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A Compounding of Errors: The Case of Bone Marrow Donation between Non-Intimate Siblings

Lainie Friedman Ross and Walter Glannon

Lainie Friedman Ross, MD, PhD, holds the Carolyn and Matthew Bucksbaum Professorship at the University of Chicago; is a Professor in the Departments of Pediatrics, Medicine, and the College; is Section Chief of Community Health Sciences, Institute for Molecular Pediatric Sciences; and is Associate Director, MacLean Center for Clinical Medical Ethics at the University of Chicago in Chicago, Illinois, *lross@chicago.edu.*
Walter Glannon, PhD, is Canada Research Chair in Medical Bioethics and Ethical Theory at the University of Calgary; and is an Associate Professor in the Departments of Philosophy and Community Health Sciences.

INTRODUCTION

In this issue of *The Journal of Clinical Ethics,* Opel and Diekema describe the disturbing case of a nine-year-old, L.R., who serves as a bone marrow donor to A.R., her 15-year-old brother who has relapsed acute myelogenous leukemia (AML). A.R. is incarcerated because he had been found guilty of sexually assaulting L.R. In their analysis, Opel and Diekema consider three questions. First, should prisoners have access to costly medical interventions like bone marrow transplant? Second, should parental permission for the use of bone marrow obtained from a minor sibling be considered valid? Third, should a minor sibling be permitted to act as transplant donor when the recipient has sexually assaulted her in the past? Our answers to the first two questions would be similar to theirs. Yes, A.R. should have access to costly medical interventions, and sometimes parents can authorize bone marrow donation between siblings. However, the wording of the third question leads Opel and Diekema to an analysis that fails to capture what is most disturbing about this case. The main ethical question is not whether it is permissible for a minor sibling to serve as a transplant donor for a recipient who sexually assaulted her. Rather, the question is, *Who should have protected a minor sibling from being asked to serve as a transplant donor to a recipient who sexually assaulted her?* The failure to protect L.R. from being medically evaluated, let alone from donating, is compounded by the social context in which her donation occurred: numerous parties had moral and legal obligations to protect her, but failed to do so, including her mother, the transplant community, and the legal and penal systems.

In this article, we will examine four questions: (1) When is it ethically permissible to ask children to serve as bone marrow donors? (2) When the relevant criteria do not hold and it is

not permissible, whose obligation is it to protect the potential child-donor? (3) Is it ever ethically permissible for an individual to donate to a recipient who sexually assaulted her? and (4) What are the appropriate next steps?

WHEN IS IT ETHICALLY PERMISSIBLE TO ASK CHILDREN TO SERVE AS BONE MARROW DONORS?

Unlike solid organ transplantation, bone marrow donation requires a living source. Because of the importance of histocompatibility, siblings, whether adults or minors, are often the best source of bone marrow or stem cells.[1]

Opel and Diekema cite Ross's arguments from *Children, Families, and Healthcare Decision-Making,* to consider when it is ethical for a child to serve as a bone marrow donor.[2] In that work, Ross was clear that such donations should only occur within an intimate family.[3] Ross argued that within an intimate family, parents can authorize the donation by one sibling for another on the grounds that the well-being of one child is intertwined with the well-being of other family members. While the donor is being used as a means to promote the recipient's well-being, the donation serves to promote the well-being of the family (on which the donor's own well-being depends). As such, the donation serves the donor's goals, albeit indirectly.[4] It also benefits the donor and treats her as an end-in-herself.[5]

In the case described by Opel and Diekema, there is no family intimacy. And in the book, Ross is very clear that children should not be asked to donate beyond the realm of intimacy. In fact, Ross specifically uses the case of not forcing a girl who is raped by her brother to serve as his living donor.[6] Ross expressed concern about the parent's inability to protect her. Although L.R. did not refuse to donate, and one could even describe her as having passively acquiesced, we believe that her mother should not have been allowed to authorize the intersibling donation because she failed to protect L.R. from her brother. Instead, the state had to intervene to protect L.R. by incarcerating A.R. Thus, the mother's ability to protect L.R. was shown to be inadequate. This is not to say that the mother was to blame for the assault. Clearly the state took this into consideration when it allowed her mother to continue to care for L.R. after her brother's incarceration.

Nevertheless, the mother had conflicting interests. She had two children, one of whom harmed the other. Ms R. had reasons to show mercy towards A.R. for what he did to his sister, but she cannot insist that L.R. do the same. Rather, Ms R. must provide L.R. with appropriate family support and protection. Ms R. must also help L.R. overcome her physical, emotional, and psychological trauma. Clearly L.R. needed therapy.[7] The failure to seek this is worrisome: worrisome on the part of Ms R., who may have been in denial; worrisome on the part of the state that it did not ensure L.R.'s psychological well-being when decisions about custody and incarceration were being made.

In fact, we fear that Ms R. failed to provide L.R. with her basic needs of protection and the promotion of her self-respect.[8] Ms R.'s decision to ask L.R. to visit her incarcerated brother was unduly demanding of L.R., particularly since she had not had adequate therapy to address the meaning of the assault. Maybe L.R. was taken along because there was nowhere to leave her; maybe her mother thought L.R. should forgive her brother; or maybe her mother did not perceive a problem, given that L.R. was no longer physically at risk. If Ms R.'s reason was pragmatic (that is, Ms R. had nowhere to leave L.R. while she visited her son), social services should become involved in protecting L.R. She required psychological and emotional support and strength to recover from the assault. L.R. needed help to heal successfully and to develop the capacities and maturity required to move beyond it. Her mother's refusal to allow L.R. counseling is a sign that her mother failed to promote her recovery. Finally, if the reason L.R.

was taken to visit her brother was because Ms R. did not perceive that L.R. was physically at risk, then the mother failed to see the emotional and psychological harm she imposed, and this in and of itself might have constituted child abuse or neglect. Thus, we have reason to question the mother's ability to protect and promote L.R.'s emotional and psychological well-being.

Even if one were to take a broader notion of parental authority, that parents can authorize a donation because it is minimal risk (a position we do not hold), we would still argue that the donation should not have been permitted because L.R. did not — indeed, could not — assent. For donation from a minor such as L.R. to be ethically permissible, two conditions would have been necessary: (1) she must not have been exposed to more than a minor increase over minimal risk;[9] and (2) she must have assented to donation. Although the physical risks of bone marrow donation are at most a minor increase over minimal risk, depending on the method used, the potential risks to L.R. were much greater, given the history of assault. Asking her to donate exposed her to the risk of additional psychological harm beyond the harm from her brother's sexual assault. In addition, although there are no clear rules about what is required for assent, it is clear that mere non-dissent is not assent.[10] L.R. could not assent because of the violence within the siblings' relationship and because of her lack of emotional maturity and strength. These points are critical to understanding both the ethical permissibility of asking and allowing L.R. to donate and the obligation to protect her from harm.

WHEN THE CRITERIA ABOVE DO NOT HOLD, WHOSE OBLIGATION IS IT TO PROTECT THE POTENTIAL CHILD-DONOR?

As mentioned in *Children, Families, and Healthcare Decision-Making,* "It is significant that parents require the aid and expertise of health care personnel to harvest their child's organ for transplantation."[11] The involvement of third parties moves the locus of decision making out of the private domain of the family. Thus, the transplant team had an obligation to protect L.R., an obligation that holds when a family is intimate, but holds to an even greater extent when the family is non-intimate and the potential donor is a minor.

L.R. needed protection from the moment her brother was diagnosed with AML. The decision to test blood samples of family members for histocompatibility (HLA testing[12] for HLA matching) is not just a minimal-risk phlebotomy.[13] Rather, it should have been realized at that time that the decision to HLA type L.R. could lead to her being a complete HLA match, and how that would lead to a request for bone marrow donation. If the healthcare providers who sought consent to the blood draw had discussed the bone marrow typing and transplant process, they would have realized the profoundness of the request from the assault victim and the likelihood of further psychological harm to her. We would argue that in this case, L.R. should not have been asked to be typed for HLA matching by the physicians in charge of her brother's care, or by her own physicians, or by her own mother. L.R. was not protected by those who had an obligation to do so.

That said, we can imagine the case when healthcare providers did not know the full story and that L.R.'s mother did not appreciate the implications of the HLA matching. Although L.R. was found to be a complete HLA match, this did not mean that she was obligated to donate. The critical ethical issue here was not histocompatibility, but the potential for further psychological harm to L.R. in the wake of the ruptured intimacy of her family. Although we have argued that there is some degree of moral obligation for family members to donate to each other,[14] our argument assumed that there was intimacy. When intimacy does not exist, there is no obligation. In fact, when no intimacy exists, not only is there no obligation, but one could also argue that there is reason to be suspicious of a desire or even an acquiescence to donate. It suggests that the donor may have such a low level of self-respect, a lack of proper regard for her

dignity and intrinsic worth, that she feels she owes something to the individual who assaulted her.[15] Given that autonomous decision making presupposes a certain degree of self-respect, the victim's consent (or in the case of a minor, the victim's assent) should be understood as a cry for help and not as an autonomous choice.

Thus, the bone marrow transplant team, having learned that A.R. had sexually assaulted L.R., should not have allowed L.R. to serve as a donor despite her mother's authorization and her acquiescence. Critics may object that this is paternalistic. Recall that paternalism is the "the intentional overriding of one person's known preferences or actions by another person, where the person who overrides justifies the action by the goal of benefiting or avoiding harm to the person whose will is overridden."[16] But the situation at hand was not about interfering with an individual's decision about whether or not to donate, but whether to interfere with a parent's autonomy regarding authorization of *her child's donation.* The issue, then, was not about whether or not to respect individual autonomy, but parental autonomy. Proxy decision making is more restricted than individual autonomy because proxies have obligations to protect their recipient from harm. This means that individuals can expose themselves to greater risks than they can authorize others to assume.[17]

In fact, the team did otherwise. Psychological work-ups are often part of living donor evaluations. Clearly this is critical when the donor is a child who may not fully understand the procedures, or the risks and benefits, and that participation is non-obligatory. By acquiescing to her mother's insistence that L.R. not discuss the assault with psychiatry, the team provided L.R. with less protection than they would give competent adults. They unconsciously threatened L.R.'s self-respect by informing her that she should be "over" the assault or that the assault was at least not worth mentioning and not a factor in her voluntary decision to participate. The team reinforced any feelings of unworthiness, shame, and self-blame that L.R. may have experienced, feelings not infrequently experienced by assault victims.[18] We do not consider it an exaggeration to say that the donation without proper preparation and counseling was a second assault on this young victim.

Thus, numerous parties failed L.R. The transplant community failed to acknowledge the psychological and emotional harms that L.R. faced when they considered her as a potential bone marrow donor for her brother. They also failed to provide L.R. with the minimum protection offered to all donors: a psychological examination that would have unveiled whether the benefits of her participation outweighed the potential psychological and emotional harms. Ms R. failed to protect L.R. by failing to provide her with the long-term and intensive psychological services she needed to successfully address the assault.[19] The legal system failed to ensure that Ms R. was prepared to protect her daughter from further assaults of a psychological or emotional nature.

IS IT EVER ETHICALLY PERMISSIBLE FOR AN INDIVIDUAL TO DONATE TO A RECIPIENT WHO SEXUALLY ASSAULTED HER?

An individual who has been assaulted has reason to feel resentment towards her attacker. In *Forgiveness and Mercy,* Jeffrie Murphy argues that the primary value defended by the passion of resentment is self-respect, and that a person who does not resent moral injuries done to him is almost necessarily a person lacking in self-respect.[20]

A competent adult woman may choose to overcome her resentment. To overcome resentment is not necessarily to forgive. She may forget the moral injury that caused her resentment; or she may choose to extinguish her resentment for her own peace of mind. The motivation for forgetting is not moral but serves to promote her own mental health.[21]

Alternatively, a competent adult woman can cease to resent and forgive her assailant. To forgive is a moral action, a deliberate action to overcome resentment motivated by regard for the dignity and intrinsic worth of the other person.[22] One could argue that, for a self-respecting person, forgiveness would be a form of liberation from resentment and an expression of the inviolability of one's dignity.

Thus a competent adult woman can overcome resentment and either show mercy or forgive her assailant. In fact, a competent adult woman can go further and aid an assailant. But to do so takes a psychological and emotional maturity and often requires third-party therapy, for prolonged periods of time.[23] But L.R. is not a competent adult woman, and, in fact, she was not allowed the tools to overcome her resentment, let alone to forgive. As such, her mother's action reinforced any shame, self-blame, or low self-esteem and self-respect that she may have felt, feelings that are common in victims of assault. Someday L.R. may forgive her brother, but clearly this requires a maturity and psychological adjustment that she was developmentally unable to attain at the time of this case, particularly given that she had not had a chance to even process the assault and its meaning in counseling.

Opel and Diekema suggest that "providing L.R. the opportunity to save her brother's life might have allowed for some forgiveness. . . ." They have the causality wrong. Whether or not L.R. overcame her resentment and either forgave her brother or showed him mercy was her prerogative; A.R. had no right to either.[24] To the extent that A.R. might have come to feel remorse for his actions, he should have sought her forgiveness, but he could not prompt or demand it. How L.R. proceeded was her decision, it was not about "allowing him to give her this opportunity."

APPROPRIATE NEXT STEPS

Despite the HLA matching, A.R.'s physicians still had a chance to not procure bone marrow from L.R. As the case was described, bone marrow transplant was not the only therapeutic option. While we agree that A.R. had a right to medical care, even expensive medical care, he did not have a right to an HLA matched bone marrow transplant without the voluntary consent of the donor.

Unfortunately, the team did perform the bone marrow transplant, and Opel and Diekema describe the subsequent events. L.R. donated her bone marrow, A.R. improved for 10 months while still incarcerated, and then relapsed. This led to another decision point: he could undergo more chemo, another bone marrow transplant, or forgo treatment. He chose the latter and died two months later.

We were not told whether L.R. and A.R. ever addressed the assault nor were we told whether A.R. apologized or asked for forgiveness. His death left many issues unresolved and had profound implications for L.R. in two respects. First, living donors often blame themselves for bad outcomes in their recipients.[25] Even with good outcomes, child donors may find their participation stressful.[26] Second, A.R.'s death may have made it more difficult for L.R. to process the assault. While the request for donation opened up opportunities to address the meaning of the assault, the opportunities were ignored, and now it is too late.

A.R. did L.R. wrong by assaulting her and by accepting her bone marrow without ensuring that he was forgiven and that her donation was voluntary. Ms R. did L.R. wrong by permitting her to be HLA matched and then by permitting her to donate. The transplant team did L.R. wrong by agreeing to her donation despite her mother's refusal to allow for a full psychiatric evaluation and treatment plan. Given the lack of intimacy, the team did wrong by not providing L.R. with a guardian *ad litem.* A guardian would have realized that a nine-year-old girl cannot morally forgive her assailant, particularly if she did not have the opportunity to process

the events. All of the parties involved in this case failed to realize that the person at the greater risk of harm and who could and should have been protected was not A.R., but L.R. All parties did L.R. wrong by not providing protections at many levels.

Opel and Diekema agree. They conclude by focusing on the "potential for harm to the donor" and acknowledge that "the harm to L.R. was likely to exceed any potential benefits." They also hold that a thorough psychiatric assessment needed to occur before determination of compatibility. They propose appointing a guardian *ad litem* because of the ruptured intimacy. We agree with these recommendations.

These suggestions are no longer possible, given that L.R. has already donated. But there are next steps that should be undertaken for L.R. We owe L.R. a second chance at coming to terms with her assault. We owe L.R. an apology for ignoring her own needs in an effort to save her brother. We owe L.R. the protection afforded to the rest of us: to avoid exploitation. We owe her a promise that transplant centers will develop policies to ensure that no future potential donors will be asked to do what she was forced to do: to serve as a bone marrow donor when it was contrary to her self-respect and potentially contrary to her interests. It also occurred without any attempt to ensure that her assent was voluntary.

NOTES

1. See, for example, R. Delage, J. Ritz, and K.C. Anderson, "The evolving role of bone marrow transplantation in the treatment of chronic myelogenous leukemia," *Hematology - Oncology Clinics of North America* 4, no. 2 (1990): 369-88; and K.J. Forte, "Alternative donor sources in pediatric bone marrow transplantation," *Journal of Pediatric Oncology Nursing* 14, no. 4 (1997): 213-24.

2. L.F. Ross, *Children, Families and Healthcare Decision-Making* (New York: Oxford University Press, 1998), see chapter 6, "The Child as Organ Donor," pp. 111-30.

3. Ibid., 124-5.

4. Ibid., esp. 112-5.

5. Ibid.; see also I. Kant, *Grounding for the Metaphysics of Morals* (1785), trans. J.W. Ellington (Indianapolis, Ind.: Hackett Publishing, 1981), par. 429.

6. Ross, see note 2 above, 121-3, and 129 n.

7. C.B. Draucker, "The psychotherapeutic needs of women who have been sexually assaulted," *Perspectives in Psychiatric Care* 35, no. 1 (1999): 18-28; M.E. Smith and L.M. Kelly, "The journey of recovery after a rape experience," *Issues in Mental Health Nursing* 22, no. 4 (2001): 337-52; and J.A. Glaister and E. Abel, "Experiences of women healing from childhood sexual abuse," *Archives of Psychiatric Nursing* 15, no. 4 (2001): 188-94.

8. J. Rawls, *A Theory of Justice* (Cambridge, Mass.: Harvard University Press, 1971), esp. 440-5.

9. The phrase "a minor increase over minimal risk" comes from the *Federal Regulations* regarding risks to research subjects. See specifically, Subpart D, Additional Protections for Children. Department of Health and Human Services (DHHS) (45 *CFR* Part 46, Subpart D), "Protections for Children Involved as Subjects in Research," *Federal Register* 48 (8 March 1983), 9814-20; revised *Federal Register* 56 (18 June 1991), 28032, *http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm,* hereinafter cited by its *CFR* number. Ross has argued that similar standards can hold for transplant donors. (See Ross, note 2 above, 112-3.) She has argued that in an intimate family, pre-adolescent children can be exposed to at most a minor increase over minimal risk in organ donation. (Ibid., 112-20.)

10. The *Federal Regulations* are quite explicit that non-dissent is not adequate for assent. "Mere failure to object should not, absent affirmative agreement, be construed as assent." See *CFR* 46.402 (b).

11. Ross, see note 2 above, p. 122.

12. Human leukocyte antigens (HLA) are histocompatibility antigens. They determine whether

a donor and recipient are immunologically compatible.

13. This was the issue raised in *Curran v. Bosze.* Mr. Bosze and Ms Curran had twins and Ms Curran had legal custody of them. Mr. Bosze had a son, Jean Pierre, with another woman. Jean Pierre had acute undifferentiated leukemia (AUL), also known as mixed lineage leukemia, and needed a bone marrow transplant for treatment. Mr. Bosze asked Ms Curran to consent to a blood test for the twins, to determine whether the twins were compatible to serve as bone marrow donors for a transplant to Jean Pierre. Mr. Bosze asked Ms Curran to consent to the twins' undergoing a bone marrow harvesting procedure if the twins were found to be compatible. After consulting with the twins' pediatrician, family members, parents of bone marrow donors, and bone marrow donors, Ms Curran refused to give consent to the twins' undergoing either the blood test or the bone marrow harvesting procedure. That is, Ms Curran refused the blood test because she understood that it could lead to a bone marrow donation, which she did not perceive to be in her children's best interest. The court agreed. See, *Curran v. Bosze,* No. 70501, Supreme Court of Illinois, 141 Ill. 2d 473; 566 N.E.2d 1319; 1990 Ill. LEXIS 160; 153 Ill. Dec. 213; 4 A.L.R.5th 1163, 28 September 1990, Announced, 20 December 1990, 475.

14. W. Glannon and L.F. Ross, "Do Genetic Relationships Create Moral Obligations?" *Cambridge Quarterly of Health Care Ethics* 11 (2002): 153-9.

15. See, for example, H.H. Filipas and E. Ullman, "Child sexual abuse, coping responses, self-blame, posttraumatic stress disorder, and adult sexual revictimization," *Journal of Interpersonal Violence* 21, no. 5 (2006): 652-72; J.A. Quas, G.S. Goodman, and D. Jones, "Predictors of attributions of self-blame and internalizing behavior problems in sexually abused children," *Journal of Child Psychology & Psychiatry & Allied Disciplines* 44, no. 5 (2003): 723-36; P. Coffey et al., "Mediators of the long-term impact of child sexual abuse: perceived stigma, betrayal, powerlessness, and self-blame," *Child Abuse & Neglect* 20, no. 5 (1996): 447-55; and G.B. Rahm, B. Renck, and K.C. Ringsberg, "Disgust, disgust beyond description — shame cues to detect shame in disguise, in interviews with women who were sexually abused during childhood," *Journal of Psychiatric & Mental Health Nursing* 13, no. 1 (2006): 100-9.

16. T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics,* 4th ed. (New York: Oxford University Press, 1994), 274.

17. See, for example, A.E. Buchanan and D.W. Brock, *Deciding for Others: the Ethics of Surrogate Decision Making* (New York: Cambridge University Press, 1989).

18. See, for example, C. Negrao et al., "Shame, humiliation, and childhood sexual abuse: distinct contributions and emotional coherence," *Child Maltreatment 1*0, no. 4 (2005): 350-63; C. Feiring, L. Taska, and K. Chen, "Trying to understand why horrible things happen: attribution, shame, and symptom development following sexual abuse," *Child Maltreatment* 7, no. 1 (2002): 26-41.

19. Glaister and Abel, see note 7 above; H.Y. Swanston et al., "Hoping and coping in young people who have been sexually abused," *European Child & Adolescent Psychiatry* 8, no. 2 (1999): 134-42.

20. J.G. Murphy and J. Hampton, *Forgiveness and Mercy* (New York: Cambridge University Press, 1988), see chap. 1, J.G. Murphy, "Forgiveness and Resentment," 14-34, 16.

21. Ibid., 23-4.

22. Ibid., 24.

23. Draucker, see note 7 above; Smith and Kelly, see note 7 above.

24. Murphy, see note 20 above, p. 29.

25. See, for example, V. Weisz and J.K. Robbennolt, "Risks and benefits of pediatric bone marrow donation: a critical need for research," *Behavioral Sciences & the Law* 14, no. 4 (1996): 375-91; and L.M. Terry and A. Campbell, "Protecting the Interests of the Child Bone Marrow Donor," *Medicine and Law* 22 (2004): 805-19.

26. W. Packman, "Psychosocial impact of pediatric BMT on siblings," *Bone Marrow Transplantation* 24, no. 7 (1999): 701-6.