

Preparing Children to Be Bone Marrow Donors

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Purpose/Objectives: To review literature regarding children as bone marrow donors and describe the evaluation of an individualized intervention to support children who will be donors for parents or siblings.

Data Source: Research studies, abstracts, and clinical reports describing interventions or psychosocial issues related to child donors, parent interviews, and clinical experiences.

Data Synthesis: Child marrow donors and caregivers benefit from interventions that illuminate the process and provide psychosocial support. Use of a teaching book enhances intervention and provides a tool for parents to use after transplantation.

Conclusions: Psychosocial distress in child marrow donors and parents can be minimized through education and therapeutic interventions. Research is needed to validate the efficacy of interventions and determine whether psychosocial complications are decreased.

Implications for Nursing: Child donors, especially those for parents, should receive support and attention for their unique psychosocial needs.

Key Points . . .

- Child donors coped successfully with physical and psychological tasks when provided with developmentally appropriate information.
- Coping improved when interventions included opportunities to ask questions, express feelings, and anticipate difficulties.
- Parents were positive about participation in a structured program to support child donors.

Fischer, et al., 1997; Packman, Crittenden, Schaeffer, et al., 1997). Pediatric donors experienced pain, guilt, psychological distress, and threats to self-esteem. Specific problems included sleep difficulties, behavior problems, refusal to discuss the process, and problems in school performance (Kinrade, 1987; Weisz & Robbennolt, 1996). Other issues were conflicts about choice of donor, resentment about being chosen, and feelings of responsibility for the outcome of transplantation (Packman, Crittenden, Fischer, et al., 1997). Psychological distress may be exacerbated when patients who receive grafts die as a result of the transplant process (Weisz & Robbennolt). Packman, Crittenden, Schaeffer, and colleagues (1997) found that sibling donors had higher anxiety and lower self-esteem when compared to sibling nondonors. Their findings suggested that siblings need follow-up beyond the transplant period.

Three approaches to the psychosocial care of child donors have been described (Dannie, 1991; Kinrade, 1987; Shama, 1998), but none discussed the use of children as marrow donors for their parents. Early work by Gardner, August, and

Bone marrow graft collected from child donors has been used to treat patients in need of transplantation for three decades. However, the preparation and psychosocial care of child donors are not well documented. This article summarizes the psychosocial literature related to child donors; describes an intervention that provides support to them, including the use of a teaching book; and discusses the clinical evaluation of the intervention.

Literature Review

In the past, literature on marrow donors has focused on adults (Andrykowski, 1994b; Hill, Chapman, Jackson, & Sullivan, 1989; Patenaude & Rapoport, 1984; Stroneck et al., 1989; Wolcott, Wellisch, Fawzy, & Landsverk, 1986). Adult donors experienced pain, mild psychological distress, and positive emotions associated with altruism. Adult donors who were related to the recipients had significantly more psychosocial problems when compared to donors who were not related to the recipients. Related donors described greater pain and more negative emotions (Hill et al.), suggesting that related donors are more vulnerable to psychological sequelae than unrelated donors.

Psychosocial issues related to child marrow donors have been addressed minimally. Pediatric donors often were discussed in the context of the family rather than the psychological impact on the individual child (Packman, Crittenden,

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Githens (1977) noted that education alone was not adequate for child donors. Kinrade noted that children should receive anticipatory guidance about the procedure and have opportunities to express their feelings, especially guilt. Kinrade recommended that efforts to teach the development of coping skills to facilitate the management of anxiety and threatened self-esteem would benefit child donors. Play therapy has been one approach recommended for providing therapy for children. Dannie outlined components of preparation for donors that included counseling, psychological assessment of stress, determination of family relationships, and play therapy for children. Shama described a program of pretransplant preparation and post-transplant follow-up. Strategies included medical play and discussion about the procedure. Program evaluation indicated that parents and children felt very positive about the program. Shama recommended that child donors meet other donors and that social workers accompany children to the operating room. Because minimal information has been provided about methods to support donors, other interventions should be developed and evaluated.

Interventions should provide opportunities to express emotions at each step of the process (Andrykowski, 1994a; Gardner et al., 1977; Packman, Crittenden, Fischer, et al., 1997). Donors need care and support to work through any concerns that are identified during all phases of the process. Key issues to be addressed are fears related to tests and the harvest, resentment about being chosen, desires to avoid being a donor, guilt, and worries about the future welfare of recipients. Education should include information about the illness involved, why and how transplantation works, and step-by-step information about tests and harvest. Heiney (1991) suggested that children especially need to know what they will see, hear, and feel. In addition, preparation and support of child donors should include parental involvement and address the importance of ongoing communication in the family. Support should extend beyond the time of harvest and recovery. These criteria are difficult to accomplish when donors spend limited time at transplant sites.

Purpose and Goals

Based on a literature review and the authors' experience working with families and siblings, pragmatic goals were established for an intervention (see Figure 1). The psychosocial team's goal was an intervention that would minimize immediate stress and enhance long-term adjustments (Bryant, Heiney, Henslee-Downey, & Cornwell, 1997; Chesler et al., 1993; Heiney, Goon-Johnson, Ettinger, & Ettinger, 1990; Heiney, Neuberg, Myers, & Bergman, 1994; Heiney, Wells, Ettinger, Ettinger, & Cannon, 1989).

- Provide anticipatory guidance about steps involved in bone marrow harvest from evaluation through recovery.
- Teach caregivers to be supportive of children's experiences.
- Reduce anxiety associated with the physical requirements of being a donor.
- Provide opportunities for catharsis.
- Assess children's awareness and understanding of the role of donor.
- Identify and correct misconceptions about being a donor.

Figure 1. Program Objectives

Format of Intervention

A structured intervention was developed to support children 18 and older who would be donors for siblings or parents. The transplantation team obtained informed consent from parents. South Carolina has no legal requirement that child donors have formal psychological examinations. Therefore, children were evaluated informally during psychiatric workups and throughout preparation. In special cases (e.g., a donor had a known psychiatric history or diagnosis), donors were referred for formal evaluation.

The intervention was designed to provide developmentally appropriate information and support, as well as recognize and meet varying levels of need for information and support. Components included (a) a parent interview and educational session, (b) a therapeutic session for the child, (c) coaching and tour the day before harvest, and (d) follow-up. Expression of feelings and other psychotherapeutic interventions were integrated into each component. Early in the program, the psychosocial staff identified the need for a book to strengthen and extend interventions beyond the immediate transplant period. The intervention included the use of a book developed by the psychosocial staff titled *The Gift: For Children Who Are Bone Marrow Donors* (Heiney & Lamphier, 1996).

Parent Session

The bone marrow transplant coordinator notified psychosocial staff when children were scheduled to be donors. During workups, psychosocial staff members informed parents about the intervention for donors. Parents or other caregivers were given an overview of the program and an opportunity to ask questions. For example, parents wanted to know the procedures on the day of surgery and whether they would be allowed to stay with the children. No parents refused to allow their children to participate in the program. Initially, some were hesitant about allowing staff to have private sessions with the children. However, with adequate support and education about the importance of the intervention, all of the parents agreed that their children could participate in the program, which was not a research study. A typical fear expressed by parents was that children would be "told too much." Although staff responded to this explicit concern, they also addressed caregivers' underlying fears of distressing children. A psychiatrist might say

"A parent's natural response is to protect the child. But the reality is that your child is about to undergo an intensely stressful experience. The unknown elements of any experience are often the most frightening. Our goal is to support the child and offer comfort. We know this is your goal as well. We believe the intervention offers the most potential for helping your child through this event."

Therapeutic Session

The nurse psychotherapist met with children prior to presurgical evaluation. Psychosocial assessment, education, and therapeutic interventions were integrated into each session. The nurse psychotherapist explained the meaning of being a donor and reviewed the process of harvest from preoperative assessment to postoperative care. Appropriate sections of the book were used to reinforce or further elaborate. For donors younger than five, the book and activities were used with adult coaches, such as parents. Teenage donors

were instructed to read the section about adult caregivers because the information would help them understand the process. Also, the nurse psychotherapist suggested that teenagers read the healing story and give opinions about its usefulness with children. Thus, the story could touch teenagers on an unconscious level without making them feel immature.

Children's cognitive levels of development and any past experiences with surgery or hospitalization were used to individualize sessions. Because children relate to their worlds concretely, the nurse psychotherapist used adjunctive teaching tools and play therapy techniques that incorporated visual, auditory, and tactile tools. For example, for children and teenagers, a large cloth bone filled with cells was used to demonstrate the effects of the treatment on the disease and how new cells enter marrow. Also, a teaching puppet was used for younger children to show the location of the iliac crest and the dressings that would be used after surgery. Older children and teenagers were shown pictures and diagrams in the teaching book. The teaching tools led donors to express concerns that they had not shared earlier. Several young adolescents wondered whether the procedure would affect their physical appearances.

Incorporated into this content was an assessment of the common problems associated with venipuncture. If children seemed fearful, parents were encouraged to request the use of the eutectic mixture of lidocaine and prilocaine cream (EMLA[®], Astra-Zeneca, Wilmington, DE) for venipuncture sites. The average procedure includes two needle sticks, one for preoperative laboratory work and one for sedation. Decreasing stress about needle sticks seemed to significantly reduce overall stress associated with the procedure. If significant needle phobia was present, the psychosocial staff initiated additional support measures, including relaxation, imagery, and medical play. Staff members coached children during actual needle sticks if needed.

Therapeutic communications were incorporated into sessions and individualized to meet the needs identified as sessions progressed. For example, one seven-year-old was concerned that his sibling (the patient) might die because he (the donor) had misbehaved at school. Using the therapeutic story in the book encouraged expressions of typical emotions. Issues of guilt were addressed specifically, as were normal feelings of dread and resentment.

If psychological difficulties were identified, they were discussed with the consulting psychiatrist, who talked with the family and made appropriate referrals or followed up. For example, an especially anxious 10-year-old was found to be suffering from acute panic attacks, as well as generalized anxiety about the procedure, and was treated appropriately.

Coaching and Tour

Psychosocial staff members accompanied children and their caregivers to the outpatient surgical area and provided anticipatory guidance about the area and preoperative preparation. When the necessary examinations were completed, staff members took children to the pediatric holding area. Using teaching tools, the staff members clarified and reviewed what would happen in the room before surgery. The children were able to observe a small area of the operating room and see staff dressed in surgical attire. Parents were told they could wait with children and that the anesthesia staff would arrive and take the children into the operating room. At the end of the tour, the staff members reviewed the therapeutic activity section of the book

and discussed how parents and children might use them to reinforce learning and expression of feelings.

Follow-Up

A liaison psychiatrist worked with parents and donors during routine visits to patients. Ideally, donors should be interviewed, but this was not possible because of staffing limitations. On rare occasions, if donors appeared to be experiencing unexpected or severe psychological difficulties, individual sessions were scheduled. If patients became terminal while at the transplant center, supplemental support was provided for the donors.

Program History

Support for donors was initiated after the establishment of the bone marrow unit in 1992. Since then, 110 individuals ages 1–18 were used as donors. Forty-seven donors were ages 9–10, and the remaining 63 were ages 10–18. Donors' relationships to recipients were diverse: 24 were brothers, 26 sisters, 33 sons, and 15 daughters, among others. The majority of donors underwent bone marrow harvest; two had peripheral stem cell collection.

This article includes six years of cumulative clinical experience of working with donors. The following clinical evaluation summarizes information from 12 children ages 5–18 who were cared for after the initial publication of the book used in the program, *The Gift: For Children Who Are Bone Marrow Donors* (Heiney & Lamphier, 1996).

Clinical Evaluation

To evaluate the program, including the book, a clinical evaluation of 12 children was prepared after book publication. Two to three days after the harvest procedure, parents or primary caregivers were interviewed to obtain perspectives on the children's experiences and the value of the program. The interview guide is shown in Figure 2. The staff member who completed these structured interviews was not the same staff member who provided sessions for children so that parents would feel more open in providing both positive and negative feedback. The interviewer used a standardized schedule of

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1. How did your child react to being chosen as a donor?
 2. How did you and your family prepare your child to be a donor (i.e., counseling, books, articles, open discussion, no action, other)?
 3. What comments has your child made about the preparation and the information he or she learned from the pretransplant tour?
 4. What comments has your child made about the preparation and the information he or she learned from the pretransplant preparation session?
 5. What comments has your child made about the preparation and the information he or she learned from the pretransplant book?
 6. What effect do you think the preparation had on your child? Have you noticed anything different about your child's behavior or attitude since the preparation?
 7. How was the book helpful to you and your family? What part of the book was most helpful to you?
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Figure 2. Parent Interview Guide for Program Evaluation

questions to ensure that the information obtained would be consistent. The age range of the children was 5–18 years. The evaluation was ongoing for 15 months.

The results of the program have been overwhelmingly positive even though parents indicated that they already had implemented several activities to help prepare children. Of the 12 parents interviewed, 7 had involved children in counseling, 7 had used books or articles, and all 12 had discussed the situation with the children.

The children had varied initial reactions when informed that they would be donors. These included apprehension, generalized and specific fears, gratitude for being chosen, and excitement about the prospect. One child commented, “I want to help my mom, I am nervous, I am so excited.”

Parents were asked to report their observations about the children, along with any comments the children made about the preparation or information they learned from the pretransplant preparation sessions. Parents reported that, although most of the children initially were hesitant, they quickly showed interest and told them about the information they had gained from the tour. One parent noted that the preparation helped the child become familiar with the surroundings in the holding area and operating room. Another parent expressed appreciation that the tour was geared to the child’s developmental level and noted that the child especially enjoyed the teaching puppet. One parent noted that, although “he is a very quiet child,” he “was helped a lot by the session.” Several children reported feeling less frightened about the upcoming procedure after the therapeutic sessions. Donors seemed more open to asking questions and expressing emotions. One child, although frightened of the prospect of the surgery, gained confidence through awareness, experience, and practice of what was to come.

Parents were asked specifically whether they noticed anything different about donors’ behaviors or attitudes after the preparation. Overall, the preparation was reported to have decreased donors’ fears. A surprising result was that donors responded with more compassion toward recipients than they had prior to harvest. Perhaps donors felt nurtured and were able to reach out to recipients. One parent commented that the donor did not hold back as much in “giving love” and spent more time with the recipient.

Parents were asked to share comments that the children had made about the pretransplant preparation or the book, *The Gift: For Children Who Are Bone Marrow Donors* (Heiney & Lamphier, 1996). Parents noted that the book gave information in positive terms and provided an opportunity to discuss questions and concerns. The book was especially helpful because it was geared to the children’s developmental level. It helped children better understand the procedure and alleviated some fears because it “explained things in a way a child could understand

and gave a clear picture of what was going to happen.” Also, the book provided a sharing venue and facilitated communication between parents and children. In many instances, parents and children read the book together. One parent said that she felt confident about her feelings after completing the book activities.

Another benefit was that the book gave children a tangible reminder of the process and a comfortable place to revisit when feeling anxious. The metaphorical story found in the first part of the book provided a nonthreatening introduction to the process for parents and children. One parent said that comparing the transplant process to planting a garden with good seeds was especially helpful. The story gave donors information in a nonconfrontational manner.

Finally, parents were asked whether they had any overall comments, concerns, or questions. They commented that preparation added a sense of openness and helped to facilitate communication. Parents noted two areas that could have been addressed better. They recommended a booklet for children younger than five because the activities were developed for school-aged children. They also suggested that, because children have great variation in pain tolerance, the preparation should address the topic to increase parents’ and children’s awareness of this variation and appropriate ways to manage it. Nursing staff noted an overall decrease in both caregiver and donor anxiety after the program. Children were more cooperative about procedures such as needle sticks and seemed more confident. The nurses also believed that communication was enhanced between donors and recipients and between families and staff members.

Summary and Recommendations

Child donors benefit from preparation and support throughout the process. Parents validated the benefits of such support. Clinicians at other transplant centers may apply this information to patients and families. Because of the current climate regarding informed consent and current research on post-traumatic stress symptoms generated by events such as surgery and cancer, a child psychiatrist should evaluate each child scheduled to be a donor. Researchers may find many fruitful areas for investigation. Particularly, researchers could explore whether long-term psychosocial morbidity is decreased in donors who are prepared by this type of intervention.

The Gift: For Children Who Are Bone Marrow Donors can be ordered from South Carolina Cancer Center, Palmetto Health, in Columbia. Call 803-434-4760 to request information or place an order.

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For more information . . .

- American Bone Marrow Donor Registry
www.abmdr.org
- BMT InfoNet: Bone Marrow and Blood Stem Cell Transplants
www.bmtinfonet.org/transplanthandbook.html
- National Marrow Donor Program
www.marrow.org

These Web sites are provided for information only. The hosts are responsible for their own content and availability. Links can be found using ONS Online at www.ons.org.