Pediatric Sibling Donors of Successful and Unsuccessful Hematopoietic Stem Cell Transplants (HSCT): A Qualitative Study of Their Psychosocial Experience

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Objective  To examine the psychosocial impact of pediatric hematopoietic stem cell transplants (HSCTs) on sibling donors, particularly in unsuccessful HSCTs. Methods  Fifteen sibling HSCT donors, 8 who had participated in successful transplants, and 7 whose recipient sibling died, were interviewed (M age = 19.6 years at time of interviews, and 13.3 years at time of sibling’s HSCT). Grounded theory methodology was used to derive themes from interviews. Results  Siblings in the unsuccessful transplant group reported greater negative impact and feelings of guilt following the HSCT and were less likely to experience positive psychological effects. Both groups reported that informed consent involved “no choice” and that psychological aspects of the procedure outweighed physical aspects. Conclusions  Some themes differentiated sibling donors of successful and unsuccessful transplants, while others were common to both groups. All emergent themes reinforced the importance of providing sibling donors with developmentally appropriate, accurate information and long-term psychological support.

Key words  sibling donor; bone marrow transplant; pediatric; HSCT.

The first successful allogeneic bone marrow transplant was performed on a 5-month-old infant with his sibling's marrow in 1968 (Johnson & O'Donnell, 1994). This procedure, then considered experimental, is now used as a viable treatment for many pediatric disorders. However, even though bone marrow transplants and stem cell transplants (referred to as hematopoietic stem cell transplants [HSCTs]) are now used more frequently, their results remain unpredictable (Andrykowski, 1994). The success rate of HSCTs, which is affected by the type of disease being treated, ranges from 50% to 70% in more favorable cases and from 10% to 25% for patients with less favorable conditions or advanced disease (Sanders, 1997).

HSCTs present many psychological and physical challenges that the pediatric patient, the donor, the family, and the medical staff must overcome (Andrykowski, 1994; Patenaude, Szymanski, & Rappeport, 1979). For the donor, the medical procedures in HSCTs are not insignificant. They typically require a general anesthetic for catheter insertion (stem cell harvest) or for bone marrow collection from the hip. They may be associated with moderate pain and discomfort (Rowley, Donaldson, Lilleby, Bensinger, & Appelbaum, 2001) and carry some risk of subsequent medical complications. Apart from the physical aspects, however, the broader psychological issues arising from donation may have an even greater likelihood of affecting the donor, as well as others associated with the transplant.

A sibling is more likely to be a compatible donor than parents, relatives, or strangers (Sanders, 1997). Thus, as HSCTs increase in number, so does the number of pediatric sibling donors. Only a few studies have focused on the psychosocial impact of the procedure on the sibling donor (Packman, 1999; Shama, 1998). Two studies have looked...
at sibling donors of surviving HSCTs (Packman, Crittenden, Rieger Fischer, et al., 1997; Packman, Crittenden, Schaeffer, et al., 1997), but, to our knowledge, none has yet examined the psychosocial experiences of sibling donors who have participated in an unsuccessful HSCT in which the recipient died.

Before siblings are identified as donors, they may already be exposed to higher levels of psychosocial stress from belonging to a family in which one sibling has a chronic illness (Chang et al., 1998; Sargent et al., 1995). These stressors may result in the healthy sibling developing feelings of jealousy, anger, fear, and resentment toward the sick sibling (Kock-Hattem, 1986), and emotional problems, psychosomatic symptoms, or behavior problems at home and school (Barbarin et al., 1995; Sahler et al., 1994; Shapiro & Brack, 1994; Zeltzer et al., 1996). Significantly, a number of studies have also identified positive effects in the healthy siblings of ill children, including a greater sensitivity to the needs of others (Heffernan & Zanelli, 1997), enhanced self-sufficiency and independence (Barbarin et al., 1995), and increased family closeness (Chesler, Allswede, & Barbarin, 1991). In a large-scale series of studies on the impact of childhood cancer on healthy siblings, 33% of the siblings were perceived by parents as coping without difficulty, and 4% as displaying “distinctly improved” behavior (Sahler et al., 1994). Thus, the interaction between the experience of dealing with a chronic illness in the family and the experience of donating is an important one that requires further study (Murray, 2000).

In two studies comparing experiences of nondonor siblings and successful donor siblings (Packman, Crittenden, Rieger Fischer, et al., 1997; Packman, Crittenden, Schaeffer, et al., 1997), a third of the siblings in each group reported a moderate level of posttraumatic stress. In addition, donor siblings reported higher levels of anxiety and lower self-esteem than did nondonor siblings. Finally, donor siblings had more adaptive skills in school while nondonor siblings showed more school problems. These studies suggest two possible explanations for the latter finding: (a) positive psychological effects may result from the donating experience, and (b) donor and nondonor siblings may express their stress in different ways. The study by Packman, Crittenden, Rieger Fischer, et al. also found that both donor and nondonor siblings reported loneliness, minimal comprehension of the transplant procedure, and a lack of attention from parents. Donor siblings also reported a lack of choice when asked to donate and the need for support groups.

While studies of sibling donors to HSCTs are scarce, the psychosocial effects for sibling donors of unsuccessful HSCTs have not been examined at all. This study was designed, therefore, to gain a better understanding of the psychosocial experiences of sibling donors in HSCTs, especially when the HSCT is unsuccessful. Because so little research is available on the topic, we chose grounded theory methodology (Glaser, 1992) to enable identification of “themes” emerging from sibling donors’ descriptions. Although exploratory, our research was based on two general hypotheses: (a) that some of the emergent themes would be similar for sibling donors of both successful and unsuccessful transplants, and (b) that because of the additional impact arising from the loss of a sibling, some emergent themes would be unique to donors of unsuccessful transplants.

**Method**

**Participants**

Participants were sibling donors (M age = 19.6 years) of living and nonliving pediatric patients who had undergone an HSCT at a children’s hospital in western Canada from 1986 to 2000. Since this study used qualitative methodology, we sought to attain limited sample sizes of 5–10 subjects per group, with approximately equal group sizes. Fifty-one patients had received sibling donor transplants from 1986 to 2000, of which 34 were still living, and 17 had subsequently died. Of this total, 27 siblings (52.9%) were excluded (not contacted) for the following reasons: (a) sibling was younger than age 6 or over the age of 20 at time of donation (n = 6), (b) the family could not be located (n = 6) or lived at too great a distance to be interviewed (n = 12), and (c) hospital staff deemed that a request for research participation might prove too stressful for the family (n = 3).

All of the remaining 24 eligible sibling donors (11 unsuccessful HSCTs, 13 successful HSCTs) were contacted. Of these, 15 (62.5%; 7 unsuccessful HSCTs, 8 successful HSCTs) agreed to participate, and 9 (37.5%) did not reply or declined participation.

Sibling donor and recipient characteristics are presented in Table I. At the time of the HSCT, donors were between 7 and 20 years of age (M = 13.3). At the time they were interviewed, participants ranged in age from 12 to 28 years (M = 19.6). Eleven of the 15 siblings were male, and all were Caucasian except one.

**Interview Measure**

Individually conducted semistructured, open-ended interviews were used to generate the data. The interview was divided into four general sections (see Table II) and followed a topical outline to identify themes on which
participants might want to expand. The topics were broad and simple, so the guide could be used for all participants regardless of age. Interview topics and questions were developed from relevant literature on the HSCT process, siblings, and the donor role (e.g., Kinrade, 1987; Packman, 1999; Shama, 1998). Three additional health professionals who were familiar with child development or pediatric HSCT procedures also reviewed the interview guide to increase the validity and appropriateness of questions.

### Procedures
The ethics research board of the participating institution approved procedures for the study. Hematology/Oncology Program staff made initial contact with families of potential participants. Informed consent was obtained from sibling donors over age 18; parents of sibling donors under the age of 18 provided informed consent for their children, and the children provided assent.

Interviews were conducted at a place most convenient for participants, usually their homes. Interviews took 30 to 60 minutes to complete and were audiotaped for subsequent analysis.

### Qualitative Data Analysis
The primary investigator (MacLeod), who also conducted the interviews, coded all transcripts. Although subject to individual bias, qualitative data analysis typically lacks a division of labor between data collection and coding. The

<table>
<thead>
<tr>
<th>Donor Number</th>
<th>Sex of Donor</th>
<th>Donor Age at Interview</th>
<th>Donor Age at HSCT</th>
<th>Time Since HSCT</th>
<th>Recipient Relationship</th>
<th>Recipient Age at HSCT</th>
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Successful HSCTs:

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<th>Donor Age at HSCT</th>
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There was a total of 18 HSCTs (10 BMTs and 8 SCTs), with 3 donors participating in two transplants each. Age is given in years. HSCT = Hematopoietic stem cell transplant, BMT = Bone marrow transplant, SCT = Stem cell transplant.

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<th>Interview Sections and Sample Questions</th>
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Each section of the interview guide covered a range of specific topics. A copy of the complete topical outline and questions for the interview can be obtained by contacting the corresponding author.
The aim of the analysis is to build theory that fits the data. Readers are then considered the judges of the credibility of the findings. The constant comparative method for producing emergent-grounded theory was used to analyze the data (Chenitz & Swanson, 1986; Glaser, 1992). Data analysis was carried out separately for the unsuccessful and successful groups, with comparisons between emergent themes made later. Each transcript was read twice before coding, and all sibling donor statements were underlined, numbered, and condensed. Statements throughout the transcript were compared and linked with similar statements, forming broad categories. Categories and coded statements within categories were systematically compared, and those that occurred repeatedly within a single transcript were considered an emergent theme. In keeping with the constant comparative method for producing emergent-grounded theory, the same systematic process was reiterated for analysis of each transcript. Once all transcripts had been analyzed, the categories and themes from each transcript were systematically compared to categories and themes from the subsequent transcript(s). While new themes could arise in any individual transcript, only those supported by data in successive transcripts were maintained and allowed to expand. As the continuous process of coding and comparing occurred across and within transcripts, both individual and group (unsuccessful vs. successful transplant) themes emerged. Validity checks, sorting, coding, categorizing, and constant comparison were documented, leaving an “audit trail” (Glaser & Strauss, 1967) that two other members of the research team then reviewed.

Results
Several prominent themes emerged from the analyses, some common to both groups, and others where the groups differed. Common themes included (a) perceptions of “no choice” in becoming a donor, which included both “forced no choice” (couldn’t say no because of pressure from others) and “deliberate no choice” (couldn’t say no because of own beliefs) and (b) the relative importance of psychological aspects of the HSCT as compared to the physical aspects. The theme for which the groups differed involved the range and intensity of areas in their lives positively or negatively affected by the donor experience and the amount of guilt they perceived afterward. The following sections address each of these themes. The proportion of sibling donors in each group endorsing each theme is presented in Table III.

| Table III. Percentages of Sibling Donors for Unsuccessful and Successful HSCTs Endorsing Each Emergent Theme |
|-------------------------------------------------|-------------------------------------------------|---------------------------------|---------------------------------|
| Perceived No Choice                              | Psychological/Physical Aspects                   | Impact on Siblings               |
| Forced % (n)                                      | Forced % (n)                                      | Positive % (n)                    |
| Deliberate % (n)                                 | Deliberate % (n)                                 | Positive % (n)                    |
| Successful                                      | Psychological Physical Equal to Psychological % (n) | Positive and Negative % (n)       |
| 37.5 (3)                                         | 62.5 (5)                                         | 100 (8)                          | 0.0 (0)                          |
| 28.5 (2)                                         | 57.1 (4)                                         | 85.7 (6)                         | 14.2 (1)                         |
| Total                                           | 33.3 (5)                                         | 93.3 (14)                        | 6.6 (1)                          |

Percentages indicate the proportion of subjects in each group for which a particular theme emerged. HSCT = Hematopoietic stem cell transplant. The total percentage for the “perceived no choice” theme in the unsuccessful group is less than 100% because one participant in this group did not recall the consent process.

Emergent Themes for Both Sibling Donor Groups
Informed Consent and the Feelings of “Forced No Choice” vs. “Deliberate No Choice.” Nearly all siblings perceived they had no choice in becoming a donor and that saying yes was their only option. However, the basis of this perception differed for individual donors. About a third of the donors in each group thought that doctors and family members limited their opportunity to say no, making them perceive they had a “forced no choice.” The rest of the donors in each group thought they had a “deliberate no choice” because they personally did not see “no” as an option due to their own beliefs about morality and death.

Siblings who perceived a “forced no choice” in their decision to be a donor reported pressure from their families or doctors, as illustrated by the use of statements such as “guilt,” “propaganda,” “lucky one,” “bribed,” “privileged,” “conned,” and “knew what they had to do to get what they wanted.” Many participants stated that their hesitancy was not due to a lack of desire to help but arose because they were afraid of the procedure and the pain they would experience. A sibling donor who was 9 years old at the time of the transplant told how her family convinced her that she should “say yes”: “I was the only one who didn’t want to do it. My mom and dad would have died to do it. It wasn’t cause I didn’t want to help him but I was scared . . . and they made me feel privileged to be the one that got to do it but I did not want to.”

Several participants recognized by the time of the in-
terview that even though they had not decided to say yes on their own at the time of the HSCT, they probably would now. A sibling donor explains that “I refused at first because I was little at that time and so I didn’t understand that cancer could kill anyone.”

Some donors also felt that a lack of appropriate information about the procedure encouraged their fears and contributed to their desire to say no. One donor who was 8 years old at the time of the transplant said: “I thought that you might have died through it. I didn’t know that you could make more bone marrow and stuff. . . . I was pretty wrapped up in that it was a life and death procedure so I didn’t really think about asking anyone. . . . I should have been told a lot more about the operation. . . . I didn’t feel very prepared.”

Older sibling donors reported focusing mainly on the consequences to their sick brother or sister if they chose not to donate. If they were poorly informed about the procedure, it was not as troubling, as they endorsed a “de-liberate no choice.” One donor who was 17 years old at the time of transplant stated: “I didn’t really even think about that [personal risk]. I just thought about my brother all the time. . . . It helped me a lot because I wasn’t thinking about myself and what was gonna happen to me, so I wasn’t really concerned about the operation.”

Older siblings were able to think globally about the HSCT and in ways that were oriented toward the future. They were able to understand that if they chose not to donate, then the other option was to lose a family member. This can be seen in the way one sibling viewed the question of informed consent: “Well it’s a stupid dumb question because of course I would rather donate than let my brother die.” Some of the older donors even acknowledged that tactics such as “propaganda” were used, but they understood its basis, as they felt the same way. A participant who was 17 years old at the time of transplant stated: “They were trying to be convincing and rightfully so I suppose . . . [It] was a loaded conversation. However, before they even asked me I knew I was going to do it so I didn’t take any offense into what are you trying to con me into.”

**Relative Importance of Psychological versus Physical Aspects of Procedure.** Most donors described fear prior to the HSCT about the medical procedures they would have to go through and were worried about the pain. However, following the HSCT, donors realized that the pain was less severe and the procedure less physically demanding than they originally thought. Younger donors, who focused most on the physical aspects prior to donation, especially noticed this. One participant who was 7 years old at the time of transplant shared how he felt before the HSCT: “At first I was only worried a little bit but when it got closer to me having to go into the hospital I got really worried because this was the first time I would have surgery. . . . I didn’t really want to do it because it was so scary.”

The same participant then commented that he no longer felt this way and would tell other sibling donors: “Don’t worry much because the surgery isn’t really that bad.”

Older donors also mentioned that the physical demands of the procedure were not much of a concern for them, but that the psychological issues resulting from donation had a significant impact. One donor commented: “It’s not a huge life altering experience where your body’s gonna change. I came out of the transplant and I played soccer the next two days. Ah, but mentally I think it is. You have prevented a life from, you know, disappearing.”

The psychological impact of the HSCT could be both positive and negative. As one donor recognized, “The participation and stuff in it, it’s easy, but you’re giving, helping somebody with a life so when it fails it’s not the best thing to be dealing with.” Another stated: “I don’t think anyone should be afraid of it. It’s not a life ending experience; it’s actually a life growing experience. It’s a valuable experience in family and don’t be afraid of it, it’s a good thing to do.”

**Emergent Theme for Sibling Donors Who Participated in Successful HSCTs**

Nearly all sibling donors who participated in a successful HSCT believed their participation had a **predominantly positive impact on many life domains**, including relationships, view of world, feelings about self and decreased helplessness, and insight into their sibling’s illness. This theme also emerged in the unsuccessful transplant group, but to a far lesser extent.

**Relationships.** Donors felt that the HSCT brought their family closer together and improved the relationship they shared with their ill sibling. The following comments illustrate this theme: “My dad . . . he kind of looks up to me for what I did,” “saving my brother’s life was a really tight thing. . . . [W]e now have closer relations in the family.”

**View of World.** Many donors reported changes in how they saw the world, such as “[It] . . . made me more aware of what diseases are and how people can help.” Some participants found themselves thinking about issues related to life and death and how the HSCT affected this, as shown by one donor’s comments: “Hugely, I think if you look at it in the grand scheme of things. We didn’t lose a family member and that’s the hugest thing you can think of, losing a family member is devastating.”

**Feelings About Self and Decreased Helplessness.** Many siblings felt good about themselves after donating and thought they had done something worthwhile. One donor
recalled that, when he left the hospital, he wanted to “tell friends what a great thing I did.” Siblings also reported they were happy that they were finally able to contribute to their sibling’s treatment. As one donor commented, “I was glad that I could do something because I kind of felt helpless leaving it up to the doctors.”

Insight Into Sibling’s Illness. Feelings of decreased helplessness were often accompanied by increased insight into the sibling’s illness. As one participant said, “I gained a little insight into what he goes through.” Another said: “Before, I saw it as easy. My parents never really told me about the pain he was going through.”

Exception to Positive Psychological Effects. Sibling donors who participated in a successful HSCT rarely described a negative experience. However, negative emotions were reported when their brother or sister developed severe and long-lasting complications from the procedure and the donor lacked the support to deal with the resulting emotions. There were still positive psychological effects from the HSCT, but many went unrecognized until years later. The donor was usually not well informed about the process. A sibling donor in this situation described her donating experience: “I’ve dealt with the good and the bad because the end result is good and he’s still alive. . . . I think somebody should have pulled me aside and explained it and reassured me that it [complications] wasn’t my fault. . . . I remember how much blame I put on myself.”

Emergent Theme for Sibling Donors Who Participated in Unsuccessful HSCTs

Both positive and negative impacts, with feelings of guilt and blame, often overshadowed positive effects. Many donors in the unsuccessful HSCT group reported both positive and negative impact of the donor experience, and in one case the negative impact became predominant. A donor described his feelings years after the HSCT and his sibling’s death: “I’m angry about everything. I feel a little depression and anger will change . . . the way you think.” Anger, guilt, and blame were common emotions expressed by some of the donors with unsuccessful HSCT outcomes. This was especially so when they felt they were poorly informed about the complications of the procedure or did not receive support from doctors or family members after the death, or when they kept their feelings hidden from others.

Another common view expressed by these donors was that it was hard to not feel responsible for the death of their sibling and that support was needed to overcome these feelings. One donor described his struggle: “It’s human nature I guess. I would really second guess myself and think about what if it was my bone marrow?”

In some cases of unsuccessful transplants, donors were informed that their sibling had subsequently died because of the disease, rather than as a result of failure of engraftment, or graft versus host disease. Some donors used this information to their benefit to lessen their feelings of personal responsibility. However, resisting the development of negative feelings was harder for sibling donors who lacked adequate emotional support following the death or when the death was directly related to complications of engraftment or graft versus host disease.

For some participants, this guilt and blame did not develop right away but grew over time. This was especially true when they did not find the opportunity to discuss these thoughts with others. One donor reflected on her experience: “I knew that I was the last chance and knowing that it didn’t work, I felt guilty. Now I know I should never of felt that way, but people didn’t discuss it afterwards and make me really understand that I shouldn’t feel that way. It was something that built up and nobody probably even realized that I felt that way.”

Discussion

Sibling donors’ descriptions of their psychosocial experiences supported the hypotheses that the two groups would express both shared and unique themes relating to their HSCT experience. Siblings in both groups identified concerns about the manner in which they had reached a decision to participate in the transplant, with most indicating that they recalled having “no choice” but to agree with the request that they serve as donors. For approximately two thirds of sibling donors, this had been perceived as a “deliberate no choice” in which they recognized that there was no other choice but to donate, and willingly chose to do so. However, about a third of sibling donors identified the dilemma of feeling “forced” or coerced to participate.

The other theme that emerged from interviews with both groups concerned the extent to which psychological, as opposed to physical, aspects of the transplant were of greater significance to them as donors. Most donors reported that the pain they experienced from the medical procedures was minimal and that their prior fears about the HSCT were not substantiated. Pre- and postviews of the HSCT were different. For most, the psychosocial aspects of the procedure were of greater importance than physical aspects after the HSCT. Most sibling donors also stressed they were not prepared for the range of emotions they would experience throughout the HSCT and that more information should be directed at the emotional aspects of being a donor.

Qualitative findings from this study further suggested
that a number of factors influenced both the sibling donor's emphasis of the two shared themes and the psychological impact of the transplant. Among those factors that emerged most clearly from the interviews were the age of the donor at transplant, the donor's perception of the adequacy of information provided prior to and after the transplant, and the outcome of the transplant (both the morbidity experienced by the transplant patient and their survival or death).

The older donors in the study recognized the severity of the situation for their sick sibling and believed their only option was to "say yes" regardless of the pressure from others. For them, a "free choice" was not an option because they identified the consequences to their sick sibling and family as greater than the physical consequences they would endure. Older children are able to think in abstract ways and can weigh the options of donating or not donating (Wass, 1991). However, younger sibling donors focused more on the immediate pain and how frightening the procedure would be. It was difficult for them to understand the implications of their donation, and most of them believed they were "forced" to say yes. Parents and professionals need to be conscious of these developmental differences in order to provide donors with ongoing age-appropriate information. This will help pediatric donors to increase their competency in making a decision to donate, basing less of their decision on fear, and coping more adaptively with the stresses involved with the HSCT procedure.

Many donors from both groups reported feeling unprepared prior to the transplant and subsequently had difficulty understanding what was happening. They also reported that the way in which some information was presented to them was frightening. For example, sibling donors wanted to know that there was a possibility of side effects, but they did not want to know specifics until a particular side effect occurred. They also suggested that it was important to have two sources providing emotional support and information, both professionals and parents. Information from parents helps to comfort the donor, while information from professionals helps to make it real and truthful. Sibling donors felt that professionals need to do a better job of making parents aware of siblings' feelings and supplying them with the skills needed to deal with these emotions.

Taken together, these findings raise obvious ethical and clinical issues concerning the child donor's participation in HSCTs. The competence of children to consent to bone marrow or stem cell donation for transplantation has been a matter of some debate (e.g., Delaney, Month, Savulescu, Browett, & Palmer, 1996; Mumford, 1998) that is not resolved. Competence can be thought of in terms of the child's ability to understand the information offered and his or her ability to make a decision based on what is presented, with insight into the consequences of the decision (Koocher & DeMaso, 1990). One can only imagine the psychological consequences a potential sibling donor would face within the family system if she or he were to refuse donation. The sibling donor's status as a family member would likely be affected (Mumford, 1998), and feelings of guilt might also result, particularly if the child were younger. Years after the HSCT, most "forced no choice" sibling donors understood why they were forced to donate but wished they had had more influence and autonomy in deciding that "no" was not an option.

The HSCT has the potential to decrease feelings of helplessness and divisions within the family by allowing the family to work together to achieve a meaningful common goal: saving the life of a family member. If sibling donors experience positive feelings as a result of the HSCT, they may be able to cope better with any negative events associated with having a family member with a chronic illness. Most of the sibling donors did experience positive psychological effects from the HSCT, but individual donors differed in the intensity and range of those effects. Feelings of guilt may not develop until the donors reach a later stage of cognitive maturity and starts to analyze the death of the sibling or until they have reached further stages in the grieving process.

The findings from this research need to be interpreted cautiously in light of limitations of the study. The sample of sibling donors studied was small and was fairly narrow in its demographic representativeness. Siblings in both donor groups were predominantly male and Caucasian. The limitation of small sample sizes may be a challenge to overcome in future research, as the number of sibling donor HSCTs at most transplants centers will be limited. Sibling donors were included who had participated in more than one HSCT, and both stem cell transplants and bone marrow transplants were combined. Collapsing across subjects in this manner may have obscured the specific psychological impact of repeated medical procedures, or of one medical procedure over another (bone marrow transplant vs. stem cell transplant).

In this study, a single interviewer, who was also responsible for analysis of the interviews, conducted interviews. Sibling donors were interviewed at only one point in their ongoing developmental trajectories and at different ages for different donors. Children's experience of the events surrounding HSCT, their recall of those events, and their impressions of their own reactions to those events likely would be affected by their age both at the
time of the transplant and at the time of the interviews. It is not clear that the retrospective recall of events that occurred when subjects were very young was always consistent with those actual experiences. Finally, we could not control for the number of years since the time of donation, which was somewhat longer for unsuccessful versus successful HSCTs (7.3 years vs. 4.1 years). This difference may have affected recall and interpretation of the donation experience and potentially the themes that emerged for the two groups.

This study is the first to report the experiences of sibling donors participating in an unsuccessful transplant in which the recipient died. The findings suggest that the psychological and emotional aspects associated with the sibling donor experience are significant, varied, and worthy of further study. Future research will require longitudinal methodology to identify which sibling donors experience the greatest impact from HSCTs and which factors contribute to these outcomes. Future work should also focus on development of systematic procedures to provide sibling donors optimal interventions before, during, and after the HSCT so that the likelihood of negative effects may be minimized and the opportunities for positive psychological effects enhanced.

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