of caring for their child with cancer at a distance from the cancer treatment centre, emerged. From this shared experience, four themes became apparent from the data. These themes were: (1) travelling for care, (2) learning to navigate their journey with healthcare providers, (3) coping with change, and (4) giving back. Each of these themes is comprised of sub-themes that support the main theme (See Table 4.2).

Themes

Table 4.2

Parental themes and sub-themes of moving on with childhood cancer

THEME	SUB-THEMES
Travelling for care	<ul style="list-style-type: none"> • Being away from home • Returning home • Practical issues
Learning to navigate their journey with healthcare providers	<ul style="list-style-type: none"> • Learning the diagnosis • Being at the cancer treatment centre • Responsibility for care
Coping with change	<ul style="list-style-type: none"> • Support from: <ul style="list-style-type: none"> ○ Family ○ Friends ○ Community ○ Healthcare providers ○ Support groups • Faith • Returning to 'normal' life: <ul style="list-style-type: none"> ○ Work ○ School • Perspective
Giving back	

Travelling for care. In the current study, the parents' treatment and cancer journeys were influenced by the distance between their home and the tertiary cancer centre but not defined by it. Travelling for cancer treatment was part of their treatment journey but was not the focus of their cancer journey either during treatment or afterwards. Parents described a willingness to travel wherever, no matter the distance, in order to ensure that their child received the best care. Knowing their child was receiving care from the expert cancer specialists helped them to move on psychologically with their child's cancer diagnosis. Because of where the families lived, travelling was connected inextricably to the diagnosis of cancer itself. Parents had no choice but to travel to the city where the tertiary cancer centre was located for treatment and follow-up care and they understood and accepted this as part of their cancer experience. For the parents in this study, even though their child had completed cancer treatment, they continued to travel to the cancer centre for regular check-ups for years. Parents are able to move on with their child's cancer diagnosis in part because they are travelling to receive treatment and follow-up care. This highlights the nature of the essence that the parents and children's lives are moving on from the treatment journey but their cancer journey remains part of their lives.

Parents understood that living in a small community means that they do not have all the healthcare services that are available in a bigger city. This is their reality so when their child was diagnosed with cancer, parents knew they needed to travel to the cancer centre in the city for treatment. There was a trade-off for parents in this study: they had to travel to receive cancer treatment but because of this, their child received care from healthcare providers with experience and expertise in caring for children with cancer. For one parent, travelling was not considered difficult as she describes it as follows:

I think where we live...there is a lot of people that go for treatment for cancer...I think that we are just so used to being where we are...It's just something that just happens. And because we don't have the facilities...I would rather her be there and you don't look at it so much as much as a negative or inconvenience though, you feel you are getting the better care. (Pause) A1

This willingness to go to the cancer centre continued for follow-up treatment because parents felt a sense that their child was receiving additional care that other children their age do not receive which was a benefit for the child. One parent described it as follows:

It definitely interrupts your life but like I say, I would rather bring her there for her check-ups because you feel they are the best at what they do...Actually, I feel good going in to [city with cancer treatment centre] now. It's like you get this extra check-up that nobody else gets to make sure everything is good...I mean now we get to go and get those specialists looking at us for a while. A1

There was recognition that healthcare providers in their local community did not have the exposure to or experience with caring for children with cancer. Because of this, according to the parents, local healthcare providers could not provide the same level of care as the healthcare providers at the cancer treatment centre. There was gratitude that there was a facility within the province that could care for their child with cancer and for the knowledge that the pediatric oncology team had who work at the cancer treatment centre. Parents spoke about how they felt reassured that healthcare providers at the cancer centre had the necessary skills and experience of working with children with cancer. One parent explained:

It's very comforting after it all happens that's what those people do specifically and you do have to trust them. Here they just don't do it enough...They're experts in the field...It's good that it's there. A5

Being away from home. Parents and the child with cancer had to be away from home for periods of time in order to receive treatment as well as follow-up care. As a result, families were separated from each other and from their regular routines because some of the family members remained at home while the child with cancer and a parent went to the city. When the children

had to be in the city but were not admitted to the hospital, some families stayed at Ronald McDonald House while they were in the city while others had family members with whom to stay. One parent described her situation while they were away from their home:

...During that time we finally moved over to the Ronald McDonald House because my mom was with us...so she had [sibling]. My husband was back and forth between work and all this, and I always stayed with [child receiving cancer treatment] while I was at the hospital, just slept on the chair or whatever. A3

A couple of the parents talked about how they thought it could have been if their child could have been treated closer to home so that they would have been able to return home after radiation treatment. One parent suggested that a shorter commute for treatment would have made their life easier by allowing them to be at their home surrounded by family and friends. This family had several children who stayed at home for the course of the child's three-month-long treatment at the cancer centre. The other parent and one of the siblings came to visit at the treatment centre but stayed at home for the majority of the time. This sibling had a particularly hard time being away from the child with cancer and became anxious during follow-up appointments when separated again from his mother and sister. The mother explained that:

It would be nice if we had a facility here, you know, it would be easier...we all would have been better off being at home and being able to do it. We could have just went to the hospital, had radiation, came home at night, you know, and they could see her and we could see everybody. I think it would have been easier being at home, like closer to home, whereas even [smaller city with adult cancer treatment centre], it's an hour and a half. It's still a drive but it's doable. A4

Due to the distance from their home to their child's tertiary cancer centre, families often had to stay in the city after discharge which kept them away from home for longer periods of time. Even though they no longer had to stay at the hospital, they still were not allowed to leave the city. This would create a time of being in 'limbo' between being the hospital and home and accentuated the fact that they are not at home like their urban counterparts would be:

So, in between rounds of chemo we weren't allowed to come home because we lived too far from the hospital. So home, when I said they discharged us home I mean it was to Ronald McDonald House. A3

We got home...[over a month after diagnosis]...he got to come home to [city with the cancer centre] because grandma and grandpa lived in the city which is a godsend. I couldn't have done it without them and without that house being there. A5

All parents talked about having to be away from home for some period of time because of their child's cancer treatments. A couple of the parents spoke about being away from home repeatedly as they went back-and-forth to the cancer centre for treatment. Other parents spoke about being away for longer periods of time spanning the duration of the treatment.

So she had, I think it...took about 5 or 6 months of chemotherapy and probably another month and a half, 2 months of radiation over the course of a year, off and on, back and forth. A2

So they did [surgery] and we did 6 weeks of radiation. We stayed there for 3 months; she stayed a couple of weeks in the hospital. My husband came in until she got out of ICU and then he came back home to be with the other kids. A4

Whether it was for one long or several short intervals, when the child was away from home, families were separated. All the children had siblings, most of whom stayed at home while the child and one or both of the parents went to the treatment centre. As previously mentioned, one of the siblings had a lot of anxiety about being separated from his sister and mother. One of the siblings only came to the city for one night then returned home because she did not like being away from home. In both cases, other family members looked after the siblings while the child with cancer and one of the parents were in the city.

For one of the parents, being away from home at the treatment centre made her envy the parents who lived in the city and reminded her that she was not at home. She wished she had a place where she could be alone and have some privacy while she was in the city.

I envied the parents...who all lived in [city with cancer centre]...I did envy that they could go home and have a shower and sit on the couch for even five minutes. Like what I would have given to come back to my house in the city. I couldn't have imagined what that would have been like because I never left that hospital because I just felt there was nowhere for me to go. I always felt there was nowhere for me to go when I was there...I just never had a place to be alone. That's why I thought that if I had a home there and I could shut my bedroom door for a while and I could cry my eyes out or whatever. And I just didn't have that private place when we were at [tertiary cancer centre]. I didn't have a place to be, which was just horrible and I know that – not that the diagnosis would have been any easier because if you talked to a parent who lived in [city with cancer centre], they would say it sucked too. But you don't know until you can't be at home. They got to go home every night, eat a meal, you know. I just think that maybe things would have been different for me if I had a home to go to during the treatment – that was my home, my place to be! Everyone's so supportive but it just wasn't like this is my house and you know. It sucked. A3

Thinking about how other parents were able to be at home when she could not be, made being away from home even harder for this parent. She had to relocate for several months and only got home for a couple of days a couple of times over many months of her child's treatment.

Returning home. In between treatment cycles and after treatment was over, families were allowed return to their home. Most of the families had mixed feelings about returning home. On one hand they were grateful to have their own space and for their children to have their friends and family close by and on the other they were concerned about being away from the cancer treatment centre and their pediatric oncology team in case anything went wrong.

After treatment was complete parents talked about a variety of feelings they had returning home. For some parents their emotions changed over time and differed from the time immediately after getting home to a time after being home for awhile. One parent spoke about the excitement and the terror she experienced and the fear that she would have to leave home again:

I was excited and completely terrified at the same time about coming home. Excited to sleep in my own bed and enjoy my home once again, and get back to a routine. Terrified it was going to happen all over again and we would have to go back to [city with cancer

centre]. I kept bags packed for about a year after, always afraid something was going to happen, and I wanted to be prepared. A3

The importance of her own home and her own routines were recognized when she had to be away from her home during treatment. The delight of returning to her own world was tainted by the fear that she might have to leave it again and return to the city for more treatment. When she returned home, she was unable to live exactly as she had before her child's diagnosis because she felt the need to be prepared for the worst-case-scenario. For this mother, having to return to the city for further cancer treatment for her son was her worst-case-scenario.

Another parent talked about how she felt relieved to be home initially when she returned home and felt that life was returning to pre-cancer days. That only lasted for about a month when she started to feel as though the cancer was in the forefront of her world.

I honestly felt like a big part of my world revolved around it...three months in between appointments, you just, you never know. I really became consumed...I felt, with it for months honestly...It wasn't even right when we first got home, it wasn't until probably, I don't even think until a month or so after. I think just everything was awesome. Everything resumed. I think it wasn't until a month or so after. I was, I think everything just crashed down, actually. A1

Parents talked about the fear they felt when they returned home from the treatment centre. For some of the parents, their fear was related to being at home and being away from the healthcare providers at the cancer centre. Parents had a sense of security when they were staying at the hospital that was lacking when they returned home:

Mom: ...I just didn't want to be here because we were so far away from the hospital, I was scared. Now this is fine, I am fine where we live and I am fine with the two and a half hour drive, no big deal.

Interviewer: And what were you scared of specifically about the distance?

Mom: To tell you the truth, there probably wasn't too much to be scared of...so I don't know what I was so scared about...when I look back on it. But at the time I know I was terrified of being that far from the hospital, being where we live here. I just know I was really scared of just having to go back into [city with cancer centre] and leave home again and being so far, I guess, I don't know why. A3

But I remember the first time even just going to my mom's, I was very frightened because you feel safe at the hospital - you are very secure. I mean maybe I went overboard but people are right there and if he breathed wrong I knew that they were there and I could ask someone. A5

The safety and security that parents felt at the treatment centre were not shared by the children with cancer themselves, according to the parents. Some families shared that while they were uncomfortable being at home, their child's feelings about being home were entirely positive:

It was good to come home, she was happy to be at home, she was happier being here. Myself, personally, I liked seeing the doctors more often...But all and all everybody was better once we got home. A4

But then, we hadn't been home in so many months, I just hated the city. Yet the same time, I hated being at home. Like right after, I was at that point for me that - he thought it was great, awesome - and I was so not comfortable not being at the hospital anymore. I couldn't sleep, I couldn't eat, the anxiety was like horrendous, awful and I was always on the phone with our nurses [at the cancer centre]. A3

One mother spoke at length about the difficulties she faced upon returning home. Her child had the longest treatment of all the children in the study during which she and her child had to relocate to the city with the cancer centre for over six months. After such a long time away, she had thought she would be so happy to be back home but instead she felt afraid of her child's cancer returning, being so far from the treatment centre and having to go through the process of leaving home all over again. Being away from the cancer centre and the constant monitoring of her child was a hard transition for her. She had thought she would have been much better off being home but instead, she was stressed out and concerned for her child. When asked about her main worries, she responded:

I worried more – my anxiety and worries increased like 10-fold once we came home. Once we moved home, that fell apart for me. I was like, done. Being here now, there are still times I wished we lived closer to [city with treatment centre] just because of what

happened to [her son] because the worry is still there that it's going to happen again. I don't want to go through all that and the whole trauma of leaving my home again. It was so traumatic because that's what happened; I had post-traumatic stress when I broke down. I think a lot of it had to do with being away from where his doctors were and his nurses...I would say that my emotions were stronger, more volatile, more...worse after treatment than during treatment. Because during treatment, we were working toward a goal... - I fell apart after it all happened once he got home. That was a tough part for me as a mom. It was after moving back home for me that was the worst thing for me...I was scared. I don't know all the things, yeah it was more after than during. I guess when he is not under the care of those professionals like for every minute. Like, you're the care. I had to rely on me. That's when the light bulb went off. It was such a big responsibility, I guess but...I felt like their life is in your hands literally and that you've got just be...maybe it's too big of a responsibility sometimes. A3

This mother described in detail how difficult it was for her to return home and be far from the healthcare providers who look after children with cancer. She was so scared of being home and having to leave again. It was not until she was back at home that she recognized the magnitude of the responsibility that she had to assume as the sole caregiver for her son now that they were not at the treatment centre or in the city. The realization of this responsibility was shocking and fear-inducing for this mother. She felt totally unprepared to be at home with her son and felt that it would have been helpful to have been given psychological preparation of some kind about what it could be like when she got home. She recognized that everyone is different but said that she spoke with several other parents who also thought they would be happy to be home but then went through a very hard time adjusting.

It's the emotional stuff like maybe they need to be a little bit more, maybe even forceful about giving you the [social worker's] phone number. So maybe regardless of your status in life or whatever getting you ready to be at home alone. Tell you about this. I didn't know it would be like this when we got home. I thought it was going to be the best thing on earth. I thought "Oh my God we're going home! Hooray! Finally!" And then...crash. No one told me about that – nobody. And I know I can't be the first person, this has been going on forever, that felt that way. Maybe they don't want to scare us but maybe they should tell you – you know when you go home things are going to be tough, maybe not, maybe there's a chance you will do okay but I don't know. I know I didn't and I know of other moms who didn't and still aren't so I don't know maybe if they could tell you after you have been in for this long, with this cancer treatment, and you live this far from the

city...But it would have been a nice thing to know that my anxiety might really get out of control once I go home and I am going to feel really nervous about everything. I don't know...I didn't know that it would be like that. I wasn't prepared to be home and to feel the way I did. Nope. I wasn't ready for this or for what had happened and how I felt at all. Nope, not even a little bit. A3

This mother felt strongly that she would have benefitted from some anticipatory preparation about returning home prior to being allowed to return home. It did not seem possible to her that she was the first person to experience such anxiety after treatment and so she could not understand why she was not warned about the possibility of feeling the way she did.

Practical issues. Parents talked about practical issues that impacted their travels that in turn, impacted their ability to move on. Some of these practical issues were related to driving itself. One of the parents did not own a car and so had to rely on friends to lend him their cars so that he could travel into the city with his child.

So, we went to [cancer centre], drove up there, had a friend of mine because I don't have a vehicle. A2

Another parent mentioned not being familiar with the city and therefore not knowing how to drive in it. This mother also was afraid that she would drive through areas of holes in mobile phone coverage.

I did not want to leave to come home because once they took the stitches out. I was scared no cell phone service half-way through or something could happen so in that respect, it would have been frightening. A1

Other practical issues related to the time it took to travel to the tertiary cancer centre. Families had to carefully plan their follow-up appointments because travelling to the city with the cancer centre meant taking time off school and work and meant organizing childcare for the child with cancer's sibling:

It's the middle of the week, you have to take the time off work and she would have to have ultrasound or whatever so it meant no eating or drinking. So we always have to leave the night before because we are not going to drive four hours in the morning and after the whole night and not let her eat or drink in a vehicle and whatnot. So I think in that respect it's probably different – I mean it really does alter your whole – you know, it's not an hour appointment. It's a trip. It's a day. You know it means missing school, missing work. And of course...it's making arrangements for the other one [child] and that sort of thing. A1

Public transportation was not used by any of the families in the study. One family explained the lack of availability of public transportation between their home and the cancer treatment centre. She talked about how much longer trips to the tertiary centre would take if you had to take the bus from her town:

We don't have buses that travel, you know it takes 2 days itself because they don't link up properly from [home town] to [closest city], you spend the night in [closest city], [closest city] to [city with cancer centre] and the same thing on the way back. You know so...you have to start adding in that kind of time. If you're there a week or a couple of weeks... A1

One of the provinces from which the children came to be seen at the cancer treatment centre had travel grants for families who have to travel for services not provided in their local communities. Such programs acknowledge that families who travel for cancer treatment have different needs than their urban counterparts. One parent spoke highly about these financial aids:

There are travel grants. That's another benefit...When you go to [a major city for healthcare services], I think for us it's based on the kilometres. I think we got \$350 so to cover a night's hotel, cover your travel...that helps alleviate...I mean we're also lucky, we didn't have to worry about that price part of it, you know, but for a lot of people, again, when you have to pay hotels...A1

A couple of the parents spoke about being responsible for transportation of their child to the hospital because it was faster or easier than waiting for what the healthcare system could provide.

Another time her temperature skyrocketed, and we went to the hospital. I wound up having to take her to [cancer centre]. I wound up borrowing a buddy's car because it

was faster for me to put her in the car and take her to [cancer centre] than it would have been to wait for the helicopter or the ambulance to get ready to go. A2

You know, it was freezing rain come to Winnipeg the next day but stay but because they might send you an ambulance because they didn't know if we could travel. A4

Although it was only mentioned in passing, the talk of freezing rain is a reminder about the influence of the weather on how families were able to travel to and from the treatment centre.

Learning to navigate their journey with healthcare providers. Parents learned to work with the healthcare providers as part of their cancer journey from the time of the presenting symptoms through learning the diagnosis and being at the cancer treatment centre to learning the responsibility of care. Many of the families had little or no experience with the healthcare system prior to their child's cancer diagnosis and therefore had to learn everything from how to get to and from the cancer centre to how to interpret their child's blood counts to working with the healthcare providers. By collaborating with their child's healthcare provider, parents played an active role in their cancer journey. Parents and healthcare providers worked as a team to provide care to the child with cancer which created a balance of responsibility. Sometimes the healthcare team took the lead such as presenting treatment options at the time of diagnosis and sometimes the parents were in control such at the completion of treatment. Local healthcare providers and members of the pediatric oncology team were involved in the child's care throughout the cancer journey especially as the treatment journey ended:

He had gone to this new family doctor for his blood work and a bit of a check-up. Everything was good! So he's doing every 6 months now...He gets an ECG every 6 months and a regular check-up with [child's oncologist]...You know what was good was our doctors [oncologists] would talk to our GP [general practitioner]. He was on board with everything. The communication was good...I think we felt more comfortable going in [to cancer centre]. I think he just likes the doctors [at cancer centre]. A5

Learning the diagnosis. Parents started their diagnosis stories with the symptoms that the child had that started their cancer journey. Due to the rarity of childhood cancer and the vagueness of the presenting symptoms, the children had to see their local healthcare provider numerous times before a diagnosis was made and most of the children had been misdiagnosed originally. Some of the parents learned their child's diagnosis before going to the tertiary centre and some had to wait until they were at the children's hospital. When the parents learned of the diagnosis, it meant that they had to meet new healthcare providers during and after the diagnostic period either at their local hospital or at the children's hospital to which they were referred.

The children's presenting symptoms were typical of childhood cancer in that they were ambiguous. Symptoms included abdominal pain that was thought to be appendicitis that turned out to be a solid tumour in the abdomen and a headache leading to morning vomiting that was a brain tumour. The haematological malignancies presented as lack of appetite and swollen lymph nodes which lead the family doctors to believe the child had a virus such as mononucleosis.

When the symptoms worsened after weeks or months, parents brought their children back to the local doctor or emergency room sometimes numerous times:

It was probably in July. My daughter was sick so we brought her into the emergency at the hospital and they said she had a bladder infection at that time. They gave her some antibiotics or whatever and we went home. Then, I think it was in October or November... she was sick and...had lumps behind her ears and stuff like that. So I brought her back to the emergency and they said that she had mononucleosis. They gave us more medication and sent us home. Then it was in December, she was waking up and sweating and crying and she had lumps underneath her armpits so I brought her back into the emergency. A2

She was getting headaches and I took her to the doctor here, just the walk-in doctor her who said it was just stress, migraines from stress...That's what they told me. So, a week later they were getting worse and she wasn't feeling good at all. They was aching and she was crying they were aching bad so I took her back ...And then the following week, she started throwing up in the morning with it and I walked in to the doctor...And they sent her across the street for an emergency CT scan and...they told us to go home. A4

The child's local doctor played an important role in the diagnosis even though they had little or no previous experience with childhood cancer:

[Local doctor] was absolutely amazing and he's amazing with her even now. They found a mass in her stomach and they weren't sure what it was. So, at this point [local doctor] was already on the phone contacting [tertiary centre]. At this point, it was early afternoon. So, we went back in and talked to him. He said there yeah, there was a mass there, it was quite large. He had really no idea what it was... so we were to go home. It was nothing that was going to rupture throughout the night or anything. We were to bring her home and then drive to [city with children's hospital] in the morning and they would have people waiting for us. A1

Parents talked about finding out as much as they could about their child's diagnosis and subsequent treatment as a method of moving along their treatment journey. Learning about aspects of their child's disease and treatment helped them understand their healthcare providers which was important to the parent and sometimes for the children as well:

I did a lot of reading, they gave me a lot of stuff to read. I read everything I can, you know. A4

I don't know if it was instinct or I don't know what you call it – I felt very strongly that it was my job to do the best that I could, to learn about it and so did [son]. He wanted to know everything that was going on. He studied, he learned about the drugs and the chemo... A5

One of the parents spoke specifically about the challenge of learning about her child's diagnosis while at home. She found it difficult that she could not talk to the pediatric oncology team at a moment's notice but was grateful that her child's local doctor was willing to learn along with her. She used the internet as a resource, in part, because of the distance. Information found on the internet caused her to question the treatment regimen chosen for her child but her local doctor provided support about her uncertainty:

Like I am going to tell you, I was on the computer, I was looking. It was probably me more than anyone and because then you have all these questions. Well, you don't have the doctor or hospital right there. Nobody where we are from we knew nothing about it. That's why I did spend a lot of time looking and reading. We were just very fortunate that

her doctor was very good. I mean, whatever questions we had, he would try to find out and answer or he took a lot of time for her. Not everybody is going to get that. And when you're talking four hours away, it's not like you just make an appointment (pause)... you keep looking on the Internet. Don't bother with it because even if you're looking under the [reputable site], you know they say when 99% of the cases, there's always chemo, there's always treatment, this and that, just ask your doctor. Okay what decision do you make? You know Internet is just not good. It's not good when it comes to that stuff. I wondered maybe I should get me a second opinion and finally I just asked her doctor – "if it was yours what would you do?" and he said, you know, we have the best there is and I said okay, I am going with that. A1

Being at the cancer treatment centre. Going to tertiary centre meant that the families met new healthcare providers and had to trust that they knew how to care for the child's cancer. All the children received the course of treatment that the pediatric oncology team recommended at the tertiary centre. In effect, parents felt they had no choice but to follow the treatment journey set forth at the cancer centre. Overall families were pleased with the care they received from the healthcare providers at the cancer centre. Parents felt they could trust that their child was receiving care from highly skilled professionals which helped the parents travel to move along with their cancer journey:

So they asked me how I would like for them to proceed. Hopefully God has trained you people how to do your job. Like, I have no idea! They were really good at the [tertiary cancer centre]. A2

I actually did pretty good, I have to say, when we were in the hospital, for a mom with a kid with cancer. I was just comfortable, I slept well and who would have thought, but I did. There, I just felt so comfortable where we were. We were in good hands, I loved the nurses, doctors, I had no problem with that – they were just the best place on earth. And even when we were at apartment, I was like okay, they were just right across the street and he was going to clinic all the time and everything was fine. A3

One mother found it hard to have to trust the healthcare professionals immediately after meeting them. Having no time to develop a relationship with the team prior to diagnosis was stressful for her. Although she did not like the option that was suggested, she felt that it was what

they needed to do for her child. Once she had time to develop a relationship with her child's healthcare providers, she was very happy with the care they provided to herself and her child:

There was no time. The lousy part is that you are not in control. These people are saying to you "Your son is actually dying and we don't know if we can fix him but in order to try - these are the things we have to do." The options weren't good...chemo, gobs of chemo. All you could do was try and absorb what they are trying to tell you and really just hope for the best...You totally have to trust these people you've never met before in your life. It's a totally different situation than you have ever been exposed to...The nurses were really good; that's what they do. We felt that they cared and had done it before so they were kinda used to the questions. They helped us a lot. We have no complaints about the doctors. A5

Responsibility for care. Parents spoke about working with a variety of healthcare providers both at home and at the cancer treatment centre along their cancer journey; all of whom shared some proportion of care for the child with cancer. Healthcare providers at the tertiary cancer centre were currently responsible for childhood cancer follow-up care. Parents had to learn to care for their child while at home between and after the completion of treatment. Local healthcare providers had varying levels of interest and knowledge about childhood cancer both before and after the children in this study were diagnosed. For this reason, some parents were comfortable taking their child to see their local healthcare provider during and after treatment and some were not. One of the parents trusted their local doctor, in between and after treatment was over, to care for their child and to being to transfer the follow-up care to them from the tertiary centre:

Well, what's going to happen next year is...she's not going to have to go back to [cancer centre]. She'll go two years from the September and he will do all the blood work in [our town]. That's something that her doctor in [cancer centre] said, he's able to do and then they will do the actual whole complete check-up the year after. So, yeah, he's amazing... He had no idea what it was and he did a lot of...So we lucked out big time. (laughs) We really did!...He was so great and he was so interested and wanted to find out as much as he could...[child with cancer] had a question. He said: "You know what, I am not sure, but I will find out." He was awesome. A1

For a couple of the families, even though they were totally satisfied with their local doctor, they continued to return to the treatment centre for follow-up and were happy to go there:

This doctor here is the one that found it on the CAT scan...I asked her “would you be [daughter’s] doctor” and she said “oh yeah” and I mean she’s been a wonderful since then. But this doctor, she is excellent, like with her. [Daughter] can tell her whatever she wants. She’s good. She’ll just phone us if she has anything and like I said, she’s got us in twice for CAT scans...[We] went in [to cancer centre] every 3 months – well, no every 2 months for a couple of times...But now we went to 3 months and we now go in every 4 months. A4

Contrary to the families who had local support, one parent talked about her lack of trust in the local healthcare providers in regards to her son. She felt that she had no choice but to return to the cancer centre no matter what her query was about her child with cancer. She trusts the pediatric oncology team to take expert care of her son so she feels good about taking her child to see them whenever she needs to:

The doctors here are fine but they even admitted that “[son] is beyond our realm of what we do.” They don’t want to...As soon as I have to take him in for something, even now – it’s like you got to go to [tertiary centre]. They are still nervous about taking care of [son]. So that’s nerve racking! If I was concerned about something, we would need to go to [tertiary centre]. Never [closer city] or [local community] was an option... Basically there are no doctors in [closer city] that can care for kids with cancer. And they don’t. You go to [cancer centre] – that’s what you do. If it’s a fever you go to [children’s hospital] and you go to [cancer centre in-patient unit] or if it’s a concern you go to the cancer [centre day unit]. That’s just the way it is for all of us, I think. They wouldn’t even take blood from his central line the day before even when I suggested it so they could have too nervous about it. Doctors who aren’t oncologists for kids are scared of kids with cancer. They really are! Maybe there are some good ones out there that I don’t know about but like in this community and other parents that I know of and talk to - their doctors are the same way – it’s always – you’ve got to go to [tertiary centre]...So my immediate reaction that if something happens is just [cancer centre] because that is where the care is and where they know stuff, where I trust. I totally...I don’t have any choice and like I trust them implicitly there with [son] which is a good thing. A3

Coping with change. Parents talked about many people and things that helped them deal with their child’s cancer journey and their travels along the way from diagnosis, through treatment, and afterwards. The changes in their lives brought about from their child’s cancer

diagnosis necessitated parents to cope with the changes in order to move on with childhood cancer.

Support. Parents talked about a variety of means of support that was available to them along the cancer trajectory. This support came from family, friends, their community, healthcare providers, and support groups. Families felt they were fortunate to have such wonderful amounts of support along their cancer journey:

We just had a really amazing support network like when it came to family and friends and that sort of thing. A1

Regardless of the horrible circumstances, being there, the diagnosis...but things worked out along the way. The way everything's gone...the support has always been amazing, whether it's been the doctors, nurses, family, and friends whatever. We've been very lucky. A3

Family. All the parents spoke about the importance of their spouses, siblings, and extended family in their lives prior, during, and since their child's cancer diagnosis. Having a family member who lived in the city that contained the tertiary cancer centre was indispensable during their treatment journey. Families were grateful to that person was for allowing them to stay with them when they were in the city:

So, we are in [city with cancer centre], my mom and dad actually came out with us. So her and my dad are actually very, very close. (laughs) I was very fortunate that I had my family there and my husband and I have three sisters back home and we're all very, very close. My youngest one who at the time was 5, she stayed with my sister. My husband's parents too, they were in a situation where they could come and be with us too. We were very fortunate that [husband's] sister actually lived two or three blocks from the [tertiary center]. I mean it was very nice for us in that respect. Everything just kinda fell into place I guess for the situation. A1

My wife at the time, her aunt lived in [city with cancer centre]...So, we had a place where we could stay when we were there. A2

When the child was at the treatment centre, someone had had to look after the child's siblings who remained at home while one or both of the parents went to the city with the child

with cancer. Parents talked about who was able to look after their children and how the siblings felt about having to be at home while part of their family was away:

My mom and dad live close and I knew they would come and take care of everything for us. A3

Well, she [eldest daughter] did and my mom came to stay, my mom and dad live here in town[where the family resides].So and then my husband would come in on the weekends and bring [son] in because he had it the hardest, like separation I guess. A4

Mom and Dad [at the treatment centre] were gone and Mom used to cook so they had to take over the business...and they had to take over the farm and learn how to fend for themselves, right now, so it was hard...a lot of changes and a lot of growing up over night. And they were concerned about their brother. They cared about him a lot and even though they were older, they were still at home. A5

One of the parents had her parents living in the city with the cancer centre. She found this to be an incredibly integral source of support for her and her child with cancer. She described how emotionally exhausting it was for her to have to be strong for her family and how being able to talk with her mother about it helped her to become re-energized:

I would come home and want to share or vent or go through all my things but I couldn't because I had to be strong for everybody else. That got wearing so I think what happened in our situation was my Mom and Dad were the daily support to me. Like when I would come home, Mom would also have [child with cancer's] bed ready for him and food and things like that. They were our comfort. Without them it would have been really tough... Because as a caregiver you get drained yourself and you have to look after yourself as well. For me it was good to have my Mom look after me, because she did. A5

Several families felt that the experience of having their child complete treatment for childhood cancer brought their families together. Their experiences throughout their cancer journey helped make them a stronger family.

Well my husband, we were good, we talk all the time about everything. If it did anything, it brought our whole family closer. Like this, usually it pulls everybody a part but, you know, it kinda brought all of us closer and opened our eyes up. You know, we spend more family time together. That's what we do more of, like I said, because you get your eyes opened. Now, we eat more meals together, we do more things together...Do more...family

stuff. We always did a lot of family stuff, we always did game nights and stuff, but we just make it more of a priority now. A4

We are closer in a different way, I think, because we had to grow and sort of feel how everybody was dealing with it and everybody dealt with it differently and had to support each other. A5

One of the parents felt conflicted about the amount of time he spent with this child who had cancer in comparison to his other child. Although he felt guilty at times about the amount of time he spent with his child with cancer during the treatment journey, he and his children are closer as a family than they were prior to the diagnosis:

I was fearful and I knew that I had to be strong and appear that I knew what was going on, because I didn't want my children to be afraid. I spent a lot of time with my daughter during this time and just felt like I was neglecting my son that was 2 years younger than her... We are closer now because we spent so much time talking, praying and being together in close quarters. I feel my children know me better and trust me more because of it. A2

One of the marriages ended during the course of the treatment journey but despite this, the parent felt that his relationship with his children was strengthened as a result of their family's experience with cancer.

My wife and I went through a divorce during that time and the children chose to stay and live with me. It's still...the whole experience has brought me and my daughter and my son a lot closer together. Although it pushed their mother away throughout it all." A2

One of the parents shared that she need professional help to cope with being at home after her child completed childhood cancer. Through that experience and throughout the entire cancer journey, the support she had from her family as well as her friends helped her through. With her family's assistance, she learned that she needed to look after herself as well:

And I was going to therapy for that but I ended up having a bit of a break-down last fall. I ended up in the hospital for two weeks and it was the best thing that ever happened to me! Really. I got a break from here, a break from the kids because I knew I couldn't do it. Everyone stepped in, the whole family and friends. It was the best thing that ever

happened to me. I got myself straightened out and actually since then I have been phenomenally fantastic because I started taking care of myself. A3

Although all the parents spoke about the tremendous amount of support from their family members, some parents had a few family members who were not supportive during their cancer journey. Fortunately for them, these families had other family members who supported them and other sources of support.

My wife wasn't very supportive throughout it probably because she didn't know how to handle it. I don't blame her for that; it was just tough sometimes...on me and on my daughter and my son at the time. I wound up getting divorced anyways in the end. I just didn't feel that she was very supportive of us while we were going through that and probably because emotionally, she didn't handle it, didn't know how to handle it. I don't know, you would have to ask her what went on. A2

Some people don't want to talk about it at all. Like my husband's family, they don't ever talk about it. Like if you don't talk about it or don't see it, it's not there...They didn't come into the city to see her or nothing, eh? A4

Friends. Parents talked about friends who were essential means of support along their cancer journey. Some of the families had friends from home who helped them during the treatment journey:

So, we went to [cancer centre], drove up there, had a friend of mine because I don't have a vehicle. Had a friend of mine, we drove up there and we went to a big consultation room with doctors and oncologist and all that. A2

We did. I have a very good long time friend who was a nurse at [children's hospital]. [She] met us at the hospital and she stayed with us and she wrote notes. When [child with cancer] was put into ICU, there was the team, pretty much of the five doctors there. They were really good but you know your brain is just – Yeah, it's so much to absorb. [She] took notes and she wrote down everything for me so that we could remember. She was fabulous so we were very fortunate to have her. A5

A couple of the parents talked about new friends who they met at the tertiary centre while their child was in for treatment. Often the new friends were parents whose children were also

going through treatment for childhood cancer. New friends continued to support the parents after the completion of treatment:

Interviewer: I know you said you were there for so long you met lots of people on the unit. So like, did you find they were a good source of support?

Parent: Yes. Absolutely!

Interviewer: Do you still keep up with some of them?

Parent: I do. Quite a few like Facebook. We keep up daily on Facebook, just little messages or whatever. Yup, a couple of mums in particular... So yeah, the parents got me through a lot. Yeah, it was good. Lots of support up there. A3

A couple of the workers at Ronald McDonald House, just more friends, you know got me through it. A4

Community. For the parents in this study, living in a small town/community meant that many people knew about their child's cancer diagnosis and wanted to know about it. Parents did not complain that the whole town knew about their child's cancer diagnosis. They presumed that the majority of people knew about it:

We come from a small town and so everybody's kind of heard a little bit... A1

Yeah, and the community is still incredible. [Nearest town] is big enough, I don't know everybody but everyone knows us. Everyone has always been phenomenally fantastic! Yeah, they really rallied. That's the one nice thing, okay maybe that's the one pro of being from a small community. The support was beyond your imagination where I know in [city with tertiary centre] it's not the same. Because like I said, I've met a lot of people in [city with tertiary centre] and you get but nothing like what happened to us. A3

I am sure probably three quarters of the town would know about her. It's a small town and I've lived here all my life, well small city. Most people would know, well some people wouldn't know – those that moved in. A4

Many of the members of the community wanted to help the family in some manner. For one family, this meant that community members helped to look after their property while they were away at the treatment centre:

The community took over our farm for us for a while. We had so much support it was unbelievable. A5

Several families mentioned that their child was in their local newspaper in relation to their cancer journey:

Lots of people know her so lots of them would know her story. It was in the news paper but I don't know. They maybe know that that was the kid that had cancer. They might not know everything, you know what I mean? A4

Some of the children did not mind being having their story in the public eye but according to one parent, his child did not like it at all:

[Child with cancer] didn't like the, she didn't like the glamour of it or whatever, like the newspaper article. She didn't like that at all. She didn't like the attention of it...They had her picture in the newspaper. She didn't want to be known as the cancer girl. A2

One of the parents submitted updates to the newspaper herself in order to ensure the accuracy of the information:

The paper's been great! They carried his story right from the beginning to let everyone know, because it was a small town and the rumours went wild when he was diagnosed. So I talked to, I know the people who own the paper so gave accurate information to everybody and everyone was so appreciative of that. The little stories we put in every month or so because they could see what was really happening because in between it all everybody was talking about everything and none of it was true. Well they were able to say "Oh, wow that's how [son]is doing!" I still get "How's [son] doing?" every time I go into town. Every time I go into the bank I get "How's [son] today?" I say, "Oh good, you know." To this day...and that's kinda nice, I never thought about that so everywhere I go almost every day people ask about [son]. There not just asking because they don't have to ask even two and a half years later. They're like "How's [son]doing?" and they really want to know. That is nice. A3

Community members found many ways to support the families. Some of the parents talked about how their communities provided financial support by conducting fundraisers for the families:

They had a [party] and raised twelve thousand dollars...Then they had this meat draw out in [small town] and raised twenty thousand dollars...So it's just unbelievable how people come together for stuff – for sick kids. It was great...If we were from [city with tertiary centre], we wouldn't have had that support. We wouldn't have had the [party] like that, the money to help us out because that was awesome. A3

They did a benefit hockey tournament for her when she was sick. A4

Healthcare providers. All the parents mentioned how valuable the support from the tertiary centre healthcare providers was both during and after treatment. There were many positive comments about the healthcare team at the cancer centre.

I tell you the nurses there and the surgeons were absolutely amazing. They are definitely well fitted for their job...For doing what they do. A1

After their treatment journey was completed, the parents found that being able to get in contact with their healthcare providers at the tertiary cancer centre was extremely comforting. They felt they could call whenever they needed to at any time of day or night with concerns about their child. Parents said that did not have to worry that they were being troublesome to the healthcare providers because the healthcare providers were always happy to provide them advice and reassurance:

I'm thankful that they didn't mind me calling – the...nurses, so I am thankful that I could do that. I am thankful that I had the pager number so if it was midnight I could do that. Whoever was on call, I could tell them [child with cancer] had a fever and I felt comfortable doing that and I felt they were welcoming me to do that. I didn't feel like "Oh, I don't want to bother them." I went ahead and did it and they never made me feel bad about it... A3

I know that I was desperately scared to come home to [hometown] the very first time. I didn't want to and I told them "I am scared – what if this, what if that?" They would say "Well, just call us. It's okay." You do feel more comfortable each time. It's a little bit longer...they were good. They would say "No, that's not a stupid thing or yes, that is cause for concern." They would say you're doing the right thing. They were good at that and we tried not to be too bad. Only calling when we were quite concerned about something. This binder was so good! They gave you instructions and things. A5

One of the parents felt that she would have liked to have more support from the healthcare providers at the cancer centre. Further recommendations from this parent are found at the end of this chapter.

You are there, you are comfortable but once you are home you are not. I have had the most supportive family ever but I still could have used more support, like more medical support. A3

Support groups. Parents talked about support groups that were available to them and their families both in person and on-line. One mother found that the on-line support group for parents of children with her child's specific diagnosis was a tremendous source of support and of information. Having people who are sharing similar experiences available to talk with, was incredibly helpful for this mother to cope with the changes along her cancer journey:

I'm on a support group I found on the computer like for [specific childhood cancer diagnosis] parents support group. I didn't talk up until probably about 6 months ago on that support group. I read and listened but I didn't write or talk. But I have been on that since she was diagnosed. Somebody found it for me. You know I read a lot with them, having conversations and there are lots on there that didn't talk until a short time ago. You know, everybody is living the same thing; we're all fighting for your kids... There are two or three moms that I got to be pretty good friends with when I was there [at cancer centre] which was good... We've have a lot of friendships that way. It was good that way. Yeah, [parent's support group] was good too. A4

One of the parents would have liked a support group that was more specific to her child's treatment. She felt that it would have been helpful during the treatment process to talk to parents who had completed the same treatment because she wanted to talk with someone who had been through what she was currently going through:

Parent: It would have been nice to have a [specific treatment] support group... more available to me. I needed to talk to somebody who was going through what I was going through. And maybe who made it through. You know, that kind of...

Interviewer: Like a mentor program or something.

Parent: Exactly what I needed. Absolutely, for them to connect me with someone to call other than the hospital or the nurses for a little bit of that support. I'm sure that would be no easy task but how many of us want to do that? I could be that person now for somebody that's coming out of [treatment] and I would be more than happy to be that person but how many of us would? Good Idea! That's a great idea! That would be very helpful! Yeah, for afterwards. A3

Two parents mentioned a specific parental support group that was available through the cancer treatment centre but had different perspectives about its availability for themselves personally:

But we do our [parent's support group] weekend and we really like it. It's good for me to see how other parents feel because those people understand us more than our own family. A4

If I lived in [city with tertiary cancer centre] I would have kept going to that support group they have – [parent's support group]. Like I got their info. I didn't keep in touch with it, it seemed like a [city with tertiary cancer centre] thing. A3

Faith. Three of the parents discussed how certain aspects of their faith helped them cope with the changes brought on by their child's cancer. Two families spoke about using prayer as a way of dealing with the diagnosis and between follow-up appointments:

They did some X-rays and they thought they found something in her chest, they found a spot in her chest so we actually had called the priest in and stuff. I thought there was stuff like everywhere in her but here it was just the way the X-ray was. But for about 4 or 5 hours, it was intense and so actually we just prayed...and then when they came in the afternoon and they said that it was just the angle they were looking at the X-ray. And, from that point on actually, I knew everything would be okay. A1

You just get that rotten feeling and it just all comes back. You try and put it on the back shelf in between appointments as best you can. Like I say it's always there. I don't know, you just feel sick. You get that wave and you feel nauseous and you say "What are you going to do?" and you just pray. A5

One parent spoke at length about how his faith helped him cope with the changes to his life that were brought about as a result of his child's diagnosis, treatment and follow-up care. His faith was embedded within his cancer journey:

I knew it was going to be a long process, I was afraid. I had arguments with whatever God is out there...And I remember the night that I found out she had cancer, I was looking at her lying on the couch and I was kinda like arguing with God about why her not me...Those thoughts come to me and I was able to let it go and turn it over to a higher power. And when I did that, I was okay with it – no matter what the outcome was it was out of my hands...But it's going to be up to whatever God is out there and hopefully he's trained these people well and when I did that, then I was okay with it in my own head. A2

At the time of diagnosis I realized how fragile life can be. During the treatment, I learned how caring other people are and how much work and dedication they put into their jobs. When the treatment was completed, I change my thinking from why should my child get this cancer to why has my child being allowed another chance at life when so many others don't take to the treatment well. Faith, Hope and Love are still alive and well in this world. A2

Just prior to the time of the interviews, a child with cancer in one of the parent's local community died as a result of her disease. This prompted the parent to think about his own child and their experience with childhood cancer:

There was some more questioning about why, whatever God is out there let [daughter] live and this poor girl pass. It probably changed a little bit of my perspective on my ideas of God. With that girl dying the other day (pause), give me a better idea of what could have happened and how fragile life is. You know, and again, what is really important in life, you know? We talked about why did God choose her to get better and not some of the other children...I think she is blessed and should be an example to others. A2

This parent was grateful that the healthcare providers that cared for his child were competent at their job and felt it was God's doing.

I honestly believe that the healthcare providers (doctors, nurses, etc...) that attended to my child in this time of sickness only need to thank God that they were blessed with the wisdom and knowledge to do their task well. A2

Returning to 'normal' life. As their treatment journey ended, their cancer journey continued. All the parents said that they had returned to lives that looked similar to their lives prior to their child's diagnosis.

And every day is a new day but today is a good day for all of us... Health-wise and like emotionally everything around the house is much better now and we're just pretty much normal, I'd say now or as normal as can be! A3

Work. Parents spoke about the need to alter their work schedules during their child's treatment and to accommodate follow-up care. Changing work schedules affected all the families' finances to some degree.

I didn't quit but I went on leave from work. [Husband] worked as much as he could still because we didn't have a choice...I didn't have to work at the time, things were going okay. [Husband] was working and I was able not to go back to work and still be okay. The last thing you want to worry about is money and paying the bills and all that! We never had to worry. I have to say. My parents helped us out immensely, of course with anything that had to be bought. And then, just that money we got from...we didn't have to worry, it just wasn't there at all which was good because I wouldn't have wanted to worry about losing my house at a time like that and it was never a thought. A3

Although I didn't make a lot of money, I was responsible for a vehicle payment and my money went towards extra things. That was cut off - right now - because somebody had to be with him. A5

School. All the children missed some school; most missed close to a year during their cancer treatment regimen. Parents reported that all the children were able to catch up in their studies when they returned to school although it was easier for some than for others:

It set her back a year. She had a hard time going back to school. A2

I got her to go [to school] in the hospital when I could get her to go because she didn't like it. She missed those few months but she's caught up and that's good. She's not behind. A4

One parent spoke about how she felt it was important for her child to continue to do schoolwork while at the hospital undergoing treatment. She believed that making him do schoolwork symbolized more than schoolwork because it kept part of his regular routine during his long and intense cancer treatment. She did not want her son to feel like she was giving up on him because she had always been vigilant with his schoolwork. She also said that returning to school helped her child return to 'normal' life.

But I felt like if I wasn't making him go to school then what was the point of it all. Like, I didn't want him to think he was dying. It was all about "You're going to be okay, we're going to do this. We're not gonna give up." I thought if he's not going to school and learning then he might get that feeling of despair. I didn't want him to think, oh, because I was always strict with school before that...I didn't want him to think "Oh mom's not making me go to school so that must mean I don't need to now, you know, what for?" So I did, I made him. I mean, he hated it but...he did it. A3

He's doing phenomenal, just totally perfectly normal ten year old...He has friends over every single weekend for sleepovers or he goes to someone's house for the weekend. Completely back to normal, well he has since he went back to school. He does phenomenally well in school, like incredible. He missed a whole year and he pretty much gets straight A's. His report card is pretty much the best one yet, we just got one last week. At the teacher conference, the teachers love him...So I have to say everything is pretty good, really good. A3

Perspective. Several of the parents stated that they always knew that it could have been worse for their child than it was. Looking at it from this perspective seemed to help the parents cope with their child's diagnosis. Comparing their child's situation with others, particularly during their treatment journey, improved their state of mind:

I think we knew it could have been a lot worse... A1

On that site, there are younger ones that are doing perfectly fine and yet there's other ones who are relapsing numerous times. She is lucky though, compared to most of them I read about...When we were going through treatment. Sitting in there, there were always kids off worse than mine. When she was in ICU, there were kids who were dying – like dying right then and there! She wasn't dying. You know what I mean. So I always look at it and I still do look at it – there's always worse than us so that helps - thinking that way. A4

The parents also talked about how their outlook on life had changed as a result of their child's cancer. Parents reported positive consequences to their child's diagnosis such as living in the moment and appreciating each day which lead them to express their love for their families more readily:

So now I'm 100%, pretty much. (laughs) I don't have anxiety. I sleep good – the whole 'live in the moment now' and appreciate every day. And we are such a better family for what happened to us. I wish this didn't happen but I am a much better person now...just emotionally. Our lives are better because of it now. We communicate better because of what happened...more I love yous, more hugs and kisses. We did live differently and my parents too because they're super close to us and for my parents, for us - everything has changed for the better. A3

The reality of seeing and knowing children who died as a result of their cancer had a profound effect on one of the parent's perspective on life:

[A local child dying from cancer] give me a better idea of what could have happened and how fragile life is. You know, and again, what is really important in life, you know? A2

Giving back. Parents felt that they were in a fortunate position to have a healthy child who had completed treatment for childhood cancer and wanted to show their appreciation in some way. They talked about how they and their children spoke at and participated in fundraising events for cancer and associated causes such as Ronald McDonald House. Parents and the children who had completed cancer treatment were willing to share their stories in order to educate others and to raise funds to further improve the experience of others.

I feel really lucky (pause). I really do... We now every year put in two relays for life and [daughter] gets the most pledges of anybody on our team, on her own. It takes her a long time, though, because every house that she goes at wants to know about her story. (A1)

One mother explained that she found it therapeutic for her to tell her story. It was a way for her to bring some good from something that was difficult for her and her family and she was happy to participate in a variety of events and studies.

And I am used to talking about it. I do speeches for Ronald McDonald House, for different charity events where I tell them what happened to us, that kind of stuff. I've done it so many times now and yet for some reason – don't ask me why – I don't get emotional when I talk about what happened... When I talk about what happened to us, it's very therapeutic for me...It's my way of doing things. (A3)

One of the children who completed cancer treatment wanted to participate in fundraising events because it gave her a chance to tell her story in her own words which was important to her.

What she wanted to do was like she did a couple of interviews for Ronald McDonald House and she talked at the golf tournament, she talked at...one of those fundraisers. She wants to tell her story. She wanted to tell them HER way. Not how we felt, but her. A4

The parents who participated in this study said they did so in order to help other parents who may be going through what they have already experienced. Their altruism extended to other ways of sharing their stories but it was always in order to help other families with cancer.

Anything I can do to help you and help maybe somebody else, some other parents or whatever...I just want to try to help out. (A2)

I did a radio interview not long ago. If I can talk about it or help anybody, that's my way to kind of do things and I don't get all...you know, I can stand there and talk. Some people can't do that but I'm fine. (A3)

You know what...I don't mind talking to you, that doesn't bother me anything that kind of gives insight to other people – that doesn't bother me. I don't mind doing that. They had something here at the hotel and they wanted to talk to caregivers of cancer patients and I did. I mean, how are they going to learn anything if, how are they going to learn what is in people's heads if they don't do it. I don't mind talking about it, I get teary eyed, that's just part of the thing – you know what I mean. That's just life. I don't mind telling it. (A4)

Helping others who may be experiencing a family member with cancer was very important to these parents. Whether or not the parents found it difficult to tell their cancer journey story, the parents participated in this research study in order to help other parents or families as well as to help the author of the study. Prior to starting one of the interviews, one mother said that her head was pounding because she does not like to talk about her child's cancer but that she had agreed to speak with me because she wanted to help others. She was willing to overcome her physical discomfort in order to tell her story in the hopes that it will improve someone else's experience with their child's cancer.

Parents' Recommendations to Healthcare Providers

For the most part, parents stated that they felt very satisfied with the care they and their children received from the healthcare providers at the tertiary cancer centre. Resources that were provided to the parents from the cancer treatment centre, such as a binder with information pertaining to their child's course of treatment, were valuable sources of information for the

parents and were recommended to other parents. The parent who found support through a disease-site-specific support group recommended that parents be encouraged to find support groups that are helpful to them and to look to their children's healthcare providers as a source of information and support. Healthcare providers must recognize the important role they play for families with children with cancer as sources of information and support.

One parent who had difficulty returning home after the completion of treatment thinks that she would have benefitted from more anticipatory emotional preparation before going home. She was not sure who should be responsible for it but thought that the social workers phone number should be given to everyone before they go home. She wished that someone had talked to her about the potential fear and anxiety that she experienced when she returned home. Although, she did not want families to be frightened about going home, she felt that some warning would have normalized the experience for her as she felt she was not the first person to ever experience anxiety after going home.

The parent who received travel grants as part of their provincial program felt that this was helpful for her family and thought it would be a good program for other families of children with cancer. It respects the fact that even though families do not pay for cancer treatment, there are many costs associated with travelling for cancer care.

Chapter Summary

Chapter four presented the findings of this research study. The demographic data was provided about the parents and their children, including diagnosis information. Following this was a discussion of the essence of parents caring for a child who has completed cancer who do not live near their child's tertiary cancer centre and four themes that describe this essence. The essence of the experience for these parents was *a journey within a journey* and the four themes

were: (1) travelling for care, (2) learning to navigate their journey with healthcare providers, (3) coping with change, and (4) giving back. The following chapter will be a discussion about these findings; about the appropriateness of the research method; recommendations for nursing research, practice and education; and conclusions about this research project.

CHAPTER FIVE: DISCUSSION OF FINDINGS

Introduction

Chapter five contains a discussion of the findings of the phenomenological study of the lived experience of parents caring for a child who has completed cancer who do not live near their child's tertiary cancer centre. The chapter begins with an examination of the essence and the themes that support the essence in relation to the literature. An evaluation of the appropriateness of the methodology and methods chosen to undertake this study will be explained in relation to the research question. An assessment of the suitability of the conceptual framework will be discussed in addition to an explanation of how the findings relate to the framework. Recommendations for nursing practice, education, and research will be provided prior to the chapter conclusion that contains a personal reflection.

Discussion of Research Findings

Findings from this research study, including the essence of the parents' lived experience, the themes and sub-themes that support the essence will be compared with previous research findings. The literature includes studies of families of children with cancer, families with chronic conditions, and living at a distance from healthcare services. Similarities and differences between studies will be explored as well as a presentation of findings unique to this study.

The Essence of Parents' Lived Experience

For parents who participated in this study and are caring for their children who have completed treatment for childhood cancer living at a distance from the tertiary cancer centre, the essence of their lived experience is a journey within a journey. Once their treatment journey was over and their travels to the treatment centre for the child's cancer were infrequent, the cancer journey continued to be part of the family's lives. Parents felt that their child's cancer diagnosis

influenced who they are and how they live their lives even years after the treatment was complete. Parents and their families' lives moved forward while bringing their experiences of their child's cancer with them. In a qualitative study talking to children undergoing treatment for cancer and their families, Woodgate (2006b) uncovered a narrative, "moving forward, moving on," (p. 6) that was described by the families along the course of their cancer journey. Families in this study found that during the child's cancer treatment, they had to continue trying to move forward in order to move on with their lives despite having to go on a journey that had not been planned (Woodgate, 2006b). Scott-Findlay and Chalmers (2001) studied rural families experiencing cancer and found that one theme was "life is different, but we must go on" (p. 212). These families spoke about how they had accepted the diagnosis of cancer and had tried to move their lives forward. For the parents in the current research study, the ending of their treatment journey and the continuation of their cancer journey was the essence of their entire experience with childhood cancer after the completion of treatment for their child's cancer.

Parents were able to move on from the journeys for treatment but were unable to leave their cancer journey behind. None of the parents live their lives today in a manner that has not been influenced by their experience with childhood cancer. Their child's cancer is never far from their minds and it is something that is "*...never over, never...It won't ever go away*" (A5). This mother said that even though the paper may say that her child is in remission, she thinks about it daily and will always be concerned about recurrence. This echoes another narrative from Woodgate's (2006b) study that was "it is never over with . . . always a waiting game" (p. 8). Families felt that their child's cancer journey would always be a part of their lives and that the fear of recurrence would continue to be present long after treatment ended (Woodgate, 2006b).

This had been documented for years and is known as the Damocles Syndrome (Koocher & O'Malley, 1981) which is a continually present persistent fear that the child's cancer will return.

Along with the fear of recurrence came feelings of anxiety and uncertainty about the future, according to the parents in the current study. This has been found to be true for the people of all ages who complete cancer treatment and their families (Duffey-Lind et al., 2006; Farmer & Smith, 2002; Haylock, Mitchell, Cox, Temple, & Curtiss, 2007; Labay et al., 2004; van Dongen-Melman et al., 1998; Woodgate & Degner, 2002). Adult survivors of childhood cancer reported that they felt uncertain and hesitant to plan their future because they never knew if and when late effects might occur (Cantrell & Conte, 2009; Prouty, Ward-Smith, & Hutto, 2006) and that having cancer changed their life forever (Drew, 2007). Children with cancer and their families learn to live with uncertainty along their entire cancer journey (Woodgate & Degner, 2002) and the time period after treatment ends was no exception for parents in the current study. Along each step of the cancer trajectory, the children and their family undergo negotiation and renegotiation processes (Drew, 2007) as they learn how that step will affect their cancer journey. This was certainly true for the parents in the current study. As their cancer journey unfolded, they learned what it meant for them and their families.

Themes

The four themes that comprise the essence of parents' lived experience of caring for a child who had completed treatment for cancer and living at a distance to their child's cancer centre will be discussed in this section. These themes were: (1) travelling for care, (2) learning to navigate their journey with healthcare providers, (3) coping with change, and (4) giving back.

Travelling for care. The parents in this study were willing to go wherever they needed to go for high quality cancer care for their child. Distance was not an insurmountable obstacle for

parents of children with cancer but simply part of their overall childhood cancer experience. This is a new insight into the lives of families with cancer who live at a distance from the cancer treatment centre. The distances that the families had to travel were relatively short compared to distances that people living in Northern and remote parts of Canada have to travel for specialist services such as cancer care. Further research is needed to determine whether greater distances would impact the cancer experience differently. In addition, little is known about the experiences of First Nations families living on remote reservations and communities who must travel for cancer care. Studies looking at these populations are warranted. Payne et al., (2000) reported that people with cancer considered travelling to the treatment centre in a variety of manners ranging from a minor inconvenience to a barrier to treatment. One of the parents in the current study said that she did not “*look at it so much as much as a negative or inconvenience though. You feel you are getting the better care*” (A1). The distance she had to travel for her child’s care was counteracted by the higher quality of care her child received, according to the mother. This finding was contrary to what Scott-Findlay and Chalmers (2001) and Woodgate (2001) found for rural families with cancer who reported difficulties associated with travelling for their child’s cancer treatment. Differences between the previous studies and the current study may be related to the distances that families had to travel in order for care and to the frequency of visits to the tertiary cancer centre. The mother who said the above quote had to travel approximate four hours in order to get to the tertiary centre but was only required to make infrequent visits to the cancer centre during the course of her child’s treatment which likely influenced her feelings about the distance travelled. Also, the families in the current study who had local healthcare providers in whom they trusted seemed to report fewer difficulties associated with travelling for their child’s cancer treatment than the mother who did not trust her local healthcare providers. It is possible

that with further probing during the first interview and a follow-up interview, parents in the current study may have offered further insight related to any difficulties they encountered while travelling to the tertiary cancer centre.

Time may play an important role in the parents' perspective of what it meant for their family to travel for cancer treatment. Although, families in the current study continued to travel for follow-up care, the fact that several years had passed since the time of diagnosis may have impacted their recollection of their travel experience during treatment. The fact that all the children were currently healthy may also influence the parents' feelings about travelling for care. In their cases, they also travelled for cure. Talking to families currently receiving treatment who do not know whether their child's cancer will be cured may incite different responses than the families in the current study. Further research is warranted to examine whether time and the current health status of the child influences families' feelings about travelling for care.

Parents were confident in the skills and abilities of the pediatric oncology team to provide their child with expert care at the treatment centre. This provided a sense of security that was not always present when they were at home. In rural Australia, McGrath (2001a) found that people with cancer living at a distance to the cancer centre felt a lack of confidence in local healthcare providers' knowledge about specific cancer questions and especially with regards to follow-up care.

Being away from home. Parents identified what it meant for them to be away from their home during treatment and follow-up. As was the case for rural cancer patients in other studies, families stayed in a variety of accommodations while in the city – the hospital, Ronald McDonald House, hotels, and homes of family members (Scott-Findlay & Chalmers, 2001; Wilkes et al., 2006). Parents in the current study all had extended family members who lived in

the city that contained the cancer centre and were able to stay with them at some point during their treatment journey.

For families in this study, being away from home meant that families were away from everyday routines and sources of support. Parents had to leave their lives at home, including other family members, friends, their house, work, and school, in an abrupt fashion while coming to terms with the fact that their child was potentially very ill. McGrath (1998) reported the same aspects of being away from home for families with a diagnosis of leukemia in rural Queensland, Australia. All of the families in the current study were separated from other members of the immediate family at some point which is consistent with the literature (Aitken & Hathaway, 1993; Bensink et al, 2007; Clavarino et al., 2002; McGrath, 1998; Nair et al., 2006; Scott-Findlay & Chalmers, 2001). This resulted in some degree of isolation from each other although only one parent in the current study articulated this separation. In this family, the younger sibling felt anxious when his sibling (with cancer) was away for treatment as well as for follow-up appointments. For this mother, she felt that her child with cancer would have preferred to be treated closer to home so that she could be in close contact with her friends and family.

Returning home. When the families were able to go home between and after treatment, parents had conflicting emotions about it. Parents wanted to be home especially because they knew their child wanted to be at home but there was hesitancy and fear to be away from the cancer centre and healthcare providers who know about childhood cancer. Previous research corroborates this dilemma of emotions of wanting to be at home and not wanting to leave the security of the tertiary centre (Labay et al., 2004; Ortiz & Lima, 2007; Scott-Findlay & Chalmers, 2001; Woodgate, 2001) especially at the completion of treatment. Parents in Ortiz and Lima's (2007) study described returning home as losing "the ground beneath their feet when the

child is discharged and question[ing] their capacity to cope with the child's health state when the treatment ends" (p. 415). Parents in the current study missed the sense of security that they felt at the hospital, upon returning home.

After treatment for childhood cancer ends, families may experience feelings of gratitude (Ortiz & Lima, 2007), joy (Cantrell & Conte, 2009), fear (Cantrell & Conte, 2009; Haase & Rostad, 1994), and uncertainty (Arnold, 1999; Haase & Rostad, 1994; Labay et al., 2004). Woodgate (2001) uncovered that parents were glad that the treatment was over but also expressed uncertainty and fear about no longer actively doing something to keep the cancer at bay. This was a difficult part of the transition period after treatment ends. Families may not be prepared for all these emotions and for the challenges that are presented to them at this time along the cancer trajectory (Labay et al., 2004). One mother shared that she was not prepared to feel stressed instead of happy when she returned home after her child's cancer treatment. The development of programs that transition families with children with cancer home after treatment is warranted as well as evaluations of these interventions. Maurice-Stam et al. (2007) suggest that parents continue to need support and for their needs to be regularly assessed after treatment ends as parents' needs change over time in relation to returning home (McGrath, 2001a).

Practical issues. Parents talked about some practical issues that came about because of the distance from the cancer centre. There were transportation obstacles such as needing to borrow a car and a lack of convenient public transport from some communities. The extra time and planning required for travelling to the city for treatment and follow-up care about which one parent spoke about was highlighted in the literature (McGrath, 1998; Scott-Findlay & Chalmers, 2001). In an Australian study of rural cancer patients travelling to the city for treatment, Wilkes

et al. (2006) found that practical needs included information, accommodation, transport, and the economic impact of the travels.

There are other practical issues about travelling away from home that parents talked about in this study including looking after the house, yard, and farm, looking after any siblings, taking time off work and school, and additional costs. These are well documented in the literature surrounding rural cancer patients travelling for treatment (Aitken & Hathaway, 1993; Clavarino et al., 2002; McGrath, 1998, 2001a; Wilkes et al., 2006) and will be further discussed in subsequent sections. Some of these practical issues are present for urban families as well such as childcare for other children, missing school and work, and added costs such as parking and food for the family member staying with the child in the hospital.

Learning to navigate their journey with healthcare providers. All the parents talked about having to work with healthcare providers as they learn to navigate their cancer journey. The journey begins with the presenting symptoms, continues with learning the diagnosis and being at the cancer treatment centre, which leads to learning the responsibility of care. In pediatric oncology, the most effective relationship between nurses and parents is when they work together to provide care to the child with cancer (Romaniuk, & Kristjanson, 1995). According to the parents, using the specialized knowledge of the child, that only a parent had, helps to develop a partnership between the parents and the healthcare providers in order to improve the child's health (Kars et al., 2007). In another study, parents reported that the most helpful behaviours that their child's healthcare providers were "carefully delivered, accurate information regarding their child's health status and response to cancer treatments, having the same care providers on an ongoing basis, and being prepared by them for potential treatment-related happenings" (James, Keegan-Wells, Hinds, Kelly, Bond, Hall et al., 2002, p.227).

Learning the diagnosis. Parents reported having to visit their family doctors or the emergency rooms multiple times prior to a diagnosis of cancer being given. This is a common occurrence in pediatric oncology because of the rarity of the diseases and the vagueness of the symptoms. Parents in the current study did not harbour any bad feelings about having been misdiagnosed initially by their local healthcare providers. Once there was recognition that the child required specialist expertise, families in the current study talked about travelling to the tertiary children's hospital promptly which is in contrast to findings from Scott-Findlay and Chalmers (2001) whose families reported long waiting periods before transfer to specialist care.

Parents learned of their child's cancer diagnosis over the phone, at their local healthcare facility and at the tertiary cancer centre. Discovering the diagnosis of cancer sent families on a journey of meeting and having to trust new and numerous healthcare providers. Parents wanted to know about their child's disease and would try to find as much information about it as possible which is common for parents and children with cancer (Aitken & Hathaway, 1993; Goldbeck, 2001; Kerr et al., 2007; Ljungman et al., 2003; Ortiz & Lima, 2007; Santacroce, 2002; Sawyer et al., 2000; Shields et al., 1995; Woodgate & Degner, 2002; Yeh, 2002).

In a study of women with gynaecological cancer in rural Australia, Baldwin and Usher (2008) learned how important the use and availability of the internet was for certain women in order to learn about their diagnosis, treatment options, and prognosis. Having access to this information at any time of day or night from their own home was helpful to some of these study participants (Baldwin & Usher, 2008). However, one of the women in their study found that conflicting information between internet sites and her treatment centre caused her additional distress and made her question what was the best course of treatment (Baldwin & Usher, 2008). One of the parents in the current study also found that the internet was a helpful resource, at

times, but at other times caused additional stress for her because the course of treatment for her child's cancer listed on several reputable websites proved not to be the course her child received. This parent felt that healthcare providers should advise parents about this type of occurrence in order to relieve some of the confusion about what treatments are available to which patients.

Being at the cancer treatment centre. Upon arrival to the tertiary cancer centre, families met new healthcare providers whom they needed to trust immediately and with whom they would work closely in order to treat their child with cancer. One parent spoke about not having time to get to know the pediatric oncology team but needing to trust them immediately with their child's life. This situation was difficult but worthwhile. Trusting the pediatric oncology providers is an integral part of treatment for childhood cancer (Kerr et al., 2007; Woodgate & Yanofsky, 2010). Pediatric oncology healthcare providers play an important partnership role with the family along the cancer journey starting at the cancer centre during treatment and provide valuable support for families during and after treatment (Kerr et al., 2007; Scott-Findlay & Chalmers, 2001; Woodgate & Yanofsky, 2010). Parents in this study felt strongly that their child was receiving the highest quality care by the experts in the field who worked at the tertiary cancer centre.

Responsibility for care. Parents had to navigate a healthcare system both while at the tertiary cancer centre for treatment and at home between and after the completion of treatment. One parent did not feel comfortable taking her child to their local healthcare provider if she had questions about her child because they had told her that her child was 'out of their realm.' Two of the parents talked about local healthcare providers being unable to use their child's central line to draw blood which was frustrating and time-consuming. This was also reported by Scott-Findlay and Chalmers (2001) and McGrath (1998) in relation to local care providers having a

deficit in knowledge of caring for children with cancer and their unique needs. For some parents, this increases the amount of responsibility they have for their child's health. One parent in the current study said felt a tremendous amount of responsibility for her child's life when at home after treatment, "*maybe it's too big of a responsibility sometimes*" (A3). She felt she needed more guidance from her child's healthcare providers. Similar to how this mother was feeling, Labay et al. (2004) reported families of children with cancer feeling anxious about their abilities to respond to their child's health and psychosocial concerns after the completion of treatment as a result of the decreased contact with the healthcare providers. The mother in the current study did not have a local healthcare provider whom she trusted with her son's care. This may have influenced how she felt about being totally responsible for her child while at home. The other parents in the study did have local doctors with whom they felt comfortable and they did not comment on the amount of responsibility they had for their child's care. Further research with larger sample sizes is required to delineate whether there is a relationship between sense of parental responsibility and comfort with local healthcare providers. Programs that support the family while at home such as a liaison nurse who visits or video-conferences with them shortly after they return home to provide information and reassurance may lessen the burden of responsibility felt by parents upon returning home from treatment.

Parents experience a tremendous amount of responsibility for their child's cancer care along the cancer trajectory. A major source of responsibility is a result of all the decisions that parents must make prior to and throughout the course of treatment (Woodgate & Yanofsky, 2010). In their study examining parental perspectives of their participation in decisions about childhood cancer clinical trials, Woodgate and Yanofsky (2010) found that parents not only have to make a number of decisions in regards to treatment and participation in clinical trials, but also

must learn to live with their decisions. For some of the parents, coming to terms with their decision was not easy. However their distress was lessened by knowing they could change their minds and opt out of the research at any time and more importantly, that their decision to opt out would be supported by their child's oncology healthcare providers (Woodgate & Yanofsky, 2010). Healthcare providers must recognize the incredible responsibility that parents feel when their child is diagnosed with cancer. Healthcare providers play an important role in providing information and support to parents of children with cancer about the decisions parents must make along their cancer journey.

Several of the families had local care providers in whom they trusted and had travelled along their journey with them starting prior to diagnosis. One parent in particular was extremely pleased with her child's local doctor and his willingness to learn about her child's disease, treatment, and follow-up needs. This parent stated she felt lucky to have him. Healthcare providers in rural locations should have access to educational activities that can inform them about aspects of care about which they may be unfamiliar. Such education could be provided in-person, via video-conference or on-line with the latter two addressing geographical challenges. It is a shared responsibility between the healthcare provider and the healthcare system to continue to educate the professionals who work within the system in order to provide the most up-to-date and safest care possible to patients and their families.

Coping with change. Parents talked about the many changes that their child's cancer diagnosis introduced into their lives. Fortunately, these parents reported a variety of things and people that helped them to cope with the changes in their lives. The capacity to cope with the changes brought on by their child's diagnosis facilitated the parents' ability to move on with their child's cancer.

Support. For families with a child with cancer, social support is an important need that must be met (Dahlquist et al., 1996; Hoekstra-Weebers et al., 1998, 2000; Kerr et al., 2007; Ljungman et al., 2003; Shields et al., 1995; Woodgate & Degner, 2003a; Yeh et al., 2000). The availability of social support influences how families and parents in particular, are able to cope with the diagnosis of childhood cancer (Kerr et al., 2007) and the subsequent changes to their lives brought about by that diagnosis. According to past studies about children with cancer, support may include family, friends, other parents whose child had cancer, and healthcare providers (Aitken & Hathaway, 1993; Enskar et al., 1997; Lindahl Norberg & Boman, 2007; Shields et al.; Woodgate, 2001; Yeh et al., 2000). Woodgate (2001) discovered the concept of family members needing to “be present” as a strategy to “keep the spirit alive” through the course of the child’s cancer treatment. Part of being present was being with others, being there for others and being there for oneself which allowed the family a feeling of connectedness (Woodgate & Degner, 2003a). In interviews with adolescents with cancer, they shared the importance of “being there” that they associated with the people who supported them through their cancer journey (Woodgate, 2006c). Adolescents had six main ways that their family, friends, and healthcare providers could support them:

- (1) being there to comfort me, (2) being there to hold my hand, (3) being there to keep me from feeling less lonely, (4) being there to help me feel like I have a life, (5) being there to keep me positive, and (6) being there for me despite everything. (Woodgate, 2006c)

Subsequently, Kars et al. (2007) found that parents of children with cancer needed to ‘be there’ for their child and this need focussed on the protection and preservation of their child. Parents’ actions towards and with their child’s healthcare providers were in relation to their need to ‘be

there' (Kars et al., 2007). Parents in the current study relied on family, friends, and healthcare providers during and after treatment as well as their community as a whole.

Family. All parents in this study talked about the support they received from their immediate as well as extended families. For the women in Baldwin and Usher's (2008) study, partners and immediate family proved to be "an essential element of their overall coping capacity" (p. 325). This was also the case in the current research study. One of the parents in the current study got divorced during the course of their child's cancer treatment and the spouse's inability to cope with the changes brought about by the diagnosis was listed by the parent participating in this study as one of the reasons for the divorce. Marital distress is frequently reported by parents of children with cancer (Aitken & Hathaway, 1993; Grootenhuis & Last, 1997; McGrath, 2001b; van Dongen-Melman et al., 1998). For the other couples, many parents said that their spouse was an important source of support for them during and after treatment. Some of the parents felt that their relationship with their partner was strengthened by coping with their child's cancer together which had also been documented (McGrath, 2001b; van Dongen-Melman et al.).

Families were often separated during treatment and follow-up care. For two of the families, older siblings had to stay home and look after themselves which has been reported by Clavarino et al. (2002). One of the families in the current study left their younger child at home with other family members, one brought the younger sibling and the grandmother along, and one brought the sibling periodically to the treatment centre. Where siblings are and who looks after them is extremely context-specific for each family. It was difficult for the parents to leave the other children at home and parents reported that some of the siblings found it difficult to be at home when their sibling was at the treatment centre. Siblings who were at home are without their

sibling and at least one of their parents for a period of time which corroborates previous findings (Aitken & Hathaway, 1993; Harding, 1996; Ortiz & Lima, 2007; Scott-Findlay & Chalmers, 2001). Not only to the siblings have to learn to live with an ill sibling (Harding, 1996) they must deal with their worries about their ill sibling (Enskar et al., 1997).

Woodgate (2006a) explored the experience of siblings of children with cancer and found that the siblings felt they had a 'different way of being in the family' (p.408). For these siblings, they experienced a loss of the family's way of life from normal routines to family roles and responsibilities to special events (Woodgate, 2006a). Siblings in this study reported having unmet needs that contributed to a feeling that they were less cared for than their sibling with cancer (Woodgate, 2006a). In addition to the loss of the family's way of life, siblings felt a loss of their sense of self within the family unit which was characterized by their refusal to acknowledge their participation in the family's cancer journey rather it belonged to their ill sibling (Woodgate, 2006a). In a study talking to siblings of children undergoing bone marrow transplant, Wilkins and Woodgate (2007a) siblings explained that they want to be considered part of the family in family-centred care, need information to be provided to them, and want a chance to talk other siblings their own age about their unique experiences. Because the current study did not include interviews with the siblings, we cannot presume to know their experience by relying on parental reports alone. More research required to learn about siblings experience (McGrath, 2001a) along the entire cancer trajectory.

Even though the families were separated, parents considered their immediate family as an important source of support. Many of the families reported feeling closer as a family as a result of going through their cancer journey which has been described in other studies of children with cancer (Clarke-Steffen, 1993; Mattsson, Lindgren & von Essen, 2008; Parry & Chesler, 2005;

van Dongen-Melman et al., 1998; Woodgate, 2003a, 2006b, 2006c). A couple of the families described that they now prioritize time together as a family which is consistent with the literature (Lindahl Norberg & Steneby, 2009; Woodgate & Degner, 2004). Lindahl Norberg and Steneby (2009) found that families appreciated each other more intensely after going through the experience of childhood cancer. In a study of families with childhood cancer, Woodgate (2003a) found that the family was identified as “the support from the family unit that was most important in helping or not helping families get through the cancer experience” (p. 115) and their family provided strength to continue along their cancer journey. This was echoed by the parents in the current study.

All the parents had a family member who lived in the city containing their child’s cancer treatment centre with whom the parents stayed at least once during treatment. This is likely a reflection of the geographical area as a whole in that there is only one major centre in the province and cannot necessarily be generalizable to other locations.

Friends. Parents spoke about how friends, both old and new, were sources of support for them and for their children with cancer. New friends were often people parents met at the treatment centre either on the cancer unit or at Ronald McDonald House. Sharing such an important experience with other parents in similar situations seemed to strengthen these new friendships. Other parents of children with cancer have been reported to be an important resource for parents of children with cancer (Enskar et al., 1997; Scott-Findlay & Chalmers, 2001; Woodgate, 1999). This is because of the mutual understanding of the experience of parenting a child with cancer that most other people do not possess.

Community. For families living in small communities, when their child is diagnosed with cancer, the whole community hears about it and in many cases, joins together to support the

families. The parents in the current study did not speak negatively about the fact that the majority of the community knew about their child's diagnosis. Community members wanted to know about the child and how he or she was doing and for the most part, parents were happy to share their information. Parents found this a benefit of living in a small community because there was a sense of camaraderie among the community members. Parents were provided support from community members in the forms of looking after their home and farm while away for treatment and in the form of financial support. The community can be an important source of emotional, financial, and practical support for children with cancer and their families (Labay et al., 2004; Scott-Findlay & Chalmers, 2001) if the family is comfortable accepting the support that is offered. Cultural differences may influence the acceptance of community support, for example if disclosure of a cancer diagnosis is not allowed families may be reluctant to accept support (Labay et al.). For the women in Baldwin and Usher's (2008) study, they felt reluctant to share their diagnosis and treatment information with their local community which was not the case in the current study of children with cancer. Whether this difference is due to the age and developmental stage of the person with cancer or whether it is due to cultural variations is unknown.

Healthcare providers. Parents spoke highly about their child's healthcare providers. At the tertiary cancer centre, healthcare providers were a valuable resource for parents' informational and psychosocial needs. These findings are consistent with Kerr et al.'s (2004; 2007) supportive care framework for parents of children with cancer. Scott-Findlay and Chalmers (2001) suggested that urban families may experience a closer relationship with the pediatric oncology team than their rural counterparts. This was not reflected in the current study as parents talked about feeling satisfied with their relationship with the pediatric oncology team.

For adolescents with cancer in Woodgate's (2006c) study, the healthcare team was called their "second family" because the support from the team was so important to the adolescents. Support from their children's healthcare providers was important to all the parents in the current study.

When leaving the hospital after the completion of treatment, some of the parents in the current study talked about missing the support that the healthcare providers gave them while in the hospital. This was also revealed by Labay et al. (2004) that families feel "a loss of important practical, informational, and emotional support" (p. 166) upon completing childhood cancer treatment. Children with cancer who have completed treatment have reported experiences of disconnection as a result of the loss of attention and support from their healthcare providers (Cantrell & Conte, 2009) and a loss of the therapeutic relationship with their providers (Woodgate, 2006c). This is because of the closeness that develops during repeated visits in a long cancer journey (Woodgate, 2006c). Adolescents and families of children with cancer have reported feeling a sense of abandonment by the healthcare providers after they completed cancer treatment (Labay et al., 2004; Woodgate, 2006c). After treatment was complete, parents in the current study were extremely reassured by the informational support afforded to them by the healthcare providers at the tertiary centre. Having their phone number and feeling comfortable calling was highlighted by several parents as valuable and necessary for them in their capacity to cope with the changes associated with being home after the completion of their child's cancer treatment.

Support groups. Only two of the parents talked about support groups as a source of support for themselves. One parent was a member of an on-line support group for parents of children with her child's specific diagnosis. She found this an extremely valuable source of support and information for herself. Bragadottir (2008) explains that using on-line support is

useful for populations that are dispersed for people who have time restrictions. Parents of children with cancer living at a distance from the cancer centre fit both categories as they are geographically diverse and are busy with work and their children. Computer-mediated support groups can add to or replace traditional support groups and are suitable for all parents (Bragadottir, 2008). In her study of a computer-mediated support group for parents of children with cancer, Bragadottir (2008) found both mothers and fathers showed “improvements in the health-related outcomes of anxiety, depression, somatization, and stress” (p. 35). For the mother who participated in the on-line and face-to-face support groups, she explained that she enjoyed talking with other parents who knew what she was experiencing as a parent of a child with cancer. The importance of talking to someone who has experienced what parents are experiencing has been found in studies of children with cancer (Enskar, 1997; McGrath, 2001a).

Faith. Several parents talked about their faith playing an important role in their ability to cope with changes brought about by their child’s cancer. Religion has been reported as a coping mechanism for some families with children with cancer (Goldbeck, 2001; Kerr et al, 2004; Patterson et al., 2003). In a study of siblings of children undergoing bone marrow transplant, Wilkins and Woodgate (2007b) found that siblings relied on their faith in God in order feel that their sibling would be okay. Like one of the parents in the current study who questioned his faith at times, so too did the sblings of children undergoing bone marrow transplant (Wilkins & Woodgate, 2007b). Two parents discussed how and when they use prayer along their cancer journey. Prayer use in pediatric oncology has been reported in the literature (Post-White, 2006; Wilkins & Woodgate, 2007b). Survivors of childhood cancer have reported feeling psychospiritual growth because of their illness that was characterized by “a more coherent

understanding of their place in the world” (Parry & Chesler, 2005, p. 1065). Parents in the current study did not articulate this type of understanding.

Returning to ‘normal’ life. As parents moved on with their child’s cancer, they were able to return to a life similar to one they had known before. In pediatric oncology literature, this is referred to as the “new normal” (Clarke-Steffen, 1993; Woodgate, 2001). Part of resuming their ‘normal’ life were returning to work and school which is consistent with McGrath (2001a)’s study of families returning home to rural Australia after treatment for haematological malignancies.

Work. All the parents had their work life interrupted to some degree as a result of their child’s cancer diagnosis which resulted in a loss or reduction of income. Unfortunately, this is a common occurrence for families with children with cancer (Aitken & Hathaway, 1993; Enskar et al., 1997; Mercer & Ritchie, 1997; Ortiz & Lima, 2007; Scott- Findlay & Chalmers, 2001; Woodgate, 2001). Clarke-Steffen (1993) found that mothers were often the parent who renegotiated their work after their child’s cancer diagnosis. This was the case for the four mothers in the current study whose spouses continued to work while the mother and child were at the treatment centre.

However, at the time of the interviews, all the parents were working either in their same or a different position as prior to their child’s cancer diagnosis. This is supported by a Canadian study by Limburg et al. (2007) who reported that 80% of the parents in their study were able to return to their previous work when they chose despite temporarily leaving them after their child’s diagnosis. Returning to work demonstrates how parents were able to move on after the completion of their treatment journey and return to ‘normal’ life.

Financial aspects of being a rural oncology patient are well documented (Aitken & Hathaway, 1993; Clavarino et al., 2002; Scott- Findlay & Chalmers, 2001; Wilkes et al., 2006). Families of children with cancer living in urban centres also experience financial concerns during the course of cancer treatment (Enskar et al., 1997; Kerr et al., 2007; Limburg et al., 2007; Ortiz & Lima, 2007; Woodgate, 2001). Parents in the current study did mention finances to some degree but it did not feature prominently in the findings contrary to what would have been expected based on the literature. Further probing about their financial situation during the interview may have provided additional information about the influence of their child's cancer diagnosis on the family's financial situation.

School. Although all the children missed some school, with most missing nearly a year, all the children were able to catch up and complete their studies. Returning to school was a means for the children to return to a more 'normal' life. One of the parents in particular felt strongly that for her child, the return to school was symbolic of his return to 'normality.'

One of the parents said that his teenage daughter found it difficult to go back to school which was also the case for adolescents in Duffey-Lind et al.'s (2006) study of adolescents transitioning to survivorship. Haase and Rostad (1994) also revealed challenges involved in returning to school, for children who completed cancer treatment. Many of the parents in the current study did not discuss any problems associated with their children going back to school but stated that the children were able to catch up with the schoolwork they had missed during treatment.

Although the only studies that looked at rural survivors of childhood cancer examined academic ability, it is not possible to compare results to the current study due to methodological differences. A recent population-based cohort study of children who have completed treatment

for cancer found that in general children who had been treated with cranial irradiation, had been diagnosed with a CNS tumour, were younger at diagnosis and were female were at greater risk for poorer educational outcomes (Lancashire, Frobisher, Reulen, Winter, Glaser, & Hawkins, 2010).

Perspective. A few of the parents talked about how they always compared their situation with others and felt that it could have always been worse for their child. This helped them to cope with what was happening with their child during treatment. Previous research by Woodgate and Degner (2004) found that parents rationalized their child's symptoms that lingered after treatments by thinking that it could always be worse.

Van Dongen-Melman et al. (1998) found that parents were able to put other events into perspective after going through their child's cancer treatment. Parents also talked about gaining a new perspective on life and what is really important to them. In the literature about children with cancer, several studies report positive aspects of a diagnosis of childhood cancer, such as a deeper appreciation of life (Parry & Chesler, 2005), of the present day (Lindahl Norberg & Steneby, 2009), and of the small things in life (Clarke-Steffen, 1993). Parents in the current study described that they appreciated life more than they had before their child's diagnosis and that they lived more for today which has also been found in other studies of parents with children with cancer (van Dongen-Melman et al., 1998).

Giving back. All the parents felt grateful to have currently healthy children and felt it was important to be able to give something back. Many families were involved with fundraisers for cancer or Ronald McDonald House. This sentiment is echoed in Woodgate and Yanofsky's (2010) study of parents' experience with pediatric oncology clinical trials. Parents recognized and were grateful to previous parents for agreeing to participate in the studies that had improved

treatment for childhood cancer and so wanted to give back to the childhood cancer community as a whole (Woodgate & Yanofsky, 2010).

Parents were willing to suffer physical and emotional discomfort in order to participate in the current study in the hopes that what they said could be used to improve care and therefore the experience of other families of children with cancer. Woodgate and Yanofsky (2010) also reported that parents in their study were genuinely concerned with helping future families of children with cancer.

Comparison of Urban and Rural Experiences

For the parents in this study, where the families lived in relation to the cancer treatment centre influenced every aspect of their cancer experience even though they did not consider the distance travelled as a burden. Families who live in the city with the cancer centre have many experiences similar to rural families which may be exacerbated for the families who live at a distance. For example, urban families do not travel for care but they do spend a lot of time at the hospital and potentially apart from the rest of their family. The difference is that the rest of the family can come for a visit in the evening or the parent may be able to go home for brief periods during an in-patient stay. Not having a place of her own to which to escape was incredibly stressful to one of the mothers in this study who had spent months in the city: at the hospital, in Ronald McDonald House, and in an apartment close to the hospital. Returning home may still be stressful for urban families the first time they are allowed to go but they have the children's hospital close at hand if there is something they really need. Scheduling childcare for siblings, the spouse having to continue to work and the children missing school are experienced by all families with childhood cancer whether they live near or far to the treatment centre. However, coordinating the family's schedule may prove more difficult when one of the parents is away

from homes for long periods of time. Families with children with cancer experience additional costs such as parking, food, and travel-related costs. It is likely that families who must travel for cancer treatment incur higher travel-related costs because of the longer distances that are covered which are doubled when the rest of the family are able to come to the city to visit the child in the hospital. Community support is one aspect that seems to be stronger for families who must travel for cancer treatment than for urban families. All the families in this study and in Woodgate (2001) and Scott-Findley and Chalmers (2001) studies talked about the incredible amount of social and financial support they received from their local community after their child was diagnosed with cancer. Woodgate (2001) uncovered that both rural and urban families had changes in social support and in their financial situations during the course of their children's cancer treatment but for rural families, the differences were more pronounced. Finances were negatively affected for the rural families to a greater degree than their urban counterparts. The current study and Woodgate's (2001) study included families who had to travel from a neighbouring province in order for their children to receive cancer treatment.

Discussion of Chosen Methodology

In order to learn about the experiences of parents caring for children who have completed cancer treatment living at a distance to the tertiary cancer centre, parents who have lived through and are living through the experience were the required participants. Only they could answer the guiding questions. What is it to parent a child who has completed cancer treatment while not living close to the cancer treatment centre? What impact does their child's diagnosis have on their current daily life? What does the completion of their child's cancer treatment mean to parents while living at a distance from the cancer treatment centre? In order to answer these questions, the use of human science was necessary.

As such, a study using hermeneutic phenomenology based on a constructionist philosophy in which there is an assumption of multiple realities was completed. The purpose of which was to study the uniqueness of individuals who had experienced the phenomenon of interest (van Manen, 1990). The methodology that was chosen provides the framework upon which the study is planned, executed, and reflected upon. Van Manen's (1990) human science method for hermeneutic phenomenology provided structure and continuity to the study from the initial concept through to the discussion of the findings. This was helpful to the neophyte researcher to have structure and focus from the inception of the project. Van Manen's (1990) detailed approach to studying the lived experience provided me with a guidebook that I could reference as the research study progressed. As a result of the chosen methodology, the lived experience of parents caring for a child who has completed treatment for cancer who do not live near their child's tertiary cancer centre was elucidated.

The methods of the study were informed by the methodology. In order to arrive at a detailed understanding of the parents' experience, the sampling plan and size, as well as strategies for data collection and analysis were developed with the goal of hearing the participants' words. The inclusion criteria were appropriate in order to capture parents who had experienced the phenomenon of interest. Having a sample size of five was smaller than anticipated but in phenomenology, there is no set size that much be achieved. The five parents in the study provided rich descriptions of their own unique experience of parenting their child which provided insight into their lives and the meaning of the parents' lived experience. Using van Manen's (1990) method for data analysis of writing and re-writing themes to uncover the essence of the phenomenon proved to be a challenge and a reward for both myself and my thesis advisor. The challenge was knowing how much of the findings were to come from the parents

direct quotes and how much interpretation was necessary to glean themes and the essence of the parents' lived experience in written form. The reward was that the parents' stories were accurately depicted which will serve as a foundation for future research by contributing understanding about their cancer journey.

Theoretical Framework

In addition to the methodology that provided a framework to this study, so too did King et al.'s (2002) Life Needs Model provide conceptual structure. The Life Needs Model is a family-centred conceptual framework and a model of service delivery. In many parts of the world, children who are diagnosed with cancer and their families are cared for at tertiary hospitals that practice family-centred care. Working as a team, children, families, and healthcare providers plan, decide, and evaluate the care that is required so that the child is cared for in a manner satisfactory to all members of the team. This type of teamwork is supported by and is, in fact the basis for, the Life Needs Model.

Key concepts in the Life Needs Model are the needs of the children, of the family, and of the community. This study focused on the experiences of parents along their cancer journey. As such, parents shared the needs they had through the treatment journey and after the completion of treatment. Parents talked about their needs for support and information while at home which are two of the parental needs identified in the Life Needs Model (King et al., 2002). The information and supportive needs of the children were often discussed in relation to the parents' and families' needs which are also reflected in the Life Needs Model. Because this study looked at parents who lived at a distance from the tertiary cancer centre, the community in which the family lives plays an important role in their lives and in their care. Parents talked about the support they were afforded by members of their local community in terms of helping to take care of their home or

farm when they were at the hospital and about the financial aid provided by community fundraisers. At the same time, people in the local community, including healthcare providers, had little knowledge, experience, or understanding about what the family was living through after having a child diagnosed with cancer. This highlights the needs of the community to have access to accurate information about children with cancer and families with children with chronic illnesses in general. Providing the community with information and education is one way to help support the family at home in their local community based on the Life Needs Model (King et al.).

In the Life Needs Model, transition points within the child's life are highlighted as important times at which needs may change and thus priorities may need to be re-evaluated (King et al., 2002). Parents were able to provide details about their experience and needs related to their child's diagnosis along the transition points of the cancer trajectory. Transition points for families in their children's cancer journey are diagnosis, treatment initiation, return to school, completion of treatment, and long-term follow-up care. Needs and priorities did change for parents at the transition points which are consistent with the Life Needs Model. Anticipation of changes brought on by transition points is an important aspect of the Life Needs Model and could serve as a framework of care for children with cancer and their families. As healthcare providers, we know these transition points are coming so we should be preparing these families before the fact in order to provide anticipatory guidance which may facilitate the transition experience.

King et al.'s (2002) Life Needs Model provided a solid conceptual framework for parents of children with cancer living at a distance from the cancer centre. The key players in the model, children, parents and families, and community members, are all featured in the findings of this

study. The goal of the Life Needs Model is that children is to support children so that they thrive in their communities (King et al., 2002) which is also the goal of the pediatric oncology team as they set out to treat each child's cancer.

Study Limitations

There are several limitations that must be considered in regards to the current study. The sample size of five parents is small but the participants provided rich, detailed accounts of their experiences. In phenomenology, no specific sample size is necessary to generate comprehensive findings that present the lived experience of the participants. Having only one male perspective is a limitation, however, his experience as a father did not differ significantly from the mothers who participated in this study. Having more parents of both genders may have provided additional insights on their lived experience. Parents in this study were all Caucasian; talking with parents of different ethnic backgrounds would provide a more culturally diverse picture. The children had a variety of cancer diagnoses that affected the type, length, and intensity of treatment which may influence the experience of the parents caring for these children after the completion of the treatment. The major limitation of the study is that there were no families who lived in remote locations which would have provided more information about the experience of having to travel for care. Compared to families in remote locations served by the tertiary cancer centre, the distances that the families in this study had to travel for their child's cancer treatment were relatively short. The participants in this study had to travel a one-way distance of approximately three to five hours on fairly main roads. Parents in this study did not feel that this distance was too far for them to travel in order to receive their child's treatment. There may be differences in the experience of parents travelling longer distances on less well-used roads. More research is required to explore the experiences of families who live further from the treatment

centre, especially families living in remote locations who must relocate for childhood cancer treatment. One particularity about the participants was that each of them had a family member living in the city that contained the cancer treatment centre with whom they stayed at some point during their cancer journey. This may have influenced aspects of their travelling experience.

This study would have been enhanced if the entire family would have been interviewed including the parents, child with cancer, and the siblings. A more in-depth picture of life for families after childhood cancer treatment living at a distance from the treatment centre would be provided. However, the parental experience was the focus of this study. The participants provided valuable insight into their share experience which affords a basis upon which further research can be undertaken. Findings from this study present clinicians with an understanding of the phenomenon of parenting a child after cancer treatment while living at a distance to the treatment centre from the parents' own perspective.

Recommendations

The following section contains recommendations for nursing practice, education, research, and policy based on the findings of this study.

Recommendations for Nursing Practice

Prior to this study, an understanding of what it is like to be a parent caring for a child who has completed cancer treatment while not living close to the treatment centre, was missing in the literature; findings from this study provide a detailed description of this experience. The description can inform nurses and other healthcare providers about families' experience of cancer specifically after the completion of treatment for families that had to travel to the cancer centre for care. Nurses must recognize that travelling to and from the cancer centre may create situations that differ from families living within the city containing the tertiary care centre. For

instance, families must coordinate schedules in order to travel in for follow-up care while one parent travels to the city with the child with cancer and the other parent stays at home with the other children. A follow-up appointment translates into a trip, usually at least overnight, which means missing parts of two days of school and work. Recognition of the time required for the family to travel to the cancer centre would show rural families an understanding of their experience by the healthcare team and would address parents' practical needs. This could be done by giving them afternoon appointments on admission days or follow-up appointment visits and discharging them early in the day when possible.

Regular assessment of the family's support system is important during the childhood cancer trajectory especially when families are apart for periods of time. During treatment, nurses can encourage and support families being together, whether in person, on the phone or over the internet. Allowing times for the child's or family's friends to visit or talk with the family may also facilitate the family's support network. Obviously nurses can only do such things in partnership with the child and family and only within reason of what the child is physically able to handle between the necessary aspects of treatment. Assessing social support addresses parents' emotional and psychosocial needs.

Nurses could play an integral role in providing anticipatory guidance to families of children who are completing treatment for cancer. In the study, a couple of the parents were extremely anxious to return home between and after treatment. Nurses could regularly assess the family's readiness to return home and talk with them about what going home may look like for their particular family. Informing them of possible emotions they may experience once they are home and resources for dealing with their emotions would prove valuable for all families including those who must travel for cancer treatment. This could be initiated during the last few

admissions or visits to the cancer centre and would address parents' informational and emotional needs.

Parents in this study found the healthcare providers at the cancer centre to be a tremendous source of information and support. Being knowledgeable about evidence-informed practices and approachable for families to ask questions are valuable characteristics of pediatric oncology nurses. Staying abreast of information for families and providing suggestions for such things as support groups for the child, the parent(s), and the sibling(s) is a nursing function both during and after treatment. Providing information about the child's cancer and possible sources of support that can be accessed at home is important as parents may think they will be happy to be home only to find out, it is harder than they thought. Parents in this study really appreciated being able to call the nurses at the cancer treatment centre after they had gone home. This addresses parents' informational and psychosocial needs.

Having healthcare providers in their local communities in whom they trust is important for families of children with cancer. Although many of the families in this study did have a family doctor they felt comfortable looking after their child, the doctor had little or no knowledge or experience with childhood cancer prior to their child's diagnosis. A link between the tertiary cancer centre and the primary healthcare provider, such as using teleconferences and having a nurse clinician who could serve as a liaison for the family may prove useful on many fronts. The use of teleconferences and a nurse clinician would provide information and support to the families when they are at home, education about pediatric oncology to the local healthcare provider, and facilitate communication among all members of the team especially the families. Teleconferences could be scheduled on a regular basis throughout the cancer trajectory. The

nurse clinician could meet the family shortly after diagnosis and be a liaison for them and their local healthcare provider throughout their treatment journey and beyond.

Along with assessing all families' coping mechanisms, families who must travel for care should be assessed regularly to identify areas of strengths and weaknesses. The communities in which these families live may or may not have the facility or human resources to help families cope with their child's diagnosis, treatment, and completion of treatment for cancer. For example, there may not be a psychiatrist close to home, so nurses could help organize such appointments either in the city or in a town closer to the family's home.

Assessing and addressing families' needs on a regular basis are important nursing roles in pediatric oncology. Parents, children with cancer and their siblings may have differing needs throughout the cancer trajectory. These needs may change as symptoms lessen and worsen and as the focus of care changes such as at the end of treatment. For families who travel for cancer care, their needs may or may not be influenced by their travelling journey so regular assessment is necessary even after the completion of treatment.

Recommendations for Nursing Education

As discussed in the previous section, nurses are a tremendous source of support and information for families with a child with cancer. Parents look towards nurses as a wealth of knowledge and experience. Keeping up to date with current practices using evidence-informed practice is one method of maintaining continuing competency for nurses. Nurses must receive education on how to keep up to date as well as how to share the information gleaned from their education activities with colleagues and families with cancer. Nurses must also be well versed in supportive care for parents and families with cancer. This will service the parents' emotional and psychosocial needs in addition to providing much needed information.

Educating nurses about existing linkages and supports for families with cancer who travel for care would help increase the usage of such programs while providing an opportunity to learn about the services that are currently available to families living outside the big cities. Nursing linkages such as a liaison nurse who connects with the family at home and at the tertiary centre may be one idea of a linkage between home and the hospital both during and after treatment. Nurses and healthcare providers who work in smaller communities could be given basic oncology training in order to be able to care for children and their families when the families are at home. A nurse educator from the cancer centre could facilitate this education after a child in the community is diagnosed with cancer.

Recommendations for Nursing Research

Findings from this research study support aspects of the childhood cancer experience in previous studies as reported in the literature. However, this study added insight into the experience of parents who must travel to the cancer centre in order for their child to be treated. One such insight was that all the parents were willing to travel to the tertiary cancer centre in order to receive expert care. Further research is needed to look at the essence and the themes that emerged from this study about the lived experience of parents caring for their child after cancer treatment while living at distance from the centre.

This research study had a small sample size so further research should be done to corroborate the findings. There seemed to be a relationship between type, length, and intensity of treatment and ability to cope when returning home. The mother whose child had the longest, most intensive treatment, who had to relocate for almost the entire time of the treatment had the most difficulty being at home when they returned home after treatment was completed. Further study is required to establish whether there is such a link. Research studies involving children

with cancer and their siblings are needed to learn about their experiences of living at a distance from the cancer treatment centre after the completion of treatment.

Future research is required to examine whether families in other parts of Canada and the world, share similar experiences in similar situations. For example, how would longer distances between home and the cancer treatment centre affect the travelling journey? Would families who had to relocate to the city in order for their child to receive cancer treatment have different feelings towards travelling for care? Are the experiences described by parents in this study unique to parents with a child with cancer or do they relate to other family members with cancer who must travel for cancer care?

There remains a paucity of research on families with childhood cancer living outside the city that contains the cancer treatment centre. Studies with larger sample sizes and a longitudinal study design would provide additional information about the rural experience of cancer.

Recommendations for Policy

One of the parents mentioned a governmental travel grant program that was helpful to her family by providing funds for having to travel for cancer treatment. Not only does this type of policy provides money to families, but also recognizes their unique situation. Policies such as travel grants are an important starting point for financial aid for families with cancer and other chronic conditions that require travelling for specialized care. The provision of accommodation, such as government provided apartments, to families that must relocate for treatment is another policy option that would help families with cancer and other chronic conditions. More flexibility in work hours and caregiver's benefits would provide additional financial aid to families with chronic illnesses.

Conclusion

A discussion of the findings was presented in this chapter. All parents in the study revealed the essence of their experience as a journey within a journey while incorporating their child's cancer into the parents' way of being. The four themes that supported the essence were discussed in relation to other research studies that found similar and differing experiences. The appropriateness of the methodology and relevance to the conceptual framework were presented along with limitations of the study. Recommendations for nursing practice, education, policy and future research were suggested.

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LIST OF APPENDICES

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APPENDIX A
ENREB approval



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APPROVAL CERTIFICATE

21 July 2009

TO: Erin Shepherd (Advisor R. Woodgate)
Principal Investigator

FROM: Lorna Guse, Chair [REDACTED]
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2009:072
"Caring for the Child who has Completed Treatment for Cancer:
The Lived Experience of Parents who do not Live near their Child's
Tertiary Cancer Centre"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to Eveline Saurette in the Office of Research Services, (e-mail eveline_saurette@umanitoba.ca, or fax 261-0325), including the Sponsor name, before your account can be opened.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html) **in order to be in compliance with Tri-Council Guidelines.**

APPENDIX B
Participant access approval: CancerCare Manitoba



CancerCare
MANITOBA
Action Cancer Manitoba

○ 675 McDermot Avenue
Winnipeg, Manitoba
Canada R3E 0V9

July 27, 2009

○ 409 Taché Avenue
Winnipeg, Manitoba
Canada R2H 2A6

Erin Shepherd RN

www.cancercare.mb.ca

Re: RRIC #36-2009: Caring for the Child Who Has Completed Treatment for Cancer: The Lived Experience of Parents Who Do Not Live Near Their Child's Tertiary Cancer Centre

The above-named study has been approved by the CancerCare Manitoba (CCMB) Research Resource Impact Committee (RRIC), pending receipt of a copy of the REB letter of approval for the study. Please provide the CCMB RRIC secretary (Cybel de Juan) with a copy of the REB letter of approval as soon as it is available.

Any significant changes in this research should be reported to the Chair for consideration in advance of implementation of such changes. The RRIC should be notified regarding discontinuation or study closure. Please cite the RRIC number for this study in all future correspondence with the RRIC about it.

This approval is for RRIC use only. For ethics of human use and/or regulatory bodies, approval should be sought from the relevant parties as required.

Yours sincerely,


Rochelle Yanofsky, MD FRCPC
Chair, CCMB Research Resource Impact Committee

cc: File copy

APPENDIX C

Invitation Letter

NB: Typed on University of Manitoba letterhead

An Invitation to Participate in the Following Study:

Caring for the Child who has Completed Treatment for Cancer: The Lived Experience of Parents who do Not Live Near Their Child's Tertiary Cancer Centre

October 6, 2009

Dear Parents:

Hello, my name is Erin Shepherd. I am a Registered Nurse and a graduate student at the Faculty of Nursing at the University of Manitoba (UOM). I am writing to you to tell you about a study that I am doing in order to complete my Master of Nursing degree. This letter has been sent to you on my behalf by CancerCare Manitoba. (I do not know your name or have any information about you or your family.)

The name of my research study is "**Caring for the Child who has Completed Treatment for Cancer: The Lived Experience of Parents who do Not Live Near Their Child's Tertiary Cancer Centre.**" The purpose of the study is to learn from parents like you what it is like to care for a child who has completed treatment for cancer while living at a distance from the cancer treatment centre. I am inviting parents of children who have a child who has recently completed treatment for cancer (in the past 6 months to 5 years ago) and who live at least an hour away from Winnipeg.

If you decide to take part in the study I would interview you about your experience. In the interview you would be telling me about your child's cancer and treatment and your experiences at the time your child completed treatment and you returned home. It will be up to you how much you want to tell me. The interview should take between 1 and 2 hours to complete. If you feel that more than one interview is needed then we would plan for a second interview. You will be given an honorarium of \$20 in appreciation of your time. This will be provided at the end of the first interview regardless of the length of the interview. Interviews will be done between October and December 2009.

You may decide when and where you would like to be interviewed. If you have a partner or spouse, you have the option to be interviewed together with that person, or alone. If only one of you wants to be interviewed that would also be fine. The interview may occur in person at your home or in a quiet location at CancerCare Manitoba, or over the phone depending on what you would prefer.

Once I have completed all interviews I plan to summarize what you and the other families have told me and then write a paper that reflects as accurately as is possible, what it is like to care for a child who has completed treatment for cancer while living at a distance from the cancer treatment centre. I will write the paper in a way that would ensure your confidentiality and the confidentiality of the other families. Direct quotes may be used in the paper but will be quoted in such a way as to maintain your confidentiality. I then plan to share this paper with nurses, doctors, and other health professionals so that they may learn from your experience. You will also receive a copy of paper if you want one.

If you would like to consider participating in my study, I will provide you with a consent form for you to sign. Your decision about whether or not to participate is entirely voluntary and will NOT affect the health care that your child receives. If you decide to take part in the study, I

will not reveal your name or identity to anyone, including the health care team that is looking after or has looked after your child. I will take special care to ensure that your privacy is maintained throughout the study.

I understand taking part in this study and talking about your child's illness may uncover uncomfortable feelings and unanswered questions. If this happens to you or your child, I will suggest with your permission, names of appropriate individuals at CancerCare Manitoba for you to contact for further follow-up. As well, Ms. XXXX XXXXX (Social Work, Children's Hospital/Cancer Care Manitoba-Pediatrics) would be available to talk with you.

A research nurse at CancerCare Manitoba will be making a follow-up phone call to you in approximately three weeks to remind you about this letter and the opportunity to participate in this research project. This is simply a friendly reminder; you do not have to tell her whether or not you will be participating in this study. If you do tell her anything about the study, she will not tell anyone whether you decide to participate or not. You may contact Erin Shepherd anytime after you receive this letter.

If you are interested in my study and/or have any questions, concerns, or need additional information, please contact me at XXX-XXX-XXXX or at my email address: XXXXXXXXXXXX. If you would prefer not to call or send an email, you can also indicate your interest in taking part in the study by **filling out page three** of this letter, and mailing it back to me using the self-addressed, stamped envelope that has been included for you.

Thank you for considering my study.

Sincerely,

Erin Shepherd
Master of Nursing Student
Faculty of Nursing
University of Manitoba
Winnipeg, Manitoba

An Invitation to Participate in the Following Study: Caring for the Child who has Completed Treatment for Cancer: The Lived Experience of Parents who do not Live Near Their Child's Tertiary Cancer Centre

I have read this letter and would like further information about the study. You may contact me at the phone number or email address given below:

Name: _____

Phone Number(s): _____

Email: _____

The best time to contact me is: _____

APPENDIX D

Explanation to Parents who Contact me – Via Phone/E-mail

Hello, my name is Erin Shepherd. Thank you for contacting me about the study entitled **“Caring for the Child who has Completed Treatment for Cancer: The Lived Experience of Parents who do not Live Near Their Child’s Tertiary Cancer Centre.”** As was written in the invitation letter from CancerCare Manitoba, I am a student in the Masters of Nursing program at the University of Manitoba. I am also a Registered Nurse working a casual position at Children’s Hospital. The purpose of this project is to learn about the experiences families with a child who has completed treatment for cancer who live at a distance from the cancer treatment centre. 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 in person or on the phone, and at a time that is convenient for you. In the interview you would be telling me about your child’s cancer and treatment and your experiences at the time your child completed treatment and you returned home. It will be up to you how much you want to tell us. The interview should take between 1 and 2 hours to complete. If you feel that more than one interview is needed then we would plan for a second interview. You will be given an honorarium of \$20 in appreciation of your time. This will be provided at the end of the first interview regardless of the length of the interview.

You may decide when and where you would like to be interviewed. If you have a partner or spouse, you have the option to be interviewed together with that person, or alone. If only one of you wants to be interviewed that would also be fine.

The purpose of the study is to learn about the experiences of parents who are caring for a child who has completed treatment for cancer who live outside Winnipeg. The interview will involve discussing your experience with your child’s illness and your feelings at the time after the completion of treatment. I would like to record the interview so that I will not have to take detailed notes while you talk. There are two short forms (a consent form and a demographic form) to complete and I may take a few brief notes during the interview. The information from the interview will be transcribed and analysed with information from other parents with a child who has completed treatment for cancer living outside Winnipeg. When the project is written up the information will be grouped in such a way that it is impossible to identify you.

Only I will know your name and contact details. No one other than my thesis chair, Dr. Roberta Woodgate (Faculty of Nursing, University of Manitoba) will listen to the tapes and read the transcripts. Dr. Christine Ateah (Faculty of Nursing, University of Manitoba) and Dr. Yanofsky (CancerCare Manitoba) will have access to only grouped/unidentifiable 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 E
Demographic Form

Thank you for your interest in this project.

Erin Shepherd, RN, MN Student, Faculty of Nursing – University of Manitoba

What is the age of your child? _____

What was your child's diagnosis? _____

What was the date of diagnosis? _____

What was the age of your child at diagnosis? _____

What is your child's current grade in school? _____

Do you have other children? _____

If yes, what are their ages? _____

What is your age? _____

What is your occupation? _____

Circle: Full Time Part Time Casual

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

Who else lives in your home with you?

- Mother
- Father
- Pets
- Someone else _____

What is the distance to nearest medical facility? _____

What is the distance to Winnipeg's 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 cancer history?

Who is primarily responsible for the child's medical care? _____

APPENDIX F 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 healthcare providers. All information will be kept confidential and you may withdraw from the study at any time.

Questions:

1. Tell me about your experience of your child’s cancer.
2. Tell me about your experience of your child’s completion of treatment for cancer.
3. Can you describe what it was like for you during the time when your child completed his/her cancer treatment? Probes:
 - a. How did you feel?
 - b. What did you do?
 - c. Who did you turn to for support?
 - d. What did you wish you had known at the time?
4. Who was most responsible for your child’s care:
 - a. Prior to his/her cancer diagnosis?
 - b. When your child was receiving treatment for cancer?
 - c. Since his/her completion of treatment?
5. Can you describe what it was like for your family during the time when your child completed his/her cancer treatment?
6. Can you describe a typical day for you and your family during that time?
7. Can you describe a typical day for you and your family now?
8. How does your child’s cancer diagnosis impact your life now?
 - a. In general?
 - b. In specific situations?
9. How would you describe your child’s current health condition?
10. Is your child currently receiving long-term follow-up care?
 - a. Where?
 - b. From whom?
11. Do you have confidence in your local health care provider?

- a. In general?
 - b. In relation to your child's history of cancer?
12. What recommendations do parents who live outside the city with the tertiary cancer centre have about how nurses and other health professionals can best support parents at the end of his/her child's cancer treatment?

Thank you for giving me the opportunity to meet with you to discuss your experiences as a parent of a child who has had cancer.

I may contact you by telephone within the next few weeks to clarify any information from the interview. Is that okay? As well, I will be selection 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 parents who live outside Winnipeg after their children have completed treatment for childhood cancer. Would this be okay for me to call you? You could decide then if you want to meet/talk with me.

APPENDIX G

Consent Form

NB: Typed on University of Manitoba letterhead

Parent Consent Form

Research Study Title: Caring For the Child Who Has Completed Treatment For Cancer: The Lived Experience of Parents Who Do Not Live Near Their Child's Tertiary Cancer Centre

Study's Researcher: Erin Shepherd, RN, BScN, MN student, University of Manitoba

Supervisor/Committee Chair: Dr. Roberta Woodgate, Professor, Faculty of Nursing, University of Manitoba

Committee Members: Dr. Christine Ateah, RN, Faculty of Nursing, University of Manitoba; Dr. Rochelle Yanofsky, Pediatric Oncologist, Cancer Care Manitoba / Faculty of Medicine, University of Manitoba

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I, "Parents' name", agree to participate in the above study.

I have been told that the purpose of this study is to gain an increased understanding of the lived experiences of parents from outside Winnipeg as they transition to a time when their child has completed treatment for cancer. I understand parents of children who have completed cancer treatment who live outside Winnipeg are being asked to participate in the study. I understand that parents are being recruited from CancerCare Manitoba in Winnipeg.

I understand that if I agree to participate in the study, I would be asked to participate in one to two open-ended, audio recorded interview(s) that are expected to take about 1 to 2 hours to complete. I understand that I will be asked questions related to my experiences at the time of completion of my child's cancer treatment. I understand that the Master of Nursing student, Erin Shepherd under the supervision of Dr. Woodgate will be doing the interviewing for the interviews. I understand that I will be asked to complete this Consent Form and a Demographic Form that should take about 10 - 15 minutes to complete. The Demographic Form includes information about me and my family including medical information about my child who had cancer. I understand that after each interview, field notes will be recorded by the interviewer describing what took place during the interview.

I understand that my participation in the study is completely voluntary. I understand that my child's health care team will not know what I and my child decide to do. I understand that even if I decide to participate, I may withdraw at any time and refrain from answering any questions I prefer to omit, without prejudice or consequence. I also understand that I can decline from participating in a second interview or from reading the final findings.

I understand that there are no direct benefits for my child to participating in the study. However, I understand that this study will result in knowledge that may help health care professionals to develop meaningful policies and programs specific to families with children with cancer who do not live in the city containing the cancer treatment centre. I understand that there are no undue risks for me by taking part in the study.

I understand that findings from this study may be presented at a health or educational conference or published in a professional journal. In all instances, my child's or family's identity would not be discussed or revealed to anyone. If direct quotes are used in the findings, my confidentiality will be maintained. Only Erin Shepherd will have access to our names. As well, I understand that in all instances, our names and identities would not be discussed or revealed to anyone. I am aware that our names will be replaced with a code number so that no one will be able to identify us. Only Dr. Woodgate and Erin Shepherd will have access to the raw data (tape recordings and transcripts). I understand that confidentiality will be maintained except in situations in which there is a legal requirement to disclose identity (i.e. abuse situations). I understand that all data including the audiotapes, interview transcripts, and demographic information, will be stored in a locked filing cabinet and computer protected by a password known only to Dr. Woodgate and Erin Shepherd. I understand that all data will be securely kept for seven years following the completion of the study after which it will be destroyed in a confidential manner. I understand that if I decide that I will participate in the study, a summary of the study will be provided to me if requested.

I understand that I will be given an honorarium of \$20 for my participation in this study. This honorarium will be provided at the end of the first interview regardless of the length or number of interviews. In addition, if the interview occurs at CancerCare Manitoba, my parking fees will be reimbursed.

My signature on this form indicates that I have understood to my satisfaction the information regarding participation in the research project and agree to participate. In no way does this waive my legal rights nor release the researchers, or involved institutions from their legal and professional responsibilities. I understand that my continued participation should be as informed as my initial consent, so I should feel free to ask for clarification or new information throughout my participation. I understand this research has been approved by access committee at CancerCare Manitoba and the Education/Nursing Research Ethics Board at the University of Manitoba. If I have any concerns or complaints about this project I may contact Dr. Woodgate at XXX-XXX-XXXX or the Human Ethics Secretariat at XXX-XXX-XXXX. A copy of this consent form has been given to me to keep for my records and reference.

I agree to participate in an individual Interview

Yes ___ No ___

Signature of parent

Print name of parent

Date

Signature of witness

Title

Print name of witness

Date

I would like a summary report of the findings:

YES NO

Please mail a summary of the report findings to:

Name: _____

Address: _____

Postal Code: _____

APPENDIX H
Follow-up questions (general)

1. How did you feel after our first interview? Did you have any other thoughts, feelings, that you think are important for me to hear.
2. Are there any changes since our first interview? Please describe.
3. Are there aspects of being a parent that changed for you because of your child's cancer diagnosis? At the time of diagnosis? During treatment? After the completion of treatment?
4. As a parent, what were your feelings about returning home after the completion of treatment? Now?
5. How did your daily life change upon returning home after the completion of treatment?
6. Do you have advice for other parents who are going/have gone through cancer treatment for their child about returning home after treatment is completed?
7. Do you have advice for health care providers (doctors, nurses, etc.) about what you would have like to have known about returning home after the completion of treatment? Any suggestions about how/when that information could have been given to you?