Published in final edited form as:
Psychooncology. 2008 March ; 17(3): 304–307.

Sibling stem cell donor experiences at a single institution†

Lori S. Wiener*, **Emilie Steffen-Smith**, **Haven B. Battles**, **Alan Wayne**, **Cynthia P. Love**, and **Terry Fry**
Pediatric Oncology Branch, Center for Cancer Research, National Cancer Institute, National Institutes of Health, Bethesda, MD, USA

Abstract

Allogeneic bone marrow (BM) and cytokine mobilized peripheral blood stem cell (PBSC) transplantation can be curative for patients with malignant and nonmalignant hematologic diseases. Siblings are most often selected as a donor match; however, research on sibling donors is limited and has focused primarily on conventional BM donors. This exploratory study describes the experiences of PBSC sibling donors at a single institution. Through retrospective interviews, 14 sibling donors shared their perceived needs and concerns before and after their stem cell collection. Donors identified fears about the donation procedure, and expressed the need for more information about transplant outcome and complications. The inclusion of the sibling donors themselves, rather than the report of their parents or health-care providers and the qualitative nature of the structured design allowed sibling donors to describe their concerns and thoughts without being restrained by the beliefs of the participant's parents, researcher or sibling's medical team. Suggestions for visual educational tools, psychosocial interventions and future research are provided.

Keywords

hematopoietic stem cell transplantation; bone marrow and peripheral blood stem cell transplantation; pediatric sibling donors; psychosocial adjustment

Introduction

Allogeneic stem cell transplantation is an aggressive and demanding medical therapy with an unpredictable outcome that presents both psychological and physical challenges to recipients and their families. To increase survival and lower complication risks, an immunologically compatible donor is selected using a laboratory assessment technique called human leukocyte antigen typing (HLA-typing). Siblings are most often selected as a donor since they have the greatest chance (25%) of being HLA-matched with the recipient [1].

Studies examining psychological functioning in sibling donors are primarily limited to bone marrow transplant (BMT) donors. Significant psychological reactions to the experience include depression, withdrawal, behavioral problems, lowered self-esteem, identity problems, psychopathology, guilt, resentment, and anger following the donation procedure [2–5]. Risk factors for poor psychological functioning include age at donation with a risk of unresolved developmental crises in adolescence [4], recipient death [3], transplant complications such as graft-versus-host disease (GVHD) or graft failure [2,3], limited involvement in donation decisions [3,4], feeling coerced to donate [4], limited preparation for transplant complications [3,4], and individual sibling characteristics such as pre-existing psychopathology [6].

* Correspondence to: Pediatric Psychosocial Support & Research Program, National Cancer Institute, 9000 Rockville Pike - Building 10, 1 SE Pediatric Clinic, Rm 6466, Bethesda, MD 20892, USA. E-mail: wienerl@mail.nih.gov.

Peripheral blood stem cell (PBSC) donation has been increasingly used as an alternative to BM harvest. Studies of adult PBSC donors have reported that overall adult donors perceive the procedure as acceptable with manageable pain and anxiety comparable to population norms [7,8]. Since peripheral blood is collected using apheresis, does not require anesthesia or surgery, and has a relatively quick recovery time, the procedure may seem more benign to parents and hospital staff. However, PBSC collection requires the injection of granulocyte colony stimulating factor (G-CSF) prior to collection and involves the placement of two intravenous catheters. Previous research in pediatric stem cell donors has not examined the psychosocial risks of pre-donation preparation or G-CSF administration. Moreover, the psychosocial risks of PBSC collection for pediatric donors are largely unevaluated. As PBSC collection is used more frequently in pediatric allogeneic stem cell transplants, an understanding of the psychosocial impact of collection in sibling donors is required in order to assess the complex needs and concerns of this patient population. The goal of this retrospective exploratory study was to evaluate the pre-and post-donation experiences of PBSC donors at a single institution and to describe how they felt their experience could be improved.

Methods

Sibling donors were eligible if they were ⩾7 years old, had been enrolled on a National Cancer Institute (NCI) protocol involving PBSC donation for a sibling recipient during the preceding five years, and were fluent in English. The study was approved by the Office of Human Subjects Research at the National Institutes of Health. The principal investigator or the research nurse for the PBSC protocol contacted eligible donors ≤18 years and the caregivers of those under 18 by telephone. If interested in participating, they were told that they would be called by one of the authors of this manuscript (E.S.) to schedule the interview.

Sample

Fourteen of the 16 (87%) eligible donors were successfully contacted and agreed to participate. Participants were an average of 18.6 years old (range 9–28). Donors were contacted ⩾4 months post-donation (range = 4–48 months, mean = 21.6 months). Sample characteristics are described in Table 1.

Instruments

A structured interview, consisting of 45 open- and close-ended questions, was designed for the study to obtain information about the donor experiences during HLA-screening, pre-donation preparation, stem cell harvest, and post-transplant. Questions pertaining to the stresses associated with being a donor were developed based on findings from previous research on pediatric sibling donors [2–5]. Items asking about medical preparedness were derived from information found in the NCI transplant protocol consent form and relevant literature on the PBSC process and pediatric donors [1,9–11]. The principal investigators, and research nurses for the stem cell transplant protocols reviewed the interview to assess the appropriateness of the questions.

Procedure

Structured interviews were conducted over the phone ($n = 12$) or face to face during a sibling's clinical visit ($n = 2$). Each interview was conducted by an interviewer (E.S.) specifically trained for this study, and took between 15–20 min to complete.

The participants were encouraged to share their experiences as a donor and were not given any time limits. Confidentiality was assured for all participants. Interview results were coded and entered into an Excel database for analysis. Open-ended questions were content analyzed by

the interviewer and the PI with emergent themes noted and coded accordingly. Due to small sample sizes, data presented here are descriptive.

Results

Preparation for donation experience

Sixty-four percent of donors were informed of their HLA-match status by a parent and 86% received specific information about stem cell donation and apheresis from a medical team member. Sixty percent of donors ⩾18 thought the information was very easy to understand compared to only 33% of donors <18. Ninety-three percent of donors reported that meeting with the transplant team prior to the procedure yielded the most helpful information about the apheresis. However, almost a third of the donors felt that multiple preparation sessions would have been helpful. Ninety-three percent reported that being well informed about the donor experience is 'pretty important' to 'very important.'

Anxiety

Sibling reports of anxiety prior to the stem cell collection were varied. Forty percent of those ⩾18 were 'pretty nervous' or 'extremely nervous' about the procedure while only 22% of the donors <18 reported being 'pretty nervous' or 'extremely nervous.' When given a list of possible sources for their anxiety, 64% of donors, regardless of age, cited needles as their primary concern. Other sources of anxiety were possible central line placement (21%), G-CSF shots (36%), procedural pain (29%), possible physical harm (21%), seeing blood (14%), and transplant outcome (14%).

Transplant outcome

Donors were asked to reflect on their sibling's transplant, specifically if they felt their sibling's transplant was successful or not. The majority of donors (71%) felt that the transplant was 'mostly successful' ($n = 5$) or 'totally successful' ($n = 5$). When asked to further explain their answer, many donors stated that while the transplant procedure was successful, their sibling experienced complications such as GVHD or disease progression, which made the success difficult to determine. For example, one donor explained that even though her sister died from disease progression, she believed the transplant was still somewhat successful because 'for 2 months after the transplant, she felt the best she ever felt since her cancer [diagnosis].'

Life changes

Donors were asked to discuss how being a stem cell donor for a sibling has affected their lives. Nine donors (67%) reported positive changes to their personal life including a closer relationship with the recipient sibling ($n = 3$), closer relationship with family members ($n = 2$), sense of pride for donating ($n = 2$), and feeling good or happy about donating ($n = 2$). Others described the stem cell harvest as a 'good experience' and expressed feeling proud for being able to help their sibling. Two donors (15%) also expressed that they are now more interested and involved in the science of stem cell research and the politics that accompany it. Negative effects since the transplant were also reported (21%), with several donors expressing regret that the transplant did not cure their sibling's cancer. Two donors (15%) expressed guilt about their sibling developing GVHD and reported wishing they had been more informed of the possible side effects prior to the transplant.

Discussion

Even without the risks of anesthesia and surgery used in conventional BM harvest, PBSC donors still felt anxious about the procedure and expressed concerns about physical harm to

themselves and their sibling recipient. Age appears to play a role here as a larger percentage of older donors reported feeling ‘pretty nervous’ or ‘extremely nervous’ about the apheresis procedure compared to younger donors. The trend between older donor age and greater comprehension of the preparation information may indicate that more age-appropriate preparation for younger donors is needed. Donors reported that while the informational session with the transplant team staff provided useful information, additional preparation sessions would be helpful. Recent reports suggest that providing comprehensive procedural information both improves memory and reduces distress in children undergoing medical procedures [12, 13] yet limited educational material on stem cell donation is available for children and adolescents. Preparatory educational materials that reflect the different learning styles of individuals (visual as well as auditory) may be useful.

Donors also expressed the need for more information about transplant outcome and complications. One donor stated, ‘I was taken by surprise. I needed to know more about GVHD.’ Preparing sibling donors for possible post-transplant medical sequalae is a critical factor to consider when planning programs and clinical services for this patient population. Along with realistic post-transplant expectations, it is important to assess for feelings of guilt if the recipient sibling develops complications such as graft failure, GVHD, or disease relapse.

A positive response to the donor experience, such as improved family relationships, is consistent with heightened intimacy between recipient and donor described in previous research on conventional BMT donors [3,5]. Maladaptive responses, including withdrawal, depression, and low self-esteem reported in previous research were not specifically addressed or reported in the interviews, though some siblings did express guilt or responsibility for transplant complications.

The strength of this study is the inclusion of sibling donors themselves, rather than the reports from their parents or health-care providers. Previous research indicates that siblings of children with cancer experience a more significant burden from the illness than parents or caregivers may perceive [14]. The qualitative nature of the structured design allowed concerns and thoughts to be described without being restrained by the beliefs of the participant’s parents, researcher, or sibling’s medical team. Siblings had the opportunity to report what was important to *them* rather than the attention being placed on their brother or sister’s disease or the transplant outcome.

Limitations of this study include the use of only one interview per donor, the wide range of age of sibling donors and varied length of time from transplant to interview per participant. Based on the diseases of study and the requirement for fluency in English, the sample lacks ethnic diversity and is therefore not representative of all sibling donors. Furthermore, the study was retrospective and cross-sectional in design, so reports were limited to what the sibling donor remembered and wished to share about the transplant experience. A more complete picture of the donor experience might be obtained from serial interviews, each at specific time points prior to and following stem cell collection. Finally, the sample size is small and results should be considered preliminary. Continued research with larger samples is warranted.

Conclusion

With the increasing number of allogeneic BM and PBSC transplants performed annually in the United States, a greater understanding of the donor experience is needed. Siblings represent the largest percentage of matched donors for allogeneic transplant procedures, yet little information is available on the psychological effects of stem cell donation in this population. This exploratory study presents the first report on the experiences of sibling stem cell donors undergoing PBSC collection and provides insight into the needs and concerns of these donors.

Only with more comprehensive and inclusive research can clinicians and health-care providers provide effective, age-appropriate interventions for this often overlooked population.

Acknowledgements

This research was supported by the Intramural Research Program of the National Institutes of Health, National Cancer Institute, Center for Cancer Research. The views expressed do not necessarily represent the views of the National Institutes of Health or the United States Government.

References

1. Grupp SA, Frangoul H, Wall D, Pulsipher MA, Levine JE, Schultz KR. Use of G-CSF in matched sibling donor pediatric allogeneic transplantation: a consensus statement from the Children's Oncology Group (COG) Transplant Discipline Committee and Pediatric Blood and Marrow Transplant Consortium (PBMTC) Executive Committee. Pediatr Blood Cancer 2006;46(4):414–421.10.1002/ pbc.20800 [PubMed: 16463346]
2. Gardner GG, August CS, Githens J. Psychological issues in bone marrow transplantation. Pediatrics 1977;60 :625–631. [PubMed: 400708]
3. MacLeod KD, Whitsett SF, Mash EJ, Pelletier W. Pediatric sibling donors of successful and unsuccessful hematopoietic stem cell transplants (HCST): a qualitative study of their psychosocial experience. J Pediatr Psychol 2003;28(4):223–231.10.1093/jpepsy/ jsg010 [PubMed: 12730279]
4. Packman WL, Crittenden MR, Schaeffer E, Bongar B, Fischer JBR, Cowan MJ. Psychosocial consequences of bone marrow transplantation in donor and non-donor siblings. J Dev Behav Pediatr 1997;18(4):244–253. [PubMed: 9276831]
5. Wiley FM, Lindamood MM, Pfefferbaum-Levine B. Donor–patient relationship in pediatric bone marrow transplantation. J Assoc Pediatr Oncol Nurses 1984;1(3):8–14. [PubMed: 6381691]
6. Packman WL, Gong K, VanZutphen K, Shaffer T, Crittenden M. Psychosocial adjustment of adolescent siblings of hematopoietic stem cell transplant patients. J Pediatr Oncol Nurs 2004;21(4):233–248.10.1177/ 1043454203262698 [PubMed: 15490868]
7. Rowley SD, Donaldson G, Lilleby K, Bensinger WI, Appelbaum FR. Experiences of donors enrolled in a randomized study of allogeneic bone marrow or peripheral blood stem cell transplantation. Blood 2001;97(1):2541–2548.10.1182/blood. V97.9.2541 [PubMed: 11313239]
8. Williams S, Green R, Morrison A, Watson D, Buchanan S. The psychosocial aspects of donating blood stem cells: the sibling donor perspective. J Clin Apher 2003;18(1):1–9.10.1002/jca.10042 [PubMed: 12717786]
9. Bolan C, Yau YY, Cullis HC, et al. Pediatric large-volume leukapheresis: a single institution experience with Heparin versus citrate-based anticoagulant regimens. Transfusion 2004;44:229–238.10.1111/ j. 1537–2995.2004.00668.x [PubMed: 14962314]
10. Pulsipher MA, Levine JE, Hayashi RJ, et al. Safety and efficacy of allogeneic PBSC collection in normal pediatric donors: the pediatric blood and marrow transplant consortium experience (PBMTC) 1996–2003. Bone Marrow Transplant 2005;35(4):361–367.10.1038/sj.bmt.1704743 [PubMed: 15608659]
11. Sevilla J, Diaz MA, Fernandez-Plaza S, Gonzalez-Vicent M, Madero L. Risks and methods for peripheral blood progenitor cell collection in small children. Transfus Apher Sci 2004;31(3):221–231.10.1016/ j.transci.2004.07.013 [PubMed: 15556470]
12. Salmon K. Commentary: preparing young children for medical procedures: taking account of memory. J Pediatr Psychol 2006;31(8):859–861.10.1093/ jpepsy/jsj072 [PubMed: 16135851]
13. Salmon K, McGuigan F, Pereira JK. Brief report: optimizing children's memory and management of an invasive medical procedure: the influence of procedural narration and distraction. J Pediatr Psychol 2006;31(5):522–527.10.1093/jpepsy/jsj081 [PubMed: 16177227]
14. Houtzager BA, Grootenhuis MA, Caron HN, Last BF. Sibling self-report, parental proxies, and quality of life: the importance of multiple informants for siblings of a critically ill child. Pediatr Hematol Oncol 2005;22(1):25–40.10.1080/08880010590896233 [PubMed: 15770829]

Table 1

Donor information (n = 14)

Characteristic	*n* (%)
Gender	
Male	6 (43%)
Female	8 (57%)
Ethnicity	
Caucasian	14 (100%)
Age relationship to recipient sibling	
Older	6 (43%)
Younger	8 (57%)
Age at time of donation procedure	
⩾18 years	9 (64%)
<18 years	5 (36%)
Status of sibling recipient at interview	
Living	11 (79%)
Deceased	3 (21%)
Sibling diagnosis	
Rhabdomysarcoma	5 (36%)
Ewing's sarcoma	6 (36%)
Desmoplastic small round cell tumor	1 (7%)
Hodgkin's lymphoma	2 (14%)