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Duty and Altruism: Alternative Analyses of the Ethics of Sibling Bone Marrow Donation

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Douglas Opel and Douglas Diekema present a careful analysis of a difficult sibling donor case in this issue of *The Journal of Clinical Ethics:* 15-year-old A.R. and his mother chose to pursue a bone marrow transplant for his relapsed acute myelogenous leukemia (AML). The best HLA matched bone marrow[1] was that of his nine-year-old sister, L.R., whom A.R. was incarcerated for having sexually abused. Was L.R.'s participation as a donor for her brother ethically justifiable? Opel and Diekema divide the analysis of this case into three issues: (1) Should prisoners have access to bone marrow transplants (BMTs)? (2) Should parental permission be considered valid in this case? (3) Should a minor sibling who was sexually assaulted by the patient be allowed to donate bone marrow?

I agree substantially with the conclusions offered by Opel and Diekema — prisoners should have access to BMTs, but L.R. was at such risk for psychological damage that, at a minimum, a complete psychological assessment of the child without her mother present should have been required. Opel and Diekema are skeptical that the donation met the physician's duty to do no harm. However, I would like to offer a different method of analyzing this case that I think fits better with the moral foundations of family decision making. I will not discuss the issue of prisoners' rights to BMT, agreeing completely with Opel and Diekema's analysis.

Undergirding the proffered analysis is the goal of protecting L.R.'s well-being. First, Opel and Diekema ask if the mother could have been a trusted decision maker who would protect L.R.'s well-being, since she was inherently conflicted, being the primary decision maker for her son as well as for L.R. There is no doubt that parents are conflicted as decision makers for transplant and sibling donation, and I have argued that this conflict requires that special protections be built into the process of sibling donation.[2] Opel and Diekema then consider Ross's view that L.R.'s well-being could have been protected as long as her basic interests were protected. They conclude that since the R. family lacked the intimacy required by Ross's model of constrained parental autonomy — A.R.'s abuse introduced a destructive element into the family and A.R. did not live with his mother — to enhance the well-being of the family would not necessarily enhance L.R.'s well-being. The authors then offer their own preferred analysis using the harm principle: parental decisions should be respected as long as they do not result in a harm that is higher than an appropriate harm threshold. They conclude, I think correctly, that although the physical harm from bone marrow donation does not exceed this harm threshold, the little empirical evidence that exists suggests that, for L.R., the risk of psycho-

logical harm could have well exceeded this threshold. Further, the mother's refusal to allow an unfettered psychological assessment made a determination of the potential for psychological harm difficult, if not impossible. The authors conclude, "the harm to L.R. was likely to exceed any potential benefits." Notice the framework throughout this analysis: How do we protect L.R's well-being by ensuring the proper decision maker for her?

In contrast to this approach, there is a thread in the bioethical literature that tempers the focus on the individual's well-being with various approaches to including family interests. I think one version of this family focus may provide a better justification for sibling donation in general and can inform the analysis of this case.

In his seminal article, "What about the Family?" John Hardwig argues that the medical attention to the patient's interests can allow the patient to shirk responsibility to the family.[3] Hardwig therefore proposes that family conferences in certain cases be given decisional authority, so that the interests of the family can be treated on a par with the interests of the patient. James Nelson continues this concern for the family, arguing that family interests should be factored into medical decisions, with the patient's interests having a "rebuttable presumption of authority."[4] Yet, Nelson also interestingly describes how loving families do not always try to maximize each member's well-being, and may somewhat cavalierly put members at risk to achieve family goals. For example, responsible, loving parents put small children in the car for a drive in snowy weather to go buy a bottle of wine for guests. Ross's view of constrained parental autonomy is in line with this literature that allows parents to trade the best interests of the child for family interests *as long as the child's basic interests are not compromised.*

Some have pushed this emphasis on the family beyond suggesting that family interests must be considered to an account of family duties, namely that family members have obligations to one another.[5] This view shifts the focus from rights and interests to family duties, a switch that may better explain the underlying intuition that in many cases siblings should donate bone marrow. Opel and Diekema are completely right in their analysis that the prevailing justification for sibling donation — that the donor benefits — is weak. The scant empirical evidence does not completely support this view. Further, this view requires that donations take place in intimate families in which the donor's well-being is enhanced when the family flourishes, which excludes dysfunctional and even partly functional families. Yet, the courts have frequently supported the even riskier donation of solid organs, and the general practice in oncology is to allow sibling donation of bone marrow without special review. Perhaps the true grounding for this consensus is not that the donor necessarily benefits, but that a sibling has a duty based on family relationships to undergo some risk for a sibling.

Let me sketch the family duty justification. Family members, because they are in family relationships, owe each other care, respect, and a certain level of sacrifice, regardless of whether or not the sacrifice benefits them. James Dwyer and Elizabeth Vig are correct, I believe, that different levels of relationship demand different levels of sacrifice — with parents owing their children more than siblings owe each other. And, as Benjamin Freedman argued, children owe their parents considerable duties.[6] The relationships that undergird these obligations are social relationships, not biological. A child who has no social interactions with a sibling or parent does not have duties to that parent or sibling, even if biologically related to them.[7] However, these duties do not hinge on the family being intimate or harmonious and functional. For example, a parent owes a wayward daughter the duty of care, even if she is disobedient and self-destructive. It may be that care is best shown by allowing the consequences of the daughter's actions to befall her without rescue, but this "tough love" would still be fulfilling the duty of care. Similarly, siblings still have duties to each other, even if their relationship isn't intimate. We expect an older brother to walk his younger brother home from school, even if, that month, he detests his younger brother. My account differs here from that of Walter Glannon and Lainie Friedman Ross, who believe that intimacy is the foundation for family obligations, although their use of "intimacy" may be closer to my use of "social."[8] On the other hand, there are limits to these duties.[9] Family relationships do not necessitate any level of sacrifice. We do not expect or allow parents to donate lungs to children, even if they want to. The sacrifice is too great. Dwyer and Vig, who claim

that obligations are implicit in relationships, argue that sibling donations for transplants are justified if there is "a moral match between the relationship and the risks to the donor relative to the benefits to the recipient."[10] This formula seems reasonable: a sibling may owe some risk for the potentially lifesaving bone marrow transplant. Yet, given Opel and Diekema's analysis of the potential for harm to L.R., one might reasonably conclude that the risks, given her psychological vulnerability, may be too great to justify the donation.

There is another caveat in a family duty view that is particularly relevant to the case of L.R. It is possible to so fracture the relationship that undergirds the familial duty that the duty is no longer operative. Take, for example, an abused wife. Her abusive husband has fractured any relationship of care and respect by abusing his wife. She therefore no longer owes him care and respect and sacrifice. Similarly, I would argue that A.R. has so fractured the sibling relationship by sexually assaulting L.R. that any duty she had toward him is no longer operative. She does not owe him the sacrifice required in a bone marrow donation. Although I do not have a formula for exactly how fractured a relationship must be for duties to no longer be operative, and I do think duties are operative in mildly dysfunctional families, I do believe that criminal behavior toward a sibling or spouse qualifies as sufficient fracturing.

In short, I think the most cogent justification for our intuition that siblings should donate bone marrow is not that this donation benefits the donor either directly or through an enhanced family, but that the sibling, in many cases, *owes* this duty of sacrifice. But, in L.R's case, this duty is no longer operative due to the sexual abuse, and even if the duty were operative, the sacrifice could be deemed too great.

Yet, there may be a reason why L.R. could still be allowed to donate bone marrow to A.R. — altruism. Although the research is far from definitive, there is some indication that children as young as nine years old can act altruistically,[11] that is, act to benefit another without being motivated by either a material or social reward. Altruistic actions are morally praiseworthy and should be allowed, if not encouraged. For adults, altruistic acts that require great personal sacrifice are even more praiseworthy: "Greater love has no man than this, that he lay down his life for his friends." (John 15:13)."[12] Yet, for a child of nine, we reasonably put limits on altruism, because we do not judge that a nine-year-old has the capacity for mature judgment nor for complete cognitive understanding of the situation. Therefore, once again, since the potential for harm may be great for L.R., we would be reluctant to allow her to act altruistically for her brother without a thorough psychological assessment, which could determine whether her altruism would bring such benefit to her that it outweighed the harm.[13] If such an evaluation revealed that she understood that her brother's treatment of her was wrong, but that she wished to help him since he was still her brother, and she understood adequately the risks to herself, we might conclude that the donation should proceed. But if the evaluation revealed that L.R.'s motivation for offering to help her brother was not altruistic, but rather based on some masochistic view that she was a victim and deserved to be victimized again, the professionals should refuse to qualify L.R. for the donation. Such an evaluation should be a prerequisite for donation, and should not have been dependent on the mother's choice.[14]

In sum, although I reach conclusions identical to Opel and Diekema's, I do so using a very different approach: siblings have duties to each other that include some personal sacrifice; these duties are not unlimited and do not require great sacrifice; these duties can be negated by fractured sibling relationships; and, finally, siblings can donate bone marrow altruistically, if, once again, the harm is not too great. Like Opel and Diekema's analysis, my analysis requires a careful weighing of harms. For a vulnerable child like L.R., the harms might have been too great.

NOTES

1. Human leukocyte antigens (HLA) are histocompatibility antigens, which are used to determine whether a donor and recipient are immunologically compatible.

2. R.D. Pentz et al., "Designing an Ethical Policy for Bone Marrow Donation by Minors and Others Lacking Capacity," *Cambridge Quarterly for Healthcare Ethics* 13, no. 2 (2004): 149-55.

3. J. Hardwig, "What About the Family?" *Hastings Center Report* 20, no. 2 (March 1990): 5-10.

4. J.L. Nelson, "Taking Families Seriously," *Hastings Center Report* 22, no. 4 (July 1992): 6-12.

5. C. Weijer, "Family Duty is More Important Than Rights," *Western Journal of Medicine* 174, no. 5 (May 2001): 342-3; B. Freedman, "Respectful Service and Reverent Obedience," *Hastings Center Report* 26, no. 4 (July/August 1996): 31-7.

6. J. Dwyer and E. Vig, "Rethinking Transplantation between Siblings," *Hastings Center Report* 25, no. 5 (September/October 1995): 7-12; Freedman, see note 5 above.

7. See note 2 above, p. 153.

8. W. Glannon and L.F. Ross, "Do Genetic Relationships Create Moral Obligations in Organ Transplantation?" *Cambridge Quarterly of Healthcare Ethics* 11 (2002): 153-9.

9. D. Steinberg, "Kidney Transplants from Young Children and the Mentally Retarded," *Theoretical Medicine* 25 (2004): 229-41.

10. Dwyer and Vig, see note 6 above, p. 11.

11. E.M. McGee, "Altruism, Children, and Nonbeneficial Research," *American Journal of Bioethics* 3, no. 4 (Fall 2003): 21-3; R.M. Nelson and W.W. Reynolds, "We Should Reject Passive Resignation in Favor of Requiring the Assent of Younger Children for Participation in Nonbeneficial Research," *American Journal of Bioethics* 3, no. 4 (Fall 2003): 11-3.

12. N. Eisenberg, *The Socialization and Development of Empathy and Prosocial Behavior* (East Haddam, Conn.: National Association for Humane and Environmental Education, 1983), *http://www.nahee.org/research_evaluationPDF/Socialization%20and%20Development.pdf.*

13. B.J. Seelig and W.H. Dobelle, "Altruism and the Volunteer: Psychological Benefits from Participating as a Research Subject," *American Society for Artificial Internal Organs (ASAIO) Journal* 47, no. 1 (January 2001): 3-5.

14. Personal communication from B.J. Seelig, MD, a Professor of Psychiatry at Emory School of Medicine who has done extensive work on altruism, on 8 July 2006.