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: Elaine Morgan

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Peer Review of Manuscript “A Critique on the Policy Statement of the American Academy of Pediatrics-Children as Hematopoietic Stem Cell Donors-conditions too easy to fulfill

MAJOR COMPULSORY REVISIONS

A-Risk –benefit assessment for the “savior” Well documented risks

1-The authors cite John Stuart Mill stating the “the only purpose for which power…..

The implication of this citation is that the “savior” is being forced to donate against his/her will. There needs to be discussion of the meaning of “will” in a young child and the data that support that these “donors” would indeed refuse to donate if they could make such a determination. The other issue here is who determines what the will of these young children is.

2-The authors speak about the risks of general anesthesia and CVL placement. There is data on the level of risk which should be included. The percent of bad events needs to be compared to the percent risk encountered by a child in day to day life to understand the degree to which the donor is at risk.

B-Speculative Benefits

There are several assumptions in the first paragraph which are not substantiated. There are potent counterarguments to these points that should be included in the discussion.

1-The authors speak about the uncertainty as to whether the siblings will remain close. This assumes that the altruistic benefit is entirely dependent on future closeness rather than initial relationship. One may feel a filial responsibility whether or not the siblings remain close.

2-It is stated that the sibling’s survival will reduce the amount of free time the parents have for the donor. By this argument parents should not have second children (or more) since a priori a new infant will dilute the individual attention. Furthermore a sibling who develops chronic illness related to chronic GVHD (more likely from an unrelated donor) or who is ill with progressive disease and/or who dies will also reduce the amount of free time of the parents.

3-The “savior” might be subject to blame. However, equally the “savior” might be subject to blame for not being the donor.
This section needs to consider the risks to the “savior” of not donating. Likewise these arguments would apply to all marrow and organ sibling donors whether conceived for the purpose or simply resulting from the normal frequency of sibling matches.

4-The authors argue that the medical risks of harvest violate a “saviour’s right” to bodily integrity. The same could be said of vaccination and other medical procedures where the benefit is potential and never guaranteed. We grant parents the right to make these decisions for their children since the parents are assumed to be the best surrogate and have the responsibility to make these decisions for their children.

5-The authors state that it is worthwhile to take risks only if benefits are well proven. But many medical treatments associated with risk are undertaken for children for the potential but not guaranteed benefit. One would better argue that risks are worth taking if the potential benefit is equal to or greater than the risk.

C-Balance of Interests between the “savior” and sick sibling

1-In Re A. This case is used to illustrate the “least detrimental choice. However, the relevance to the “savior” donor is questionable since in the case of In Re A, there could be benefit to only one of the conjoined twins, whereas in the case of a sibling donor, there is at least potential benefit to both children.

D-The least detrimental approach

1-The authors query whether there is another alternative transplant. However, they fail to consider the increased risk of such a transplant including delay, higher risk of non-engraftment and of chronic GVHD. This argument should consider the increase risk of physical harm, emotional stress to the patient and family and financial costs related to the increased medical complexity. Thus the balance is not simply life and death but must consider the associated medical and nonmedical costs of the proposed type of transplant.

Also the authors do not make any statement about at what age an “altruistic donation” can reasonably be made.

2-The authors refer to the Children’s Act of 1989. They correctly state that the child’s welfare is the court’s paramount consideration. While this is correct, the act primarily addresses custody and placement of needy children and does not state that the court can decide whether a medical treatment is in the best interest of the child. In the case of a marrow donation, the medical treatment is directed to the sick child and the court cannot indeed determine the best interest of the patient since they do not have medical training. The donation is better termed a medical procedure as it is not deemed to be a treatment. It does not seem that this act was intended to cover this situation.

Furthermore, in the US likewise the court’s primary concern is the child’s welfare. When bone marrow donation was first initiated the courts appointed a guardian for the donor to protect his/her rights. However, over time this responsibility was delegated to the parents as they were deemed the most appropriate persons to make these decisions. This historical change in policy should be mentioned in the argument
3-The authors refer to In Re C(HIV test). Again the relevance of this decision to the current discussion is questionable. In In Re C the parents refused HIV testing based on personal beliefs with obvious and substantial harm to the child. This was disallowed on the basis that the child’s welfare was paramount. This argument is correct. However, this case is more relevant to a situation of refusal of standard medical care than a discussion of who can make a decision about a sibling marrow donation.

4-The authors state that but for “the benefits of the sick sibling in the first place it would be unlawful to subject the savior to…. And the court would not sanction the transplantation taking place save in the most extenuating circumstances.” However, the parents are motivated to allow the donation for the same reasons and would certainly not be allowing a donation if not for the sick child. The court therefore is not differing in this from the decision of reasonable parents.

5-The authors exclude umbilical cord donations from the algorithm since there is no medical risk. However, arguably the risk of loss of parental attention and emotional risks (guilt) of the donor child would in fact not be different from any other type of marrow donation.

E-Conclusions

1-The authors state that the benefits for the “savior” are speculative whereas the risks are definitive though moderate. Quantification of the risks to the donor including frequency and severity are needed to support the second part of this statement. As to the “speculative” benefits, we all make decisions for ourselves and our dependent children based on “speculative” benefits.

2-The authors distinguish between “savior” and donor based on the inability of the child to make an altruistic donation. However, I would argue that conceived child is in fact making a “donation” which is based on a presumption of altruism. However, since the harvested cells are used for the sick child, semantically speaking I believe that the word donor is more appropriate to the situation.

Furthermore the authors could perhaps augment the discussion of altruism by looking at what the majority of siblings who are competent to decide do in the parallel situation.

Summary comments:
Overall this is an interesting and provocative critique of the AAP policy which was designed to allow broad parental discretion in the decision to allow any sibling, including the “savior” sibling to donate marrow. Their argument for the least detrimental choice is a valid frame for parental decision making.

However, I believe they fail to consider the question of whether the decision should rest of whether there is ANY alternative treatment versus the question of optimal medical treatment as not all transplants are equally beneficial or relatively safe.

Further their arguments could all equally apply to any sibling donation and are not specific to the “savior” donors. If there are specific concerns for this group of donors then the argument should be more focused on these concerns.
There is no discussion furthermore on the ethics of the decision to “create” a donor and whether such PGD conceptions should be allowed. Obviously the logistics of disallowing this are prohibitive but the discussion should probably include this. The question of whether to allow a donation once the donor is actually born has other ethical aspects which were not addressed.

There is an additional reference, Morgan et al concerning conceiving a child for this purpose which might provide additional discussion points.

This manuscript is well written but would benefit from some modifications and more even considerations of both sides of the argument. The recommendation to revise the AAP policy, while conceivably valid, is not well supported by the author’s arguments.

Level of interest: An article whose findings are important to those with closely related research interests

Quality of written English: Needs some language corrections before being published

Statistical review: No, the manuscript does not need to be seen by a statistician.