Siblings of Pediatric Bone Marrow Transplant Recipients: Their Lived Experience as They Transition Through the Bone Marrow Transplant Trajectory

By

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ABSTRACT

Bone marrow transplantation (BMT) is the treatment of choice for many malignancies and other childhood disorders. Acknowledging that the entire family is affected when a child undergoes a BMT, increasing research attention has been given to understanding this experience from the perspectives of recipients, parents and the family as a whole. Yet, minimal attention has been directed at understanding the experience of healthy siblings as they transition through the BMT experience. Before intervention studies can be undertaken that will help healthy siblings transition through the BMT experience, knowledge about the impact of the experience on siblings is needed. Accordingly, a qualitative study guided by the philosophy of hermeneutic phenomenology was conducted to elicit detailed descriptions of the lived experience of siblings.

Participants were children, adolescents and young adults with a sibling who had undergone a BMT during childhood. Participants were recruited from a pediatric BMT clinic in Western Canada. Semi-structured, open-ended interviews that explored siblings' memories about what it is like to be a sibling of a child who has had a BMT were conducted with each participant. Demographic data and field notes were recorded. All interviews and field notes were transcribed. The transcripts were reviewed repeatedly for significant statements in an attempt to find meaning and understanding through themes.

The data analysis revealed the essence of siblings' lived experience of transitioning through the BMT trajectory as an interruption in family life. Four themes communicated the essence of siblings' lived experience: (1) life goes on, (2) feeling more or less a part of a family, (3) faith in God that things will be okay, and (4) feelings around

families. Differences between donor and non-donor siblings are highlighted. Siblings' recommendations for health care professionals are also provided. Results from this study will help health professionals better anticipate the diverse and shifting needs and demands of siblings of pediatric BMT patients. Recommendations for future research and innovations in nursing interventions are provided.

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CHAPTER 1: INTRODUCTION

Introduction

Bone marrow transplantation (BMT) is the treatment of choice for many malignancies, hematologic disorders, immunodeficiency disorders, and genetic disorders of childhood (Packman, 1999). In 1980, physicians at The Montreal Children's Hospital performed the first pediatric BMT in Canada (McGill University Health Centre, 2005). The number of transplants has since increased exponentially because survival rates have improved, it is indicated for more diseases, and the potential recipient pool has expanded to include those without an identical sibling donor (Andrykowski, 1995).

When a child undergoes a BMT, the entire family is affected by the demands of the transitions encountered throughout the BMT experience (Heiney, Byrant, Godder, & Michaels, 2002; Packman, 1997a; 1997b; 1999; Shama, 1998). Increasing attention has been given to the recipient, their parents and the family as a whole (Andrykowski, 1994; Brown & Kelly, 1976; Carr-Gregg & White, 1987; Freund & Siegel, 1986; Forinder, 2004; Gardner, August & Githens, 1977; Heiney, Neuber, Myters, & Bergman, 1994; Patenaude, Szymanski, & Rappeport, 1979; Phipps & Mulhern, 1995; Rodrigue et al., 1997). Minimal attention has been directed at understanding the psychosocial impact of the procedure on healthy siblings as they transition through the BMT experience. This is despite the fact that siblings and their interactions with each family member contribute to the family's functioning and to the individual development of the children (Brody, 1998).

This study will lay the groundwork for future intervention studies that will help healthy siblings transition through the bone marrow transplant experience. Knowledge about the impact of the experience on siblings that is grounded in their lived experiences

is urgently needed. This objective is best suited to the qualitative research paradigm, particularly phenomenology. Fundamental to phenomenology is developing a rich understanding of an individual's lived experience (Speziale & Carpenter, 2003). A hermeneutic phenomenology approach was used to provide insight into how siblings live, see and interpret the BMT experience throughout the BMT trajectory.

Significance of the Problem

Sibling outcomes to the transitions made during the BMT experience are implied in terms of their adjustment to the experience. Some studies suggest donor and non-donor siblings are at increased risk for emotional and behavioral problems (Freund & Seigel, 1986; Gardner, August & Githens, 1977; Heiney, Byrant, Godder & Michaels, 2002; Kinrade; 1987; MacLeod, Whitsett, & Pelletier, 2003; Packman et al., 1997a, 1997b; Pot-Mees & Zeitlin, 1987; Parmar, Wu & Chan, 2003; Wiley, Lindamood & Pfefferbaum-Levin, 1984). The stresses associated with the transplant experience are so severe that the concept of post-traumatic stress disorder has been considered an effective model for studying sibling reactions. However, only two studies to date have examined posttraumatic stress symptoms in donor and non-donor siblings (Packman et al., 1997b; Packman et al., 2003). Other studies have reported that the BMT experience may promote some aspects of psychological growth (Carr-Gregg & White, 1987; Freund & Seigel; MacLeod, Whitsett, & Pelletier; Packman et al., 1997a; Wiley, Lindamood & Pfefferbaum-Levin).

Recent research has begun to examine why some siblings are at higher risk for adjustment difficulties and why some are well adjusted. Siblings' appraisal of the experience and their coping resources (i.e., social support needs and the degree to which

their needs have been met) have received recent attention (Dannie, 1991; Freund & Seigel, 1986; Gardner, August & Githens, 1977; Heiney, Byrant, Godder & Michaels, 2002; Kinrade, 1987; MacLeod, Whitsett, & Pelletier, 2003; Packman et al., 1997a; Parmar, Wu & Chan, 2003; Patenaude, Szymanski, & Rappeport, 1979; Shama, 1998; Wiley, Lindamood & Pfefferbaum-Levin, 1984).

All in all, knowledge about healthy donor and non-donor siblings continues to be limited in amount, scope and conclusiveness. Lacking is an understanding about the transitions that healthy siblings encounter throughout the BMT experience, and how health professionals can best help siblings through these transitions. Gaining insight and understanding into the BMT experience, particularly from the perspective of healthy siblings, can facilitate the development of knowledge that may be useful to nurses who provide care for siblings of children undergoing a BMT. Furthermore, knowledge about siblings' individual responses and perceptions of the BMT experience may provide insight into the experiences of the larger family system.

Purpose of the Study

The purpose of this phenomenology study was to arrive at an understanding of the lived experience of healthy donor and non-donor siblings as they transition through the BMT trajectory. Special attention was paid to what characterizes the experience of transitioning, the meaning the siblings assign to the experience, differences between donors and non-donors, and their recommendations for health care professionals

Research Questions

The research questions addressed in this study include:

1. What characterizes the healthy donor and non-donor siblings' lived

experience of transitioning through the BMT trajectory?

2. What meaning do healthy donor and non-donor siblings assign to the experience?
3. What differences in the BMT experience exist between healthy donor and non-donor siblings?
4. What recommendations do healthy donor and non-donor siblings have about how health professionals can best support siblings as they transition through the BMT trajectory?

Assumptions

Assumptions for this research study are grounded in the beliefs stemming from naturalistic inquiry, and family, developmental and qualitative paradigms (Benoliel, 1984; Lincoln & Guba, 1985; Brody, 1998; van Manen, 1990; Woodgate, 2000a, 2001a). These assumptions include that (1) realities are multiple and must be perceived holistically, (2) pediatric BMT has some effect on every member of the family and the family as a whole, (3) every family member has a perspective of his or her own experience, and (4) siblings are the experts in identifying and describing their experiences that are impacted by the changing nature of their brother or sister's BMT trajectory.

Definition of Major Constructs

For the purpose of this study, the major constructs will be defined as follows:

Meanings

Meanings refer to the sibling's perception of the BMT and their capacity to handle it (Richer & Ezer, 2000). Meanings attached to illness experiences and events may be positive, negative or neutral, and may change as changes occur in situations and

relations (Woodgate, 2001b). 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).

Transition or "To Transition"

Transition is defined as a process, which involves movement from a state of equilibrium to a state of disequilibrium and to a new state of equilibrium that results from siblings' perception and awareness of change in themselves or the environment (Wilkins & Woodgate, in press).

Interpretation or "To Interpret"

Interpretation is the process that aims at explicating the meaning of an experience (van Manen, 1990). Interpretation brings out the meaning embedded in phenomenological text.

Understanding or "To Understand"

Understanding is the process of grasping what has been interpreted in a text (van Manen, 1990). It may be emotional, cognitive, or both (Woodgate, 2001b).

Chapter Summary

Chapter one provided an overview of the BMT process and the rationale for further research on siblings' lived experience of transitioning through the BMT process. There has been very little published exploring healthy siblings experience of having a brother or sister who has had a BMT. With more pediatric BMTs being performed for more diseases, it is reasonable to predict that healthy siblings will become increasingly involved in the lives of children who have had a BMT. Nurses who have a comprehensive understanding of healthy siblings' experiences may be better able to promote positive sibling outcomes.

CHAPTER TWO: LITERATURE REVIEW

Introduction

This chapter reviews the literature to establish a background that might be useful against which to examine the sibling experience of transitioning through the BMT process. A review of research related to the familial and sibling experiences of childhood chronic illness is presented. This is followed by an overview of the childhood BMT process. The family and sibling perspectives of the BMT process are also discussed and critiqued.

Childhood Chronic Illness

Childhood chronic illness is relatively common, with approximately 15% to 18% of children having some type of chronic health condition (Lorie, 2004). It is predicted that by 2015, worldwide, 623 million children younger than 5, and 1.2 billion children aged 5 to 14 will have some kind of significant chronic disease (Buekens & Boerma, 2001). Common chronic childhood conditions include cancer, anemia, asthma, cystic fibrosis, muscular dystrophy, spina bifida, congenital heart disease, cystic fibrosis, diabetes mellitus, epilepsy and chronic renal failure (Jackson & Vessey, 2000). These conditions are different in their etiology, stability and predictability, threat to life, complexity and restrictions they impose. They are, however, similar in the sense that they result in limitation of functions, require more medical care or related services than usual for the child's age, and require readjustment (Jackson & Vessey, 2000).

Childhood Chronic Illness and the Family

Childhood chronic illness impinges on the functioning of the family. Faced with an unpredictable, medically intensive and potentially life threatening disease, the

experience challenges families' sense of normalcy and stability (McGrath, 2001a). Attempts to maintain any semblance of normalcy are challenged by practical obstacles, such as frequent hospitalizations and clinic visits, loss or change of employment status, financial difficulties, and redistribution of parental responsibilities (Grinyer & Thomas, 2001; McGrath, 2001a; Patistea, Makrodimitri & Panteli, 2000; Scott-Findlay & Chalmers, 2001; von Essen, Enskär & Skolin, 2001; Woodgate, 2001b). These obstacles limit the ability of family members to gain access to the support systems on which they normally rely. Contact and communication among family members and with social support systems outside of the family such as relatives and friends are often limited (McGrath, 2001b, 2002; Patistea, Makrodimitri & Panteli; Scott-Findlay & Chalmers; Trask et al., 2003; von Essen, Enskär & Skolin). This means that families are unable to benefit from the support that these relationships have to offer.

Families respond to chronic illness in an ongoing process in their day-to-day lives (Clarke-Steffen, 1993, 1997). Many describe the experience as an unpleasant emotional roller coaster (McGrath, 2002; Woodgate, 2001b). Family transitions in response to the diagnosis of cancer have been characterized by a fracturing of reality upon realization of the diagnosis, a period of limbo marked by uncertainty, utilization of strategies to reconstruct reality and construction of a "new normal" for the family (Clarke-Steffen, 1993). More recently, how children and their families move through the cancer symptom trajectory of the entire cancer experience has been represented as the 'passage through the transition periods,' with each transition period accompanied by changes in roles and responsibilities and in how a family exists in the cancer world (Woodgate, 2001b; Woodgate & Degner 2004).

No family member is left untouched by childhood chronic illness. Several studies have highlighted the impact of chronic illness on each family member and the larger family system (Fife, Norton, & Groom, 1987; Grinyer & Thomas, 2001). Overall, researchers have concluded that the majority of families do not experience pathological maladjustment (Fife, Norton, & Groom; Koocher & O'Malley, 1981; Trask et al., 2003). However, within this body of research, there has been a scarcity of research on the systems that involve the healthy sibling of the ill child.

Research efforts have just begun to gain an understanding of the impact of changing demands on healthy siblings in order to build knowledge of both the family and individual chronic illness experiences. Much of the earlier work on siblings of chronically ill children approached the sibling experience mainly from a deficit-centered focus, examining siblings' psychosocial functioning and identifying adjustment problems (Eiser, 1990, 1994; Woodgate, 2001a, 2001b). Increasingly more researchers are documenting that there is much variability in how siblings react to the chronic illness experience. Some siblings experience behavioral and emotional problems, while others experience personal growth from having gone through the experience. These positive and negative findings indicate that the outcome of sibling adjustment is neither simple nor direct.

Much of what has been learned about the sibling experience has been learned from the parent's perspective rather than asking siblings themselves (Wilkins & Woodgate, in press). Only few studies have been designed to give voice to the experience of siblings using their words. Another limitation of the work on sibling adjustment is that much of this work relies on standardized instruments (Woodgate, 2001a). The

instruments used in the quantitative studies have not fully explored the richness of the experience, particularly due to the fact that the instruments addressed limited concepts such as behavioral problems, and social and psychological adaptation. More research that seeks to gain an understanding of healthy siblings' own views about the chronic illness experience is needed.

Overview of Childhood BMT

Childhood BMT is an aggressive, rapidly evolving treatment for many childhood chronic illness, including cancer, hematologic disorders, immunodeficiency disorders, and genetic disorders (Packman, 1999). Sanders (1997) recommends that children considered for a BMT should have (1) a disease in which conventional therapy is likely to result in less successful disease-free survival than transplantation, and (2) a suitable donor or source of stem cells available. The procedure involves ablation of the recipient's bone marrow by a preparatory regimen of high doses of chemotherapy often combined with total body irradiation, followed by replacement with healthy bone marrow cells, specifically stem cells (this is why BMTs are also called stem cell transplants, or SCTs) (Andrykowski, 1994; Sanders, 1997). After transplantation, the child may die early, enter remission and later die from relapse, survive with prolonged disability as a result of the side effects of transplantation, or enter remission and achieve lifelong cure (Hare, Skinner, & Khewer, 1989). In a successful BMT, the new bone marrow migrates to the cavities of the large bones, engrafts (grows) and produces normal blood cells. This section will detail the goals of BMT, sources of healthy stem cells, types of transplants, potential complications, and survival rates.

Goals of BMT

The goal of a BMT is to regenerate or "rescue" hematologic and immunologic function of the recipient (Gonzalez-Ryan, Kristovich, Haugen, Coyne, & Hubell, 2002). This can be achieved in three ways (Gonzalez-Ryan et al., 2002). First, BMTs can provide an immune effect to give a child a healthy immune system. Second, BMTs can be used to replace nonfunctioning or diseased marrow with healthy donor marrow. Third, BMTs can be used to remove as much tumor as possible.

Sources of Healthy Stem Cells

There are three main sources of healthy stem cells – bone marrow, peripheral blood and umbilical cord blood (Gonzalez-Ryan et al., 2002; Stewart, 2002). Bone marrow contains the greatest concentration of stem cells and thus, is the most common source of stem cells. To retrieve this source of stem cells, the donor must undergo surgery. There are no surgical incisions or stitches involved; there are only skin punctures where the needle was inserted into the iliac crests. Peripheral blood does not contain as many stem cells as bone marrow, and collection is performed as an outpatient procedure and does not require the donor to undergo surgery. This source of stem cells requires the donor to receive an injection of filgrastin (G-CSF), which helps the stem cells move out of the bone marrow and into the bloodstream. Most donors tolerate G-CSF well, but some will develop side effects such as fatigue, bone and muscle pain, and weakness. Umbilical cord blood is another source rich in stem cells, but it contains only a small amount of cells so it best suited to smaller recipients.

Types of Transplants

There are three types of transplants – allogeneic transplants, syngeneic transplants

and autologous transplants (Gonzalez-Ryan et al., 2002; Stewart, 2002). Each will be detailed in this section.

Allogeneic Transplants

For allogeneic transplants, stem cells are obtained from a genetically compatible donor, usually a sibling or parent. A special type of allogeneic transplant is when the donor is the child's twin. This is called a syngeneic transplant. Allogeneic transplants are used most frequently to treat children diagnosed with leukemia, aplastic anemia and immune deficiency diseases (Gonzalez-Ryan et al., 2002; Stewart, 1997). They are different from autologous transplants in that the donor and recipient are two different people. See Appendix A for a summary of the medical phases of the allogeneic transplant process.

The basis for selecting the most genetically compatible donor is human leucocyte antigen (HLA) tissue typing (Filipovich, 1990; Gonzalez-Ryan et al., 2002). HLA-typing is done by studying the HLA complex on chromosome 6. HLAs are the distinguishing genetic markers (fingerprints) on the surface of white blood cells that function to protect the body against invading organisms such as bacteria, viruses and other foreign matter. They are divided into two sets; one set comes from each parent. Each set is referred to as A, B, C, DR, and DQ.

Allogeneic transplants are most likely to be successful when all six of the donor's antigens match those of recipient (Filipovich, 1990; Gonzalez-Ryan et al., 2002). Finding a perfectly matched donor reduces the risk of the recipient's immune system destroying the new bone marrow or graft rejection, and graft-versus-host-disease (GVHD). GVHD is a condition where the donor's cell perceives the recipient's organs and tissues as foreign

materials that should be destroyed. Siblings continue to be considered the best donor candidates since the chance of a bone marrow match in a sibling is 1 in 4, as opposed to 1 in 5,000 to 37,000 in the general population (Patenaude, Szymanski, & Rappeport, 1979). The optimal donor is a sibling whose HLA-A, -B, and -DR antigens match those of the child. The use of other donors is becoming more common as the chances of finding a donor among a child's siblings are only 30 to 35 percent (given the current family size of 2.7 children) (Stewart, 2002). Other donor options include: (1) family members who are HLA identical or who have a single HLA antigen mismatch with the child, (2) unrelated individuals who are HLA matched or one-antigen mismatch with the child, and (3) family members who are haploidentical (two- or three- antigen mismatched) with the patient (Sanders, 1997).

Autologous Transplants

Depending on their disease and current condition, children may be able to use their own stem cells. This is called an autologous transplant. Autologous transplants are used most frequently to treat children diagnosed with solid tumors such as neuroblastoma, Hodgkin's disease and non-Hodgkin's lymphoma (Sanders, 1997; Stewart, 2002). With the exception of leukemia, these diseases start with cancerous tumors that are responsive to treatment with high-dose chemotherapy and/or radiation. Children receiving autologous transplants do not encounter GVHD (Sanders). Furthermore, the risk of infection is somewhat less in these transplants because the children do not need the immunosuppressive medications that prevent GVHD (Sanders). The disadvantage of autologous transplants is that there is a risk of tumor cells being present in harvested marrow.

Survival Rates

The success of a BMT depends upon type of transplant, the type and extent of the disease, amount of previous therapy the recipient has received, tissue-matching of donor, and age and sex of donor and recipient (Andrykowski, 1994; Bennett-Rees & Soanes, 1999). In Manitoba from 1992 to 2002, the primary cause of death was relapse (Schroeder, 2003). The overall survival rate was 64% with a rate of 39% for autologous transplants and 70% for allogeneic transplants (Schroeder). More specifically, the survival rate for related allogeneic transplants (81%) was much higher than that of unrelated allogeneic transplants (51%) (Schroeder). Furthermore, 95% of recipients with non-malignant disease survived in comparison to 48% of those with malignant disease (Schroeder). These survival rates are consistent with those found in the literature (Bennett-Rees & Soanes; Sanders, 1997).

BMT and the Family

Having a child undergo a BMT impinges on the functioning of the family, creating new demands and stresses that disrupt usual patterns of family functioning and overwhelm the family system (Heiney, Byrant, Godder, & Michaels, 2002; Packman, 1999; Packman et al., 1997a, 1997b; Shama, 1998). These families face issues common to any family with a chronic illness.

The BMT experience has been divided into three psychosocial stages that parallel the transplant process (Haberman, 1988; Patenaude, Szymankis & Rappeport, 1979; Pfefferbaum, Lindamood, & Wiley, 1978). These stages are: (1) pre-transplant stage, (2) transplant stage, and (3) post-transplant stage. Each phase of the transplantation process presents the family with a variety of issues and tasks that need to be integrated into their

family life, and adaptations that need to be made.

During the pre-transplant stage, family stresses originate with the discovery of life-threatening illness (Hare, Skinner & Khewer, 1989; Uzark, 1992). The decision to proceed with the transplant is the next stressor that families encounter (Forinder, 2004; Packman, 1999). This decision is not easy as families must balance the threat of losing the child with the hope treatment will work. Families endure much anxiety and frustration in waiting for the results of HLA-typing (Patenaude, Szymankis & Rappeport, 1979). Family separation is common with the frequent hospital visits. Alterations in family roles often result in increased parental strain, financial strain, caregiver burden and family stress (Rodrigue et al., 1997).

The transplant stage is both physically and psychologically arduous (Forinder, 2004). Much of personal care is left to parents and parents struggle to balance health care professionals' demands with the needs of the recipient (e.g., subjecting children to painful examinations and life threatening medications). Moving into a sterile room and witnessing the effects of the conditioning regimen on the recipient can be disturbing experiences for families (Packman, 1999; Patenaude, Szymankis & Rappeport, 1979). Families frequently comment on how innocuous the transplant procedure itself seems (Packman, 1999).

The post-BMT stage is marked by a period of waiting for the marrow engraftment. This is a stressful time because the proximity of death is stressful (Packman, 1999). When the transplant is successful, families return to their everyday life (Forinder, 2004). Common parental concerns following the return home include: learning the rules of infection precautions and supportive care, returning to normal activities, dealing with

setbacks, feeling worried about the possibility of relapse, and depending on the health care system in the long-term (Forinder, 2004; Uzark, 1992; White, 1994).

Research suggests that the stresses families encounter during the BMT process may be disease-specific. Over a 3-year period, Freund & Siegel (1986) observed families with a child diagnosed with leukemia, aplastic anemia, or severe immunologic deficiency (SCID). For the families of children with leukemia, they had time to accept the illness and confront the stresses and changes associated with the transplant procedure (e.g., living with uncertainty, interruption in family routines) because they learned of the diagnosis long before the BMT was introduced into the child's care plan. Families of children with aplastic anemia faced a different set of circumstances in that they learned of the diagnosis shortly before the transplant and had little opportunity to assimilate the illness in their family life. Issues common to the families of children with SCID included feeling guilty because the disease is inherited, fear of another child dying from the disease, and having little time to care for the infant at home because diagnosis is usually made within the first few months of life.

Overall, the literature supports the perspective that the BMT experience impacts every member of the family unit. Throughout the research literature, siblings are dubbed the 'forgotten grievers' because the focus of family, friends and health care professionals is on the ill child (Hefferman & Zanelli, 1997; Murray, 1999). Research that seeks to understand the experience from the perspective of the sibling is in its early stages.

Siblings' BMT Experience

Sibling outcomes to the transitions made during the BMT experience are implied in terms of sibling adjustment to the experience. This section will detail research efforts

focusing on: (1) sibling adjustment in response to being a donor or non-donor sibling of a successful transplant or unsuccessful transplant, (2) factors related to sibling adjustment, (3) what helps siblings adjust to the BMT process and (4) siblings' appraisal of the experience.

Sibling Adjustment to the BMT Process

A number of studies have documented that adjustment difficulties in donor siblings differ from those found in non-donor siblings. Research by Gardner, August and Githens (1977) suggested that donors were at increased risk for psychopathology ranging from very mild to severe. Other researchers have found that donor siblings (55%) have higher levels of behavioral problems compared to non-donor siblings (10%), including bed-wetting, eating difficulties, sleep disturbances and disobedience (Kinrade; 1987; Pot-Mees & Zeitlin, 1987). Also more common in the adolescent donor sibling experience than in the non-donor experience is difficulty resolving the developmental crises of the first five age-related psychosocial stages of Erikson's developmental theory (i.e., trust versus mistrust, autonomy versus doubt and shame, initiative versus inferiority, identity versus role confusion) (Packman et al., 1997b).

For donor siblings, the initial reaction to being a donor is marked by apprehension, confusion, fears, gratitude, pride, and excitement (Heiney, Byrant, Godder, & Michaels, 2002; Packman et al.; Parmar, Wu, & Chan, 2003). Once their bone marrow has been collected, donor siblings commonly report feeling relief and pride (Packman et al.). However, donor siblings often experience guilt when complications arise and feel responsible for the recipient's death (Gardner, August, & Githens, 1977; MacLeod, Whitsett, & Pelletier, 2003). Most recently, post-traumatic stress has been associated with

the donor experience, but not the overall sibling experience (Packman et al., 2003).

Other research efforts suggest that non-donor siblings endure more adjustment difficulties than donor siblings. For example, according to parent and teacher reports, non-donor siblings experience more school problems and show fewer adaptive skills in school than donor siblings (Packman et al., 1997a; Packman et al., 1997b). Furthermore, at the time of identifying a suitable donor, siblings may compete for the role of donor, causing non-donors to feel excluded from the treatment process (Freund & Seigel; Wiley, Lindamood, & Pfefferbaum-Levin, 1984). When not chosen, non-donor siblings report feeling disappointment, relief, fear, and guilt about having these feelings (Packman et al., 1997a, 1998; 2003; Wiley, Lindamood, & Pfefferbaum-Levin).

Although some studies suggest that donor siblings are at higher risk for behavior and emotional problems than non-donor siblings or vice versa, other researchers have found no differences between donor and non-donor siblings. Common to donor and non-donor siblings is the experience of intense feelings of abandonment, anger, bitterness, jealousy, loneliness, isolation, depression, anxiety and low self-esteem (Freund & Seigel, 1986; Packman et al., 1997a; Packman et al., 2003). Similar levels of psychological distress have also been documented in the projective drawings of donor siblings (33-52%) and non-donor siblings (33-60%) (Packman et al., 1998; Packman et al., 2003). In addition, comparable levels of post-traumatic stress reactions have been documented in donor and non-donor siblings. In a cross-sectional study of donors and non-donors, Packman et al. (1997b) reported that one-third of donors and one-third of non-donors had moderate to severe post-traumatic stress reactions within the first seven years post-BMT.

Furthermore, other research efforts have shown that changes in family life provide

opportunities for growth in siblings. Common positive effects of the BMT on siblings include increased family cohesion, closer bond between recipient and donor, increased sensitivity, positive self-perceptions, decreased helplessness, and more compassion and caring (Carr-Gregg & White, 1987; Freund & Seigel, 1986; MacLeod, Whitsett, & Pelletier, 2003; Packman et al., 1997a; Wiley, Lindamood, & Pfefferbaum-Levin, 1984). Evidence from these studies demonstrates that siblings are not necessarily at an increased risk for adjustment problems.

The limited amount of the research that has been conducted on sibling adjustment to the BMT process has thus far failed to distinguish the effect of the experience on siblings' short-term versus long-term adjustment (i.e., three or more years after the BMT). This distinction is critical because the effect of the BMT on siblings' life experience may have significant consequences for later development (Murray, 1998). Also problematic is that researchers have not examined how sibling adjustment changes over time. Research guided by the phase of the illness would provide a more accurate picture of siblings' adjustment over the entire illness trajectory.

Predictors of Sibling Adjustment

Researchers have just begun to move toward understanding the complex, multiple factors that may explain why some donor and non-donor siblings are at higher risk for adjustment difficulties and at greater need for intervention, and why some appear to cope or even rise above the potential stress. Researchers have examined the influence of sibling characteristics, family variables and illness-related variables on sibling adjustment.

Sibling Characteristics

Siblings' age, gender, and degree of the stress have been shown to predict non-donor siblings' adjustment. In a study of 44 siblings (21 donors, 23 non-donors, ages 6-18 years), Packman et al. (1997b) found that older non-donors, female non-donors and non-donors with higher stress have more emotional problems. Other sibling variables that have received attention include temperament, emotional development, ethnicity, own medical history, pre-existing psychopathology, and donor status (donor versus non-donor) (Packman, et al., 1997; Packman et al. 1998). Overall, the research on these characteristics has been inconclusive.

Family Variables

Pot-Mees and Zeitlin (1987) found that siblings were at increased risk for developing adjustment problems when resources such as maternal attention were not available. Research efforts suggest more favorable outcomes for siblings in families with higher levels of family cohesion and adaptability (Carr-Gregg & White, 1987; Freund & Seigel, 1986; MacLeod, Whitsett, & Pelletier, 2003; Packman et al., 1997a; Packman, 1998; Wiley, Lindamood, & Pfefferbaum-Levin, 1984). Other family variables that have received research attention but for which no significant results have been found include: family size, socio-economic status, mother's emotional functioning, length of separation from mother, family relationships, communication style, family's social support at BMT, and quality of sibling relationship (Packman et al., 1997b). Research in this area has consistently suggested that sibling adaptation is a function of the extent to which a family can create an atmosphere in which siblings perceive themselves to be an integral part of the family system.

Illness-related Variables

Research attention has been directed at such illness variables as the patient's disease category, time from diagnosis to BMT, and time since the BMT (Packman, et al., 1997b). To date, only the patient's disease category has been shown to predict donor sibling adjustment (Packman, et al.). Specifically, donors of children with genetic disorders (e.g., thalassemia, severe combined immunodeficiency syndrome) had higher self-esteem than donors of children with cancer. This finding has been attributed to the fact that siblings of children with genetic disorders endure shorter and less intensive treatments prior to the BMT in comparison to siblings of children with cancer for whom BMT represents another stage in an ongoing, intrusive treatment protocol.

The problem with much of the research conducted to date is that it is deficit-centered, emphasizing the negative aspects of the illness experience (Eiser, 1990, 1994; Woodgate, 2001a; 2001b). This approach focuses on eliminating or reducing problem behavior. When we are focused in this way, it is much harder to notice siblings' strengths, abilities, efforts, interests and values. An alternative to a deficit approach is a strength-based, asset approach. This approach recognizes siblings of children who have had a BMT as people with strengths and abilities who are in the process of overcoming challenges. Identifying and building upon siblings' existing strengths and resources requires a shift in research efforts toward understanding how siblings deal with the BMT experience.

What Helps Siblings Adjust to the BMT Process

During the past two decades, researchers have proposed that social support is important in moderating the physical and psychological distress of stressors such as

cancer (Dunkel-Schetter, 1984). Evidence from social support intervention studies indicates that social support is positively associated with donor sibling adjustment (Kinrade, 1987; Shama, 1998; Heiney, Byrant, Godder, & Michaels, 2002). Kinrade found that donor siblings, who had problems adapting to role of donor, adjusted well after such nursing interventions as anticipatory guidance and play therapy were introduced. In a study by Shama, donors and their parents evaluated a pre-transplant and post-transplant follow-up program offered at Sick Kids Hospital in Toronto, Ontario. Close to 98% of donors and their parents rated the program as helpful. Positive effects of the program included giving the donor a sense of importance, and helping the donor manage stress and feel comfortable. Similarly, Heiney and colleagues (2002) found that individualized interventions to prepare donor siblings for the transplantation process reduced siblings' fears and anxiety, increased their compassion toward the recipient, increased their confidence, and enhanced familial communication.

Empirical evaluations of the psychological changes that occur in siblings following participation in social support interventions are in its infancy. Although researchers conclude that donor siblings find the interventions to be beneficial, it is not clear why these interventions work or what limitations they may have. Efficacy of the interventions requires more evidence than siblings' comments that the intervention was okay or that they might participate in the intervention again. Another limitation to social support interventions is that they focus on the donor sibling to the exclusion of the non-donor siblings. This is unfortunate because all siblings are affected by the BMT experience.

Social Support Needs of Siblings During the BMT Process

Research on support needs for donor and non-donor siblings is in the early stages. Researchers have identified three needs that siblings consistently report as important to them. These needs include: adequate information about the transplantation procedure and possible outcomes of the transplant, involvement in decisions, and support to express their feelings. The impression from the literature reviewed is that these needs are not being met.

Information

Knowing what to expect is one of the most important factors in siblings' adjustment to the BMT process. Siblings want accurate, age-appropriate explanations of what to expect including the donor role, bone marrow donation, entire transplantation process, and long-lasting complications the recipient may develop (Dannie, 1991; Heiney, Byrant, Godder, & Michaels, 2002; Kinrade, 1987; MacLeod, Whitsett, & Pelletier, 2003; Packman et al., 1997a; Parmar, Wu, & Chan, 2003; Shama, 1998). However, many siblings perceive that the information shared with them is inadequate, incomplete or misleading, if shared at all (MacLeod, Whitsett, & Pelletier; Packman et al.).

Involvement in Decisions

Another need that has emerged from the literature is that siblings want to be more involved in decisions, particularly decisions about whether or not they would be the donor (MacLeod, Whitsett, & Pelletier, 2003; Packman et al., 1997a). Siblings frequently report feeling compelled to donate whether or not they wanted to (MacLeod, Whitsett, & Pelletier; Packman et al.; Patenaude, Szymanski, & Rappeport, 1979). In fact, in a study

by MacLeod et al., donor siblings reported that not agreeing was not an option either because there were no opportunities to say “no”, or because they would rather donate their marrow than see their brother or sister die. Older siblings were able to understand the consequences if they did not donate their marrow and reported that they willingly chose to be a donor. Younger donor siblings reported feeling coerced to be a donor. Moreover, they hesitated to agree to be a donor on their own because they perceived the procedure to be a threat to their body integrity and physical self given pain they expected to endure (Kinrade, 1987; MacLeod, Whitsett, & Pelletier). After the BMT, young donors explained that they would agree to donate on their own had they known the procedure would have been less physically demanding and less painful than originally thought. This evidence suggests that siblings desire more influence and autonomy in deciding that not being the donor is not an option (MacLeod, Whitsett, & Pelletier, 2003).

Support to Express Their Feelings

Research has shown that being able to express their feelings is important to siblings (Dannie, 1991; Kinrade, 1987; MacLeod, Whitsett, & Pelletier, 2003; Packman et al., 1997a; Parmar, Wu, & Chan, 2003; Shama, 1998). Participation in support groups and counseling is consistently recommended in the literature (Gardner, August, & Githens, 1977; Kinrade; Packman et al.; Shama). However, many siblings report not having the opportunity to discuss their feelings with family members or peers (Packman et al.). This often means that siblings, who accept responsibility for complications that arise or for the recipient’s death, are not able to overcome their feelings of guilt and shame (MacLeod, Whitsett, & Pelletier).

All in all, results of these studies reinforce the fact that siblings’ needs are often

overlooked and unmet as the needs of the sick child become visibly more pronounced. The most significant limitation of these studies is that social support has been approached as a discrete, one-time event. However, social support is not static rather it is an ongoing process (Woodgate, 1999). This means that longitudinal research methods are necessary to better understand support processes.

These findings also highlight the importance of recognizing siblings as active interpreters of their own situation. That is to say that siblings' perceptions of their needs are different from those of both their parents and nurses and therefore, siblings' views require further attention. An understanding of the thoughts, feelings, emotions and perceptions of being a sibling of a child who has had a BMT and the language they use to express their needs and experiences is still lacking. Understanding the meaning siblings ascribe to their experiences is critical if the care of siblings is to be improved.

Siblings' Appraisal of the BMT Process

Recognizing that siblings have their own unique culture, with their own distinct thoughts and perceptions, several researchers have examined siblings' perceptions of the BMT process. Some studies highlight the perceptions of both donor and non-donor siblings, while others are specific to the perceptions of donors.

Perceptions of Donor and Non-donor Siblings

Siblings perceive the hardest part of the entire transplant experience to be the time when the recipient first became ill (Packman et al., 1997a). Much of the research highlights siblings' negative perception of the tremendous changes that occur as a result of the BMT. These changes include separation from parents, differential treatment, decrease in parental tolerance and attention, disintegration of familiar family dynamics,

roles and routines and restriction of activities (Freund & Seigel, 1986; Parmar, Wu, & Chan, 2003). The BMT process also establishes new relationships among siblings in a family and affects the entire family system (Freund & Seigel; Packman et al.; Wiley, Lindamood, & Pfefferbaum-Levin, 1984). Other researchers have shown that siblings have positive perceptions of the BMT experience, describing the experience as valuable. Maturity, independence, increased sensitivity and increased family closeness are frequently reported as positive aspects of having a brother or sister who has had a BMT in the family (Carr-Gregg & White, 1987; Freund & Seigel, 1986; MacLeod, Whitsett, & Pelletier, 2003; Packman et al., 1997a; Wiley, Lindamood, & Pfefferbaum-Levin).

Perceptions Specific to Donor Siblings

Donor siblings perceive learning that they would be the donor and contemplating their own surgery to be rough time (Packman et al., 1997a). Being chosen as the donor is often interpreted as an unfair burden (Parmar, Wu, & Chan, 2003). Donors perceive that the life of the ill child depends on their bone marrow (Gardner et al., 1977; MacLeod, Whitsett, & Pelletier, 2003; Parmar, Wu, & Chan). To this end, donors perceive that an unsuccessful BMT is a punishment. Thinking their marrow was not good enough for the recipient, donor siblings often blame themselves for complications or the recipient's death.

Donor siblings also have positive perceptions of the donor experience. Feeling like a better person and willingness to donate again are frequently reported as positive aspects of being a donor (Packman et al., 1997a). Similarly, MacLeod and colleagues (2003) found that donors of successful transplants perceived the experience to have a positive impact on their life in terms of their relationships, views of the world and

feelings about themselves. In addition, the donor experience gives siblings insight into the recipient's illness (MacLeod, Whitsett, & Pelletier).

Chapter Summary

This literature review demonstrates that there is an expanding body of literature regarding the family and sibling perspectives of childhood chronic illness, particularly as it relates to the BMT. Most of the studies reviewed were quantitative in nature and used instruments selected for their psychometric properties rather than their suitability to the task at hand. Given the lack of studies focusing on the subjective experience using qualitative methodology, little is known about siblings' lived experience of transitioning through the BMT trajectory, their day-to-day living, the meanings they assign to the experience, or the best way to help them through these transitions. Approaching the study of siblings of children who have had a BMT from the qualitative paradigm is warranted to enhance our understanding of transition-related issues from the perspective of siblings, and to help nurses better anticipate the diverse and shifting demands that siblings will likely encounter throughout the BMT experience. This literature review supports the need for a study that examines the lived experience of healthy siblings as they transition through the BMT experience.

CHAPTER THREE: METHODOLOGY & METHOD

Introduction

Chapter three will describe the methodology of the research study and method used. Methodology refers to the philosophical framework, whereas method is the research technique and procedure for carrying out the research (van Manen, 1990). Accordingly, the methodology section of this chapter will introduce the reader to the philosophical framework adopted for this study. In the method section, the research design, population selected, sample size, setting, data collection methods, and approach to data analysis are described. Ethical issues considered for the study and criteria for establishing methodological rigor are also presented.

Methodology

The methodology section of this chapter will introduce the reader to the philosophical underpinnings of hermeneutic phenomenology and explain the reasons why hermeneutic phenomenology was embraced as the appropriate methodology for exploring siblings' experiences of transitioning through the BMT trajectory.

Philosophical Underpinnings of Hermeneutic Phenomenology

The methodology used in this qualitative study is phenomenology, specifically hermeneutic phenomenology. It is a philosophy; however it is also concerned with approach and method (Rose, Beeby & Parker, 1995). Hermeneutic phenomenology as defined by van Manen (1990) is "systematic attempt to uncover the structure, the internal meaning structures, of lived experience' (p. 10). The aim of hermeneutic phenomenological research is to transform lived experiences into textual expressions of its essence, such that a good description will enable us to grasp the nature and

significance of this experience. In hermeneutic phenomenological research, the researcher is not attempting to validate a pre-selected theory or produce empirical information that be generalized because it goes beyond the interest of facts. As van Manen (1990) explains, the meaning or essence can only be understood by studying the "particulars or instances as they are encountered in the lived experience" (p.10). To gain a full understanding of any phenomenon derived from an experience, the experience needs to be described as well as interpreted (van Manen). The principles of hermeneutic phenomenology include an interest in understanding phenomena from the 'inside', in the study of the life world, or where people live, and in understanding the essence, or nature, of lived experiences as they are brought to light through the experiences of individuals (van Manen).

Hermeneutic phenomenology informed by van Manen (1990) is a relatively new philosophy, derived from the traditions of Husserl and Heidegger. In order to demonstrate the origins of the ideas expressed by van Manen and implemented in this study, the works of founding authors of phenomenology will be discussed.

Husserlian Phenomenology

Edmund Husserl (1859-1938) is attributed the honor of being the founder of phenomenology (Laverty, 2003; Maggs-Rapport, 2001). Husserl argued against the then prevailing positivist philosophy, and proposed a return to the study of phenomena as they appeared through the consciousness (Maggs-Rapport). According to Husserl, consciousness is unavoidable and is implicit in everything that is spoken about or referred for all consciousness is consciousness of something. He saw access to the structures of consciousness as result of direct grasping of a phenomenon. Husserl's approach to

phenomenology is epistemological or descriptive phenomenology, the goal of which is to describe the life world or human experience as it is lived (Laverty). In his view, what shows up is described precisely as it really is rather than as it is constructed through acculturation, so there is no need to go beyond the data (Maggs-Rapport).

Husserl envisioned phenomenology to be a process of describing the lived experience taking into account three domains of focus – intentionality, essences and bracketing (Koch, 1995). Related to consciousness and how it cannot be separated from our being is Husserl's concept of intentionality. Intentionality is a process of awareness of an object of study as it relates to our thinking, doing and hearing. Here, object is a generic term, referring to things in the external world, facts, concepts, dreams, or anything else that presents itself to consciousness (Paley, 1997).

As originally envisaged by Husserl, the goal of phenomenology is to develop a description of the universal structures of phenomena, essences, as they are in the consciousness of the people to who they appeared, rather than in matters of fact (Annells, 1996). Essences give common understanding to the phenomenon under investigation and identify what an experience means to the person concerned (Paley, 1997). In Husserl's view, essences can be abstracted from the lived experience without consideration to context and result in a generalized description of an experience.

Husserl proposed that bracketing is a process of suspending one's preconceived ideas, knowledge and beliefs, as an act of phenomenological reduction (Koch, 1995). Bracketing allows a researcher to return to "the things themselves" as they exist in and with our being (Lopez & Willis, 2004). In Husserl's view, bracketing shows the pure character of conscious experience by means of careful description. However, the

language we use to describe phenomena is culturally constructed and words only have meaning in relation to general agreement about their use (Paley, 1997). Thus, one's ability to forgo the objective understanding produced by acculturation as demanded by Husserl has come under criticism in more recent phenomenological works, such as those of van Manen and Heidegger.

Heideggerian Phenomenology

In modifying and building on the work of his mentor Husserl, Heidegger (1889-1976)'s pursuit of the meaning of Being led to the evolution of hermeneutics or interpretive phenomenology, with different emphases from Husserlian phenomenology (Lopez & Willis, 2004; Maggs-Rapport, 2001). Hermeneutics goes beyond a mere description of essences to uncover hidden meanings embedded in the interpretation of phenomena (Lopez & Willis). It based on the assumptions that (1) humans experience the world through language and (2) that this language provides understanding and knowledge (Bryne, 2001).

Similar to Husserl, Heidegger was concerned with the life world (Laverty, 2003). Husserl and Heidegger disagreed about the way the exploration of lived experience proceeds (Laverty, 2003). Husserl focused on understanding phenomena, whereas Heidegger believed that understanding was the realization of 'Dasein', which is being-in-the-world (Annells, 1996). Heidegger used the term being-in-the-world to emphasize that humans are inseparable from the world and understand the world through our existence within it (Annells). Accordingly, he stressed the importance of discovering how people came to experience the phenomenon in the way that they did, as subjective experiences are inextricably linked with one's history or background (Laverty).

Unlike Husserl, Heidegger suggests that presuppositions are not to be eliminated or suspended because they are essential to the interpretive process (Lopez & Willis, 2004). In Heideggerian terms, the hermeneutic circle addresses the researcher's interpretive influences on phenomena that in Husserl's phenomenology need to be bracketed. The premise of the hermeneutic circle is that all understanding is circular because all interpretation must itself be based on a prior understanding of what is to be known through interpretation (Annells, 1996). To this end, the Heideggerian approach asks researchers to engage in a process of self-reflection so that the biases and assumptions can be embedded in the interpretation (Koch, 1995). The blending of meanings articulated by the researcher and participant means there could be more than one interpretation of an experience. However, as Annells notes the meanings must be logical and plausible within the framework of the study, and they must reflect the realities of study participants.

Appropriateness of Hermeneutic Phenomenology for This Study

Hermeneutic phenomenology was chosen as the methodology for this study because this approach will provide insight into how donor and non-donor siblings live, see and interpret the BMT experience throughout the BMT trajectory. Moreover, this approach is recommended when the intent is to understand the lives of individuals within their own context by taking into account individuals' life experiences and meanings derived from these experiences (Speziale & Carpenter, 2003).

Method

This section details the research design that was applied to obtain information-rich data, study sample, setting, data collection methods, and approach to data analysis.

Ethical issues considered during the planning and conducting of the study, and issues of methodological rigor are addressed.

Research Design

A qualitative research design was ensued to elicit detailed descriptions of the lived experience of siblings of children who have undergone a BMT. When little is known about a situation, qualitative research, particularly phenomenology, can make valuable contribution by helping to understand life's experiences as individuals live them. The experience of what it is like to be a sibling of a child who has had a BMT is an example of such a situation warranting further investigation. The emphasis of this study was the exploration of the experience of individuals living in the world. Thus, every attempt was made to foster the voice of siblings themselves in the exploration of their experience.

The work of van Manen (1990) was used to guide the data collection, analysis and interpretation. The six methodological themes within van Manen's approach were used to structure the research process into specific research activities (see Table 1). The research process did not proceed linearly instead all activities were carried out intermittently or simultaneously (van Manen).

Table 1

The Research Process

van Manen's (1990) Methodological Themes	Research Activities for this Study
Turning to a phenomenon of interest	Literature review, proposal, recruitment of participants
Investigating experiences as it is lived	In-depth interviews
Reflecting on the essential themes	Analysis
Describing the phenomenon through writing and rewriting	Interpretation of emerging themes, writing and re-writing themes
Maintaining a nursing relation to the phenomenon	Refer to the research question and purpose, nursing experience and literature
Considering the parts and the whole	Movement from themes to the entire transcripts of individual interviews

van Manen's approach was chosen because it has been widely adopted by a range of health care professionals, sociologists and social scientists (e.g., Chard, 2000; Giles, 2003; Hilton & Henderson, 2003; Nahalla & Fitzgerald, 2003; Rapport, 2003; Woodgate, under review; Woodgate, Secco & Ateah, 2003). Furthermore, the use of van Manen's method in a range of research scenarios (e.g., perioperative nursing haemodialysis, bladder cancer, hospitalization of children with thalessemia, reproductive health, adolescent depression, autism) reinforces its versatility.

Sample Recruitment and Access

The criteria for sample selection, sample size, and processes for participant access and recruitment are described.

Criteria for Sample Selection

Criteria for sample selection guided the recruitment and selection process of eligible participants. In phenomenological research, the only legitimate informants are those who have lived the reality (Baker, Wuest, & Todd, 1992). Therefore, in recruiting participants, attention was directed at selecting individuals based on their knowledge of

the experience of transitioning through the bone marrow transplant experience, and their ability and willingness to reflect on and communicate this knowledge. Participants in this research study met the following criteria: (1) were able to speak, read and write English, (2) had a sibling who has had a BMT during childhood regardless of the disorder for which the BMT was indicated, and (3) was a school-aged child or adolescent at the time of the BMT.

Sample Size

A sample of 8 participants was selected. Statistical techniques for determining an appropriate sample size for qualitative studies do not exist. Therefore, the aim was to recruit a large enough sample to elucidate the richness of the individual experience (Speziale & Carpenter, 2003). Data was collected until redundancy occurred and the researcher found no new data emerging. All but two participants were interviewed twice. A total of fourteen interviews were conducted.

Participant Access

Participant access was sought through the CancerCare Manitoba Research Resource Impact Committee (RRIC). An application requesting permission to access siblings of children who had a BMT was sent to the committee. RRIC granted permission to access siblings for the study. Please refer to Appendices B and C for a copy of RRIC provisional approval (dated January 26, 2005) and official approval (dated March 30, 2005).

Sample Recruitment

Siblings were recruited from a pediatric BMT clinic in Winnipeg, Manitoba. The clinic serves Manitoba, northwestern Ontario and parts of Saskatchewan. From 1992-

2003, the Manitoba pediatric BMT experience included 87 transplants for 84 patients (Schroeder, 2003). Of these transplants, 22 were autologous and 65 were allogeneic with 43 related donors and 22 unrelated donors. Indications for transplantation included leukemia, solid cancer, SCIDS, metabolic disorders, bone marrow failure syndrome, and lymphoma. Fifty-seven patients survived the transplant, and 27 died from complications related to the transplant or disease relapse.

The assistance of a clinical research professional from the Pediatric Oncology Clinical Investigation Office at CancerCare Manitoba was solicited to help in sample recruitment. He/she acted as an intermediary and was responsible for the initial contact with all eligible participants by letter (see Appendix D). Potential participants and parents or legal guardians were asked to notify the researcher of their interest in participating in the study by returning a reply form (see Appendix E). Follow-up telephone calls to ascertain interest in the study were made by the intermediary for potential participants from whom there was no response within two weeks from the mailing of the recruitment letter.

Recruitment letters were initially mailed to 11 families who met the inclusion and exclusion criteria. Follow-up telephone calls were made to nine of these families. Seven siblings from six families were interested in learning more about the study, three declined participation, and two were never reached. A second mail-out of nine recruitment letters yielded the interest of one sibling and no response from the other families.

Eight potential participants were contacted by telephone after receiving an affirmative response on the reply card or in the follow-up telephone call. The researcher's initial contact was by phone to briefly describe the study, identify siblings who met

inclusion criteria, and explore siblings' willingness to participate (see Appendix F for telephone script). The study was described to siblings once permission had been granted from their parent or legal guardian. All siblings who were contacted agreed to participate in the study.

Another way of recruitment was through posters displayed in the pediatric BMT clinic at CancerCare Manitoba, which will describe the research project and give the researcher's contact information (see Appendix G). Permission to put up the posters will be obtained from CancerCare Manitoba. The use of posters for recruitment did not elicit any potential participants.

Data Collection Methods

Data was collected using a demographic form and semi-structured interview format. Field notes were also maintained. Interviewing techniques are described in this section.

Demographic Form

To begin the process of engagement whilst gathering useful data to understand the context of the participant, a demographic form was used to gather data related to the participant and sibling who underwent the bone marrow transplant (see Appendix H). The researcher developed the demographic form for this particular study. Participant and recipient demographic variables provided a picture of who participated in the study. The form took about 10 minutes to complete.

Semi-structured Interview

Since the phenomenological approach seeks to understand the lived experience of participants, the major source of data collection involved siblings participating in semi-

structured, open-ended interviews that explored siblings' memories, reflections and descriptions about what it is like to be a sibling of a child who has had a bone marrow transplant. The open-ended technique allowed the researcher to focus on areas deemed significant by the siblings and not anticipated by the researcher (Faux, Walsh, & Deatrick, 1988; Kortesluoma, Hentigen, & Nikkonen, 2003).

Participants were asked to participate in two interviews. One interview is not sufficient to obtain the rich, in-depth data that is characteristic of phenomenology research (Speziale & Carpenter, 2003). A second interview (by phone or e-mail) afforded participants the opportunity to expand on their ideas and thoughts, and add anything they felt was important for the researcher to know. It also provided an opportunity for the researcher to clarify what was previously told to them. Although a second interview was planned, siblings had the opportunity to decline participating in a second interview. The length of the first interviews ranged from 30 to 90 minutes with a total of 410 minutes for eight participants. The second interviews lasted for 5 to 30 minutes with a total of 70 minutes for five participants with one participant responding to questions via e-mail. The length of both interviews was 480 minutes. Table 2 lists the participant's pseudonym, length of each interview and total length of interviews for each participant.

Table 2

Pseudonym and Length of Interviews

Pseudonym	Length of Time 1 Interview (minutes)	Length of Time 2 Interview (minutes)	Total Length of Interviews (minutes)
Becky	45	30	75
Nicole	30	-	30
Elizabeth	90	15	105
Carrie	60	10	70
Karen	45	5	50
Debbie	60	Written response	60
Marcy	30	10	40
Kelly	50	-	50
	410	*70*	*480*

The researcher conducted and transcribed all interviews. All interviews were audiotaped in order to preserve their authenticity and to facilitate detailed analysis. Care was taken to minimize errors such as unclear notes and equipment failure. Recording equipment was checked regularly to ensure it is functioning properly, and spare batteries and tapes were readily available. Despite efforts to prevent equipment failure, one interview was not audiotaped. This interview was re-done with the participant's permission.

Interviewing Techniques

Although phenomenology calls for the researcher to adopt a non-directive approach, it was necessary to use prompt questions to help siblings tell their story (see Appendix I for interview guide). The prompt questions helped siblings focus on specific events and situations, but were open enough to allow the siblings to develop the conversation in whichever ways are most relevant to their situation. This is in keeping with van Manen's (1990) view that it is acceptable to use appropriate techniques within a study as long as they are considered within the general orientation of the methodology.

The researcher used various techniques to develop an interactive, trusting researcher-participant relationship. This included giving participants the choice of where the interview took place, asking participants if they wanted to the interview to be conducted with or without their parents' presence, and asking warm-up questions prior to the interview. The researcher explained that what siblings said would not be shared with their parents or family, her interest in the research problem, and importance of the information being obtained.

Developmentally appropriate language was used to facilitate siblings' expression of thoughts and to ensure that participation in the interview was viewed positively (Faux, Walsh, & Deatrick, 1998; Woodgate, 2001a). The challenge was to formulate questions into the kind of language that siblings understand and use because the way questions are phrased can affect the substance of the answers (Kortesluoma, Hentigen, and Nikkonen, 2003). As recommended by Kortesluoma and colleagues, reflective techniques were used to identify inconsistencies in sibling's answers. For example, the researcher verbalized sibling's answers differently to check what they really meant or said. Simple words and sentences, and concrete facts were used for the younger children. Interviewing strategies for older siblings included the use of longer and more complex sentences, past and future tenses, and "why, when, and how" questions. To enrich the information obtained in the interviews, retrieval cues or probes, such as the use of silence, providing encouragement (e.g., Yes? Uh-huh?), and seeking examples, were also used (Docherty & Sandelowski, 1999).

Field Notes

The third source of data collection was field notes that the researcher kept

throughout the research study to record the setting, nonverbal behaviors, interruptions in the flow of conversations, reminders or critique on the methodology, and patterns discerned from the work in progress. The researcher also wrote down personal and theoretical assumptions regarding the BMT experience and its impact on siblings. Deliberately putting personal biases and feelings on hold, also called bracketing, will foster the researcher's ability to forego subjective responses and preferences that might creep into the interpretive process, and see the siblings' experience as it is lived (van Manen, 1990). Field notes were made subsequent to each interview. Regular meetings were held with the researcher's thesis supervisor to discuss entries and address methodological, theoretical, and personal issues pertinent to the study.

Research Setting

Interviews were conducted where the siblings desired so that they were comfortable during the interview process. For the first interview, three participants were interviewed over the telephone, three were interviewed in their home, one chose to be interviewed at CancerCare Manitoba, and one was interviewed in the researcher's office in the Faculty of Nursing. Seven follow-up interviews were conducted over the telephone. By request, one participant provided written responses to follow-up questions via e-mail.

Data Analysis

In keeping with a qualitative research approach, data analysis occurred concurrently with data collection and required the researcher to become immersed in the data (Speziale & Carpenter, 2003). Each interview was listened to following the interview, prior to transcription to review the interview experience, and after transcription

supporting the immersion process.

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). This process includes uncovering thematic aspects, isolating thematic statements, and composing linguistic transformations. The transcripts were reviewed repeatedly for significant statements in an attempt to find meaning and understanding through themes, the structures of the experience (van Manen). Thematic statements were isolated using van Manen's selective highlighting approach. In this approach, the search for themes, or structures of the experience, involves selecting and highlighting sentences or sentence clusters that stand out as thematic of the lived experience of siblings. Using all the phrases and sentence clusters, textual data was reduced until essential themes (meanings unique to a given phenomenon and without which the phenomenon would lose its fundamental meaning) and incidental themes (incidentally related or centrally intrinsic to the phenomenon) that made up the sibling experience emerged (van Manen). Essential themes were differentiated from incidental themes by asking the question: What phrases seemed particularly essential about the experience of transitioning through the BMT trajectory?

Having arrived at the essential and incidental themes, linguistic transformation was used to capture the essence of the themes (van Manen, 1990). This process involves writing and re-writing. Paragraphs were written about the essential themes to develop the interpretation. This was accomplished by shifting focus between the parts and whole transcripts, and between individual and group transcripts. Examples were used to illustrate how the description came together. The result was a description of a possible

sibling experience of the BMT trajectory and not a single complete description of the experience, because full descriptions of a phenomenon are never possible (van Manen). This description, which resulted in the development of the essence and themes, was co-created by the researcher and thesis supervisor.

Descriptive measures, including percentages and averages, were used to summarize and describe the demographic data. The small sample size precluded further statistical analyses.

Methodological Rigor

Rigor in qualitative research is important in the practice of good research and should be determined by the extent to which the research is able to portray the experience being studied (Speziale & Carpenter, 2003). Within the quantitative paradigm, criteria such as internal validity, external validity, reliability and objectivity are used. These criteria are not appropriate for use in a phenomenological study (Lincoln & Guba, 1985). Lincoln and Guba have identified four aspects of trustworthiness to ensure methodological rigor exists in qualitative research: credibility, dependability, confirmability, and transferability.

Credibility

Credibility is the process whereby the researcher assures that the study findings are meaningful and reflect the current experience (Lincoln & Guba, 1985). One strategy way to confirm the credibility of findings was prolonged engagement in the topic (Lincoln & Guba). Data collection took place over two interviews, lasting from 30 minutes to 1 hour for the first interview and 10 to 30 minutes for the second interview. The researcher engaged in general conversation with participants before and after the

interview.

Demonstrating that the findings and interpretations of the data reflected the participants' experiences also enhanced the credibility of the study (Guba & Lincoln, 1985). Participants were asked during and immediately following the interviews if the researcher's interpretation of their experience was reflective of what the experience was like for them. The second interview also served to validate that the findings represented siblings' experiences.

The criterion of data saturation also supported the credibility of the results (Guba & Lincoln, 1985) Saturation or the duplication of information obtained from siblings was reflected in the data collection and analysis process of the study. This criterion provided the basis for the researcher's decision to not seek out additional participants.

Another way to attend to the credibility of a study is through peer review and debriefing (Lincoln & Guba, 1985). The researcher met periodically with her thesis supervisor to discuss findings and impressions. The researcher and thesis supervisor jointly developed an interpretation of the essence of the sibling experience of transitioning through the BMT experience.

Dependability

Dependability refers to the stability of data over time, and tracking of changes and shifts in constructions (Lincoln & Guba, 1985). Dependability of this study was ensured through the provision of an audit trail. Documentation included in the audit trail was contextual information (setting, behaviors), methodological information, analytical decisions, and personal reflections and a priori thoughts. This audit trail allows another researcher to easily follow the decision trail used by the researcher of the study to arrive

at similar conclusions (Lincoln & Guba).

Confirmability

Confirmability is concerned with establishing that data and interpretations are derived from the data, not the researcher's personal constructions (Lincoln & Guba, 1985). It assures that interferences made by the researcher are logical. Confirmability of this study was established by (1) using direct quotes, (2) adhering the analysis process, (3) validating findings with participants during and immediately following the interviews, and (4) using a journal to record content and process of interactions between researcher and participant as well as the researcher's reactions to events in research.

Transferability

Transferability refers to the likelihood that findings of a study may have meaning for others in similar situations (Lincoln & Guba, 1985). For qualitative research, the burden of transferability rests with the users of the research (Lincoln & Guba). Transferability in this study was addressed by providing thick and detailed descriptions of the processes used by the researcher, including the time, place and context of interviews, and methodological decisions and impressions.

Ethical Considerations

Permission to conduct this study was obtained from the researcher's thesis committee, the University of Manitoba, Education/Nursing Research Ethics Board (ENREB) and the CancerCare Manitoba RRIC. A certificate of ethical approval was received from the ENREB. Please refer to Appendix J for a copy of the certificate (dated January 27, 2005). The RRIC provided access to participants. Please refer to Appendices B and C for a copy of RRIC provisional approval (dated January 26, 2005) and official

approval (dated March 30, 2005). The ethical principles of autonomy, beneficence and justice provide the organizational framework for the following dialogue of the ethical issues of this study.

Autonomy

The principle of autonomy, encompassing the notion of being a self-governing person with decision-making capacity, was upheld through the informed consent process (Speziale & Carpenter, 2003). Study information, and consent and assent forms were distributed prior to the interview. Ongoing consent and assent were obtained verbally at the beginning of each interview. This approach to consent encouraged mutual participation and took into consideration the possibility of unexpected events or changes in circumstances (Speziale & Carpenter).

Written consent was obtained from parents or legal guardians (see Appendix K). If parents or legal guardians consent, written assent was obtained from children and adolescents willing to participate (see Appendices L and M). The researcher stressed to the parents or guardians that the child's refusal to assent overrides a parent's or legal guardian's permission for the child's participation. Written consent was obtained from young adult siblings (i.e., those older than 18 years of age) (see Appendix N). If potential participants were not interested in participating, their participation in the study was not pursued. Siblings were made aware that their participation was voluntary and that withdrawal at any time was allowed without penalty. Participants were given the opportunity to decline participation in a second interview.

The process of sample recruitment took into consideration the potential participant's right to decline without the researcher knowing this decision. The first point

of contact was a clinical research professional from the Pediatric Oncology Clinical Investigation Office at CancerCare Manitoba. This meant the researcher had no knowledge of who received an invitation to participate in the study. Potential participants were contacted by telephone after receiving an affirmative response on the reply card or in the follow-up telephone call.

Beneficence

In support of the principle of beneficence, doing good and preventing harm, no harm) the risks and benefits of the study were explained to participants in the consent and assent forms (Speziale & Carpenter, 2003). No known risks to the participants were apparent. However, the researcher recognized that having the opportunity to talk about their BMT experience could have made some participants become more aware of their feelings. Participants' behaviors and expression were continuously assessed and documented in field notes. Respect, caution and sensitivity were exercised when interacting with participants in order to prevent the possibility of undue stress (Woodgate, 2001a). If participants experienced signs of increased stress, the researcher validated their feelings, changed the topic to a more neutral one, stopped the interview and resumed only when the participant felt comfortable to continue. Although referrals to psychosocial services at the Winnipeg Children's Hospital were offered, none were needed. All participants received debriefing at the end of each interview. This involved asking participants if they were feeling okay, and asking them if they had any questions.

Participants were given a movie pass upon completion of the interview(s). Monetary compensation was given to participants who for cultural reasons did not go to the movies.

Justice

The principle of justice, fair treatment, applies to providing confidentiality and anonymity (Speziale & Carpenter, 2003). Confidentiality and right to privacy was maintained. Participants were informed of their right of confidentiality as well as how this was protected. The researcher explained that what siblings said would not be shared with their parents or family. While the names of participants and their parents or legal guardians were known in order to secure their written informed assent and consent, no names were attached to any of the data collection methods (e.g., Demographic Form, transcripts of the interviews, journal). Only the researcher had access to the participants' names. Code numbers and pseudonyms were used on all sources of data. Two separate lists, one with the participants' names and the other with participants' code numbers were kept in separate files, locked in a cabinet in the researcher's home. Only the researcher and researcher's thesis supervisor read the interviews. Information provided by siblings was not shared with their parents. Within 7 years of the completion of the study, the data will be confidentially destroyed.

Participants were made aware that the results of the study would be written up as part of the researcher's thesis, published in a peer-reviewed journal and presented at a health conference. Because the process of publication may result in a breach of confidentiality and anonymity, care was taken to make sure that examples of raw data did not reveal the participant's identity.

Justice was also maintained in selection of participants for the study. Recognizing the importance of diversity in research, siblings included in the study were of different ages, and came from different cultural, religious and socio-economic backgrounds.

Chapter Summary

This hermeneutic phenomenological study was designed to gain an understanding of what is it like for siblings to transition through the BMT experience. Data was gathered through semi-structured interviews, demographic questionnaire and field notes. The research setting was in the participant's home, the researcher's office or a health facility room. The process of data analysis was van Manen's (1990) selective highlighting approach. In this research, analysis of the meaning of the experience began with each interview and continued through data collection and writing. The establishment of rigor and ethical considerations were also described.

CHAPTER FOUR: FINDINGS

Introduction

In Chapter four, the findings of this phenomenological study are presented. The chapter begins with a description of the participants. The main findings of the study outline the essence of siblings' lived experience of transitioning through the BMT trajectory and themes supporting this essence. Data analysis revealed the essence is an interruption in family life. The four themes that emerged from the interviews with siblings were: (1) life goes on, (2) feeling more or less a part of a family, (3) faith in God that things will be okay, and (4) feelings around families. Differences between donor and non-donor siblings will be highlighted. The chapter concludes with siblings' recommendations for health care professionals.

Description of the Participants

Eight siblings from seven families participated in this study. Demographic data describe the participants and BMT recipients.

Participant Demographic Data

The eight siblings who participated in this study had a mean age of 18 and an age range of 11 to 24 years. All siblings were female. At the time of the BMT, four siblings were school-age, two were adolescents, and two were young adults. The mean time since the BMT was 53 months, ranging from 15-139 months. Two participants were from the same family. All participants lived at home with both parents. The average number of children in each family was 4, with a range of 2 to 9. The majority of siblings were the eldest in their family. The age difference between the participant and BMT recipient was an average of 6 years and ranged from 2 to 11 years. Four siblings were in school or

university. Five siblings had jobs, two of which were full-time and three were part-time. The sample was predominantly Caucasian, with three siblings coming from a Mennonite family and one from a Hutterite family. All but two of the participants lived in a rural area of Manitoba. Table 3 presents a summary of participant demographics.

Table 3

Participant Demographics

Characteristic	Number (%)
Sex	
Female	8 (100%)
Male	0
Age at BMT	
School-age	4 (50%)
Adolescent	2 (25%)
Young adult	2 (25%)
Donor status	
Donor	3 (38%)
Non-donor	5 (62%)
Position in the family	
Oldest	5 (62%)
Middle	2 (25%)
Youngest	1 (13%)
Ethnic/racial background	
Caucasian	7 (87%)
Asian	1 (13%)
Living in rural/urban areas	
Rural	6 (75%)
Urban	2 (25%)

Five participants were non-donors and three were donors, one of whom donated bone marrow to two siblings. Donor and non-donor siblings were similar in age at the time of interview and at time of the BMT. The time since the BMT was longer for donor siblings. The mean age difference between the donor sibling and recipient, and non-donor sibling and recipient were also similar. The only striking difference was that all the non-donor siblings were the oldest in the family, and the donors were either a middle child or

the youngest child. Table 4 presents a summary of the donor and non-donor siblings' demographic data.

Table 4

Comparison of donor and non-donor sibling demographics

Characteristic	Donor Siblings (n=3)	Non-Donor Siblings (n=5)
Average age (years)	18 (15-22)	17 (11-24)
Average time since BMT (months)	87 (31-139)	33 (15-85)
Age at BMT		
School-age	2 (67%)	2 (40%)
Adolescent	0	2 (40%)
Young adult	1 (33%)	1 (20%)
Position in the family		
Oldest	0	5 (100%)
Middle	2 (67%)	0
Youngest	1 (33%)	0
Average age difference between participant and recipient (years)	5 (2-8)	7 (3-11)

BMT Recipient Demographic Data

There were eight BMT recipients in the seven families. Two of the recipients had the same donor sibling, but the interview focused only on the BMT experience of the oldest recipient. Thus, the data for seven recipients are presented here.

All BMT recipients were alive and well at the time of the interview. Two BMT recipients were male and six were female. The BMT recipients mean age was 11.14 with a range of 4 to 20. At the time of the BMT, one recipient was an infant, two were toddlers, three school-age, and one was adolescent. With respect to position in the family,

one recipient was the oldest, three were in the middle, and three were the youngest.

The majority of BMT transplants were allogeneic with a sibling donor. This finding is consistent with population statistics that identifies the most common BMT transplant as allogeneic with a related donor (Schroeder, 2003). The indications for the BMT were Philadelphia chromosome-positive acute lymphoblastic leukemia (ALL) (1), acute myelogenous leukemia (AML) (1), chronic myelogenous leukemia (CML) (1), neuroblastoma (1), aplastic anemia (2), and severe combined immunodeficiency syndrome (SCIDS) (1). All but one recipient received chemotherapy, one received radiation, and three had surgery (e.g., central venous catheter insertion). Table 5 provides a summary of recipient demographics.

Table 5

BMT Recipient Demographics

Characteristic	Number (%)
Sex	
Female	2 (29%)
Male	5 (71%)
Age at BMT	
Infant	1 (14%)
Toddler	2 (29%)
School-age	3 (43%)
Adolescent	1 (14%)
Type of transplant	
Allogeneic	6 (86%)
Autologous	1 (14%)
Position in the family	
Oldest	1 (14%)
Middle	3 (43%)
Youngest	3 (43%)
Indications for BMT	
Leukemia	3 (43%)
Neuroblastoma	1 (14%)
Aplastic anemia	2 (29%)
SCIDS	1 (14%)

Main Findings

The essence of siblings' lived experience and the themes that communicate the substance of this essence will be presented in the next section. Describing the essence and themes will address the following research questions:

Research Question 1: What characterizes the healthy donor and non-donor siblings' lived experience of transitioning through the BMT trajectory?

Research Question 2: What meaning do healthy donor and non-donor siblings assign to the experience?

The Essence of Siblings' Lived Experience

The essence of siblings' lived experience of transitioning through the BMT trajectory is described as an interruption in family life. The onset of illness and subsequent need for a BMT was described by all siblings as a sudden, unwelcome interruption to their daily family life. Family life was no longer considered "normal".

> *Uhm, I know that the changing was fast and finding out that Sarah [recipient] had cancer. (Becky, 11-year-old non-donor)*

> *And uhm, well that was just…I mean that turned over the whole house like you know like we'd been living…we were healthy we thought you know. (Elizabeth, 23-year-old non-donor)*

> *Well, we…like it was a normal life to all of a sudden we had a little sister. And then, like we found out she was sick... (Nicole, 15-year-old non-donor)*

Siblings perceived the interruption to family life to be a bad dream that turned out to be their reality. This understanding of their reality was not something that came easily or quickly.

> *It was kind of like it wasn't really happening. Like I don't know. When you experience like things like that, it's just like…it takes a while for it to sink in. So, it was a…like I knew it was happening. But uhm…yeah it took a while for me to realize everything. (Debbie, 24-year-old non-donor)*

> *I mean now just it kind of seemed like it was a dream we went through or whatever. Like a bad dream…<pause>…I don't know kind of like… Well, it was like something like this that…you'd wake up in the morning and you'd just think is it actually real you know. And it actually was real you know. And you could hardly believe because it was…something so totally out of our normal way of living. (Carrie, 22-year-old donor)*

> *I really didn't want this to be happening. It was sort of just…I…it felt like a dream or a nightmare. I didn't want it to happen. And I thought I'd wake up and nothing would have ever happened. But, it happened. (Becky, 11-year-old non-donor)*

Siblings revealed that life as they knew it before the transition had been put on hold. Family life was affected in three areas: routines, special events, and roles and responsibilities.

Routines

Family life revolved around the recipient's health, lengthy hospital stays and medical appointments. For all the families, this meant the family unit was divided. Parents or older siblings stayed with the recipient at the hospital, while the other siblings stayed at home with relatives.

> *So, I…yeah there were a lot of times that my parents would come…one parent to the hospital…one parent would go and a lot of times both were there. They were always there. So, really a lot of the time I would wake and they'd be already gone. One of them would be already gone and then I'd go to school and they'd be gone until later that night. (Nicole, 15-year-old non-donor)*

> *…I was basically at my…uhm my great-grandma came to my house and I was with her like 24-7, except for on the weekends. That was the only time I got to see my Mom and my sister. (Becky, 11-year-old non-donor)*

Special Events

Often, the family trips, birthdays, holidays and social activities that siblings had once enjoyed with their family were planned around the recipient's health or not done at all.

> *Uhm, we couldn't do as much stuff. Like we couldn't open presents together and enjoy the birthday cake together and stuff like this. (Karen, 13-year-old non-donor)*

> *I just remember those [family activities]. Cause I know it was…and then I know after that then…then you know for a long time some of things we didn't do you know. (Elizabeth, 23-year-old non-donor)*

Roles and Responsibilities

For most siblings, the BMT experience interfered with their taken-for-granted family roles and responsibilities. In the absence of their mother, some siblings took on the mothering role. Others performed additional chores and responsibilities in the home.

> *I know uhm…<pause>…yeah like some…like for me when I would spend time at home I knew like I was responsible you know for all my siblings cause usually I was the oldest at home you know. And you know…you almost felt like you had to be a mom to them. (Carrie, 22-year-old donor)*

> *And, then I had to do a lot of chores around the house, like mowing the lawn…my father used to do it…and working in the garden and stuff like this. (Karen, 13-year-old non-donor)*

> *It was different cause it was really the first time that I'd been completely self-dependent as to getting myself supper, doing my homework, keeping myself…hmmm…responsible enough to get myself up for school in the morning to make it to the bus and…stuff like that. (Nicole, 15-year-old non-donor)*

Common to all sibling experiences was a return to 'normal' family life once the BMT experience was over. Families were able to "get on with their lives". This meant that families were together once again, routines resumed, and everyone was healthy.

> *It was just more or less normal life I guess. We weren't going to the hospital every day and stuff. (Marcy, 15-year-old donor)*

> *Well, it's back to normal. She eats much Tanya [recipient]. And we have our family at home. (Karen, 13-year-old non-donor)*

> *It feels like it's well back to well normal…back to whatever you know pretty much what it was like before he [recipient] got sick. (Elizabeth, 23-year-old non-donor)*

Themes

Four themes emerged from the data in support of the essence of siblings' lived experience of transitioning through the BMT trajectory. These themes were: (1) life goes on, (2) feeling more or less a part of a family, (3) faith in God that things will be okay, and (4) feelings around families.

Life Goes On

Despite family life being interrupted, life goes on for siblings. Siblings' lives did not stop with the onset of their brother or sister's illness or the BMT. There were three aspects to life goes on - bad days, good days and coping responses.

As life went on, siblings had both good days and bad days, which for the most part paralleled the symptom illness trajectory. Bad days were those when the illness diagnosis was realized, recipient's symptoms worsened, testing was conducted to determine who could be the donor, waiting for things to happen, and donors had their surgery. Siblings' good days included: finding a match within their family, marrow stem cell infusion, learning that the recipient's marrow was engrafting, spending time with the recipients outside of the hospital, and when their brother or sister came home for good.

Bad days. At times, the difficult aspects of the experience caused siblings much distress. One of the hardest times for siblings was the illness diagnosis. What made it so difficult was the realization that their family was not immune to illness.

> *That actually someone in our family was sick. Like just like sick you know. Sick with something that wouldn't get better just over a week or something. That it had to be treated with a treatment and he could be sick for three years or he could be sick for a year you know. (Carrie, 22-year-old donor)*

> *Yeah like I hadn't really…like we visited other people. But it hasn't been anyone like close to me. So it was just different cause it was my sister and she was the youngest. (Debbie, 24-year-old non-donor)*

Difficult days were also characterized by observations of the recipient enduring more frequent and intense physical and emotional symptoms as a result of side effects and complications of treatment. Physical symptoms that were most bothersome to siblings included such symptoms as hair loss, nausea and vomiting, weight gain, and changes in skin color. For some siblings, seeing the "physical side" of the recipient's treatment, particularly chemotherapy, made the experience "more real". It also helped one sibling realize the seriousness of the recipient's illness.

> *Really the most prominent thing for me that I would remember is when she first starting taking chemotherapy...Just…it was…sorry…to seeing her laying there so sick, to see her hair falling out. (Nicole, 15-year-old non-donor)*

> *And oh, she was yellow because she had lost blood and she was throwing up all the time so it was weird. (Karen, 13-year-old non-donor)*

Seeing their brother or sister sick was experienced as something unpleasant. However, siblings believed that the recipient had to feel a lot worse to get better. Their reasoning was that some degree of suffering was justified.

> *Well, in a way it was like not happy but thankful that uhm this would maybe help her and maybe uhm cure her and stuff, or may...help her get along with it. But in another way, I was really sad that she had to go through this and all the terrible things that she had. (Becky, 11-year-old non-donor)*

> *Uhm, it was…I didn't like it, but I knew it would help her. (Debbie, 24-year-old non-donor)*

Being tested to determine if they were a donor match or not was a very difficult experience for the two siblings who did not like needles. One sibling described her traumatic experience as follows:

> *And then, uh my parents just told me that…we were in a room and they were taking uhm blood tests. And I hate needles. So, I was screaming and then my Mom…and then my Mom and my Dad took their test. And, I told them that I wasn't taking it cause I didn't want needles. And I went, no they can't make them.*

> *So, I didn't want to take it. But, then they had to put down on uhm…they held me down on one of those beds for the doctors to actually take the test cause I wouldn't let them. (Kelly, 18-year-old donor)*

Waiting for things to happen was also difficult for siblings. They waited to see who in their family, if anyone, would be a match for the recipient. They waited for the transplant to happen. They waited to see if the transplant would engraft.

> *I guess the [tense] part [of waiting] was to see if they [stem cells] would like really graft or not. And if then they…and if they didn't graft then what would happen after that. (Carrie, 22-year-old donor)*

For the donors, the transplant day was the day that they had their marrow harvested. Two of the donors recalled experiencing pain after the surgery. Despite the pain, the donors related that the pain of the procedure was worth being able to help their brother or sister feel better. One donor described her pain as follows:

> *And that it was…my pain compared to his was such a little bit you know. It…it was nothing compared to what he was going through you know. (Carrie, 22-year-old donor)*

Good days. Siblings cherished the good days they shared with their family. They related that they took the good with the bad in the experience, and that the good times made the difficult times easier to handle.

Finding a donor match within the family was a positive event for siblings. Siblings felt happy and relieved that a match was found. It was especially exciting for two of the donors who were interviewed because they could "do something" for the recipient.

The day of the transplant was an exciting day for non-donor siblings, whether they were present for the marrow stem cell infusion or not. Seeing the marrow being infused instilled the non-donor siblings with hope that the recipient would get better. One

sibling poignantly described what she saw as:

> *Uhm, you know it was exciting. It was…just to see the…the bone marrow you know like…like it just felt like there was life dripping into him or whatever you know. Uhm, and well now of course we had to wait to see if it would work you know but…it…it was…I'd say it was a good day. Uhm. You felt like that like now there…now there was a chance. (Elizabeth, 23-year-old non-donor)*

Another good day was the day when siblings learned that the recipient's marrow was engrafting. It was perceived to be an indication that the recipient was getting better.

> *Uhm, they tested her blood everyday to see how the counts were. And uhm slowly they were going up and up and up. And it was good…there was a white board in the room and they would show the counts. And so we could see it…could see it rising and going back to where it should be. And that was a really good to be able to see that she was getting better. (Debbie, 24-year-old non-donor)*

Several siblings related that having their brother or sister spend time with them outside of the hospital was a good experience. It was taken as a sign of the recipient's progress.

> *Uhm, well it was just nice to see him making progress…that he was…that he actually could be like start being out of the hospital. He didn't have to be there like the whole time and he could just go for appointments and stuff. (Carrie, 22-year-old donor)*

Not surprising, the happiest time siblings recalled was when their brother or sister came home for good. The recipient's return to home meant a return to life as it had been before the transplant. It was interpreted as an indication that the recipient was better or even cured.

> *So, at that time though when she came home, she was…it was a very happy time. And she…we finally found out she made it. Like she was out for good. (Nicole, 15-year-old non-donor)*

> *Uhm, it was almost…it actually almost felt funny to all be home again. Like cause we hadn't been all together for like how ever many months. And it was…but I mean it was…the day he could come home was really exciting. And we could actually all be home again you know. We hadn't been home for three to four months and… and hadn't sent the place for that long…and all to be home again,*

it was good. (Carrie, 22-year-old donor)

Coping responses. Siblings got through the good days and bad days by accepting their situation, assigning meaning to the experience, focusing on the present, and seeking support from family, friends and other families who had gone through a similar experience.

In describing how they were able to go with their lives, siblings commonly used the phrase "I accepted it". They realized that "that's how life was". It was not a matter of choice. It was not something they could change. It was not something that came easily or quickly. It was just something that they had to go through.

> *Well, I guess you just have to…I mean it won't help you wishing it was different. I mean yeah you wish it was, but it won't help because it can't be different. It's just the way it is now. So then, you have to just accept it and just go one with life and whatever. (Marcy, 15-year-old donor)*

> *I mean then…back then when we were going through it just uh that's just how it had to be then you know. Like it was just…it was just our life. (Carrie, 22-year-old donor)*

> *Yeah, it was [difficult] to…to just be able to accept it but once you knew that's…that's just how life would be for a little while. (Elizabeth, 23-year-old non-donor)*

In adapting to the good days and bad days, siblings were able to create meaning out of the experience and thus, make sense of it. When asked what it meant to be a sibling of a child who had undergone a BMT, siblings responded with comments of the positive impact the experience had on their family life.

> *Well, I was just thinking that…I'm really proud of Sarah [recipient] that she could make it through. And it just means that now we know my family's way more closer and way more tougher. (Becky, 11-year-old non-donor)*

> *Well it showed me that things like this can happen to any family and that it is not a bad thing. It is hard but it is not a bad thing. It made me more aware and I have a better understanding of the process of someone who has to be hospitalized and what they go through. So now I know what it is like and I can help someone*

> *or relate to someone who may go through a similar situation. (Debbie, 24-year-old non-donor)*

> *It feels…we've whatever…it feels like we have a special brother in our family. Well, he could…I mean you know he could so easily not be with us anymore. And, we have been I guess blessed with…with return of health for him and that he's you know healthy and uh active whatever…can basically…he can do what you know live a normal life. (Elizabeth, 23-year-old non-donor)*

Overall, the siblings interviewed had no regrets about having gone through the experience. In fact, some siblings related that their family was better for having gone through the experience. Positive outcomes of the experience identified by siblings included: understanding the illness, getting better grades in school, family cohesion, less arguments amongst siblings, and feeling more mature.

> *Uhm, everything is like being really good now. Uhm, me and my sister stopped fighting like a lot. We just like learned to appreciate each other. (Becky, 11-year-old non-donor)*

> *Well, I just was really glad that we went through that because we uhm…now we can feel all this…all that…all my other friends that might have gone through the same thing or something else that has something else in their family like cancer or something like that, then we can feel all…you know how they feel kind of thing. (Marcy, 15-year-old donor)*

Siblings' mindset that helped them get through the hard times was to live life in the present. They held the belief that they would get through the rough times. Several siblings adopted the philosophy "take one day at a time". Sometimes, siblings did worry about the future, but they tried to concentrate on the present.

Siblings appreciated support from family and friends during the good days and bad days. Family and friends helped siblings by visiting, praying and doing whatever they could to help the family. One sibling made the following comment about how her family and friends provided support:

> *Well, I just liked it [having friends and family take over for my parents at the*

> *hospital] very much because then you know we could be more…we could be together all of us you know. Maybe not like Megan [recipient] but all the rest of us. (Marcy, 15-year-old donor)*

Another resource for siblings was meeting other people who had gone through a similar experience. The common bond of a having a family member who has had a BMT helped siblings understand that they were not alone in the experience.

> *There were two other families going through it... at the same time. One had like a little…a baby…a baby girl. Then, there was this other little…another little girl about three I think. I don't know. It was good to see them around all the time. And just to hear about their progress. Uhm, I think it made more real. And just to see that like…like we're not the only ones. Just to see other people that…and to see their families and them also going through it. Like when you have things in common with people that really helps to deal with things. (Debbie, 24-year-old non-donor)*

Feeling More or Less a Part of a Family

The demands of the BMT experience made it challenging for siblings to feel like a part of a family. There were two sub-themes to feeling like a part of family - understanding what was happening and doing whatever they could.

Despite the interruption to family life, most siblings described the BMT experience as something that their family went through together. A sense of belonging to the family unit was a source of strength for siblings because they felt like they were still an important part of the family and that they were not alone. Moreover, siblings depended on their family to get through the experience.

> *I don't really remember the nurses or doctors. I remember just my family there. Cause my aunts were always there and my grandma. And like I think that's why I didn't feel anything or like it was something bad cause like with my aunt I've always been close with them just like joking around and just like stuff. So, like we're just in my sister's room and laughing and stuff. (Kelly, 18-year-old donor)*

Equally significant to siblings was that having gone through the BMT experience pulled families closer together. As one sibling reinforced:

> *It…the whole…like the whole experience definitely drew our family closer together. We are a very close family now. Not that we weren't before but we're a lot closer now. (Elizabeth, 23-year-old non-donor)*

Unfortunately, the BMT experience was not always perceived as a shared family experience. Some siblings related that the experience was something they went through on their own. These siblings felt left on the periphery of family life due to a triad that developed between their mother, father and recipient, who were away at the transplant centre. This led to feelings of loneliness and abandonment.

> *Well you feel very lonely as if…like you don't really feel at home anymore [when your family members are separated]. When you are with your parents, you feel a lot better and you always feel safe. (Becky, 11-year-old non-donor)*

> *I just detached myself mostly. So, I really wouldn't have went to talk to anybody. I would refuse to most likely. Just basic things like that. So, it was basically something I went through in my head. I got myself through it. (Nicole, 15-year-old non-donor)*

Two things were important for siblings to feel a sense of belonging with their family throughout the BMT experience. The first was the need to understand what was happening in their family. The second was the need to do whatever they could for other family members so as to be a source of comfort.

Understanding what was happening. The majority of the siblings interviewed were informed about what was happening in their family. However, the amount and quality of information varied from sibling to sibling. This meant that some siblings were satisfied with the information they received and some were not. Typically, siblings who felt more informed also felt more like a part of the family.

> *We pretty much knew. Like, my Dad was…every pamphlet that they gave us, he would read everything and he would like…he drew us a chart of everything – this is what happens, this is the donor and this is the procedure. So, that he made it really easy for us to understand. So, uhm that would…that was…I think yeah so I was pretty well informed. (Debbie, 24-year-old non-donor)*

> *I never really found out until after they told…like nothing was really told to me until after it was decided. So, I really…I kept…I didn't know much about what was going on until it was happening. (Nicole, 15-year-old non-donor)*

Although parents were the most common source of information, siblings also sought information from other adults with whom they felt comfortable. One sibling described her discussions with a school counselor:

> *Oh, my school counselor was really smart. And she had uh a cousin that went through cancer too. So, I asked her…I could ask her a bunch of questions about what was going on and why…what next would happen to Sarah [recipient] with the medication they gave her. She…she was able to tell me what happened…like what could happen. (Becky, 11-year-old non-donor)*

Siblings related that the best way to fully grasp the seriousness of the recipient's illness was to see what was happening in the hospital. Despite being difficult to see their brother or sister sick, it was important for siblings to see how the treatments worked, and to meet the nurses and doctors who were caring for the recipient. This tangible evidence satisfied their curiosity, providing siblings with an accurate picture of what was happening and of their role within the family,

> *It's good to know what's going on. Uhm…<long pause>…yeah, it's really, really good to know… what is going on. And just I think being there. Like a really good thing was being there. And to see everything. (Debbie, 24-year-old non-donor)*

> *And we always went to hospital. And when they got an apartment, my grandma's family sometimes went there for...to spend the week and then we went with them. It was better than talking on the phone. We could actually see it and watch it and that stuff. Check the nurse checking her and seeing how everything works. (Karen, 13-year-old non-donor)*

> *I was slightly curious honestly as to how it [marrow stem cell infusion] would help her [recipient], how it was done. And I was there when the transplant took place. I wanted to see how it was done and how it worked. (Nicole, 15-year-old non-donor)*

It is important to note that knowing what is happening in the family was not always a positive experience for siblings. Some siblings felt that the more they knew, the

more they worried about their ill brother or sister. As one sibling related:

> *Well, I was thinking…I was thinking lucky them [younger brother and sister] cause they really don't know what's going on so they wouldn't have to worry about what was going to happen. All they knew was that Sarah [recipient] was in the hospital. They never knew why. (Becky, 11-year-old non-donor)*

Doing whatever they could. Siblings were often more concerned about other family members' sense of comfort than their own. Siblings needed to be do whatever they could to help the recipient get better. Siblings related that how they approached their brother or sister was very important. They were especially careful not to upset their brother or sister in any way. One sibling commented that it was particularly difficult to speak to her brother on the telephone when he was first diagnosed because she was worried about the impact of her crying on her brother. As she noted:

> *Uhm, well I guess you know I…I didn't know uhm quite how he would be taking it you know. Like like how he would be…how would uh you know affect…affected his emotions you know. (Elizabeth, 23-year-old non-donor)*

Most important to siblings was for them to be involved in the care of the recipient. It made siblings feel good to know they were needed. One of the things that siblings did was "being there". "Being there" involved chatting, watching television, or playing with the recipient. Sometimes, siblings were at the hospital "just to be company". Siblings perceived that staying at the hospital with the recipient was not only a source of comfort for their ill brother or sister, but also for their parents.

> *For my parents like that was a comfort for them too cause someone would be there. Cause they were working. I think that just to know that my sister had somebody with her. Cause then like if I was going to school or working, she would just be by herself. And I don't know if my parents would have taken off work for that length of time. So, it was good. (Debbie, 24-year-old non-donor)*

Some siblings reported doing whatever they had to do in order to be able to spend time with the recipient, even if it meant missing school or being mischievous in the

process. As one sibling related:

> *I'd always complain of a sore stomach because uhm a lot of times I would trick my grandma into thinking I was sick and she would take me to the emergency. So I could see my Mom and Sarah [recipient] instead of really actually being sick. (Becky, 11-year-old non-donor)*

Siblings who were not able to be at the hospital felt less like a part of the family. One sibling reinforced:

> *That's a mistake I made. I disconnected. I didn't take part in that much. I tried to stay away. (Nicole, 15-year-old non-donor)*

Siblings' sense of belonging with the recipient was further maintained by attending to the recipient's specific health needs. When a bone marrow donor was sought within the family, all siblings were tested to see if they were a match for their ill brother or sister. This was done despite personal concerns of discomfort from the testing procedure or marrow harvesting. It was something that was "just done" because it was their brother or sister that was ill, and siblings wanted to help them.

Being the donor also afforded siblings an opportunity to do something for their ill brother or sister. Siblings' sense of personal satisfaction at being able to donate the marrow is reflected in the following comment:

> *Well, just uhm whatever I…I could actually do it for my brother…that this would actually maybe help him get well you know. (Carrie, 22-year-old donor)*

Although donors acknowledged their critical role in the transplantation process, the extent to which they felt responsible for the transplant outcome varied. For example, one donor believed her sister would have gotten better with or without her help. She stated:

> *I don't look at it as a big thing though. Cause to me, I would've been like…she would've been fine anyways. So, I don't…like I don't look at it as a big thing. (Kelly, 18-year-old donor)*

From another donor's interview came a discussion of the possession of the stem cells that were engrafting in the recipient. She poignantly stated,

> *Uhm, it was really exciting when they actually said they were grafting you know. And…<pause>…and I know like in a way almost didn't really think of them being my cells or whatever you know cause I mean whatever they were in him or…and yeah but people would say oh their yours or see if…but I mean the doctors would come in and would like say oh like your sister is whatever…your cells are grafting or whatever. (Carrie, 22-year-old donor)*

Another way siblings connected to their ill brother or sister was by assisting them with their daily medical needs. One sibling explained how she took on the responsibility of caring for the recipient's central line.

> *It was weird…<chuckle>…not weird…it was weird cause I was young. I didn't really have those kind of responsibilities. It was just…I was just… I was young…just out of high school. So my parents I think they spoiled us. So, they took care of mostly everything. So, for me to have to do that and not my Mom that was different cause my Mom would just usually be the one to take care of us without me having to do it. It was different at first it was. Uhm, yeah they asked and I said sure why not… So, I helped her change her bandages and stuff. So after awhile, I was like okay no big deal. (Debbie, 24-year-old non-donor)*

Siblings also expressed a desire to protect their ill brother or sister. Aware of the risks associated with a weak immune system, siblings took care to protect the recipient from infections, although it often meant restricting whom they could and could not spend time with. Siblings' selflessness is apparent in the following comments:

> *Like I think… well yeah it was…she couldn't…she had to…we couldn't uhm have our friends over. Like cause we didn't want my sister…uhm we didn't want to get sick. So, we had to go over…we couldn't be sickness kind of things cause we didn't want to get her sick. (Marcy, 15-year-old donor)*

> *I developed mono. And, I was with my sister, brother…like my sister that's 5 and my little brother and my dad. And I couldn't see my Mom or Sarah [recipient] cause I could give it my Mom and she wouldn't be able to see Sarah. And my Dad couldn't see my sister and…Actually I think it would be lot more sad than my sister…instead of me just, just not seeing two people, she would've being not seeing four. (Becky, 11-year-old non-donor)*

Faith in God That Things will be Okay

Five participants spoke about their spirituality and religious beliefs providing a personal and familial philosophical context for dealing with life events. This coping response stood out from all the others siblings employed because siblings' devotion to and reliance upon a higher being was echoed over and over again through their words and their tone of voice.

Siblings believed that their faith in God got them through the difficult times. Their faith gave them strength, and provided a basis for meaning and hope. Siblings endowed spiritual meaning and value to their experience. For example, having survived the BMT experience was deemed "a blessing" from God.

Prayer was the most common religious/spiritual coping strategy identified by the siblings. Siblings felt connected to God through prayer, experiencing an intensified relationship with God. This sense of connectedness with God engendered hope and comfort among siblings.

Inherent in a description of siblings' prayer experience is what happens after prayer, the result of prayer. All siblings believed that prayer was beneficial. They described the power of prayer as a healing force that could touch the recipient and help them cope with the experience.

> *Uhm, I know I prayed a lot about it. And that definitely helped. (Elizabeth, 23-year-old non-donor)*

> *Well, just if you pray, you feel…I mean often that will touch another person…they'll feel it that kind of thing. (Marcy, 15-year-old donor)*

> *Well, I know prayer does a lot. Like to…even for the hard times like…that to pray about it sure…sure helps for a person to cope with things better and everything else. (Carrie, 22-year-old donor)*

For some siblings, having gone through the BMT experience increased the strength of their belief in prayer. One sibling expressed her belief that praying, whether by an individual or faith community, more frequently and more intensely would be meaningful in coping with BMT experience.

> *I think it would've been good to know [the seriousness of my sister's illness] cause then I would've…I think would've prayed more…prayed harder. And just got everyone to pray for her more cause I wasn't really…I didn't really like say oh pray for my sister. (Debbie, 24-year-old non-donor)*

Answered prayers were described as a literal outcome of prayer. One sibling poignantly expressed her discontent with God when her prayers seemed "unanswered". Through her tone of voice came not anger but rather feelings of disappointment and abandonment. Her doubts in the efficacy of prayer were evident. She had a strong conviction and trust in God to act on her requests to maker her sister better. This belief, however, denied the possibility that God may have limitations or other reasons for not honoring her requests. In time, this sibling learned how to trust God's wisdom.

> *Oh, I believe in God so much that…I…I thought if I prayered…if I prayered, then He would answer my prayer. But uhm He never did answer my prayers. But uhm uhm there uhm there was some priest or something. He was supposed to be a priest in the Children's…for the children. And, he said uhm most…uhm God…some of God's…or most of God's unanswered prayers are the best. But, the more He uhm didn't answer my prayers, then the more Sarah [recipient] would get better. (Becky, 11-year-old non-donor)*

Another source of spiritual social support for siblings was their faith community. Others' praying or visiting the recipient and family made siblings feel good. Being able to share their experiences with fellow church members created a united effort to help siblings and their families get through the experience.

> *Just I think letting other people like your church group or whatever know. And so yeah we had like more people prayed, more people came to visit because of that.*

(Debbie, 24-year-old non-donor)

Feelings Around Families

All the siblings in this study reacted to the interruption in family life associated with the BMT experience with feelings of anger, worry, fear, sadness, hopefulness, and pride. The predominance and prevalence of these emotional reactions to the BMT experience varied from sibling to sibling, and changed over time as the siblings adapted to the day-to-day realities of having an ill brother or sister.

Anger. Siblings' were angry that their lives were disrupted. Siblings posed questions such as "Why did this happen to us?" and "Why can't things be the way they used to be?" Siblings' anger was attributed to three main reasons. Siblings first experienced anger in relation to the additional responsibilities they took on. They were angry because they had put off doing things they wanted to do. Their anger is reflected in the following comments made by siblings:

> *The extra responsibility honestly I was pissed off. I didn't want it. I didn't understand why it had to be all me. (Nicole, 15-year-old non-donor)*

> *I mean you know at times it was tough you know [to take on the additional responsibilities] because I mean if you wanted to do anything in the evening with you know your friends or…well you had your little brothers and sisters and what do you do with them. So you'd stay home. (Carrie, 22-year-old donor)*

A second reason for feeling angry was attributed to siblings' perception that other peoples' lives were better than their own. Two siblings expressed:

> *Well, I meant…I like…oh some people have a better life because uhm their sister doesn't have cancer. They don't know what it feels like to go through it and some people were like laughing at me cause my sister had cancer. And I was thinking well their life must be perfect, must just be great for them to be laughing at me like this. (Becky, 11-year-old non-donor)*

> *Uhm, well there was some you know relationship with friends…with friends. Uhm, there was also uhm…<short pause>…oh, how should I put it? Yeah, relationships with some of my friends. And you know wondering how come it had to happen to*

> *me. And my friends it looked like you know their life was all kind of all roses. It was just kinda going you know going how they'd hope it would. (Elizabeth, 23-year-old non-donor)*

The third reason for sibling' anger was not having control over their lives. A sense of not knowing what to expect because of inadequate information contributed to sibling's loss of control. One sibling related not understanding why she was in the hospital or why she had to endure painful procedures. She explained:

> *…it was the control factor. They don't explain anything to you and they're just taking you everywhere, and you don't know why and stuff. (Kelly, 18-year-old donor)*

Worry. Siblings really worried about their ill brother or sister's condition. They worried that their brother or sister would not get better, or would suffer from complications, like graft versus host disease.

> *…she was able to get sick easily. Like they told us if you had chickenpox or if you hadn't had chickenpox…then you couldn't come to visit and all this stuff. So, uhm just things like that. Like she could get sick easily like cause she had a new body on the inside…(Debbie, 24-year-old non-donor)*

Both donor and non-donor siblings worried about the donor having surgery. They worried about what was going to happen to the donor and whether the donor would be all right. One sibling's reasoning for worrying about the donor was explained as follows:

> *Oh, I was just worried that if he never made through the transplant. I had heard of so many other people's stories of how uhm their brother or sister died and stuff. I was just really afraid cause I…it really sounds silly to think that I…uhm to be afraid uhm that Danny [sibling donor] might die in the bone marrow transplant. But…it…I wasn't really thinking and all I knew was that if Danny died, then Sarah wouldn't get her bone marrow transplant and if Sarah [recipient] didn't get her bone marrow transplant, she would've died. (Becky, 11years, non-donor)*

Fearful. The prevailing fear discussed by siblings was the fear of the unknown. Siblings were afraid of what was going to happen to the recipient. They did not know if

there would be a donor within their family. They did not know if the transplant would be successful in curing their brother or sister's illness.

> *[I was scared] of Tanya [recipient] not getting a donor and not getting real help and stuff like this. (Karen, 13-year-old non-donor)*

> *Uhm…<pause>…well you know you're always kindof scared you know about what the outcome would be. (Elizabeth, 23-year-old non-donor)*

> *Uhm just I guess more scared like of the unknown. Like I didn't know like if she was going to get better or…so it was like more a scared, nervous kind of feeling. (Debbie, 24-year-old non-donor)*

Some siblings were scared that their brother or sister might die. One sibling poignantly discussed her fear of her sister dying:

> *Well, I know I'm <emphasis on I> not afraid of dying, but if my sister did… that would be like…that was one thing…death…I didn't want my sister to die. I didn't want anyone to die. (Becky, 11-year-old non-donor)*

Sadness. Some siblings expressed a sense of sadness about the BMT experience. Their sadness was echoed in their words and tone of voice. Some siblings showed their sadness by crying and others withdrew. It was hard for siblings to watch someone they love be hurt by needles and sickened by treatments as is reflected in the following statements:

> *Like I just felt too terribly bad for him. Uhm…<pause>…and well I knew that…I mean that he was who would have to go through it all. He was the one that was sick. (Elizabeth, 23-year-old non-donor)*

> *Yeah, it was…yeah she was sick and she had to go through bone marrow transplant. And it probably hurt. (Marcy, 15-year-old donor)*

> *Uhm, she did come home without a feeding tube, but then got sick again with pneumonia and hives and she had to go back in. This time I don't know if she received a feeding tube but it was like really sad for me. (Becky, 11-year-old non-donor)*

It was also hard for siblings to feel so healthy and full of energy when their brother or sister could not participate in the same activities that they participated in before

getting sick, like playing. As one sibling said:

> *Uhm, that she had to go through a lot of stuff that we didn't have to do. We had fun playing again and she had…stuck in the hospital all day long with uhm…with IV and feeding tube through her nose. (Karen, 13-year-old non-donor)*

Hopefulness. Despite their worries and fears, siblings remained hopeful throughout the BMT experience. It was their sense of hope that siblings attributed to ability to cope with their new role of a being a brother or sister to a child who had a BMT. Siblings' hopefulness arose from their faith in God, the recipient's progress and support from their family.

Siblings were hopeful that a donor would be found within their family. Two siblings expressed:

> *And so I was very hopeful that…cause they said it's pretty much…usually there's one in the family that could be a donor. (Debbie, 24-year-old non-donor)*

> *Well, I think…well I think we wanted…we wanted…we hoped…I mean between whatever the rest of us children…seven of us I mean we thought there should be somebody surely that would. Uhm, I don't…I think all of us…we all wanted to be because we not…maybe not necessarily that we wanted the match. But we wanted…you know we wanted someone to uh…to be able to help him. (Elizabeth, 23-year-old non-donor)*

Siblings were also hopeful that the BMT would be successful and that family life would return to normal. These hopes are reflected in the following statements:

> *Well, I remember we were waiting [for the stem cells to engraft]. I mean we were hoping that she would get better and everything. (Marcy, 15-year-old donor)*

> *Well, I guess I just…I hoped you know…I was hoping that it would graft. And that once like long-term <emphasis on long> that you know we would be able to live like we had before you know like uhm or that you know things would like kind of settle down and that we would uhm just be able to…to uh be all be at home again. That…that was definitely a big thing… to uhm not all…you know some…some living here and some there was…to all be home again that…that was really good. (Elizabeth, 23-year-old non-donor)*

Pride. Siblings expressed great pride in the recipient and their family for having

made it through the BMT experience. It made siblings feel good to be part of their family's accomplishments.

> *Well, you kind of feel proud after the end. And like when you have the donor in your family, you feel kind of proud that it was in your family and stuff like this. (Karen, 13-year-old non-donor)*

> *Well, I was just thinking that…I'm really proud of Sarah [recipient]…that she could make it through. (Becky, 11-year-old non-donor)*

Differences Between Donor and Non-donor Siblings

The third research question will be addressed in this section. The question asked: What differences in the BMT experience exist between healthy donor siblings and non-donor siblings?

The BMT experience was similar for both donor and non-donor siblings because the essence of the experience was the same for all participants. The only difference was that that donors had the advantage of helping siblings beyond what non-donor siblings could do. Both donor and non-donor siblings were a source of comfort for the recipient and their family by "being there", undergoing HLA-typing, and attending to the recipient's daily medical needs. However, only donor siblings contributed to the treatment itself.

Siblings' Recommendations for Health Care Professionals

This section will address the fourth research question. The question was: What recommendations do healthy donor and non-donor siblings have about how health professionals can best support siblings as they transition through the BMT trajectory?

The siblings identified many ways that health care professionals could help siblings feel more like a part of the family unit during the BMT experience. The most important thing that siblings want health care professionals to do is include them in the

definition of “family” when providing care to families of children who undergo a BMT. Siblings in this study reported that health care professionals do a good job at providing care for the BMT recipient and their parents, but in general continue to overlook siblings’ needs. Siblings reported six needs that were important to them. These needs include: to be cared for, adequate information about their brother or sister’s illness and the BMT process, choices, opportunities to share their feelings, peer support, and healthy hospital environment.

To Be Cared For

Siblings expressed a need for health care professionals to show that they care for them. Being treated as an individual with their own needs and concerns rather than “just a number” was important to siblings. Siblings recommended that health care professionals embrace a cheery attitude when interacting with families. A warm greeting or a smile was always very much appreciated.

> *To always be uhm upbeat about things. And uh let’s say in the morning you come in like come into their room and always like say like a cheery good morning or you know just little things like that. (Carrie, 22-year-old donor)*

Information

Siblings needed help in understanding and appreciating the nature of their brother or sister’s illness and the treatment procedures involved. Siblings had general questions about what to expect and specific questions about the matching process, marrow stem cell infusion, and potential complications from the BMT. Siblings recommended that health care professionals create a climate of openness, so that siblings feel at ease in asking questions. Some siblings were satisfied with getting information from their parents. Others wanted information directly from health care professionals.

> *Uhm…[pause]…they [health care professionals] really mainly talked to my sister and my Mom. But, I think they should have like…like I know they'd sit down and have tea or coffee with the parents. But like I think they should do that with the kids except for the tea and coffee part. (Becky, 11-year-old non-donor)*

> *Keep them informed too. I noticed that the doctors would come in and they'll talk to the parents. They'll just come in and talk to the parents and a lot of the times, I was asked to leave the room…[pause]...Just to keep them informed as well. Consider them a part of the procedure. (Nicole, 15-year-old non-donor)*

Siblings also learned about what was happening in their family by visiting the hospital and going on a tour of the facility. Providing siblings with visual information was also particularly helpful as is reflected in the following comment:

> *Like, my Dad was…every pamphlet that they gave us, he would read everything and he would like…he drew us a chart of everything – this is what happens, this is the donor and this is the procedure. (Debbie, 24-year-old non-donor)*

Choices

Siblings expressed a strong desire for control over their lives. Siblings had no control over their brother or sister getting sick or subsequent changes in family life. Some donor siblings perceived a further loss of control when hospitalized for the bone marrow harvest. Siblings in this study recommended that the best way health care professionals can help siblings regain control is by giving them choices. Some choices that health care professionals can offer siblings include: participation in the recipient's care, type of anesthesia for the bone marrow harvest (general versus local), and location of intravenous line.

Opportunities to Share Their Feelings

Siblings wanted health care professionals to acknowledge their feelings. They wanted to know that what they were feeling was normal. Siblings suggested that health care professionals could help siblings process their feelings by creating a safe

environment in which they could express their feelings.

> *Uhm…well they [siblings] definitely need to be open with their feelings. Uhm and not…yeah they need be open, not you know bottle up. (Elizabeth, 23-year-old non-donor)*

Peer Support

Siblings wanted to meet other brothers and sisters who are going through a similar experience. Meeting peers fostered hope and let siblings know that they were not alone in having a brother or sister undergo a BMT. Siblings suggested that health care professionals could fulfill this need by introducing siblings to each other.

Healthy Hospital Environment

Siblings related that it was important for the hospital environment to be as homey and kid-friendly as possible. Having access to things like a playroom, video games and television made siblings and their families comfortable in their new environment. The hospital décor also had a positive impact on siblings' morale.

> *And then, the balloons and like posters and pictures so we didn't feel…and then you have your Nitendo so you didn't feel like you weren't…you were in a hospital I guess. (Kelly, 18-year-old donor)*

Chapter Summary

Chapter four presented the research findings. A demographic profile of the participants and BMT recipients was presented. This was followed by a discussion of the essence of siblings' lived experience of transitioning through the BMT trajectory and four themes that communicate the substance of this essence. The four themes were: (1) life goes on, (2) feeling more or less a part of a family, (3) faith in God that things will be okay, and (4) feelings around families. The first theme spoke to the idea that life does not stop when a sibling's brother or sister undergoes a BMT. The second theme described

how the BMT experience impacted siblings' sense of connectedness with their family. The third theme presented siblings' spiritual and religious beliefs. The fourth theme described the multitude of feelings that siblings experienced throughout the BMT experience. Differences between donor and non-donor siblings and siblings' recommendations for health care professionals were also presented.

CHAPTER FIVE: DISCUSSION OF FINDINGS

Introduction

Chapter five presents a discussion of the findings. The purpose of this phenomenological study was to arrive at an understanding of the lived experience of healthy donor and non-donor siblings as they transition through the BMT trajectory. The essence of siblings' lived experience, themes supporting the essence, differences between donor and non-donor siblings, and siblings' recommendations to health care professionals were identified through the analysis of the experiential descriptions of participants. In this chapter, these research findings are compared to previous research studies and possible explanations for discrepancies are presented. Methodological strengths and limitations of the study are also identified. The chapter concludes with recommendations for nursing practice, education and research based on the knowledge gained from this group of siblings.

Research Findings

The essence of siblings' lived experience, themes supporting the essence, differences between donor and non-donor siblings, and siblings' recommendations to health care professionals are discussed in this section. The following discussion includes a comparison of the current study to previous research findings related to siblings of chronically ill children, and more specifically, siblings of children who have had a BMT.

The Essence of Siblings' Lived Experience

The essence of siblings' lived experience transitioning through the BMT trajectory was described as an interruption in family life. Simply put, siblings in this study felt that family life was no longer "normal". Changes in family life, particularly

with respect to routines, special events, and roles and responsibilities, have been well documented and supported in the research (Clarke-Steffen, 1993; Barrera, Chung, Greenberg, & Fleming, 2002; Chesler, Allesewede, & Barbarin, 1991; Chung, 2000; Freeman et al., 2000; Iles, 1979; Kramer, 1984; Sargent et al., 1995; Sloper, 2000; Woodgate, 2001b; Woodgate & Wilkins, under review). Research consistently shows that family life is disrupted when routines revolve around the BMT recipient (Heiney, Byrant, Godder, & Michaels, 2002; Packman, 1999; Packman et al., 1997a, 1997b; Shama, 1998). Schedules are rearranged to accommodate hospitalizations and treatments. Special events, like birthdays, and social events are planned around the BMT recipient or not done at all. In the mothers' absence (mother is usually with the recipient), older siblings in this study adopted the mothering role. Wanting to help ease the burden on their parents, siblings also assumed additional chores and responsibilities.

Common to all sibling experiences was a return to 'normal' family life once the BMT experience was over. This finding is reflective of previous research conducted with parents of children who had undergone a BMT. For example, in a qualitative study by Forinder (2004), parents indicated that after the BMT, the family "entered a period when they had to pick up the threads of normal daily life" (p. 140). Additionally, while able to return to 'normal' family life, siblings in this study nonetheless approached life differently than they did prior to having a brother or sister undergo a BMT. Previous research has also found that families of children with cancer experience a "new normal" after experiencing childhood cancer (Clarke-Steffen, 1993; Woodgate, 2001b).

Themes

The four themes supporting the essence of siblings' lived experience of

transitioning through the BMT trajectory will be discussed in this section. These themes were: (1) life goes on, (2) feeling more or less a part of a family, (3) faith in God that things will be okay, and (4) feelings around families.

Life Goes On

Despite family life being interrupted, life went on for siblings. Three aspects of life goes on will be discussed in this section – good days, bad days and coping responses.

Good days and bad days. In transitioning through the BMT experience, life went on for siblings with good days and bad days that frequently paralleled the BMT trajectory. As Fanos (1996) first reported, being a sibling of a child with a chronic illness is a mix of good and bad days. Although the good and bad days varied from sibling to sibling, what the day was going to be like was associated with uncertainty, their own pain, and the recipient's progress.

Similar to previous research on the BMT experience (Heiney, Byrant, Godder, & Michaels, 2002; MacLeod, Whitsett, & Pelletier, 2003; Packman et al., 1997a), this study revealed that living with the unknown is a striking feature of the BMT experience. In particular, siblings described the bad days as those associated with not knowing what to expect after the illness diagnosis or while waiting for things to happen (e.g., finding a donor match in the family, transplant engraftment).

Undergoing painful procedures was difficult for some siblings. Bad days were those when siblings had blood drawn although they were fearful of needles or when they experienced pain from the bone marrow harvest. Despite the pain, siblings related that the pain of the procedures was worth being able to help their brother or sister feel better. This is reflective of past studies in which siblings report the physical demands of the

procedure to be less concerning than the recipient's survival (MacLeod, Whitsett, & Pelletier, 2003; Packman et al., 1997a).

Additionally, a bad day was considered to be one in which the recipient's progress was slowed down by more frequent and intense physical and emotional symptoms as a result of side effects and complications of treatment. Conversely, good days were described as days when the recipient's progress was evident, such as the day siblings discovered the recipient's marrow was engrafting, when the recipient could spend time outside of the hospital, and when the recipient came home for good. The fact that symptoms in and of themselves served as major turning points that lead to either positive or negative impressions of the overall BMT experience supports previous research that points to the significance of symptoms on the quality of siblings' day-to-day-living (Woodgate, 2001b; Woodgate & Degner, 2003). Underpinning the symptom experience was siblings' belief that the recipient had to feel a lot worse to get better. This reasoning that some degree of suffering was justified is consistent with the work by Woodgate (2001b) that found that children and their families accepted cancer symptoms as an integral part of overcoming cancer.

Coping responses. Despite the ups and downs, what determined how siblings in this study got through the BMT experience was how they approached getting on with their lives and the social support they received. As with past research on sibling and family coping responses (Clarke-Steffen, 1993, 1997; Packman et al., 1997a; Stewart (2003); Woodgate, 2001b; Woodgate & Degner, 2003), siblings approached the good days and bad days by accepting their situation, assigning meaning to the experience, and focusing on the present. These strategies appeared to reduce the intensity of the bad days,

making them easier to bear. This study also supports previous work that indicates social support is important in helping siblings who are experiencing traumatic life events like having a brother or sister undergo a BMT (Kinrade, 1987; Shama, 1998; Heiney, Byrant, Godder, & Michaels, 2002; Murray, 1995, 2001, 2002; Packman et al., 1998; Wilkins & Woodgate, under review). Although there were many different types of support siblings in this study relied on, support from their family was the most helpful in minimizing the disruption to family life.

Feeling More or Less a Part of a Family

Belonging to the family was important to all siblings. However, the BMT experience made it challenging for siblings to feel like a part of a family. In fact, some siblings felt the BMT experience was something they went through on their own rather than with their family. The isolation felt by siblings was experienced as a loss. This loss of feeling like a part of a family is consistent with previous research indicating that siblings perceive themselves to be alone and abandoned in the world (Bender, 1990; Chesler, Alleswede & Barbarin, 1991, Murray, 1999; Woodgate, in press; Woodgate & Wilkins, under review). For example, Woodgate (in press) first reported that siblings of children with cancer experience a sense of loss when not involved in their ill brother or sister's care. In this study, siblings' sense of belonging with their family or lack thereof was related to their understanding of what was happening in their family and their involvement in the recipient's care.

Understanding what was happening. Coming to understand what was happening in their family helped siblings in this study to get through the BMT experience. Siblings wanted accurate information about their ill brother or sister's diagnosis and the BMT

process. Previous research reinforces siblings' need for information so as to help them master change and incorporate it into their new view of their family (Dannie, 1991; Heiney, Byrant, Godder, & Michaels, 2002; Kinrade, 1987; MacLeod, Whitsett, & Pelletier, 2003; Packman et al., 1997a; Parmar, Wu, & Chan, 2003; Shama, 1998; Woodgate & Degner, 2002). As in this study, siblings commonly report wanting to see what is happening at the hospital because tangible evidence makes the situation "more real" (Haverman & Eiser, 1994). While it was important to be informed of what was happening in their family, siblings felt that sometimes knowing was a hindrance to their coping because it made them worry more about their family. This finding suggests that health care providers need to consider siblings' readiness and desire for information in helping them deal with the BMT experience.

Doing whatever they could. Concerned for other family members' sense of comfort, siblings needed to be do whatever they could to help the recipient get better. Strategies siblings adopted when trying to comfort their ill brother or sister included "being there" to provide companionship and nurturing, and being more careful around them. These strategies are supported in the research (Chesler, Allesewede, & Barbarin, 1991; Woodgate, 2001b; Woodgate & Wilkins, under review). For example, Woodgate reported that siblings express a need to be involved in the cancer experience by "being with" their parents and "being there" for the ill sibling.

Actively participating in the treatment process was also important for siblings' coping. Consistent with previous research participating in the recipient's care afforded siblings opportunities to feel like a part of the family, see gradual physical changes in the BMT recipient, become familiar with the hospital environment, and gain information

(Barrera, 2000; Kramer, 1984; Sloper, 2000; Sloper & While, 1996; Vogel, 1997). These opportunities helped siblings transcend feelings of powerlessness and isolation.

Faith in God That Things will be Okay

Siblings described depending on God to assist them through the BMT experience, particularly with the challenges. Siblings generally believed that prayer helped them get through the experience. Although siblings greatly valued prayer, some doubts and spiritual conflicts related to prayer were present. Siblings also received support from their faith communities. Siblings' reliance on religion and spirituality to cope with the BMT experience is consistent with previous research studies that have reported associations between children's spirituality and their coping with illness, hospitalization, cancer and death (Ebmeier, Lough, Huth, & Autio, 1991; Sommer, 1989, 1994; Spilka, Zwartjes, & Zwartjes; 1991; Woodgate & Degner, 2003).

What makes this study different from others that have examined siblings' coping strategies is that religion and spirituality stood out from all the other strategies siblings employed. This finding suggests that further research is needed to characterize siblings' religious/spiritual coping. However, caution should be used in generalizing the importance of religion in helping siblings cope with the BMT experience beyond this specific sample. This sample included four siblings from Mennonite or Hutterite families, both of which are religious groups bound by a strong belief in living the life of Christ. Similar studies are needed to evaluate the role of religion/spirituality in how siblings from other religious/spiritual traditions cope with the BMT experience.

Feelings Around Families

Previous work lends support to the finding that siblings experience a multitude of

feelings including anger, worry, fear, sadness, hopefulness, and pride in response to the BMT experience (Bendor, 1990; Freund & Seigel, 1986; Havermans & Eiser, 1994; Houtzager et al, 2001; Koch-Hattem, 1986; Martinson, Gilliss, Colaizzo, Freeman, & Bossart, 1990; Packman et al., 1997a; Packman et al., 2003; Sargent et al., 1995). In this study, no one feeling stood out as representative of siblings' lived experience. However, previous research suggests that sadness may be an enduring feeling in siblings' experience of having a brother or sister diagnosed with a chronic illness (Woodgate, 2001b). Thus, the potential impact of sadness on siblings of children who have had a BMT warrants further research attention.

Although some researchers maintain that the multitude of feelings siblings experience during the BMT process are indicative of emotional distress (Packman et al., 1997b, 1998, 2003), the results from this study suggest that experiencing such feelings does not mean siblings are having difficulties. In fact, experiencing these feelings may be a completely normal part of the BMT experience that siblings must encounter. This study reinforces the need for further research that approaches siblings' feelings from a qualitative research paradigm because quantitative measures used in previous studies have not fully explored the richness of siblings' feelings.

As with previous studies (Heiney, Byrant, Godder, & Michaels, 2002; Packman et al., 1997a, 1998, 2003; Parmar, Wu, & Chan, 2003; Wiley, Lindamood, & Pfefferbaum-Levin, 1984), non-donor siblings reported feeling disappointed yet relieved when not chosen to be the donor, while donor siblings expressed feeling apprehensive and excited when chosen to be the donor. However, these feelings were expressed by a small number of siblings and thus, were not as predominant in siblings' lived experience as previous

research might suggest.

Additionally, there was no indication that the siblings experienced post-traumatic stress as has been suggested in the literature (Packman et al., 1997b, 2003). However, identifying post-traumatic stress reactions was not the focus of this study. Future research might consider the concept of post-traumatic stress as a model for studying sibling reactions to the BMT experience.

Differences Between Donor and Non-donor Siblings

In this study, the BMT experience was similar for both donor and non-donor siblings. This finding was attributed to the fact that the essence of the experience was the same for all participants. The absence of differences between donor and non-donor siblings is consistent with previous research that has reported comparable reactions to the BMT experience by donor and non-donor siblings (Carr-Gregg & White, 1987; Freund & Seigel, 1986; MacLeod, Whitsett, & Pelletier, 2003; Packman et al., 1997a; Packman et al., 1997b; Packman et al., 1998; Packman et al., 2003; Wiley, Lindamood, & Pfefferbaum-Levin, 1984). However, this study finding, diverges from other research studies that have revealed the BMT experience may impact donor and non-donor siblings differently (Gardner, August & Githens, 1977; Kinrade; 1987; Packman et al., 1997a; Packman et al., 1997b; Pot-Mees & Zeitlin, 1987). This discrepancy may be related to differences in study purposes. The purpose of this study was to examine siblings' lived experience, whereas the purpose of the other research studies was to examine siblings' psychosocial functioning and identifying adjustment problems. Given the conflicting nature of the state of the BMT literature, more research is needed to determine what, if any, differences exist between donor and non-donor siblings, and how those differences

might be considered in helping siblings cope with the experience. Additionally, further research is needed to determine the impact of the recipient's death on donor and non-donor siblings.

Siblings' Recommendations to Health Care Professionals

The siblings identified many ways that health care professionals could help siblings feel more like a part of the family unit during the BMT experience. Siblings in this study reported that they needed to be cared for, adequate information about their brother or sister's illness and the BMT process, choices, opportunities to share their feelings, peer support, and healthy hospital environment. These needs have been well documented in the research (Dannie, 1991; Gardner, August, & Githens, 1977; Heiney, Byrant, Godder, & Michaels, 2002; Kinrade, 1987; MacLeod, Whitsett, & Pelletier, 2003; Packman et al., 1997a; Parmar, Wu, & Chan, 2003; Patenaude, Szymanski, & Rappeport, 1979; Shama, 1998). Consistent with the literature reviewed, the impression from this study is that siblings' needs are not being met.

Methodological Strengths and Limitations

This section includes a discussion of the study's strengths and limitations with respect to conceptualization, research design and research methods. These strengths and limitations were considered in interpreting the study data.

Conceptualization

This qualitative study was guided by four major constructs – meanings, transition interpretation and understanding. Operational definitions of the constructs were provided. A priori specification of constructs important to the study was helpful in selecting data collection methods that took into account these constructs, guiding interpretation of the

data and building upon what is already known. However, as stressed by Jorgensen (1989), it is equally important to recognize that exactly what constructs are important and how they are related are subject to refinement based on what the researcher is able to uncover during the course of the research study.

Research Design

Phenomenology, specifically hermeneutic phenomenology as interpreted by van Manen (1990), was an appropriate methodology for this study. Hermeneutic phenomenology is best suited to deepening our understanding of siblings' reality of what it is like to live the BMT experience (van Manen). Understanding the philosophical underpinnings of the study resulted in research that was clear in its purpose, structure and findings (Lopez & Willis, 2004).

A qualitative research design, particularly phenomenology, was ensued to transform siblings' lived experiences into a rich text speaking to their experiences. Phenomenological research is valuable in answering questions about human issues involving "what" and "how" questions (van Manen, 1990). This research method allowed the researcher to create a milieu for siblings to give voice to their experience. Additionally, this research design resulted in a description of a possible sibling experience of the BMT trajectory and possible interpretation of that experience. A single complete description of siblings' lived experience could not be achieved because full descriptions of a phenomenon are never possible (van Manen, 1990). This is the first study to date to adopt a phenomenological research design to discover the meaning of what it is like to be a sibling of a child who has had a BMT.

Inherent in the qualitative approach to research is the inability to generalize the

study findings to represent the broader population because the results are always contextual (Woodgate, 2000a). There were no expectations in this study that the findings would be generalizable to all siblings of children who have had a BMT or that the study could be replicated to yield the same data. It was anticipated, however, that the study would foster an understanding of the sibling experience, sufficient to form a basis for future research.

The study design was retrospective in that data was collected from siblings' memories of the BMT experience. It was not possible to prospectively collect data while siblings were going through the experience due to time constraints and population access difficulties. In phenomenological research, lived experiences gain significance "as we (reflectively) gather them by giving memory to them" (van Manen, 1990, p. 37). The lived experience is that which presents to siblings as what is true or real in their life and it is through their memories that siblings assign meaning to their experience of transitioning through the BMT process. Thus, this study takes into account siblings' life experiences and consequent meanings and behaviors derived from these experiences in an attempt to understand what it means to be in the world as a sibling of a child who has had a BMT (van Manen).

In this study, data was collected at only one time point. Longitudinal research with multiple data collection points over an extended period of time is needed to capture siblings' multiple and changing realities from various vantage points throughout the course of the cancer trajectory (Woodgate, 2000b). Furthermore, collecting data over time and in a variety of contexts adds breadth to qualitative data and is characteristic of a "good" qualitative study (Woodgate).

The risk of bias is present in all human science research studies. The researcher has a responsibility to explicate their assumptions and preconceptions so as to understand their impact on the research process (van Manen, 1990). In this study, the researcher made personal and theoretical assumptions regarding the BMT experience and its impact on siblings explicit in field notes. The aim of this exercise was to not forget about personal biases and feelings but to deliberately hold them at bay so that the researcher was able to see the siblings' experience as it was lived.

Research Methods

Employing van Manen's (1990) six methodological themes to structure the research process into specific research activities helped the researcher focus on the task at hand. It also served as a reminder that the researcher was exploring the circumstances of individual siblings, and their experiences would be their experiences, not to be compared with those of other siblings. Reflecting on the themes, writing and re-writing, and considering the parts and whole enriched the researcher's understanding of the personal meaning siblings' assign to their experiences.

The sample size in this study is small, with eight siblings participating in a total of fourteen interviews. Typically, there are no criteria or rules for sample size in qualitative research (Speziale & Carpenter, 2003). The aim in qualitative research is to recruit a large enough sample to elucidate the richness of the individual experience (Speziale & Carpenter). Therefore, data was collected for this study until redundancy occurred and the researcher found no new data emerging.

The study sample included siblings of diverse development stages (11-24 years) and illness variables (e.g., diagnosis, time since BMT). Regardless of this diversity, the

essence of siblings' lived experience was the same. However, the lived experience described in this study is limited to that of siblings of children who survived a BMT. This is unfortunate because only one study to date has included siblings of children whose BMT was unsuccessful (MacLeod, Whitsett, Mash & Pelletier, 2003). To move our understanding of siblings' lived experience forward, researchers must now build a knowledge base on siblings' BMT experiences that accounts for differences in the success of the BMT.

Consistent with previous research (MacLeod, Whitsett, Mash & Pelletier, 2003; Packman & colleagues, 1997a, 1997b, 1998, 2003), all siblings in this study were Caucasian except one. No brothers participated in this study. Brothers make up the majority of only one study sample to date (MacLeod, Whitsett, Mash & Pelletier, 2003). The sample composition was unique in that it included three siblings from a Mennonite family and one sibling from a Hutterite family. It is possible that a sample that included more ethnic variability may have revealed additional information about siblings' lived experience. Additionally, the inclusion of brothers would have provided more depth to the representation of the sample.

This study sample is only the second one to include both donor and non-donor siblings. One reported sample of donor and non-donor siblings serves as the basis for several articles published by Packman and colleagues (1997a, 1997b, 1998, 2003). Packman and colleagues found no significant differences on any sibling demographic variables were found between donor and non-donor siblings. These findings differ from those of the current study. Differences were found in the current study between donor and non-donor siblings with respect to time since BMT and position in the family. The length

of time since the BMT for donor siblings was more than double that of non-donor siblings. Additionally, all non-donor siblings were the eldest in the family, and donor siblings were either a middle child or the youngest child. The discrepancy may be attributed to Packman and colleagues using a larger sample size or including younger siblings than this study. Further research is needed to clarify what, if any, significant demographic differences exist between donor and non-donor siblings, and to determine if such differences impact their experience.

Recommendations

This study launches future directions nursing can pursue with siblings of children who have had a BMT. Some recommendations arising from the study results are presented in the areas of nursing practice, nursing education and nursing research.

Nursing Practice

From a practice perspective, the study's findings lend support for nurses and other health care professionals to be more vigilant in recognizing the concerns and needs of the siblings of children undergoing a BMT. Successful care of siblings requires that psychosocial support be provided during every phase of the BMT experience, from the time of diagnosis through return to "normal" family life.

One practical implication of this study is the need for those who care for siblings of children who have had a BMT to recognize that life goes on for siblings despite their family life being interrupted. Nurses can help siblings get through the good days and bad days by assessing how they approach getting on with their lives and facilitating interactions with their social support network.

This study calls for greater attention to the symptom experiences of siblings and

BMT recipients. Nurses need to be cognizant of siblings' concerns about the potential pain associated with such medical procedures as blood draws and bone marrow harvesting. Additionally, nurses need to consider that all family members, including siblings, are impacted by the recipient's symptom experience. This reinforces the need for nurse-initiated symptom relief strategies as a means of easing families' suffering.

Also of great importance to siblings in this study was their need to be a part of the family. However, the BMT experience disrupted the siblings' way of being in the family, which in turn affected their sense of belonging with the family. To help siblings feel like they belong to the family, nurses must work with parents to provide siblings with timely and accurate information about the BMT process, and help siblings become involved in the BMT recipient's care.

Another value of this study is that it lays the foundation for understanding the coping strategies of siblings in the context of their religious/spiritual worldview. The diversity in beliefs found in this sample reinforces the need for religious/spiritual cultural sensitivity. Thus, it is important to understand that some siblings want to have freedom to discuss these issues with nurses and some do not.

A most important finding of this study is the variety of feelings that siblings identified in response to the BMT experience. Although having a variety of feelings may be a normal response, people around siblings were not as aware of how much their feelings were a part of the siblings' experience. This reinforces the need the siblings to be given more opportunity to talk about their experiences. Siblings need to know that their feelings are justified and that the BMT experience is also their experience. Participation in support groups has been shown to be helpful for siblings by increasing their

understanding of the BMT process and facilitating changes in their mood (e.g., less fearful, less anxiety) (Kinrade, 1987; Shama, 1998; Heiney, Byrant, Godder, & Michaels, 2002).

Lastly, the study findings point to the need for nurses to consider siblings as an integral part of the family system and acknowledge their importance as participants in the treatment process. Adopting family-centered care is warranted to ensure that the entire family is included in all aspects of care.

Nursing Education

This study contributes to the existing body of knowledge on siblings by helping nurses who interact with siblings to understand siblings' lived experience and by clarifying past findings described in the review of the literature. While recognizing that each sibling's experience is unique, these findings can serve as a starting point for conversations with siblings about their experiences. Nurses may benefit from being taught, that through asking the sibling what their experience is like, much can be learned about the sibling, their experience, and interventions that would assist them. Journal articles, conferences and scientific meetings will aid in disseminating these findings to nurses.

Nursing Research

Findings from this research study support themes previously reported in the literature. However, this study further helped to highlight siblings' voices about their lived worlds as they transition through the BMT experience. Further research is needed that focuses specifically on each of the four themes identified in support of the essence of siblings' lived experience.

A transitions perspective was useful in conceptualizing siblings' responses to the BMT experience, because both the transition experience and BMT experience are complex phenomena of ongoing, dynamic transactional processes. Additional research is needed to enhance our understanding of transition-related issues, and to help nurses better anticipate the diverse and shifting demands siblings will likely encounter as they transition through the BMT experience.

This study did not reveal any differences in the perceptions between donor and non-donor siblings, younger and older siblings, or according to birth order within the family. Because all siblings had a brother or sister who survived the transplant, it was not possible to examine how the success of the BMT impacted siblings' lived experience. Accordingly, more in-depth study is warranted that seeks to describe potential differences in the changing perceptions of siblings with different sibling characteristics. Also the all female sample was mostly Caucasian, and from a Mennonite or Hutterite family. Further work is needed to build a knowledge base on siblings' BMT experiences that accounts for differences in gender, and cultural and religious backgrounds.

This study examined the BMT experience from the perspective of siblings in one transplant center. It should be replicated at other BMT transplant centers to compare and contrast siblings' perceptions of the situation within specific contexts. Additionally, this study focused on siblings' perceptions. It is important to examine the BMT experience from the perspective of all family members so that interventions designed to provide family-centered care can be implemented and evaluated.

Results from this study provide the groundwork for future research into the development of innovative and effective interventions to meet siblings' diverse and

shifting needs throughout the BMT experience. Participatory action research in which siblings work with researchers to construct a program to meet siblings' needs could prove to be beneficial for siblings.

Chapter Summary

This chapter presented the discussion of the findings. The essence of siblings' lived experience and four themes supporting the essence were discussed. The discussion of the research findings indicated siblings from this study had both similar and divergent experiences compared to other research studies. Methodological strengths and limitations of the study were presented. Recommendations for nursing practice, education and future research endeavors were suggested.

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APPENDIX A

Medical Phases of the Allogeneic BMT Process

The medical phases of the allogeneic transplant are summarized in the table below. Minus numbers indicate days leading up to transplant. Positive numbers indicate days following the transplant. From beginning to end, the process can take up to a year to complete (Andrykowski, 1994; Gonzalez-Ryan et al., 2002).

Medical Phases of the Allogeneic BMT Process

Day	Activity	Description
–100 to –28	HLA typing	BMT recipient's tissue type is matched with a suitable donor.
-6 to –1	Conditioning treatment (Day -6 to –1)	Treatment includes chemotherapy given with or without total body irradiation; exact regimen varies according to the disease being treated.
0	Stem cell harvest from bone marrow	Stem cells are gathered from the donor; the amount of bone marrow harvested depends on the size of the recipient and the concentration of stem cells in the donor's blood; usually one to two quarts of marrow and blood are harvested; risks to the donor include those associated with general anesthesia, infection at the harvest site, and mild to moderate discomfort.
0	Transplant day	Transplant is given as an intravenous infusion; it is not a surgical procedure.
+1 to +30	Protective isolation	Recipient has no immune system and is susceptible to infection; recipient has few red blood cell or platelets.
+10 to +30	Engraftment	Transplanted bone marrow grows and begins producing normal blood cells.
+30	Beginning of recovery	Recipient begins to regain ability to fight infection.
+30 to +100	Home care and outpatient management	Isolation precautions must be observed at home because recipient is still vulnerable to infection; frequent check-ups needed.
+100 and beyond	Graduation	Generally considered a milestone; recipient is on the road to recovery

Sources: Andrykowski, 1994; Gonzalez-Ryan et al. (2002); Lenarsky, 1990; Spruce, 1990; Stewart (2002); Weisz & Robbennolt (1996); Zander & Aksamit (1990)

APPENDIX B

Provisional Access Approval from CancerCare Manitoba Research Resource Impact Committee

CancerCare
MANITOBA
ActionCancerManitoba

675 McDermot Avenue
Winnipeg, Manitoba
Canada R3E OV9

409 Tache Avenue
Winnipeg, Manitoba

RESEARCH RESOURCE IMPACT COMMITTEE (RRIC)
Approval Form

Principal Investigator: Ms. Krista Wilkins

RRIC Reference No. 02-2005
Date: January 26, 2005

"Siblings of Pediatric Bone Marrow Transplant Recipients: Their Lived Experience as They Transition Through the Bone Marrow Transplant Trajectory"

This letter is to inform you that the Resource Impact Committee (RRIC) reviewed and "provisionally" approved the above-mentioned study at the RRIC meeting held on January 26, 2005 pending REB approval.

The approval is valid for one year only and a study status report must be submitted annually. Any significant changes in this research must be reported to the Chair for consideration in advance of implementation of such changes. The RRIC must be notified regarding discontinuation or study closure.

The approval is for the RRIC use only. For ethics of human use and/or regulatory bodies, approval should be sought from the relevant parties as required and must be forwarded to the RRIC Secretary as soon as possible.

Yours sincerely,

Charles L.M. Olweny, MO, FRACP
Chair, Resource Impact Committee
Cc: Ms. Erna Stiles, Manager, CIO

Please quote the above RRIC reference number on all correspondence.
Enquiries should be directed to Marilyn Meakin, RIC Secretary, CCMB, 5020-675 McDermot
Telephone: 787-4170 **Fax:** 787-2190 **Email:** marilyn.meakjn@cancereare.nib.ca

APPENDIX C

Official access approval from CancerCare Manitoba Research Resource Impact Committee

CancerCare
MANITOBA
ActionCancerManitoba

675 McDermot Avenue
Winnipeg, Manitoba
Canada R3E OV9

409 Tache Avenue
Winnipeg, Manitoba

RESEARCH RESOURCE IMPACT COMMITTEE (RRIC)
Approval Form

Principal Investigator: Ms. Krista Wilkins

RRIC Reference No. 02-2005
Date: March 30, 2005

"Siblings of Pediatric Bone Marrow Transplant Recipients: Their Lived Experience as They Transition Through the Bone Marrow Transplant Trajectory"

This letter is to inform you that the Resource Impact Committee (RRIC) reviewed and approved the above-mentioned study at the RRIC meeting held on March 30th, 2005.

The approval is valid for one year only and a study status report must be submitted annually. Any significant changes in this research must be reported to the Chair for consideration in advance of implementation of such changes. The RRIC must be notified regarding discontinuation or study closure.

The approval is for the RRIC use only. For ethics of human use and/or regulatory bodies, approval should be sought from the relevant parties as required and must be forwarded to the RRIC Secretary as soon as possible.

Yours sincerely,

Charles L.M. Olweny, MO, FRACP
Chair, Resource Impact Committee
Cc: Ms. Erna Stiles, Manager, CIO

Please quote the above RRIC reference number on all correspondence.
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Telephone: 787-4170 **Fax:** 787-2190 **Email:** marilyn.meakjn@cancereare.nib.ca

APPENDIX D

Recruitment Letter

Dear Parent/Guardian,

My name is Krista Wilkins, and I am a pediatric nurse and student in the Master of Nursing program at the University of Manitoba. This letter is being sent to you on my behalf by the pediatric bone marrow transplant team at CancerCare Manitoba (I do not know your name or have any information about you or your family). Your family's name was selected from a list of pediatric patients who have received a bone marrow transplant.

To complete my nursing program, I am doing a study about what it is like to be a brother or sister of a child who has had a bone marrow transplant. Dr. Roberta Woodgate of the Faculty of Nursing, University of Manitoba is supervising this research study. Drs. L. Degner and M. Schroeder, both from the University of Manitoba, are the other two members of my thesis committee. This study has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba and CancerCare Manitoba.

I will be interviewing brothers and sisters to learn more about how they see the transplant experience. All brothers and sisters in every family are invited to participate. With your permission, I would like to ask your child if he/she would like to be interviewed. Your child may decide where and when he/she would be interviewed. Each interview will be from 30 minutes to one hour for school-age children, and one to two hours for adolescents or older children. If your child agrees to be interviewed a second time, a second interview would be planned. Your child will also be asked to complete a Demographic Form for background information about him/herself and your family, which will take about 10 minutes to complete.

The information I get from the interviews will be written up for my thesis. I also plan to publish the study in a professional journal and present it at a health conference. In all instances, you and your child's identity would not be shared with anyone. Your child would receive a movie gift certificate for taking part in the study. A summary of the study would be mailed to you if you wanted one.

If your child agrees to be interviewed, he/she can drop out of the study at any time, ask to stop the interview at any point, or refuse to answer any question. If you and your child decide not to take part in this study, you can say no without any problem.

If you are and your child are interested in taking part in my study and/or have any questions, concerns or need additional information, please contact me at 474-9095 (office), 947-5980 (home), or at my e-mail: umwilk04@cc.umanitoba.ca. You may also contact my supervisor, Dr. Roberta Woodgate at 474-8338.

Sincerely,

Krista Wilkins, RN, BScN, BSc (Hons.)
Master of Nursing Student
University of Manitoba

APPENDIX E

Reply Form

An Invitation to Participate in the Following Study: Siblings of Pediatric Bone Marrow Transplant Recipients: Their Lived Experience as They Transition Through the Bone Marrow Transplant Trajectory

Please complete and return this form whether or no you are interested in participating in this study.

Are you interested in participating?

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

Name: _____

Phone Number(s): _____

Email: _____

The best time to contact me is: _____

_____

○ **NO, we do NOT want to participate in this study.**

Please return this sheet to let us know that you do not want to participate and no further contact will be made.

APPENDIX F

Researcher's Telephone Script

Hello <Parent or Legal Guardian's Name>.

My name is Krista Wilkins, and I am a pediatric nurse and student in the Master of Nursing program at the University of Manitoba. I understand that you have received some information about a study I am doing and are willing to hear more about it.

To complete my nursing program, I am doing a study about what it is like to be a brother or sister of a child who has had a bone marrow transplant. Dr. Roberta Woodgate of the Faculty of Nursing, University of Manitoba is supervising this research study. Drs. L. Degner and M. Schroeder, both from the University of Manitoba, are the other two members of my thesis committee. This research study has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba and CancerCare Manitoba.

I will be interviewing brothers and sisters to learn more about how they see the transplant experience. All brothers and sisters in every family are invited to participate. With your permission, I would like to ask your child if he/she would like to be interviewed. Your child may decide where and when he/she would be interviewed. Each interview would be from 30 minutes to one hour for school-age children, and one to two hours for adolescents or older children. If your child agrees to be interviewed a second time, a second interview would be planned. The interviews will be tape-recorded, so I do not miss any important information. Your child will also be asked to complete a Demographic Form for background information about him/herself and your family, which will take about 10 minutes to complete.

I will type the interviews, and then I will read them and look for common issues and concerns. My supervisor, Dr. Roberta Woodgate, will also read the interviews. I will be the only person who knows the identity of your child. All names will be replaced with a code. The tapes and interview transcripts will be stored securely and destroyed when no longer required.

The information I get from the interviews will be written up for my thesis. I also plan to publish the study in a professional journal and present it at a health conference. In all instances, you and your child's identity would not be shared with anyone. Your child would receive a movie gift certificate for taking part in the study. A summary of the study would be mailed to you if you wanted one.

If your child agrees to participate, he/she can drop out of the study at any time, ask to stop the interview at any point, or refuse to answer any question. If you and your child decide not to take part in this study, you can say no without any problem.

Are there any questions you would like to ask about the study? Do you think your

child/children would like to take part in this study?

(If “no”) Thank you very much for your time. I appreciate having the opportunity to speak with you.

(If “I would like to think about it”) I would certainly appreciate you doing that. When should I call you back to get your decision? <Date> and <Time> for return phone call.

(If “yes”) Thank you for your interest. To which child or children may I describe the study? <Child’s name>. May I describe the study to <Child’s name> now?

(If “no, not available”) When should I get back to <Child’s name> about the study?

(If “yes”) Hello <Child’s name>.

My name is Krista Wilkins, and I am a pediatric nurse and a student in the Master of Nursing program at the University of Manitoba. I have been told by your mother/father/guardian that you have received some information about a study I am doing and are willing to hear more about it.

If you decide to take part in the study, you would be interviewed about what it is like to be a brother/ sister of a child who has had a bone marrow transplant. Each interview would be from 30 minutes to one hour (for school-age children) or one to two hours (for adolescents or older children). You could decide where and when the interview will take place. If you agree to be interviewed a second time, a second interview would be planned.

The information I get from the interviews will be written up for my school project. I would also like to publish the study and present it at a meeting. Your name would not be shared with anyone. You would receive a movie gift certificate for taking part in the study. A summary of the study would be mailed to you, if you wanted one.

If you agree to be interviewed, you can drop out of the study at any time, ask to stop the interview at any point, or refuse to answer any question. If you decide not to take part in this study, you can say no without any problem.

Are there any questions you would like to ask about the study? Do you think you would like to take part in this study?

(If “no”) Thank you very much for your time.

(If “I would like to think about it”) I would certainly appreciate you doing that. When should I call you back to get your decision? <Date> and <Time> for return phone call.

If “yes”) Thank you for your interest. When would be a good time to the first interview? Would you like to do it at your home? (If “no”) where would you like to do it?

When we meet, I will ask you for to complete some questions about you and your family. For the interview, it may be helpful to think about your feelings about the transplant experience and any events or decisions that stick out in your mind. Thank you for your time. I will look forward to meeting you on <Date> at <Time> at <Location>.

(Any questions that arise out of this conversation will be answered and noted on this sheet)

APPENDIX G

Recruitment Poster

INVITATION TO PARTICIPATE IN A RESEARCH STUDY

Research Project Title: Siblings of Pediatric Bone Marrow Transplant Recipients: Their Lived Experience as They Transition Through the Bone Marrow Transplant Trajectory

Researcher: Krista Wilkins, Master of Nursing Student
Supervisor: Dr. Roberta Woodgate
Affiliation: Faculty of Nursing, University of Manitoba

Do you have a brother or sister who has had a bone marrow transplant?

WHAT IS THIS STUDY ABOUT? The purpose of this study is to gain an understanding of what it is like to be a brother or sister of a child who has had a bone marrow transplant.

HOW WILL THIS STUDY BE DONE? I plan to interview brothers and sisters of children who have had a bone marrow transplant about their experiences.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THE STUDY? This study will result in knowledge that will help doctors and nurses care for brothers and sisters of children who have had a bone marrow transplant.

WHO WILL KNOW IF I DECIDED TO PARTICIPATE IN THIS STUDY? Only Krista will know about your decision. Your name will be replaced with a code number so that no one will be able to identify that you participated in the study.

WHO DO I CONTACT FOR FURTHER INFORMATION ABOUT THIS STUDY? Brothers and sisters who are interested in this study and/or have any questions, concerns or need more information may contact Krista Wilkins by phone (947-5980) or by e-mail at: umwilk04@cc.umanitoba.ca. You may leave a message on Krista's voice mail. You may also contact Dr. Roberta Woodgate at 474-8338.

Did the transplant happen when you were a child or adolescent?

APPENDIX H

Demographic Form

Information gathered in this form will help us get to know you and your family better. All information will be kept confidential.

1. How old are you right now? _____ (years)

2. Are you:
   - q Female
   - q Male

3. Are you:
   - q Donor
   - q Non-donor

4. Do you attend school or university/college?
   - q Yes
   - q No

   If yes, what grade or year of university/college are you in? _____

5. Are you currently working full-time or part-time?
   - q Not working
   - q Full-time
   - q Part-time

   If part-time, please indicate the number of hours/week. _____

6. Which of the following best describes your racial/ethnic background?
   - q White (Caucasian)
   - q Aboriginal (First Nations, Metis, Inuit)
   - q Asian
   - q Other (please specify): _____

7. Do you live in the city or outside the city?
   - q In the city
   - q Outside the city

8. How many brothers and sisters do you have?
   _____ Brothers
   _____ Sisters

9. What are the ages of each of your brothers and sisters?
   _____ Brothers
   _____ Sisters

10. How many brothers/sisters live at home with you?
    _____ Brothers
    _____ Sisters

11. Who else lives in your home with you?
    - q Both parents
    - q Mother
    - q Father
    - q Grandparents
    - q Guardians
    - q Pets
    - q Someone else

12. Who had the bone marrow transplant in your family?
    - q My brother
    - q My sister

13. How old is your brother/sister who had the bone marrow transplant right now?
    _____ (years)

14. What illness did your brother/sister have that was treated with the bone marrow transplant? _____

15. When was your brother/sister first diagnosed with this illness? _____ (year/month)

16. When did your brother/sister have the bone marrow transplant? _____ (year/month)

17. What problems, if any, did your brother/sister have after receiving the bone marrow transplant?_____
    _____

18. Which other treatment(s) did your brother/sister receive? (check all that apply)
    - q Chemotherapy
    - q Radiation
    - q Surgery
    - q Other (please specify): _____

19. Is there anything else that you would like to tell me about yourself or your family?

Thank you for helping us learn more about the experiences of brothers and sisters of children who have had a bone marrow transplant.

APPENDIX I

Interview Guide

Introduction to the interview: I would like to learn more about what it is like for children to go through the experience of having a brother or sister who has had a bone marrow transplant. I would like you to share your experiences from the time prior to your brother/sister's bone marrow transplant to today. To help you tell your story, I am going to ask you to talk about each period of your brother/sister's illness including the time before the bone marrow transplant, when your brother/sister was getting the bone marrow transplant, and the time since then. For each period, I would like you to talk about the changes that occurred in your lives, the type of needs that you had, the type of support and help that you received, the ways that you coped, and any other thoughts or feelings that come to mind.

1. Tell me a little bit about your family and life in general before your brother/sister became ill.

2. Tell me what it was like for you when the decision was made to go ahead with a bone marrow transplant for your brother/sister.

3. Tell me what it was like for you when you were tested to see if your bone marrow was a match for your brother/sister.

4. Tell me what is like when you learned that your bone marrow was/was not a match for your brother/sister.

5. Tell me what is it was like for you as you waited for the transplant to take place.

6. (For donors only). Tell me what was it like for you on the day that you had your bone marrow taken.

7. Tell me what it was like for you on the day of the transplant.

8. Tell me what it was like for you during the first week and month after the transplant.

9. Tell me what it was like for you when your brother/sister returned home after the transplant.

10. Tell me what life is like for you now.

11. Is there any other time during the bone marrow transplant that you would like to talk about?

12. Based on your experience, what advice would you give to other children who

have a brother/sister who is going to have a bone marrow transplant?

13. What suggestions would you give to health care professionals about how they can best help children go through an experience similar to yours?

14. What suggestions would you give to families and friends about how they can best help children who have to go through an experience similar to yours?

15. Describe your experience like a story so that it had a beginning, middle and ending.

16. Draw a line to represent your experience. What does it look like?

17. What do your remember most about your experience?

18. If you had 3 wishes, what would they be?

19. Is there anything else you like to talk about that you feel is important for me to know?

Note: Probes will only be asked as necessary. They are meant to stimulate discussion.

Probes for Questions 1, 5, 8, 9 and 10

- What is day-to-day life like for you and your family?
- Can you give me some examples?
- What things or events stick out in your mind?
- Tell me about some good times or experiences that you and your family had.
- Tell me about any really bad/difficult times or experiences that you and your family had.
- How have you been feeling?
- What type of things do you do to cope when having problems?
- Tell me about the times when you need help.
- Who did you go to when you need things or want help?
- What kinds of things did you need help with?
- Is there anything that you feel would help you?
- Who else (e.g., friends) or what else (e.g., religious support) besides your family is a part of your life?
- Who else or what else is important to you and help you to cope?

Probes for Question 2 and 3

- Were you involved in the decision?
- What was explained to you?
- Can you give me some examples?

Probe for Question 12

- What suggestions would you have for others going through a similar situation?

Probes for Question 15

- For the beginning, set the stage for your experience. What events set up your problem or set of problems?
- Describe the turning point where your problems came to a head or were addressed.
- Describe the events that wrap up your experience.
- What conclusion or conclusions can you make from your experience?

Probe for Question 17

- Why are other things not as important?

APPENDIX J

Ethical Approval from Education/Nursing Research Ethics Board

UNIVERSITY OF MANITOBA
RESEARCH SERVICES & PROGRAMS
Office of the Vice-President

244 Engineering Bldg.
Winnipeg, MB R3T 5V6
Telephone: (204) 474-8418
Fax: (204) 261-0325
www.umanitoba.ca/research

APPROVAL CERTIFICATE

27 January 2005

TO: **Krista Wilkins**
Principal Investigator

From: **Stan Straw, Chair**
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol #E2004:108**
Siblings of Pediatric Bone Marrow Transplant Recipients: Their Lived Experience as They Transition Through the Bone Marrow Transplant Trajectory"

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 that, 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.

Get to know Research…at your University.

APPENDIX K

Consent Form for Parents

Research Project Title:	Siblings of Pediatric Bone Marrow Transplant Recipients: Their Lived Experience as They Transition Through the Bone Marrow Transplant Trajectory	
Study's Researcher:	Krista Wilkins	Phone: 947-5980
Supervisor/Committee Chair:	Dr. Roberta Woodgate Assistant Professor Faculty of Nursing, University of Manitoba	Phone: 474-8338
Committee Members:	Dr. L Degner, Faculty of Nursing, University of Manitoba Dr. M. Schroeder, Faculty of Medicine, University of Manitoba	

I, _____, agree to allow to my child to participate in the above study. I understand that the purpose of this study is to better understand what it is like to be a brother or sister of child who has had a bone marrow transplant. I understand the study is being done by Krista Wilkins, a registered nurse and student in the Master of Nursing program at the University of Manitoba, for her thesis. Dr. Roberta Woodgate of the Faculty of Nursing, University of Manitoba is supervising this research study. Drs. L. Degner and M. Schroeder, both from the University of Manitoba, are the other two members of Krista's thesis committee.

I understand that if my child participates in the study, he/she will be asked to participate in one to two interviews carried out by Krista. Taking part in the interviews means that my child will be asked questions about what it is like to be a brother or sister of child who has had a bone marrow transplant. The interviews will be tape-recorded. Each interview will be from 30 minutes to one hour for school-age children, and one to two hours for adolescents or older children. I understand that although two interviews are planned, my child may decline to do a second interview. The interviews will take place at a time and place convenient for my child. My child will also be asked to complete a Demographic Form for background information about him/herself and your family, which will take about 10 minutes to complete. My child can ask me for help in completing this form.

I understand that my child's participation in this study is entirely voluntary. If my child agrees to be interviewed, he/she can drop out of the study at any time, ask to stop the interview at any point, or refuse to answer any question. My child will receive a movie pass for taking part in the study. I understand that a summary of the study will be

provided, if I want one.

I understand that there are no known risks to my child taking part in the study. However, I am aware that having the opportunity to talk about his/her experiences may make my child more aware of some of his/her feelings. If my child becomes upset or if he/she needs to talk to someone about his/her feelings, I understand that, with my permission, counseling services will be offered by the Winnipeg Children's Hospital. I understand that this study will result in knowledge that will help health care professionals better support brothers and sisters of children who have had a bone marrow transplant.

I understand that what is learned from this study will be written up for Krista's thesis, and it may be presented at a health conference or published in a health journal. I understand that my child's name will not be shared with anyone. I am aware that my child's name will be replaced with a code number. Only Krista and Dr. Roberta Woodgate will read the interviews. 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 Krista. I understand that all data will be destroyed seven years following completion of the study.

My signature on this form indicates that I have understood to my satisfaction the information regarding participation in the research project and allow my child to participate if he/she wants to participate. In no way does this waive my legal rights nor release the researchers, or involved institutions from their legal or professional responsibilities. I understand that my child's continued participation should be as informed as his/her initial consent, so I should feel free to ask for clarification or new information throughout my child's participation. I understand that I may contact Krista Wilkins (phone: 204-947-5980) if I have any concerns, questions, or need additional information. I may also contact Krista's supervisor, Dr. Roberta Woodgate, at 474-8338.

I understand this research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba and CancerCare Manitoba. If I have any concerns or complaints about this project, I may contact any of the above-named persons or the Human Ethics Secretariat at 204-474-7122. A copy of this consent form has been given to me to keep for my records and reference.

_____ _____

Signature of Researcher Parent's or Legal Guardian's Signature

Date _____

I would like a summary report of the findings:
Yes _____ No_____

Please mail a summary report to:
Name _____
Mailing Address _____

Postal Code _____
_____

APPENDIX L

Assent Form for School-aged Children

Research Project Title:	Siblings of Pediatric Bone Marrow Transplant Recipients: Their Lived Experience as They Transition Through the Bone Marrow Transplant Trajectory	
Study's Researcher:	Krista Wilkins	Phone: 947-5980
Supervisor/Committee Chair:	Dr. Roberta Woodgate Assistant Professor Faculty of Nursing, University of Manitoba	Phone: 474-8338
Committee Members:	Dr. L Degner, Faculty of Nursing, University of Manitoba Dr. M. Schroeder, Faculty of Medicine, University of Manitoba	

I, _____, state that I am ____ years of age and wish to take part in the above study. I understand that the purpose of this study it to learn from children what it is like be a brother or sister of child who has had a bone marrow transplant. I understand the study is being done by Krista Wilkins, a nurse and student in the Master of Nursing program at the University of Manitoba, for a school project. Dr. Roberta Woodgate, from the University of Manitoba, is in charge of the study. This study has been judged safe for me to take part in it, if I want to do so.

Agreeing to be in this study means that I will be asked to take part in one to two interviews. Each interview will take about 30 minutes to one hour to complete. Taking part in the interviews means that Krista will ask me questions about what it is like to be a brother or sister of child who has had a bone marrow transplant. The interviews will be tape-recorded. I understand that, if I am asked to take part in a second interview, I may decide not be interviewed again. I understand that it is my choice if I want to do a second interview. I will also be asked to fill out a short form for information about my family and myself, which will take about 10 minutes to do. I can ask my parents (legal guardians) for help in filling out this form.

I understand that I may ask Krista any questions. I understand that no one will know how I have answered the questions because Krista will replace my name with a code number. I also understand that Krista will not tell anybody how I answered the questions including my parents and family. Only Krista and Dr. Roberta Woodgate will read the interviews.

I understand that taking part is this study is all up to me and that if I decide not to take part in it, no will get mad at me. I understand that even if I decide to take part, I can still

quit at any time. I will be given a movie pass for taking part in the study.

I understand that nothing in the study will be done to me that could hurt me. However, I understand that if I become mad or sad, I may ask for help or may need to talk to my parents or someone else. I understand that what Krista learns from me will help doctors and nurses in the care of other brothers and sisters of children who have had a bone marrow transplant.

I understand that this study will be written up for Krista's school project, and it may be presented at a health conference or put into a health magazine. Once the study is completed, a copy of the research report will be given to me, if I ask for it.

I understand that it is my choice in whether or not I want to be in this research project. I have read the information and:

I agree to being interviewed Yes _____ No _____

_____ _____
Signature of Researcher Child's Signature

Date _____

I would like a summary report of the findings:
Yes _____ No_____

Please mail a summary report to:
Name _____
Mailing Address _____
_____
_____
Postal Code _____

APPENDIX M

Assent Form for Adolescents

Research Project Title:	Siblings of Pediatric Bone Marrow Transplant Recipients: Their Lived Experience as They Transition Through the Bone Marrow Transplant Trajectory
Study's Researcher:	Krista Wilkins Phone: 947-5980
Supervisor/Committee Chair:	Dr. Roberta Woodgate Phone: 474-8338 Assistant Professor Faculty of Nursing, University of Manitoba
Committee Members:	Dr. L Degner, Faculty of Nursing, University of Manitoba Dr. M. Schroeder, Faculty of Medicine, University of Manitoba

I, _____, state that I am ____ years of age and wish to take part in the above study. I understand that the purpose of this study it to learn from children what it is like be a brother or sister of child who has had a bone marrow transplant. I understand the study is being done by Krista Wilkins, a nurse and student in the Master of Nursing program at the University of Manitoba, for a school project. Dr. Roberta Woodgate, from the University of Manitoba, is in charge of the study. This study has been judged safe for me to take part in it, if I want to do so.

Taking part in this study means that I will be asked to take part in one to two interviews. Each interview will take about one to two hours to complete. I understand that I will be asked questions about what it is like to be a brother or sister of child who has had a bone marrow transplant. The interviews will be tape-recorded. I understand that, if I am asked to take part in a second interview, I may decide not to be interviewed again. I understand that it is my choice if I want to do a second interview. I will also be asked to fill out a short form for information about my family and myself, which will take about 10 minutes to do. I am aware that I can ask my parents (legal guardians) for help in filling out this form.

I understand that I may ask Krista any questions about the study that I want to. I understand that no one will know how I have answered the questions because Krista will replace my name with a code number. I also understand that Krista will not tell anybody how I answered the questions including my parents and family. Only Krista and Dr. Roberta Woodgate will read the interviews.

I understand that taking part is this study is all up to me and that if I decide not to take

part in it, no will get mad at me. I understand that even if I decide to take part, I can still quit at any time. I will be given a movie pass for taking part in the study.

I understand that nothing in the study will be done to me that could hurt me. However, I understand that if I become mad or sad, I may ask for help or may need to talk to my parents or someone else. I understand that what Krista learns from me will help doctors and nurses in the care of other brothers and sisters of children who have had a bone marrow transplant.

I understand that this study will be written up for Krista's school project, and it may be presented at a health conference or put into a health journal. Once the study is completed, a copy of the research report will be given to me, if I ask for it.

I understand that I may contact Krista Wilkins (phone: 204-947-5980) if I have any concerns, questions, or need additional information. I may also contact Krista's supervisor, Dr. Roberta Woodgate, at 474-8338.

I understand that it is my choice in whether or not I want to be in this research project. I have read the information and:

I agree to being interviewed Yes _____ No _____

_____ _____
Signature of Researcher Child's Signature

Date _____

I would like a summary report of the findings:
Yes _____ No_____

Please mail a summary report to:
Name _____
Mailing Address _____
_____
_____
Postal Code _____

APPENDIX N

Consent Form for Young Adults

Research Project Title:	Siblings of Pediatric Bone Marrow Transplant Recipients: Their Lived Experience as They Transition Through the Bone Marrow Transplant Trajectory	
Study's Researcher:	Krista Wilkins	Phone: 947-5980
Supervisor/Committee Chair:	Dr. Roberta Woodgate Assistant Professor Faculty of Nursing, University of Manitoba	Phone: 474-8338
Committee Members:	Dr. L Degner, Faculty of Nursing, University of Manitoba Dr. M. Schroeder, Faculty of Medicine, University of Manitoba	

I, _____, state that I am ____ years of age and wish to take part in the above study. I understand that the purpose of this study is to better understand what it is like to be a brother or sister of child who has had a bone marrow transplant. I understand the study is being done by Krista Wilkins, a registered nurse and student in the Master of Nursing program at the University of Manitoba, for her thesis. Dr. Roberta Woodgate of the Faculty of Nursing, University of Manitoba is supervising this research study. Drs. L. Degner and M. Schroeder, both from the University of Manitoba, are the other two members of Krista's thesis committee.

Taking part in this study means that I will be asked to take part in one to two interviews. Each interview will take about one to two hours to complete. I understand that I will be asked questions about what it is like to be a brother or sister of child who has had a bone marrow transplant. The interviews will be tape-recorded. I understand that although two interviews are planned, I may decline to do a second interview. I will also be asked to fill out a Demographic Form for background information about my family and myself, which will take about 10 minutes to do.

I understand that my participation in this study is entirely voluntary. I can drop out of the study at any time, ask to stop the interview at any point, or refuse to answer any question. I will receive a movie pass for taking part in the study. I understand that a summary of the study will be provided, if I want one.

I understand that there are no known risks to my taking part in the study. However, I am aware that having the opportunity to talk about my experiences may make me more aware of some of my feelings. If I need to talk to someone about my feelings, I

understand that, with my permission, counseling services will be offered by the Winnipeg Children's Hospital. I understand that this study will result in knowledge that will help health care professionals better support brothers and sisters of children who have had a bone marrow transplant.

I understand that what is learned from this study will be written up for Krista's thesis, and it may be presented at a health conference or published in a health journal. I understand that my name will not be shared with anyone. I am aware that my name will be replaced with a code number. Only Krista and Dr. Roberta Woodgate will read the interviews. 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 Krista. I understand that all data will be destroyed seven years following completion of the study.

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 or 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 that I may contact Krista Wilkins (phone: 204-947-5980) if I have any concerns, questions, or need additional information. I may also contact Krista's supervisor, Dr. Roberta Woodgate, at 474-8338.

I understand this research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba and CancerCare Manitoba. If I have any concerns or complaints about this project, I may contact any of the above-named persons or the Human Ethics Secretariat at 204-474-7122. A copy of this consent form has been given to me to keep for my records and reference.

_____ _____

Signature of Researcher Participant's Signature

Date _____

I would like a summary report of the findings:
Yes _____ No_____

Please mail a summary report to:
Name _____
Mailing Address _____
_____
_____
Postal Code _____