Reviewer's report

Title: A critique on the Policy Statement of the American Academy of Pediatrics - Children as Hematopoietic Stem Cell Donors - conditions too easy to fulfill

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Reviewer: Wendy Rogers

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Dear Editor,

Here are my comments on the revised MS: 2994993027448304

A critique on the Policy Statement of the American Academy of Pediatrics - Children as Hematopoietic Stem Cell Donors - conditions too easy to fulfill

TK Chan and GL Tipoe

I note the history of this paper and have read the original three reviews, the authors’ response, the reviews of the revised manuscript by Drs Morgan and Mertes, the authors’ response to these and the third comment by Dr Morgan.

Dr Morgan and the authors disagree as to the safety and efficacy of matched sibling donors compared with tissue matched unrelated or haploidentical donors. As I am a bioethicist rather than a transplant physician, I am unable to adjudicate on this matter. One way to resolve this impasse would be by appeal to the literature. If this is a matter under dispute in the paediatric transplant literature, then this could be noted and discussed in the paper. If there is evidence one way or the other, then likewise this could be cited. I note that the authors do cite evidence for their position but Dr Morgan has not specifically commented this on, and the authors have noted that this was not a comprehensive literature review but have not commented on whether or not their claims are contentious.

I have separate concerns about the nature of the argument. The authors state in several places that the only justification for using an incompetent sibling donor is if the donation will be in the donor’s best interests. They then argue that donation should only occur if the life of the recipient sibling is in danger, and there is no available (related or unrelated) adult donor. The grounds for these two conditions are not clearly related to the potential donor’s best interests. It may be more straightforward to talk of the balance of benefits and harms, rather than of best interests per se, or if the language of best interests is retained, then these should be further specified. Talking explicitly about the balance of benefits and risks would allow the authors to argue that the even though the risks to donors of serious harm are low, they are significant harms and therefore should only be incurred if there are no equivalent alternatives and the risk without transplant to the recipient sibling is grave. This structure would allow them to discuss medical equivalence of other kinds of donors earlier in the paper.
Second, the discussion of the psychological effects of donation can be tightened up as per my notes on the manuscript. This section has some important material but to make the argument as compelling as possible, it needs to be rewritten to bring out these points more strongly. The main point seems to be that there are long term psychological benefits to sibling donors if the recipient sibling fares well after transplant. In what follows, the authors claim that this benefit seems to relate solely to survival of the sibling rather than from being a donor. To me it seems quite plausible that a donor may feel pride in having been the donor even if there were others who might also have fulfilled this role. This sense of pride is a potential psychological benefit even if it doesn’t materialize for the reasons given by the authors, and therefore may be legitimately considered by the parents when making decisions for incompetent minors. In the discussion of unsuccessful transplants, there is no mention of guilt or shame that may be felt by a sibling who was not a donor, or potential anger towards parents for not allowing them to be a donor, given the subsequent death of the sibling. Thus there may be a particular kind of survivor guilt in matched siblings who were not used as donors.

Finally, the suggested new clause 6 for the Policy seems to be an amendment to clause 1 rather than a new point. Clause 1 reads: “there is no medically equivalent histo-compatible adult relative who is willing and able to donate”.

Removal of the word “relative” would open the pool of potential donors to unrelated adults as per the suggested clause 6, and “medically equivalent” may be taken to mean “similar chance of survival and risks of complications for the recipient”.

Conclusion
The question of equivalent alternatives to matched sibling donors is not within my expertise.

The ethical arguments should be revised for clarity and to consider counter-arguments.

A new clause 6 does not seem justified given that a minor modification to existing clause 1 would make the same point.

A number of minor suggested amendments are noted on the manuscript.

I have no competing interests to declare.

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Declaration of competing interests:
I have no competing interests to declare.