

The Need to Promote All Pediatric Stem Cell Donors' Understanding and Interests

Contrary to their interpretation,¹ Pentz and colleagues' results support the American Academy of Pediatrics' (AAP's) recommendation that a donor advocate (or similar mechanism) be appointed for all minors who are being considered as hematopoietic stem cell donors.² The primary role of the donor advocate is to help potential donors and their parents understand the donation process and to promote potential donors' interests and well-being. The article describes a number of situations in which understanding could have been improved. Delaying or preventing donation is a secondary aspect of the advocate's role, and the need to exercise this authority would not have been expected in such a small sample.

Pentz and colleagues' article has several significant methodologic limitations. It is based on a secondary analysis of interviews conducted from 2007 to 2010, before the publication of the AAP's policy statement. This limitation has broader implications than the authors acknowledge. In their previous publication reporting the results of their initial interviews, the authors describe their goal as "to create a substantive theory of family decision-making regarding pediatric allogeneic transplantation for the treatment of childhood cancer."³ The authors are unlikely to have systematically collected data relevant to donor advocates. Publishing the interview schedule as an addendum to this study would help clarify this issue.

In addition, there are issues with recruitment. Twenty-five percent of families declined to participate in the study, and 2 families in which the recipient died did not participate in the follow-up interviews. Regret, blame, and posttraumatic stress are more likely in both groups.⁴⁻⁸ The results may therefore underestimate negative adverse events. The current study also contains limited information from donors; less than half of the donors were actually interviewed (16 of 33, 48%).

In regard to their framing of the issues, Pentz and colleagues mischaracterize the role of the donor advocate. They focus on the advocate's power to deny or delay the donation process. The AAP statement is clear that the primary role of the donor advocate "is to help the donor (and parents) understand the process and procedures and to protect and promote the interests and well-being of the donor."² The donor advocate is modeled after living donor advocates and advocate teams for solid organ transplantation,^{9,10} whose primary purpose "is to protect the safety and welfare of potential living organ donors."⁹

To the extent that their results are relevant to donor advocacy, Pentz and colleagues in fact provide examples of the need for greater understanding and increased protection of donors' interests. With respect to histocompatibility typing, a 12-year-old donor stated that he was not informed that he would have his blood drawn or the reasons why. A minor sibling was also concerned about her brother with cognitive

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hematopoietic stem cell transplantation, pediatric donors, minors, donor advocate, policy, ethics

ABBREVIATION

AAP—American Academy of Pediatrics

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defects being tested because of the possibility for a negative psychological outcome if the recipient died. With respect to donation, the authors report that the same 12-year-old donor “was also not informed about the number of needle sticks or the side effects of GCSF [granulocyte colony-stimulating factor], which were significant for him” and the sibling whose brother was cognitively impaired also expressed concern about donation.¹ In the follow-up interviews, 1 donor regretted her participation.¹ In all of these cases, a donor advocate or similar mechanism may have been beneficial to improve understanding and promote donors’ interests.

The lack of a case in the sample in which the donation was or should have been delayed or prevented does not

undermine the AAP’s recommendation that the advocate have this authority. The policy cites several examples (including the case of LR, a teenage girl who donated bone marrow to her brother who was incarcerated for raping her) that justify its recommendation.¹¹ Pentz, in a previous publication, describes the development of a bone marrow donor policy at her previous institution that required that pediatric donors have a separate health-care team,¹² an ideal form of donor advocacy not exclusively recommended by the AAP because it is not feasible in many smaller institutions.¹³ If any member of the donor’s team expressed concern, a special task force of the Clinical Ethics Committee would be consulted. In the first 6 years of the policy, 8 consultations were

performed, and the ethics task force recommended that 1 transplant not proceed.¹² Such cases are rare, and one would not have been expected in a sample of 33 donations.

Pentz and colleagues’ work adds to the growing literature about benefits, harms, and risks of pediatric siblings donating hematopoietic stem cells. The current secondary analysis, however, has substantial methodologic limitations. The available data nonetheless support the broad role the AAP has articulated for a donor advocate or similar mechanism. Additional research is needed that focuses on advocates and other mechanisms both to improve support, education, and counseling and to promote a more positive donor experience, regardless of recipient outcome.

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