

Douglas J. Opel and Douglas S. Diekema, "The Case of A.R.: The Ethics of Sibling Donor Bone Marrow Transplantation Revisited," *The Journal of Clinical Ethics* 17, no. 3 (Fall 2006): 207-19.

The Case of A.R.: The Ethics of Sibling Donor Bone Marrow Transplantation Revisited

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INTRODUCTION

Since its development in the 1950s, bone marrow transplantation (BMT) has become an increasingly common treatment for an expanding number of childhood diseases. Not only is it a mainstay of salvage therapy for childhood cancers such as leukemia, but it also offers the prospect of cure in several nonmalignant disorders such as aplastic anemia, immunodeficiency disorders, leukodystrophies, and some forms of juvenile rheumatoid arthritis and systemic lupus erythematosus.¹ As the therapeutic applications for BMT in children continue to broaden, so do the ethical dilemmas that surround those indications.² In pediatric allogeneic BMT, the recipient's chance for cure is best if the bone marrow comes from a human leukocyte antigen (HLA) identical donor, usually a sibling.³ Out of all pediatric BMTs from 1985 to 1990, 76 percent utilized HLA identical sibling donors.⁴ The ethical implications of the matched sibling donor (MSD) BMTs are numerous, and include the nontherapeutic nature of bone marrow donation, the vulnerability of the minors involved, the inability of most minor donors to provide a valid consent, and the inherent conflict of interest that exists for the minor's parent or parents who consent to the nontherapeutic donation of bone marrow from one child so that the therapeutic outcome of another child can be optimized.⁵

The goal of discussing such dilemmas is ultimately to protect the rights of both the child recipient and the sibling donor. As minors, both participants are generally considered incompetent to make legally binding decisions regarding their healthcare. Therefore, parents are empowered to provide informed permission, and their decision is nearly always respected by the courts unless it poses significant risk to the child's health, well-being, or life.⁶ In making medical decisions for a child, the ethical duty of parents is to act in the best interest of the child. However, in MSD BMT, a conflict of interest arises since the interest of one child (the recipient) may conflict with the interest of the other child (the donor). To choose not to consent to sibling donation limits options for treatment to options that may be much less likely to benefit the child with the illness.⁷ Can a parent in this difficult situation adequately protect the interest of the child donor?⁸ Is this a

situation where the courts or a guardian *ad litem* should determine whether the minor's best interests would be served by being a donor?⁹

While some data exists to aid decision making in these situations, there is much that remains unknown. The physical risks of the bone marrow aspiration procedure are known to be relatively minimal.¹⁰ However, there are aspects of risk that remain unexplored. Are there psychological risks to a child acting as an involuntary donor? What are the psychological risks of not donating? Do these risks outweigh the benefits? Although these issues are addressed on a routine basis when siblings are considered for participation in a BMT process, and child donors are often psychologically evaluated and counseled with regard to their ability to adjust, handle strong emotions, and deal with stress, little is known about the acute and long-term psychological effects of BMT in sibling donors, and much tends to be assumed.¹¹

We present the case of a 15-year-old convicted sex offender in need of a BMT. His case raises several important ethical issues related to BMT. First, this case prompts the need for a discussion of the appropriateness of high-cost medical treatments in the burgeoning juvenile incarcerated population.¹² We will argue that it would be unjust to deny a lifesaving opportunity to an incarcerated minor and that patients such as the one described in this case should be offered the same medical treatment afforded non-prisoners. Second, this case presents unique features that underscore the need to better understand the psychological effects of BMT in sibling donors. We will argue that psychological harm is a potential risk of any MSD BMT, that the potential for psychological harm should be given serious consideration in the assessment of potential risks and benefits of donation for the sibling donor, and that any assessment of psychological risk must consider additional risk factors that might compound the risk of significant harm to the child donor. Finally, we will utilize a harm-based analysis to explore the question of whether the BMT should be allowed to proceed in a case such as this one.

CASE

A.R., a 15-year-old boy, presented with a two-week history of headache, sore throat, fever, and night sweats. Physical examination revealed subconjunctival masses, and a complete blood count disclosed a white blood cell count of 43,000. The patient was in state custody and incarcerated at a state correctional facility for a history of sexual assault of his younger sister, and was transferred to a tertiary care center where further tests confirmed the diagnosis of acute myelogenous leukemia (AML).

With a predicted cure rate of approximately 50 percent, the patient underwent intensive induction chemotherapy. His leukemia was initially refractory to standard induction therapy, but remission was ultimately achieved with intensive salvage chemotherapy. He suffered severe but anticipated toxicities, including admissions to the intensive care unit for sepsis and fungemia (the presence of fungi or yeast in the blood).

Despite continued aggressive conventional chemotherapy, an early bone marrow relapse (less than 20 percent blasts) was confirmed by cytogenetic evaluation six months after diagnosis. Options for treatment of his marrow relapse included a BMT immediately or further chemotherapy to induce a second remission followed by BMT. Given that his leukemia had already proven to be refractory to conventional chemotherapy and that further conventional chemotherapy would heighten risks for additional infectious complications prior to transplant, the patient and his mother chose to proceed with a BMT. A family and unrelated donor search initiated six weeks following diagnosis had identified his nine-year-old sister, L.R., the victim of his prior sexual assault, as an identical match. An identical match donor would optimize the chances for a good outcome, and the probability of relapse with BMT was estimated to be as high as 40 percent, with the probability of long-term disease-free survival and cure also estimated to be 40 percent. Due to the history of abuse, L.R. underwent a brief psychological assessment that concluded that she would be suitable as a BMT donor. This assessment was limited, however, by the fact that L.R.'s mother would not allow the psychiatrist to talk with L.R. about the past abuse, and would not allow her to be interviewed alone. BMT was performed seven months after initial diagnosis and the recipient experienced a relatively uneventful course of donor engraftment. L.R. had an uncomplicated bone marrow harvest and post-operative recovery. A.R. was dis-

charged back to the state correctional facility 10 months after his initial diagnosis, but suffered relapse 10 months later. He decided against re-induction chemotherapy, his mother did not challenge his decision, and he died two months after diagnosis of his relapse.

DISCUSSION

This case is unique because not only does it require one to address whether a convicted sex offender should be offered BMT, but it raises the much more complicated issue of whether his victim should be considered a potential donor. To our knowledge, this is the first such situation to appear in the medical and ethics literature, and it raises three distinct questions. First, should prisoners have access to costly medical interventions like BMT? Second, should parental permission for the use of bone marrow obtained from a minor sibling be considered valid? Finally, should a minor sibling be permitted to act as transplant donor when the recipient sexually assaulted her in the past?

PHYSICIANS' OBLIGATION TO PROVIDE OPTIMAL CARE VERSUS SOCIAL JUSTICE

The first question was whether A.R., as a sex offender, should have been offered a BMT at all. In 1976 the United States Supreme Court ruled in *Estelle v. Gamble* that under the Eighth Amendment an incarcerated individual has a right to medical care, as it is "but just that the public be required to care for the prisoner, who cannot by reason of the deprivation of his liberty, care for himself."¹³ While the Eighth Amendment requires that a prisoner not be denied medical care, it does not explicitly address just how much care should be provided. Much of the debate thus revolves around whether prisoners are entitled to high-cost medical treatments such as organ transplants.¹⁴ Proponents argue that prisoners should be entitled to the same health-care as members of the general community,¹⁵ and that this includes even high-cost treatments that are considered the standard of care for a given disease or illness. This level of care, the argument goes, is in line with the Supreme Court's interpretation of the basic concept underlying the Eighth Amendment: "nothing less than the dignity of man."¹⁶ Furthermore, some prisoners may serve their sentences, rehabilitate, and become reintegrated as contributing members of the community. It would be unfair to remove that opportunity by denying a level of healthcare that would be available outside of prison.¹⁷ Furthermore, for those who re-enter society, it is better for all that they enter as healthy citizens, thereby minimizing "the risk of poorer health to the community."¹⁸

Not everyone agrees with that sentiment, however, and the more expensive a medical treatment, the more people tend to disagree.¹⁹ The cost of providing healthcare to correctional institutions is estimated at \$3.75 billion a year,²⁰ and the inclusion of high-cost treatments would increase that amount even more. Further, how can society justify providing prisoners, who are guaranteed at least some level of healthcare by *Estelle v. Gamble*, better healthcare than many of its law-abiding citizens who remain uninsured or uninsurable and cannot afford even routine healthcare? Is it really right to grant a prisoner access to a very high level of healthcare when some law-abiding members of society have only limited access? Finally, some would argue that when high-cost treatments involve scarce resources (for example, kidneys or livers available for transplantation), a convicted murderer on death row should not have equal access.²¹ How can we make sense of these two conflicting views?

Around the time of *Estelle v. Gamble*, accreditation agencies were formed to help develop a standard of healthcare for prisoners.²² Today, organizations such as the American Academy of Pediatrics and the American Medical Association are represented on the board of directors of the National Commission on Correctional Health Care and routinely publish policy statements as guidelines for care in jails.²³ No guidelines have been established for prisoners in need of solid organ or BMT, however, leading to inconsistent care for those prisoners. Navari and colleagues relate the case of an adult prisoner serving a life sentence for first-degree murder when diagnosed with chronic myelogenous leukemia (CML). In response to his need for a BMT, the authors state that such a prisoner should "receive the same health care as individuals who are not

incarcerated and that the costs of care should play no greater role for prisoners than for other members of society."²⁴ Other case reports of prisoners evaluated for transplant offer similar conclusions.²⁵ Jeffrey Spike advocates trying to avoid a "categorical exclusion" for prisoners, but states, "transplant center(s) should consider each case individually."²⁶ In addition, J. Paul, responding to the case of an adult prisoner serving a sentence for third-degree murder who required a BMT for CML, wonders what "retribution is morally appropriate for a certain type of criminal." He argues that BMT should not have been offered to the prisoner, nor should the prison system have paid for his care, because the "severity of his crime militates against either."²⁷

Without consensus, then, we turn to the case of A.R. The decisions about whether A.R. deserves a transplant may be helped by first distinguishing him from others, based on two criteria. First, A.R. was not a prisoner on death row, and therefore was subject to a different set of considerations than those prisoners condemned to death who require lifesaving treatments. Second, A.R. did not require a solid organ transplantation. Solid organs are a scarce resource, and therefore are subject to discussions of rationing and justice, whereas bone marrow is not.

With these distinctions in hand, Lawrence Schneiderman and Nancy Jecker's model of medical versus societal justice provides an appropriate framework in which to answer the question of whether A.R. should be offered a BMT. The authors argue that physicians "lack the moral authority to deny beneficial medical treatments on any grounds," specifically on grounds of societal worth.²⁸ The nature of a patient's crime should be irrelevant to the physician, they contend, and the decision to treat should be made solely on clinical grounds: this is medical justice. How to distribute scarce resources, like a limited number of solid organs for transplant, lies within society's realm: this is societal justice. A given society might consider convicted murderers or other criminals to be in violation of the societal contract, and, by virtue of that violation, not entitled to deprive those who have kept the social contract of scarce resources like organs. In that case, society might impose upon the medical field that only a "rudimentary decent minimum" be provided for convicted murderers.²⁹ However, if society feels that everyone, regardless of whether they are a criminal or not, deserves equal access to any and all medical care, those in the medical field should respect such laws. The point of Schneiderman and Jecker's theory is that with a lack of consensus in society regarding how much medical care prisoners are entitled to, it is not within the moral realm of physicians to treat prisoners differently than any other patient. Whether a prisoner should receive a transplant should be governed strictly by the clinical situation, not the social situation, unless society has dictated otherwise.

Since the arguments surrounding the ethics of lifesaving medical treatments to a prisoner on death row fell outside the discussion involving the case of A.R., to deny him a BMT would constitute medical injustice, using Schneiderman and Jecker's model. Refusing to provide A.R. with a potentially lifesaving BMT would be equivalent to the medical team handing him a death penalty in a situation in which society has already determined that his crime was not severe enough to justify death. Furthermore, since the BMT A.R. needed is not a scarce commodity, no one else would be deprived of a transplant if he received one, and therefore comparative justice principles did not apply. For these reasons, we argue that A.R. should have been offered the same medical treatment that was afforded to non-prisoners.

A CHALLENGE TO PARENTAL AUTONOMY

The second question that A.R.'s case raised was more difficult: was it ethical to ask L.R., the child sibling whom A.R. sexually abused, to donate her bone marrow to help save his life? To get to an answer, we must first ask whether it is appropriate for any minor to be subject to a nontherapeutic medical procedure for the benefit of another. If there are conditions in which that is appropriate, we can then turn to whether that same minor should have been asked to donate when she had been the victim of a crime perpetrated by the recipient of her donation.

Under United States law, minors are generally considered incompetent to provide legally binding consent regarding their healthcare, so parents or guardians are generally empowered to make those decisions on

their behalf, and the law has respected those decisions except when they place the child's health, well-being, or life in jeopardy.³⁰ In this case, the decision rested with the mother of both children (the father of the children was no longer involved as a decision maker). As long as the mother's decision did not place either of her children's health, well-being, or life in jeopardy, it would be legally respected. The situation A.R.'s mother found herself in, however, was inherently full of conflict: if she refused to allow L.R. to act as a donor, she placed A.R. at increased risk of death; yet, if she authorized L.R. to act as donor, she might have caused her daughter the potential harm of being forced to donate to a person who victimized her.³¹ While the courts do reserve the right to review the procedure of informed consent in situations such as this one, because "the parent's concern for their ill child may cloud their judgment for the safety of the donor,"³² it is not often exercised, and parents' decisions are usually respected without review.

Some authors have suggested that, to ensure that the interest of the donor is represented in an unbiased manner and therefore that surrogate consent be valid in the case of MSD BMT, a guardian *ad litem* should be appointed by the court.³³ When courts do exercise their prerogative "to review the procedure of informed consent in order to satisfy itself that the process of informing had been sufficient to give a clear estimate of the risks and benefits," as established by *Nathan v. Farinelli* in the Massachusetts Court, they have not usually assumed the position of surrogate parents, but instead rely on a court-appointed child advocate, or guardian *ad litem*.³⁴ As advocate for the child donor, the guardian *ad litem* must judge "that transplantation is preferable to alternate therapy, that medical risks such as general anesthesia and blood loss are acceptable, that the parents and donor have indeed given their consent after being fully informed of the risks and benefits, and that the consent was not given under duress."³⁵ Despite the availability of this option, however, a guardian *ad litem* is only occasionally used in situations of MSD BMT, and, under most circumstances, this may be reasonable.

Through a model of decision making on behalf of children that advocates for trust in parental discretion in most situations, Lainie Friedman Ross offers an explanation for why.³⁶ In her model of "constrained parental autonomy," she breaks from the *best interest standard*, in which decisions are made on the basis that they are in the patient's best interests, and instead argues for promotion of a child's *basic* interests. By doing so, her model then allows parents to "trade the best interests of one child for familial interests as long as the basic needs of each child in the family is secured: abuse, neglect, and exploitation are prohibited, and children must be provided with goods, skills, liberties, and opportunities necessary to become autonomous adults capable of devising and implementing their own life plans."³⁷ In situations like the donation of bone marrow, where the degree of risk or harm to the sibling donor does not exceed a "minor increase over minimal risk," Ross's model of constrained autonomy "allows parents of intimate families to authorize bone marrow donation" as long as their authorization "simultaneously respects the child as the developing person that she is" and "does not sacrifice any of the child's basic needs." Ross's model therefore envisions a child's well-being in an intimate family as being fully intertwined with the well-being of other family members, and by donating bone marrow to help save the life of a sibling, a child serves to promote the well-being of the family, and indirectly, serves her or his own goals.³⁸ Others have also argued for a similar position.³⁹

Ross's model would argue for allowing a parent to have one child act as a bone marrow donor for another family member in most situations. However, there are elements of the case presented that do not allow a direct application of Ross's model. A prerequisite of Ross's model is that it applies to an intact "intimate" family. The intimacy between family members fulfills Ross's intent to "respect the freedom of parents to balance competing claims of family members, provided that each child-member's basic needs are satisfied."⁴⁰ The more intimate a family, the more likely that enhancing the family's well-being will enhance the well-being of each child in the family, and the more one is able to respect the parents' decision making when one child is in the position to endure medical risk for another. Subjecting one sibling to the bone marrow donation process to help save the life of another child is thus, according to Ross, morally justifiable in an intimate family.⁴¹

We argue that this family intimacy may be compromised in the case of A.R. Foremost, A.R.'s past abuse of his sister introduced a destructive element into the family's ability to function in a healthy or intimate way.

In addition, since being sentenced to a juvenile detention center nearly a year prior to his diagnosis, he was not physically around any family members; prior to his incarceration, he had not been living with his mother, the primary medical decision maker during his illness. Although contact with his mother and sister redeveloped once he was hospitalized, and even if that contact represented a genuine attempt to repair family relationships, it remains true that the relationship between A.R. and his family prior to his illness had been less than ideal. Such family conditions fall short of the prerequisites for Ross's constrained parental autonomy model, and should call into question whether a parent in this case should be permitted to trade the interests of one child for those of another.

Ross, in fact, imagines a similar scenario in which a sibling donor's refusal to participate might be so strong that it makes her willing to "rupture family bonds."⁴² In such a case, Ross contends that the donor must not be ignored: "it could be a grave mistake to allow a child's immature selfishness to override parental autonomy, particularly if there is a good chance that the child will come to regret the decision at a later date . . . But it could be a more egregious error to ignore the child's dissent if her refusal is due to genuine non-intimacy."⁴³ Such a scenario could be a reality, Ross footnotes, if the donor, for example, refused because her sibling repeatedly raped her and her parents refused to protect her. Ross's hypothetical scenario bears some resemblance to A.R.'s case. Although his sister never vocalized a refusal to donate, it was not clear that this was something she was comfortable expressing. Her mother's desire to provide her son with the best possible opportunity for survival might have altered her ability to evaluate the impact of donation on L.R. We would argue that Ross's model of constrained parental autonomy was not applicable in such instances, as the break in family intimacy "moves the decision into the public forum."⁴⁴ A.R.'s mother should not have been relied upon to protect L.R.'s basic interests under such extreme conditions of family dysfunction.

In a situation like this, in which there was a reason to question whether parental permission adequately protected the interests of the donor, the appointment of a guardian *ad litem* should have been considered. The apparent lack of intimacy within A.R.'s family, the possibility that the interests of A.R. directly conflicted with the interests of L.R., the likelihood that this constrained their mother's autonomy and might have compromised her ability to protect L.R.'s basic interests and needs, the mother's refusal to allow a psychological assessment of L.R., and her desire to solicit L.R.'s willingness to donate, suggest the healthcare team should have sought the involvement of a guardian *ad litem* as an alternative to protect L.R.'s rights and interests.

There is legal precedent for disallowing transplant donation when there is a lack of established intimacy between sibling donor and recipient. In 1975, the Wisconsin Supreme Court denied the request to approve a kidney transplant from a 39-year-old institutionalized catatonic schizophrenic to his 38-year-old sister.⁴⁵ The court's reasoning was that "the death of the sister would not have resulted in mental anguish for the incompetent brother."⁴⁶ In contrast, the case of *Strunk v. Strunk* held that the converse would also be true.⁴⁷ The two brothers were found to have such a strong emotional bond that the Kentucky Court of Appeals approved the transplant of the 29-year-old's kidney to his 28-year-old sibling, even though the donor sibling was an "institutionalized adult with the mental capacity of a 6-year-old."⁴⁸

Although both cases involve solid organ transplants, they underscore the importance of an intimate relationship between donor and sibling before a surrogate can reasonably consider the procedure to represent a benefit to the donor. Solid organ transplants convey more medical risk to donors than BMTs do, but the present case added the potential for psychological risk to a young donor who was subject to a procedure and donated her bone marrow to an individual who sexually abused her. The risks and benefits of donating under these conditions will now be considered.

FIRST, DO NO HARM

We have argued in the past that the harm principle is the actual standard used in courts and by medical providers to justify interfering with parental decisions.⁴⁹ Although the best interest standard is most fre-

quently employed in such instances, it provides insufficient guidance for decision making regarding children: "the real question is not so much about identifying which medical alternative represents the best interest of the child, but rather about identifying a harm threshold below which parental decisions will not be tolerated."⁵⁰ The case we have presented raises the question of whether the harm to which the donor will be subjected by donating bone marrow under these circumstances is significant enough that her parent should not be allowed to authorize it.

What is the threshold above which a parental decision poses sufficient risk to a child that it should not be tolerated? Several possibilities have been suggested. Some commentators have identified the harm threshold as any decision that will result in loss of life, health, or some other major interest, and the deprivation of basic needs.⁵¹ Ross sets the harm threshold at a level at which a child is deprived of its basic needs.⁵² Joel Feinberg suggests that the threshold is exceeded when a parental decision "interferes" with interests necessary for more ultimate goals like physical health and vigor, integrity and normal functioning of one's body, absence of absorbing pain and suffering or grotesque disfigurement, minimal intellectual acuity, and emotional stability.⁵³ Others suggest that any decision that places a child at significant risk of serious harm should be challenged.⁵⁴

How do the risks and harms of BMT donation compare to the harm-based examples cited above? Medically, the procedure is considered to be very low risk. It usually requires multiple needle aspirations from the iliac crests while the donor is under general or spinal anesthesia. Ross categorizes bone marrow donation as constituting a "minor increase over minimal risk," citing the risks associated with general anesthesia as posing the greatest risk.⁵⁵ Mortimer Bortin and C. Dean Buckner reviewed the complications associated with more than 3,000 allogeneic BMTs submitted to the International Bone Marrow Transplant Registry and Seattle Marrow Transplant Team from 1970 to 1983, and found a very small incidence of adverse effects (9/3,290, or 0.27 percent), the majority of which (5/9) were attributed to the use of general anesthetic.⁵⁶ Other risks and harms involved with BMT donation include infection at the puncture site, bleeding, transient bone pain, and minimal skin scarring.⁵⁷ Although it is not a trivial procedure, evidence suggests that BMT donation is exceedingly safe and the nonanesthetic complications relatively minor.

In this case, L.R. was physically healthy and free from any medical conditions that would either impede her ability to donate or to elevate the risk of physical complications. From a medical and physical perspective, the risk of donating bone marrow to her brother fell short of any suggested harm threshold. The medical and physical risks did not appear to place her at significant risk of serious harm.

The psychological aspects of MSD BMT, however, should have been included in the equation. "Emotional stability" and "integrity" were both factors that should have been considered in determining whether having L.R. act as a bone marrow donor for her brother actually posed a significant risk of serious harm. Furthermore, a vital component to the psychological sequelae of MSD BMT was L.R.'s premorbidity. It was pertinent that she was psychologically at risk, and this must not be minimized. There is growing evidence that victims of sibling incest manifest emotional and behavioral problems that are as severe as those found among children who have been sexually abused by adults,⁵⁸ and the effects common to female victims of sibling incest include "mistrust of men," chronic low or negative self-esteem," and intrusive thoughts of the incest."⁵⁹ Such effects are crucial to the analysis of harm when the psychological aspects of MSD BMT are considered, in general.

L.R.'s mental status and emotional suitability to serve as a donor were evaluated. This was a 50-minute conversation with a psychiatrist. Since L.R.'s role as the victim of A.R.'s abuse was known to medical staff, there was considerable concern that the procedure might cause re-traumatization or other emotional distress. The interview included both the mother and L.R., but the mother requested that the abuse not be discussed with L.R., since that was in the past and would further harm her. if it was brought up. L.R. was described as polite, friendly, cooperative, and reflective in her responses during the interview. As the interview focused more on L.R. and the BMT, she became "slightly guarded" when asked about her brother and his illness, but not "inappropriately so." She was felt to have age-appropriate concerns and anxieties as well as an age-appropriate understanding of the process of bone marrow donation.

The evaluator concluded that the assessment of L.R. was hampered by her mother's guardedness toward the interview. While the evaluator found L.R. to be well-adjusted, happy, and possessing a genuine concern for her brother and his physical health, the evaluator noted that L.R. had never received any counseling regarding the abuse, and it was possible that L.R. simply "avoided overt manifestation of the trauma through defensive denial." In summary, however, the evaluator concluded, "this interview did not provide any information to suggest that [L.R.] is at high risk of traumatization from the bone marrow transplant due to her previous experiences with her brother."

Recent evidence on the psychological impact of BMT on sibling donors might suggest otherwise. During the 1970s and 1980s, several anecdotal observations suggested that potentially serious psychological reactions might result from the donation procedure.⁶⁰ In the first systematic investigation of the psychosocial effects of BMT on donor and non-donor siblings (albeit small: 44 siblings, 21 donors, and 23 non-donors), Wendy L. Packman and colleagues found that "sibling donors reported significantly more anxiety and lower self-esteem than did non-donor siblings,"⁶¹ but donors had better adaptive skills in school than non-donors.⁶² While symptoms of post-traumatic stress presented equally in each group, the manifestation appeared to be different in each group: "donor siblings might respond with more internalizing behaviors, such as anxiety and depression, withdrawal . . . in contrast, non-donor siblings might respond with more externalizing behaviors such as attention and learning problems at school."⁶³ Such increased anxiety and low self-esteem in the donors may reflect that children may perceive surgical interventions as aggressive attacks on their bodies.⁶⁴ In fact, one sibling donor remarked, "I felt like I was the one being violated."⁶⁵ Overall, the six common themes that emerged among donors were that they:

1. Felt relieved and proud when picked to give bone marrow and after giving marrow,
2. Felt they had "no choice" and wanted to be more involved in the donation decision-making process,
3. Felt lonely and isolated after their surgery,
4. Developed a closer bond with the patient,
5. Reacted to the transplant by withdrawing and keeping their feelings to themselves,
6. Felt like a better person after the BMT and would give marrow again.⁶⁶

Although some positive aspects were present for some donors, it is disconcerting that many of the above themes denote a negative and potentially harmful experience. Furthermore, Packman and colleagues' subjects in the study were mostly from two-parent homes (73 percent), were part of families who had not recently experienced other significant stressors, and were all part of successful BMTs,⁶⁷ healthy conditions that were not present for the young donor in this case. Yet, many donors in Packman and colleagues' study experienced significant anxiety and depression, and the potential for post-traumatic symptomatology at rates higher than siblings who did not donate. If sibling donors from apparently stable family environments suffered from feelings of powerlessness, loneliness, withdrawal, and isolation, it is not unreasonable to be concerned that these feelings might prove overwhelming to a donor whose family and psychological past appear to offer even less stability. Some also have found that sibling donors experience the donation procedure as "an act of robbery."⁶⁸ One could argue that a victim of sexual abuse has been robbed in a violent way once before, and should not be placed involuntarily in a situation that would cause her to feel that way again. The available data would seem to suggest that having L.R. donate bone marrow to A.R. poses a significant risk for serious harm to her psychological and mental health.

There is also data to suggest that in the event that a BMT recipient ultimately dies, a very real possibility in this case, the risk of suffering psychological harm may be even greater. One study compared the effects of BMT on pediatric-aged donors whose siblings ultimately died to those whose siblings did not.⁶⁹ In both groups, the psychological aspects of donating were more important than the physical aspects (100 percent and 86 percent in the successful and unsuccessful BMT groups, respectively), reinforcing the importance of seriously addressing the psychological consequences of BMT donation. All but one of the 15 participants in the study felt either forced to donate or that saying "no" was not an option. Common findings among the successful donor siblings group included increased self-esteem, fewer feelings of helplessness, a broadened

view of the world, feelings that the process brought the family closer together, increased insight into their sibling's disease, and a greater likelihood of negative emotions if the sibling developed severe and long-lasting complications. For donors of unsuccessful transplants, anger, guilt, and blame were common emotions: "the positive and negative impacts, with feelings of guilt and blame, often overshadowed positive effects . . . ; in one case, the negative impact became predominant."⁷⁰ Further, the investigators report the donors said "it was hard not to feel responsible for the death of their sibling and that support was needed to overcome these feelings."⁷¹ The authors found that for those donors that lacked the "adequate emotional support . . . , resisting the development of negative feelings was harder."⁷²

While this study involved a small sample size (15 participants), it reinforces the potential for significant negative psychological impact on the sibling donor, especially if the transplant is unsuccessful. Those who were part of an unsuccessful transplant had more negative psychological effects, and those who were younger were more likely to believe they were forced to say yes. Years later, the authors note, these younger donors usually come to understand why they were forced to donate, but still requested "more influence and autonomy in deciding that 'no' was not an option."⁷³ These data would further suggest that the psychological risk to a young donor who had been assaulted in the past by the prospective recipient may be quite significant.

To be thorough, we must also recognize any potential psychological benefits that L.R. might have obtained from donating marrow to her brother. One might imagine that providing L.R. the opportunity to save her brother's life might have allowed for some forgiveness, a strengthening of their relationship, or might have enabled L.R. to "move on." Although there is little empiric data available to support that supposition, Packman and colleagues and Kendra MacLeod and colleagues do hint at such possibilities.⁷⁴ Other benefits to L.R. might have included a strengthened relationship with her mother, who clearly desired that L.R. act as donor. Alternatively, it is possible that L.R. might have felt some satisfaction in donating bone marrow to keep A.R. alive, so that he could live out his sentence. L.R. may have interpreted the act of not donating as helping A.R. to "cheat" the system that was punishing him.

To optimize the likelihood of most of these benefits, however, it would have been essential to provide L.R. with emotional support, to allow her to move in a positive direction, post-donation. Here there is evidence of a suboptimal environment. When L.R.'s mother refused to allow staff to address the issue of past sexual abuse with L.R., it created an environment in which an open exploration of post-donation issues and feelings was probably hampered.

Given the potential for psychological harm, and the common feeling of "having no choice," it was particularly important to obtain L.R.'s assent to donate bone marrow to A.R. While her age almost certainly did not allow for a full understanding of risks and benefits, she was certainly old enough to appreciate what she was being asked to do and why. The value of assent in this case was that it allowed L.R. to express whether she was willing to undergo this procedure voluntarily. If nothing else, assent in this situation might have allowed L.R. some sense of control and less a sense of being "forced" to do something she did not wish to do. The purpose of assent was not the same as consent in this case, that is, to make a formal assessment of risks and benefits, but rather to recognize that, under the circumstances, soliciting the willing participation of L.R. should have been a minimal requirement to minimize harm. Her assent, or affirmative agreement, should have been sought by the medical care team, and should have been sought in a way that would have helped to answer L.R.'s questions and to assure that she was truly willing to do what she was being asked to do.

It must also be emphasized that an MSD BMT was not the only therapeutic option that was available. While MSD BMT was considered the best option for cure of A.R.'s disease, patients with refractory AML can also be treated with an allogeneic BMT from a matched unrelated donor, an allogeneic BMT from an unmatched unrelated donor, further chemotherapy, or palliation. The decision to proceed to BMT in patients with refractory AML is a complex process and involves taking into consideration a number of factors, only one of which is the type of donor available. While it is true that the likelihood of success was lower with an unrelated BMT as compared to a MSD BMT, it was not the case that pursuing a therapeutic option other than

MSD BMT would have condemned A.R. to a certain death. In A.R.'s case, the advantage of having an HLA identical donor should have been weighed against the potential risks to L.R. Risk-benefit calculation can be a difficult task, and having to weigh the interests of one party against the interests of another increases that complexity. In cases when the interests of the recipient and donor align, it seems reasonable to focus primarily on the best available therapy. However, when there is concern about the potential for significant harm to a donor, it is important to consider whether acceptable therapeutic alternatives exist, to put those alternatives on the table for discussion, and to consider them seriously as a way to minimize risk to a vulnerable potential donor.

In summary, there were multiple reasons to be concerned about the potential for harm to the donor in this case. Psychological harm is a potential risk of any MSD BMT, and L.R.'s young age, less than optimal family environment, and past history of sexual assault at the hands of the transplant recipient all seem likely to have compounded the risk of significant harm. The harm to L.R. was likely to exceed any potential benefits. She was already psychologically vulnerable, and should not have been subjected to the further risks of low self-esteem, increased anxiety, the possible feelings of having "no choice" or of being the victim of an "act of robbery." This situation offered significant potential to deprive L.R. of a basic need — her emotional stability — and negatively affect her ability to become "an autonomous adult capable of devising and implementing [her] own life plans."⁷⁵ Physicians had a duty to "first, do no harm," and allowing L.R. to donate her bone marrow to A.R. under these circumstances had the potential to exceed an acceptable level of risk for a nonvoluntary minor. In such cases, a minimal requirement should be a thorough psychological assessment that includes time alone with the child. The goal of that assessment should be to establish a reasonable degree of certainty that the child donor will not be harmed by proceeding with the donation, and that the child feels that he or she has some choice in the decision. This assessment would ideally occur before any determination of compatibility, to minimize any pressure that might arise from the knowledge that the child is a potential donor. In addition, the appointment of a guardian *ad litem* should be strongly considered to provide an objective assessment of the child's best interests. Finally, we suggest that institutions that perform MSD BMT write policies to guide the process of testing for donor suitability, and create a process that minimizes any potential harm to a child donor, to the greatest extent possible.

CONCLUSION

The case we present raises unique and important ethical questions. We have argued that incarcerated minors should not be denied medical treatment that would be offered to minors who had not broken the law. Second, we have argued that an inherent conflict of interest exists for parents who must make decisions for two children in MSD BMT, and that appointment of a guardian *ad litem* should be strongly considered in any case when there is evidence that family structure is not intact and parental decision making is at risk of compromising any of a child's basic needs. Furthermore, we have reviewed evidence that suggests that BMT may cause significant psychological harm in otherwise psychologically well sibling donors, and that the potential for harm is likely to be greater when the potential donor is young and psychologically at risk. Such risks should be taken as seriously as medical risks in the process of evaluating siblings as potential donors. When the donation process poses a significant risk of serious psychological harm, the medical team should seriously consider not proceeding with sibling donation and fully explore alternative treatments. A comprehensive psychological assessment should occur before testing for compatibility to alleviate any additional pressure that may be associated with being a potential donor with known compatibility.

NOTES

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16. Posner, see note 13 above.

17. Thorburn, see note 13 above.

18. Levy, see note 14 above; Thorburn, see note 13 above; J.B. Glaser and R.B. Greifinger, "Correctional Health Care: A Public Health Opportunity," *Annals of Internal Medicine* 118 (1993): 139-45.

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20. Navari et al., see note 14 above.

21. Lowes, see note 14 above.

22. Thorburn, see note 13 above.

23. See note 12 above.

24. Navari et al., see note 14 above.

25. Cohen, see note 14 above; Schneiderman and Jecker, "A Different Kind of Prisoner's Dilemma," see note 14 above.

26. Spike, see note 14 above.

27. Paul, see note 14 above.

28. Schneiderman and Jecker, "Should a Criminal Receive a Heart Transplant?" see note 14 above.

29. Schneiderman and Jecker, "A Different Kind of Prisoner's Dilemma," see note 14 above; Schneiderman and Jecker, "Should a Criminal Receive a Heart Transplant?" see note 14 above.

30. See note 6 above.

31. Interestingly, refusing to allow the BMT, in fact, might prompt state intervention anyway, as it would itself jeopardize the life of A.R.

32. *Nathan v. Farinelli*, Suffolk Eq. 74-87 (Mass. July 3, 1974); Williams, see note 8 above.

33. M.D. Levine et al., "The medical ethics of bone marrow transplantation in childhood," *Journal of Pediatrics* 86, no. 1 (1975): 145-50; Williams, see note 8 above; Brant, see note 8 above.

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61. See note 4 above.

62. *Ibid.*; Packman et al., "Siblings perceptions," see note 11 above; Packman, "Psychosocial impact," see note 11 above.

63. See note 4 above.

64. *Ibid.*

65. *Ibid.*

66. Packman et al., "Siblings' perceptions," see note 11 above.

67. See note 4 above.

68. Pinegger-O'Connor and Bender-Gotze, see note 60 above.

69. MacLeod et al., see note 11 above.

70. *Ibid.*

71. *Ibid.*

72. *Ibid.*

73. *Ibid.*

74. Packman et al., "Siblings perceptions," see note 11 above; MacLeod et al., see note 11 above.

75. Ross, see note 36 above.