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Through the Eyes of Young Sibling Donors: The Hematopoietic Stem Cell Donation Experience

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This qualitative study used a grounded theory approach to explore how pediatric sibling donors of a successful hematopoietic stem cell transplantation conceptualized their donation experiences. *Saving my sister's (or brother's) life* describes the central phenomenon identified by this purposive sample of 8 sibling donors. Five themes captured their memories: being the perfect match, stepping up, worrying about the outcome, the waiting process, and sharing a special bond. Further research surrounding changes in relational issues will provide insight into inter-sibling support and the developmental course of the sibling relationship into adulthood when intensified by a health crisis.

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HEMATOPOIETIC STEM CELL transplantation (HSCT) is routinely used to treat various types of malignant and non-malignant disorders affecting hematopoiesis. HSCT recipients receive either autologous (their own) or allogeneic (from someone else) hematopoietic progenitor cells (Bollard, Krance, & Heslop, 2011). The outcome of an allogeneic transplant is affected by the degree of human leukocyte antigen (HLA) matching between the recipient and the donor. Each sibling who shares biological parents with the recipient has approximately a 25% chance of being HLA-matched. An HLA-matched sibling continues to be the donor of choice due to the decreased risks of severe graft-versus-host disease and graft rejection, resulting in a more successful transplant outcome when compared to alternative donors (Bollard et al., 2011).

Minimal research has focused on the experiences of pediatric sibling HSCT donors. This study explores how sibling donors who participated in the HSCT process during childhood and young adulthood conceptualized their dona-

tion experiences, including critical contextual influences and life events across the transplant trajectory. Study findings will guide the development of theory and the design of developmentally appropriate interventions to improve the care of pediatric sibling HSCT donors.

Background

Allogeneic HSCT remains an arduous medical therapy that challenges the psychological and physical reserves of the recipient, donor, and family unit. It entails significant physical risks and psychosocial impact for a donor of any age. A pediatric sibling donor may be particularly vulnerable to these potential effects due to their young age and limited physical and cognitive capabilities and social experiences. In addition, the family impact is intensified when two minor or young adult siblings must undergo invasive medical procedures.

Only four small studies have focused on varied aspects of the transplant experience for pediatric sibling donors. Wiener, Steffen-Smith, Battles, Love, and Fry (2008) explored the pre- and post-donation experiences of 14 sibling peripheral blood stem cell donors, ages 9–28 years

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(time since donation: 4 months–4 years). The donors reported having fears and anxieties about the donation procedure, especially in regard to procedural pain and the use of needles. They reported needing more information about transplant outcomes and potential complications. Nine of the donors reported positive life changes as a result of participating in the donation.

Packman and colleagues (Packman, Crittenden, Schaeffer, Bongar, Fischer, & Cowan, 1997; Packman, Gong, Van Zutphen, Shaffer, & Crittenden, 2004) used a multi-method, multidimensional design to evaluate the psychosocial consequences and adjustment problems of 44 sibling bone marrow transplant donors and non-donors, ages 6 to 18 years (mean time since donation: 34 months for donors, 42 months for non-donors). Donors ($n = 21$) had significantly higher levels of anxiety and lower self-esteem than non-donors ($n = 23$). Interestingly, sibling donors and non-donors reported comparable levels of post-traumatic stress symptoms, while non-donors showed significantly more problems at school.

MacLeod, Whitsett, Mash, and Pelletier (2003) investigated the psychosocial impact of successful versus unsuccessful HSCTs for 15 sibling donors ages 12 to 28 years (time since donation: 2–15 years). Sibling donors of successful transplants ($n = 8$) reported increased self-esteem, improved family relationships, and decreased feelings of helplessness. Sibling donors of unsuccessful transplants ($n = 7$) reported higher levels of guilt, sadness, and worry. These siblings felt there was “no choice” regarding whether to serve as a donor.

Wilkins and Woodgate (2007) examined the bone marrow transplant experience for 8 female sibling donors ($n = 3$) and non-donors ($n = 5$), ages 11 to 24 years, whose sibling was a transplant recipient during childhood and still living. These siblings described their experiences along the transplant trajectory as “an interruption in family life”. They reported providing support to the recipient and their families by “being there”, participating in HLA-typing, and assisting in providing care to the ill sibling. The experiences of these donors were overall very positive, with the stories of donor siblings differing from non-donors in one area: their ability to contribute to their sibling’s actual treatment.

The findings of the above studies, although not generalizable to all pediatric sibling donors, provide a beginning picture of the physical risks and psychosocial impact of a donation through the eyes of children. Although researchers have used appropriate methodologies to explore the transplant experience, only the study by MacLeod et al. (2003) focused specifically on the experiences of the pediatric sibling donor in the context of the transplant outcome. The purpose of our study was to capture the perceptions of pediatric sibling donors who participated in a successful transplant outcome. By listening to their stories about the transplant experience, health care professionals may be able to improve the experiences of future donors and to develop a standard of care that best facilitates their adjustment.

Methods

Design and Sample

A grounded-theory approach was used to guide this exploratory qualitative research (Strauss & Corbin, 1990). A purposive sample of eight participants who served as pediatric sibling donors for a successful transplant between January 1999 and September 2009 were recruited from a single pediatric bone marrow transplant center in the southeastern United States. The inclusion criteria for the study included participants who: (a) were English-speaking, (b) served as a minor/young adult sibling donor, (c) participated in a successful transplant where the recipient was still living, (d) were between the ages of 10 and 30 years at the time of the interview, and (e) provided consent and/or assent as applicable. Fourteen donors met the inclusion criteria of the study and were invited to participate. Of the 14 eligible participants, 8 agreed to participate in the study, 3 were lost to follow-up (invalid contact information), 2 were non-responsive to communication attempts, and 1 declined participation. The 8 participants who agreed to participate did not have any known late-effect outcomes related to the bone marrow donation. The median participant age at the time of donation was 13 years (range, 2–23 years). Median time between donation and the interview was 6.5 years (range, 2–10 years), and the median age at the time of the interview was 18.5 years (range, 13–30 years), 3 being minors. Of the 8 donors, 7 were male and 1 was female. Five of the participants were White, 2 were African-American, and 1 was Hispanic.

Instruments

Demographic information was collected to obtain descriptive characteristics of the participants such as chronological age, gender, ethnicity, age at the time of donation, and selected family and medical characteristics. A semi-structured open-ended interview guide allowed participants the opportunity to describe their memories of critical events and situations before, during, and after the transplant.

Procedure

Following approval by the Institutional Review Board (IRB), the names of potential participants who met study criteria were obtained by the research team from the database of the Bone Marrow and Stem Cell Transplant Program. Eligible participants and their parents, if appropriate, were contacted first in the form of an IRB-approved letter explaining the project. A follow-up telephone call was made by the research assistant to explain the study and invite them to participate. Informed consent was obtained from the participant or parental consent and child assent was obtained for participants under 18 years of age. Contact with potential participants and their families was through the research assistant for the study; other members of the clinical team did not interact with the donors or their families.

Each participant interview was conducted in a private setting by the research assistant, who was not a member of the clinical bone marrow transplant team and had no previous relationships with the donors, recipients, or their

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