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The Ethical Justification for Minor Sibling Bone Marrow Donation: A Case Study

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ABSTRACT
Using a case study of a mentally delayed minor sibling donating bone marrow for his older sister, we discuss an alternative ethical justification for minor donation. The accepted justification for permitting minor siblings to donate bone marrow or peripheral blood stem cells is that the donor will benefit because of the greater likelihood of survival and less suffering of the sibling. Based on the limited data from four small retrospective studies of the risks and benefits for minor donors, we argue that there is a possibility, illustrated by this case, that the donor may not benefit, particularly if the transplant is unsuccessful. We, therefore, encourage the oncology community to increase support for minor donors, particularly mentally delayed ones. We also argue that the donation can be ethically justified based on the donor’s familial duty to his sister. The basis of familial duties is complex, including such factors as the nature, intimacy, and history of the relationship and the specific risks and benefits to all involved. We examine each of these factors for our case study. The Oncologist 2008;13:148–151

Chris* is a 16-year-old young man with a mental capacity of an 8-year old. He has been chosen to be the bone marrow donor for his 19-year-old sister, Jordan, who has relapsed for the second time with leukemia. Both Chris and his mother were HLA typed; Chris shares eight of eight antigens with Jordan and the mother shares six of the eight antigens. The parents, in consultation with the physicians at the transplant center and at home, decided that Chris was the best donor for his sister, and the transplant and donation were scheduled. Chris is very excited about the donation, proclaiming “YES. YES. YES. I get to save my big sister’s life.” Yet other members of the family are concerned about Chris’ role because of his mental age, his tendency to blame himself for mishaps, and his sensitivity to pain.

The accepted justification for permitting minor siblings like Chris to donate bone marrow (BM) or peripheral blood stem cells (PBSCs) is that the donor will benefit because of the greater likelihood of survival and less suffering of their

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*This case is a fictionalized case based on preliminary research performed by this research team with minor bone marrow donors.
sibling [1]. Courts that have authorized kidney donations by minor siblings, including mentally delayed siblings, have relied predominantly on this justification [2, 3]. Some transplant physicians agree [4]. As Month [5] states, “I do not believe that a day of minor discomfort and an extremely small risk of anesthesia outweigh a lifetime without a healthy older brother or sister and the years of joy it potentially brings.” One minor sibling donor reported, “You have prevented a life from, you know, disappearing” [6]. Extensive research with adult (mostly unrelated) donors, by Switzer et al. [7], has established psychological benefits to donors, including increased self-esteem, pride in donating, feeling like a better person, and increased meaning and worth of life. These occur even among bereaved adult sibling donors [8]. The assumption that minor related BM donors benefit similarly is largely untested.

After careful review of the literature, it appears that only four psychosocial studies of minor BM donors have been published. The first study, reported in three separate manuscripts [9–11], compared 21 donor siblings with 23 non-donor siblings 3–3.5 years post-transplant. Donor siblings reported higher levels of anxiety and lower self-esteem than non-donors. Self-reports of depression and post-traumatic stress disorder were not significantly different between the two groups. Parent-report measures suggested that donors showed more depression and withdrawal than non-donors, though this difference only trended toward statistical significance. Interestingly, teacher-report measures indicated that donors showed more leadership and adaptive skills in the classroom than non-donors. The generalizability of this research is limited because only siblings whose ill brother or sister survived were interviewed.

The second study [6] compared BM donors whose ill siblings were still alive (n = 8) with those whose siblings died (n = 7). Nearly all donors whose siblings lived believed that the experience had a predominantly positive impact on many aspects of their lives, including perceptions of self (i.e., self-esteem), relationships within the family, and world view. In contrast, donors whose siblings died reported both positive and negative aspects. Feelings of guilt, shame, and anger often overshadowed the positive effects.

The third report [12] included interviews with 19 siblings of children with chronic diseases as a part of a larger study. In general, these siblings were quite concerned about the patient but felt like they were “outside the circle,” that is, not involved in the discussions or decisions about their ill sisters/brothers. The siblings reported a heavier family chore workload and greater loneliness. Six of the siblings interviewed were BM donors. They explained that the opportunity to donate allowed them to “join the circle” and help their ill sibling, though they also reported reluctance to undergo a second donation because of the pain and worries about the efficacy of their donation.

Finally, a study of eight female siblings of seven BM transplant patients, three of whom were donors, did not find a significant difference between donors and non-donors but identified that all the children experienced an interruption of normal family life and greater responsibility. As one child 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” [13].

These studies have some limitations: (a) as small descriptive studies, they provide important details about the participants, but not about how these experiences compare with those of siblings not included in the studies; (b) some outcomes may be influenced by pre-existing conditions, which were not controlled for; and (c) because the data were captured years post-transplant, some of the immediate benefit that donors experienced may not have been captured. In spite of these limitations, these studies present an interesting, if mixed, picture of both positive and negative outcomes. There are suggestions that minor donors may experience greater psychological distress, particularly if the transplant is unsuccessful. Clearly, more research needs to be done. Given the preliminary nature of the data, what can the oncology community learn from these studies?

First, because there are risks to donors, support for the donor needs to be strengthened, both at the transplant center and in the referring oncologist’s practice. For example, at The University of Texas M.D. Anderson Cancer Center, each donor is assigned an independent medical team including a child life worker, a social worker, a nurse, and a physician [14]. This team focuses solely on the welfare of the donor, whereas the cancer patient’s team focuses solely on the patient. Conflicts of interest inherent in one medical team caring for both the patient and the donor are avoided and, presumably, more attention can be paid to the donor’s needs. Within this model of care, sibling donors could receive a careful psychological evaluation prior to transplant, and systematic follow-up could be designed for implementation at home. If problems emerge, empirically supported therapies could be recommended to the family’s home health care team.

Second, the ethics and oncology communities may need to rethink the ethical justification that minor sibling donors benefit from donating BM or PBSCs for their sibling’s transplant. The ethics community has offered two nuanced justifications, both expanding the definition of “benefit” such that one person’s benefit includes what happens to others: (a) intrafamilial justification—the well-being of one family member is intimately tied to another family member’s well-being, so indirectly the donor benefits by donat-
ing to a close family member [15, 16] and (b) the intimate attachment principle—one’s life is diminished when anyone, family member or not, dies and so a minor’s interests are served by being allowed to donate BM to an intimate friend or family member [17]. For sibling donation, a third ethical justification should also be considered: the duty justification [18]. Family members have obligations to each other, just because they are in the same family [19–21]. For example, we expect parents to provide care and support for their children. Likewise siblings have duties toward each other. Even if subsequent research shows that the negative sequelae for some donors, particularly those whose sibling dies, outweigh even an extended view of benefit, the duty justification argues that a sibling may simply owe his brother or sister the donation because of their family relationship.

Even if one agrees that family members have duties to one another, one must still determine whether a specific act, in this case donating BM, is one such duty. This determination is complex, and involves factors such as the nature, intimacy, and history of the relationship and the circumstances of the specific need that the family member is expected to fill, including the risks and benefits to all involved [22]. Actions that require great sacrifice are usually considered “beyond the call of duty,” so the level of risk must be determined. In intimate families in which the siblings are close, a low-risk BM donation for a transplant with a good likelihood of success would be considered a duty under this view.

Let us return to the case of Chris to consider the duty justification. Chris and his older sister are part of an intimate family. Their relationship has always been close, with the older sister taking care of Chris even more than usual, because of Chris’ mental delay. The circumstances of the need are that Jordan has an approximately 10% chance of survival without the transplant and an at least 50% chance with a transplant from a matched sibling donor.

Jordan’s need is great, and Chris is a suitable donor. A transplant with a matched unrelated donor (MUD) could have a similar probability of survival at an experienced pediatric transplant center, but would increase the risk for graft-versus-host disease. Further, a MUD would place a stranger at a slight risk. If Jordan’s mother, who is a partial antigen match, served as the donor, the transplant prognosis would significantly worsen. Not only would Jordan’s chance of survival be less, but the possibility of graft-versus-host disease would be greater, significantly impacting her quality of life. Jordan’s well-being is therefore best served if Chris is the donor.

The risk assessment must also assess the risk to Chris, which is based in part on the method of donation. While a pediatric BM donor would typically undergo general anesthesia for the harvest, a pediatric PBSC donor may or may not need anesthesia, depending on whether central venous access is needed. However, PBSC donation, though medically safe itself [23], requires the use of a growth factor that involves some risk [24–26]. Further, a PBSC transplant may increase the risk to Jordan [27]. Either method is expected to result in temporary pain. Other risks include multiple needle sticks and a possibility of anemia. Assessing the psychological risk is more difficult. With the mental age of an 8-year old, Chris is not competent to make the decision to donate. The literature suggests that most children do not attain the ability to reason comparably to an adult until about 14 years old [28–31]. However, a transplant team would assess an 8-year old’s willingness to undergo a donation, asking him what his options are, what the outcomes of each option are, and his reason for agreeing to be a donor. When Chris was asked about donation, after a first tearful, fearful response, he became very enthusiastic, almost elated. He told his school friends that he gets to save his sister’s life. This elation is a cause for concern. An unrealistic assessment of the success of the transplant and his role as “savior” may put Chris at a higher psychological risk, particularly if Jordan experiences severe complications or dies.

Given these concerns, and the suggestion in the literature of greater risks if the transplant is unsuccessful, one could argue that Chris himself might not benefit from the donation, particularly if the transplant is unsuccessful. However, in a duty analysis, a donation may be justified even if it does not benefit Chris, as long as there is “a moral match between the relationship and the risks to the donor relative to the benefits to the recipient” [19].

One obvious concern remains. Does Chris’ developmental delay preclude him from having family duties? We think not, although his duties must be aligned with his abilities. Eight-year olds usually have family duties appropriate for their age. It could be argued that a low-risk medical procedure is one such duty. In sum, because Chris and Jordan have an intimate relationship with a long history, and because the risks to Chris are small compared with the potential benefits for Jordan, this donation can be justified as Chris’ familial duty to Jordan, even though Chris may not benefit overall from the donation.

Although further research is clearly needed into the risks and benefits for minor sibling donors, transplants between siblings can be ethically justified using other bases than benefit to the donor. As research proceeds, the oncology community may want to enhance its support of donor and nondonor siblings to help avoid the negative sequelae experienced by some. In cases such as Chris’, in which the donor has unrealistic expectations, the family could be given strategies to help the donor. For example, all family
members could discuss the upcoming transplant using phrases like “all of us, together as a family, are trying our best to give Jordan a better chance.” Finally, oncologists in the community can work with families upon their return home to attend to the needs of the donor, particularly vulnerable, mentally delayed donors like Chris.

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