Asking children to donate bone marrow: 5 must-meet conditions

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Sometimes the only realistic match for a child in need of a bone-marrow transplant is a sibling. In these cases, the donor might appear to be willing, but the scenario remains fraught with ethical issues, not the least of which is whether a child can truly assent to an invasive procedure from which he or she will derive no medical benefit.

The AMA Code of Medical Ethics provides guidance on protecting the rights of organ donors and recipients, such as opinion 6.1.1, “Transplantation of Organs from Living Donors,” which lays out safeguards to help physicians balance informed consent, voluntariness and conflict of interest to create viable methods of increasing living donorship.

The following advice is summarized from an article published in the AMA Journal of Ethics® (@JournalofEthics) and based on the hypothetical case of a 15-year-old with acute myeloid leukemia and her 8-year-old sister. The 8-year-old is a match, seems excited about the possibility of helping her sister, but when the physician talks to the 8-year-old, it becomes clear that she doesn’t really understand what being a living donor would entail.

Central to this scenario is the ethical permissibility of using a child as a bone-marrow donor if he or she is reluctant, afraid or does not understand key features of being a living donor. The moral authority of parents is generally accepted due to their duties to both know and protect their children’s best interests.

It might, therefore, seem that parents would only permit their child to undergo a painful procedure when benefits outweigh risks. But how should parents decide in cases in which the child living donor reaps no benefit but is subject to substantial risk?

And which safeguards should be in place to ensure that prospective child living donors are not unduly influenced by their parents’ and siblings’ expectations? The American Academy of Pediatrics’
Committee on Bioethics deems children’s living donorship ethically appropriate only when the following five conditions are met.

First, no adult matches are available to donate. Siblings are often sought because donors unrelated to recipients can be hard to find.

The procedure provides reasonable benefit to the recipient. In the case of a bone-marrow transplant, the procedure can confer a significant, 30- to 65-percent chance of survival, depending on the stage of the disease.

A strong personal relationship exists. Sisters might be expected to have a tight bond, but open ethical questions can remain about how the relationship is assessed and by whom.

Risks to the donor are minimal compared with benefits to both donor and recipient. Bone-marrow harvesting is generally considered safe, but it is not without risks. Psychological sequelae for the donor—such as fear and post-traumatic stress—are possible and, therefore, pose additional risk of harm.

On the other hand, donation can benefit the donor in a number of ways, including by giving the sibling an opportunity to grow up with her sister and deepen their sibling bond. It could also bring the donor a sense of personal satisfaction—there is evidence that bone-marrow donors are proud of what they have done.

Not donating also has risks. For example, a sibling in need of an organ might be unlikely to receive a transplant otherwise. A child’s refusal to donate might, therefore, reasonably mean imminent death of the sibling in need. Besides being a source of guilt and remorse, refusing to be a living donor for a sibling in need could undermine stability and support provided by parents.

There is both parental consent and patient assent. If a prospective living donor child has been influenced too forcefully by his or her parents, his or her assent could be mere capitulation. Determining whether assent is voluntary can be difficult, however, raising a question of whether it is ethically permissible to move forward with bone marrow harvest despite a child’s fears. One remedy could be to appoint an independent adult advocate to meet alone with the prospective living donor child to investigate his or her concerns and then speak on his or her behalf.

“Fundamentally,” the authors noted, “the ethical permissibility of using a child as a bone-marrow donor turns on whether and how her personhood is valued and respected.”

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