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An Interruption in Family Life: Siblings' Lived Experience as They Transition Through the Pediatric Bone Marrow Transplant Trajectory

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Purpose/Objectives: To arrive at an understanding of the lived experience of healthy donor and nondonor siblings as they transition through the bone marrow transplantation (BMT) trajectory.

Research Approach: Qualitative study guided by the philosophy of hermeneutic phenomenology.

Setting: Participants' homes or the investigator's university or hospital office.

Participants: Eight siblings of pediatric BMT recipients were recruited based on their knowledge of the experience of transitioning through the BMT trajectory.

Methodologic Approach: Data were collected by semistructured, open-ended interviews; demographic forms; and field notes during a period of six months. Data analysis occurred concurrently with data collection. Thematic statements were isolated using Van Manen's selective highlighting approach. Interviews were reviewed repeatedly for significant statements.

Main Research Variable: Siblings' lived experience of the BMT trajectory.

Findings: Interruption in family life emerged as the essence of siblings' lived experience. Four themes supported this essence: life goes on, feeling more or less a part of a family, faith in God that things will be okay, and feelings around families.

Conclusions: Hermeneutic phenomenologic research increases understanding of what being a sibling of a pediatric BMT recipient means. This study is one of the few that have afforded siblings the opportunity to speak about what is important to them.

Interpretation: Findings from this study provide insight into how siblings live and cope throughout the BMT trajectory and will guide nurses as they seek to provide more sensitive and comprehensive care.

Since the 1980s, the number of bone marrow transplantations (BMTs) performed to treat childhood illnesses, including malignancies, hematologic disorders, immunodeficiency disorders, and genetic disorders, has increased exponentially (Andrykowski, 1994; Packman, 1999). Having a child undergo a BMT creates a demanding situation that pervades the life of the entire family (Heiney, Byrant, Godder, & Michaels, 2002; Packman; Packman, Crittenden, Fischer, et al., 1997; Packman, Crittenden, Schaeffer, et al., 1997; Shama, 1998). Because a child's illness affects every member of the

Key Points . . .

- ▶ Life goes on for siblings despite their family lives being interrupted.
- ▶ Experiencing a multitude of feelings may be a completely normal part of the bone marrow transplantation (BMT) experience that siblings must encounter.
- ▶ Nurses can help siblings get through the BMT trajectory by assessing how siblings approach the experience and facilitating interactions with their social support networks.
- ▶ Adopting family-centered care is warranted to ensure that all family members are included in each aspect of care.

family unit, increasingly more research has focused on the perspective of the recipients, their parents, and families as a whole (Andrykowski; Brown & Kelly, 1976; Carr-Gregg & White, 1987; Forinder, 2004; Freund & Siegel, 1986; Gardner, August, & Githens, 1977; Heiney, Neuber, Myers, & Bergman, 1994; Patenaude, Szymanski, & Rapoport, 1979; Phipps & Mulhern, 1995; Rodrigue et al., 1997). However, minimal attention has been directed at understanding the effect of the procedure on healthy siblings as they transition through the BMT experience, despite the fact that the transplant process is especially arduous for siblings.

The experiences of siblings of children who have had BMTs are comparable to those of siblings of children with life-threatening illnesses, including cancer. Siblings' sense of normalcy and stability is challenged as they undergo

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tremendous changes in their lives (Wilkins & Woodgate, 2005; Woodgate, 2001, 2006b). Separation from their parents and the ill child results in siblings feeling abandoned and alone (Bendor, 1990; Chesler, Allesewede, & Barbarin, 1991; Murray, 1999; Wilkins & Woodgate; Woodgate, 2001, 2006a, 2006b). As the best stem cell donor candidates, siblings also face the prospect of being patients themselves (Gardner et al., 1977; Heiney et al., 2002; MacLeod, Whitsett, Mash, & Pelletier, 2003; Packman et al., 1998; Packman, Beck, VanZutphen, Long, & Spengler, 2003; Parmar, Wu, & Chan, 2003; Wiley, Lindamood, & Pfefferbaum-Levine, 1984).

Literature Review

Research that seeks to understand the BMT experience from the perspective of recipients' siblings is in its early stages. Much of the research conducted to date has approached the study of siblings from a deficit-centered perspective with the goal of assessing their psychosocial functioning. The research suggests that siblings react to the BMT experience in many different ways. Some siblings are at increased risk for emotional and behavioral problems (Freund & Siegel, 1986; Gardner et al., 1977; Heiney et al., 2002; Kinrade, 1987; MacLeod et al., 2003; Packman, Crittenden, Fischer, et al., 1997; Packman, Crittenden, Schaeffer, et al., 1997; Parmar et al., 2003; Pot-Mees & Zeitlin, 1987; Wiley et al., 1984). Other siblings experience psychological growth, including increased family cohesion, closer bond with the recipient, increased sensitivity, positive self-perceptions, decreased helplessness, and more compassion and caring (Carr-Gregg & White, 1987; Freund & Siegel; MacLeod et al.; Packman, Crittenden, Fischer, et al., 1997; Wiley et al.).

Although the studies provide an understanding of some of the problems that siblings encounter during the BMT trajectory, many of them are quantitative in nature and relied on standardized instruments selected for their psychometric properties rather than their suitability for the task at hand (Woodgate, 2001). Quantitative studies address concepts such as behavioral problems and social and psychological adaptation but do not fully explore the richness of the experience. Lacking are studies that detail the subjective experience of siblings' day-to-day living throughout the BMT trajectory. If nurses hope to help siblings successfully transition through the BMT trajectory, they need to be knowledgeable about how healthy siblings perceive and deal with having a brother or sister who has had BMT. To understand the BMT experience as expressed and represented by siblings, healthcare providers should allow them to tell the stories of their experiences in their own words. This objective is best suited to qualitative research. Accordingly, a qualitative study was conducted that sought to elicit detailed descriptions of siblings' lived experience as they transition through the BMT trajectory.

Methods

Design

A hermeneutic phenomenologic approach based on the work of Van Manen (1990) was selected to describe the BMT trajectory as experienced by siblings. By asking what a specific experience is like, hermeneutic phenomenology aims to "uncover the structure, the internal meaning structures, of lived experience" (Van Manen, p. 10). What is most important is to understand the

lives of individuals in their own context by taking into account individuals' life experiences and meanings derived from those experiences. Furthermore, to gain a full understanding of the meaning or essence of an experience, the experience needs to be described as well as interpreted (Van Manen).

Sample

Eight siblings were recruited from a pediatric BMT clinic in western Canada from March–August 2005. In recruiting siblings, the concern was with the representativeness of emerging concepts; therefore, purposeful sampling as opposed to statistical sampling was used (Patton, 1990). The sample size necessary for phenomenologic research is kept deliberately small to elucidate the richness of the individual experience (Speziale & Carpenter, 2003). Data were collected until redundancy occurred and the researchers found no new data emerging.

In phenomenologic research, the only legitimate informants are those who have lived the reality (Speziale & Carpenter, 2003). Therefore, in recruiting participants, attention was directed at selecting individuals based on their knowledge of transitioning through the BMT experience and their ability and willingness to reflect on and communicate such knowledge. The following inclusion criteria were met: (a) was able to speak, read, and write in English; (b) had a living brother or sister who had a BMT during childhood, regardless of the disorder for which the BMT was indicated; and (c) was a school-aged child or adolescent at the time of the BMT.

Procedure

Permission to conduct the study was obtained from a university-based ethical review committee and the participating sample site. Potential participants were identified with assistance from an intermediary clinical research professional. All siblings of 20 pediatric BMT recipients were invited to participate in the study. Despite attempts to recruit siblings through letters, posters, and follow-up telephone calls, eight siblings of seven recipients agreed to participate, all siblings of three recipients declined participation, and siblings of nine recipients were never reached. Informed consent was obtained from siblings. Parental consent also was sought for siblings younger than 18 years.

Through semistructured, open-ended interviews, siblings were asked to reflect on and describe their experiences with having a brother or sister undergo a BMT. The method afforded siblings the opportunity to describe their thoughts and feelings in their own words. The main question posed to siblings was, "What was it like for you to have a brother/sister who had a BMT?" Although phenomenology calls for the researcher to adopt a nondirective approach, the researchers also developed an interview guide to help siblings tell their stories. The guide was created from key themes identified in the literature review and from the researchers' experiences in caring for siblings. 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 were most relevant to their situations (see Figure 1 for sample questions). This is in keeping with Van Manen's (1990) view that using appropriate techniques in a study is acceptable as long as they are considered in the general orientation of the methodology. As part of the interview session, siblings also completed a brief demographic form.

- Tell me what it was like for you when the decision was made to go ahead with a bone marrow transplantation for your brother/sister.
- 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.
- Tell me what it was like when you learned that your bone marrow was/was not a match for your brother/sister.
- (For donors) Tell me what was it like for you on the day that you had your bone marrow taken.
- Tell me what it was like for you on the day of the transplant.

Figure 1. Sample Interview Prompts

Siblings were asked to participate in two interviews. The second interview afforded participants the opportunity to expand on their ideas and thoughts and allowed the researcher to clarify what had been shared. A total of 14 interviews were conducted. Two participants were not available for the second interview. The first interview ranged in length from 30–90 minutes, and the second interview ranged from 5–30 minutes. Interviews were tape recorded and transcribed verbatim. The first author interviewed siblings at a time and place that was most convenient for them. As such, siblings were interviewed over the telephone, face-to-face in their homes, or in a private office in the local hospital or university.

Field notes also were maintained that summarized the interviews as well as the researchers' personal and theoretical assumptions. Deliberately putting personal feelings on hold, also called bracketing, fostered the researchers' ability to see the siblings' experiences as they were lived (Van Manen, 1990). Specifically, the authors were surprised by how positive siblings' interpretations of the BMT trajectory were despite the fact that the experience challenged their families' sense of normalcy and stability.

Data Analysis

Data analysis occurred concurrently with data collection. After a naive reading of the interview transcripts, thematic statements were isolated using Van Manen's (1990) selective highlighting approach. This approach involves selecting and highlighting sentences that stand out as thematic of siblings' lived experiences. Textual data were reduced by asking, "What phrases seemed particularly essential about siblings' experience of transitioning through the BMT trajectory?" Essential themes (i.e., the meanings unique to the siblings' experience and without which the experience would lose its fundamental meaning) that made up the sibling experience emerged. Themes then were written and rewritten to develop the interpretation. Researchers continued the process back and forth from the parts of the text to the whole. Examples were used to illustrate how the description came together. The result was a possible description of the meaning of siblings' BMT trajectory and possible interpretation of that experience. This description was a collaborative effort between the authors.

Findings

Participants ranged in age from 11–24 years (\bar{X} age = 18 years). All were female. Two siblings from one family participated. Most siblings were the eldest children in their two-parent families. The sample was predominantly Caucasian. The mean time since BMT was 53 months (range = 15–139

months). At the time of BMT, four siblings were school aged, two were adolescents, and two were young adults. The age difference between the participant and BMT recipient was an average of six years (range = 2–11 years). Five participants were nondonors and three were donors, one of whom donated bone marrow to two siblings. Sibling demographic information is summarized in Table 1.

Six of the BMTs were allogeneic with a sibling donor, and one was autologous. The indications for the BMTs were leukemia (n = 3), neuroblastoma (n = 1), aplastic anemia (n = 2), and severe combined immunodeficiency syndrome (n = 1).

A list of the themes and subthemes is shown in Table 2. A summary of how the themes related to the essence and illustrative quotes are provided in Table 3.

The Essence of Siblings' Experiences: An Interruption in Family Life

Throughout the study, siblings reinforced that the essence of their lived experience of transitioning through the BMT trajectory was an interruption in family life. The onset of illness and subsequent need for BMT was described by all siblings as a sudden, unwelcome interruption to their daily family lives. Simply put, siblings in the study felt that family life was no longer "normal." As a 23-year-old nondonor said, "That turned over the whole house like, you know, like we'd been living. . . . We were healthy, we thought, you know."

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

It was kind of like it wasn't really happening. . . . When you experience, like, things like that . . . it takes a while for it to sink in. I knew it was happening. But it took a while for me to realize everything. (24-year-old nondonor)

I really didn't want this to be happening. . . . 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. (11-year-old nondonor)

Table 1. Demographic Data

| Characteristic | Donor Siblings (N = 3) | | Nondonor Siblings (N = 5) | |
|--|------------------------|--------|---------------------------|-------|
| | \bar{X} | Range | \bar{X} | Range |
| Age (years) | 18 | 15–22 | 17 | 11–24 |
| Months since bone marrow transplantation | 87 | 31–139 | 33 | 15–85 |
| Age difference between participant and recipient (years) | 5 | 2–8 | 7 | 3–11 |
| Characteristic | n | % | n | % |
| Age at bone marrow transplantation | | | | |
| School age | 2 | 67 | 2 | 40 |
| Adolescent | – | – | 2 | 40 |
| Young adult | 1 | 33 | 1 | 20 |
| Position in the family | | | | |
| Eldest | – | – | 5 | 100 |
| Middle | 2 | 67 | – | – |
| Youngest | 1 | 33 | – | – |

Table 2. Themes and Subthemes Regarding Interruption in Family Life

| Theme | Subthemes |
|---|---|
| Life goes on | Bad days Good days Coping responses |
| Feeling more or less a part of a family | Understanding what was happening Doing whatever they could |
| Faith in God that things will be okay | — |
| Feelings around families | Anger Worry Fear Sadness Hopefulness Pride |

Siblings revealed that life as they knew it before the transition had been put on hold. Family life revolved around recipients' health, lengthy hospital stays, and medical appointments. For all of the families, this meant that the family unit was divided. Parents or older siblings stayed with recipients at the hospital whereas the other siblings stayed at home with relatives. Often, family trips, birthdays, holidays, and social activities that siblings had once enjoyed with their families were planned around

recipients' health or not done at all. For most siblings, the BMT experience interfered with their taken-for-granted family roles and responsibilities. In the absence of their mothers, some siblings took on the mothering role. Others performed additional chores and responsibilities in the home. A 13-year-old nondonor said, "We couldn't do as much stuff. Like, we couldn't open presents together and enjoy the birthday cake together and stuff like this." A 15-year-old nondonor commented,

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 . . . responsible enough to get myself up for school in the morning to make it to the bus and . . . stuff like that.

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 were resumed, and everyone was healthy. As a 15-year-old nondonor said, "It was just more or less normal life, I guess. We weren't going to the hospital every day and stuff." A 23-year-old nondonor also stated, "It feels like it's back to normal . . . back to whatever . . . it was like before he got sick."

Additionally, although they were able to return to "normal" family life, siblings in the study nonetheless approached life differently than they did prior to having a brother or sister undergo a BMT. In fact, some siblings related that their families were better for having gone through the experience. Positive outcomes of the experience identified by siblings included

Table 3. How Themes Relate to the Essence

| Theme | Relationship to Interruption in Family Life | Illustrative Quotations |
|---|--|---|
| Life goes on | Siblings' lives did not stop with the onset of their brothers' or sisters' illnesses or the bone marrow transplantation (BMT). Siblings had bad days and good days, which, for the most part, paralleled the BMT trajectory. What determined how siblings got through the BMT experience was how they approached getting on with their lives and the social support they received. | So, at that time though when she came home, she was . . . it was a very happy time. . . . We finally found out she made it. Like she was out for good. (15-year-old nondonor) 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 on with life and whatever. (15-year-old donor) |
| Feeling more or less a part of a family | Belonging to the family was important. Being a part of the BMT experience helped increase siblings' sense of belonging. Understanding what was happening in their families helped siblings get through the BMT experience. Siblings needed to do whatever they could to help recipients get better. | And we [as a family] always went to hospital. . . . It was better than talking on the phone. We could actually see it and watch it and . . . check the nurse checking [the recipient] and seeing how everything works. (13-year-old nondonor) I was slightly curious, honestly, as to how [marrow stem cell infusion] would help [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. (15-year-old nondonor) |
| Faith in God that things will be okay | Siblings relied on a higher being. Prayer was beneficial. Doubts and spiritual conflicts sometimes existed. Faith community was a source of support. | Just, I think, letting other people like your church group or whatever know [what was happening in the family]. And so yeah, like, more people prayed, more people came to visit because of that. (24-year-old nondonor) Oh, I believe in God so much that . . . I thought if I prayed, then he would answer my prayers, but he never did answer my prayer [for my sister to get better]. (11-year-old nondonor) |
| Feelings around families | Emotional reactions varied from sibling to sibling and changed over time. A range of feelings was experienced, from happiness to sadness to anger. Having a variety of feelings may be a normal part of the BMT experience. | It was kind of sad and hard to think about it . . . that she had to go through a lot of stuff that we didn't have to do. We had fun playing again and she [was] . . . stuck in the hospital all day long. (13-year-old nondonor) |

understanding the illness, getting better grades in school, experiencing more family cohesion, having fewer arguments among siblings, and feeling more mature. An 11-year-old nondonor said, "Everything is, like, being really good now. Me and my sister stopped fighting, like, a lot. We just, like, learned to appreciate each other."

Theme 1: Life Goes On

Despite family life being interrupted, life continued on for siblings. Siblings' lives did not stop with the onset of their brothers' or sisters' illnesses or the BMT. Two subthemes to life goes on were found—bad days and good days and coping responses.

Bad days and good days: As life went on, siblings had both bad days and good days that, for the most part, paralleled the BMT trajectory. 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, such as finding a donor match in the family and transplant engraftment. Another difficult time for siblings was when they experienced pain associated with blood draws and the bone marrow harvest procedure. A bad day also was considered to be one in which a 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. For some siblings, seeing the physical side of recipients' treatment, particularly chemotherapy, made the experience "more real." Although seeing their brothers or sisters sick was experienced as something unpleasant, siblings reasoned that some degree of suffering was justified.

Well, in a way it was, like, not happy but thankful that this would maybe help her and maybe cure her and stuff, or 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. (11-year-old nondonor)

Conversely, good days were described as days when a recipient's progress was evident, such as the day a sibling discovered that the recipient's marrow was engrafting, when the recipient could spend time outside of the hospital, and when the recipient came home for good. Siblings related that they took the good with the bad in the experience and that the good times made the difficult times easier to handle.

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. Now of course we had to wait to see if it would work, you know, but I'd say it was a good day. You felt like now there was a chance. (23-year-old nondonor)

Coping responses: Despite the ups and downs, what determined how siblings in the study got through the BMT experience was how they approached getting on with their lives and the social support that they received. Siblings in the study 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 members, friends, and other families who had gone through similar experiences. The strategies appeared to reduce the intensity of the bad days, making them easier to bear.

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. (24-year-old nondonor)

Theme 2: Feeling More or Less a Part of a Family

Belonging to the family was important to all siblings. However, the BMT experience made feeling like a part of a family challenging for siblings. In the study, siblings' sense of belonging with their families or lack thereof was related to their understanding of what was happening in their family and their involvement in recipients' care.

Understanding what was happening: Coming to understand what was happening in their family helped siblings in the study get through the BMT experience. Siblings wanted accurate information about their ill brothers' or sisters' diagnoses and the BMT process. Siblings in the study reported wanting to see what was happening at the hospital because tangible evidence satisfied their curiosity, providing them with an accurate picture of what was happening and of their role in the family. A 24-year-old nondonor said, "It's good to know what's going on . . . and just, I think, being there. Like, a really good thing was being there. And to see everything."

However, knowing what was happening in the family was not always a positive experience for siblings. Some siblings believed that the more they knew, the more they worried about their ill brothers or sisters. As one sibling related,

I was thinking, lucky them [a 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 [the recipient] was in the hospital. They never knew why. (11-year-old nondonor)

Involvement in recipients' care: Concerned for other family members' sense of comfort, siblings needed to do whatever they could to help recipients get better. Strategies that siblings adopted when trying to comfort their ill brothers or sisters included "being there" to provide companionship and nurturing and being more careful around them. Actively participating in the treatment process also was important for siblings' coping. Participating in recipients' care afforded siblings opportunities to feel like a part of the family, see gradual physical changes in recipients, become familiar with the hospital environment, and gain information.

Theme 3: 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 that siblings employed because siblings' devotion to and reliance on a higher being was echoed repeatedly through their words and their tone of voice.

Prayer was the most common religious or spiritual coping strategy identified by siblings. Siblings felt connected to God through prayer. All of the siblings believed that prayer was beneficial. They described the power of prayer as a healing force that could touch recipients and help them cope with the experience.

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

Although siblings greatly valued prayer, some doubts and spiritual conflicts related to prayer were present. For example, one sibling poignantly expressed her discontentment with God when her prayers to make her sister better seemed “unanswered.” The sibling said that in time, she was able to trust God’s wisdom.

Another source of spiritual social support for siblings was their faith community. Others’ praying or visiting recipients and family members made siblings feel good. Being able to share their experiences with fellow church members created feelings of unity that helped siblings and their families get through the experience.

Theme 4: Feelings Around Families

All of the siblings in the 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 the emotional reactions to the BMT experience varied from sibling to sibling and changed over time as siblings adapted to the day-to-day realities of having an ill brother or sister.

Anger: 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 that they wanted to do. Second, feeling angry was attributed to siblings’ perceptions that other peoples’ lives were better than their own. The third reason for siblings’ anger was not having control over their lives. Their anger is reflected in the following comments. A 15-year-old nondonor said, “The extra responsibility—honestly, I was ticked off. I didn’t want it. I didn’t understand why it had to be all me.” An 11-year-old nondonor also commented,

Well, sometimes I would be mad about . . . some people having a better life than me . . . because 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.

Worry: Siblings really worried about their ill brothers’ or sisters’ conditions. They worried that their brothers or sisters would not get better or would experience complications, such as graft-versus-host disease. Donor and nondonor siblings also worried about donors having surgery.

Fear: The prevailing fear discussed by siblings was fear of the unknown. Siblings were afraid of what was going to happen to recipients. Some siblings were frightened that their brothers or sisters might die.

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, whereas others withdrew. Watching people they loved be hurt by needles and sickened by treatments was difficult for siblings.

I was really sad that she had to go through this and all the terrible things that she had. . . . Then I was sad about, hey, what if I don’t see my sister again, what if it never works out? (11-year-old nondonor)

Hopefulness: Despite their worries and fears, siblings remained hopeful throughout the BMT experience. It was their sense of hope that siblings attributed to their ability to cope with their new role of being brothers or sisters to children who were

undergoing BMT. Siblings’ hopefulness arose from their faith in God, recipients’ progress, and support from their families.

Pride: Siblings expressed great pride in recipients and their families for having made it through the BMT experience. Siblings felt good being part of their families’ accomplishments. A 13-year-old nondonor said, “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.”

Differences Between Donor and Nondonor Siblings

The BMT experience was similar for donor and nondonor siblings because the essence of the experience was the same for all participants. The only difference was that donors had the advantage of helping siblings beyond what nondonor siblings could do. Donor and nondonor siblings reported providing comfort for recipients and their families by “being there,” undergoing human leukocyte antigen typing, and attending to recipients’ daily medical needs. However, only donor siblings contributed to the treatment itself.

Discussion and Implications

Eight siblings’ experiences of having a brother or sister who underwent BMT were elucidated through qualitative interview. Findings from the study provide a unique way to understand what having a sibling who has had BMT is like. The study was one of a few that afforded siblings the opportunity to speak about what is important to them.

The essence of siblings’ lived experience was an interruption in family life. Simply put, siblings in the study felt that family life was no longer “normal.” Research consistently shows that family life is disrupted when routines revolve around a BMT recipient (Heiney et al., 2002; Packman, 1999; Packman, Crittenden, Fischer, et al., 1997; Packman, Crittenden, Schaeffer, et al., 1997; Shama, 1998). Common to all sibling experiences was a return to normal family life once the BMT experience was over. Previous research also has found that families of children with cancer experience a “new normal” after dealing with childhood cancer (Clarke-Steffen, 1993; Woodgate, 2001).

One practical implication of the present 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 lives being interrupted. In transitioning through the BMT experience, life went on for siblings with good days and bad days that frequently paralleled the BMT trajectory. As Charmaz (1991) 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, siblings’ own pain, and recipients’ progress. 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 networks.

Also of great importance to siblings in the present study was their need to be a part of the family. The BMT experience disrupted some siblings’ way of being in the family, which, in turn, affected their sense of belonging with the family. The isolation felt by siblings was experienced as a loss, which is consistent with previous research indicating that siblings perceive themselves to be alone and abandoned in the world (Bendor, 1990; Chesler et al., 1991; Murray, 1999; Wilkins & Woodgate, 2005;

Woodgate, 2006b). Woodgate (2006b) noted that siblings of children with cancer had an increased desire to maintain a sense of presence in their families by “being with” their parents and “being there” for their ill siblings. The importance of family to siblings who have brothers or sisters with life-threatening illnesses reinforces the importance of helping siblings maintain a sense of being in their families. To help siblings feel as though they belong to the family, nurses must work with parents to assess siblings’ readiness and desire for information in helping them deal with the BMT experience, provide siblings with timely and accurate information about the BMT process, and help siblings become involved in BMT recipients’ care.

Another value of the study is that it lays the foundation for understanding the coping strategies of siblings in the context of their religious or spiritual world view. 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; Wilkins & Woodgate, 2005; Woodgate & Degner, 2003). What makes the current study different from others that examined siblings’ coping strategies is that religion and spirituality stood out from all of the other strategies that siblings employed. This finding suggests that further research is needed to characterize siblings’ religious and spiritual coping. Furthermore, the diversity in beliefs found in this sample reinforces the need for religious and spiritual cultural sensitivity.

A most important finding of the study is the variety of feelings that siblings identified in response to the BMT experience. Although some researchers maintain that the many feelings that siblings experience during the BMT process are indicative of emotional distress (Packman, Crittenden, Schaeffer, et al., 1997; Packman et al., 1998, 2003), the results from the study suggest that experiencing such feelings does not mean that siblings are having emotional difficulties. In fact, experiencing the feelings may be a completely normal part of the BMT experience that siblings must encounter. The discrepancy between the present study and Packman’s work may be related to differences in study purposes. The purpose of the present study was to examine siblings’ lived experience, whereas Packman examined siblings’ psychosocial functioning and adjustment problems.

Although the siblings in the present study reported experiencing a range of feelings, no single feeling dominated the experience. This is in contrast to the findings reported by Woodgate (2006b), who revealed that although siblings of children with cancer experienced a range of feelings, sadness was predominate. Woodgate’s discovery of enduring sadness in siblings may be a function of the fact that siblings, along with their families, were followed longitudinally. A longitudinal study describing the lived experience of healthy donor and nondonor siblings as they transition through the BMT trajectory may result in a more detailed understanding of the feelings experienced by siblings.

Nonetheless, the important message from the present study is that people around siblings were not aware of how much feelings were a part of siblings’ experiences, reinforcing the

need for siblings to be given more opportunities to talk about their experiences. Furthermore, siblings need to know that their feelings are justified and that they are a part of the BMT experience.

Finally, 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.

Limitations

Although the study findings are not generalizable to all siblings, the study likely will foster an understanding of the sibling experience, sufficient to form a basis for future research. The study sample was composed only of sisters. The inclusion of brothers would have provided more depth to the representation of the sample. The study sample included siblings of diverse developmental stages (11–24 years) and illness variables (e.g., diagnosis, time since BMT). Regardless of the diversity, the essence of siblings’ lived experience was the same. Additional research is necessary to capture the potential differences in the changing perceptions of siblings with different sibling characteristics, including younger siblings, nondonor siblings, siblings with brothers or sisters who did not survive BMT, and siblings from a variety of cultural backgrounds.

The study relied on siblings’ memories of the BMT experience. Prospectively collecting data while siblings were going through the experience was not possible because of time constraints and population access difficulties. Recall inaccuracy was not a concern because in phenomenologic research, lived experiences gain significance “as we (reflectively) gather them by giving memory to them” (Van Manen, 1990, p. 37). Thus, the study presented lived experiences as that which siblings described as true in their lives.

Conclusion

Hermeneutic phenomenologic research can help healthcare providers get closer to understanding what being a sibling of a pediatric BMT recipient means. The study resulted in the description of a possible experience of having lived with a sibling who underwent a BMT. Findings from the study provide insight into how siblings live and cope throughout the BMT trajectory and help guide nurses as they seek to provide more sensitive and comprehensive care.

Additional study framed within the qualitative research paradigm is needed, specifically that which focuses on each of the four themes identified in support of the essence of siblings’ lived experiences. More research is needed to enhance the understanding of transition-related issues and to help nurses better anticipate the diverse and shifting demands siblings likely will encounter as they transition through the BMT experience.

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