Reviewer’s report

Title: Attitudes of sperm, egg and embryo donors and recipients towards genetic information and screening of donors

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Reviewer: Rosanna Hertz

Reviewer’s report:

1. page 3 line 1-3: I am not clear about the difference between sperm, egg and embryo donors

The authors write "In this study we conducted indepth interviews (should this word be interviews) with sperm, egg and embryo donors.

Are there separate embryo donors? If there are not than I am not sure why this is a separate category throughout this paper.

For the recipients interviewed they could receive embryos and this would be a separate category.

Is it the case that in this IVF clinic donors are recruited for gamete use only or as separate and that other donors are recruited to be part a donor to create full embryos (or genetically not related to the recipient?)

This needs to be clarified for a non-medical and non-Australian readership

Page 7, Line 59: Similarly in the questions: "why the participant had required a gamete or embryo donor"

Participant recruitment, methodology, interviewing protocol

Please clarify who the participants are. Right now the text tells exclusions (not this or that). Are they people who have already undergone treatment and donor selection? The quotes in latter sections make me think this is the case.

Same with donors: Are these individuals already in the pool of donors?

I would want to know this as a reader to assess the answers qualitatively.

People who are already in the pool or have already selected donors have experience with the process and are not concerned that they would not be "chosen". It might strengthen the findings. [I think it is mentioned later on in the paper but it belongs in the methods section.]

Fine. Participation rate is fine for a hard to reach population
What is the definition of "designer baby?" This is critical to the paper and since this is a qualitative in-depth study the authors should clarify this question and also how the respondents understood this idea. Is this simply equated with another level of genetic screening? Usually this means a genetic modification to a human embryo. The authors are not asking donors if they care if their genes are modified. They are asking about a lay definition that assumes more genetic information will somehow lead to "gene selection" of some kind. What understanding of "designer baby" did the respondents have? Qualitative interviews should have tapped their understanding.

Qualitative comments (Themes)

Themes are interesting. Make this a figure. A table usually had some variability or something going on. This is just straight up answers. [NOTE: I like the figure on page 29 it is more interesting and easy to follow]

a. I would consider listing the themes in A and B from ALL to some. I also think having numbers (such as 4 donors and than in other places ALL, MANY, MOST or SOME is confusing). Be consistent with the responses and maybe RANK them or at least start with from ALL Said to SOME said.

Think about a way to present this to a reader instead of a laundry list which is hard to make sense of without the authors' interpretation.

Donors answers are very interesting and I have not seen these answers before:

Both Sections: Existing Genetic information and Screening

And Future Genetic Screening

Are important.

a. Donors find it difficult to answer the medical histories presently.

Additional information from their family medical history might be difficult for donors to give and could lead to misinformation [or a turn off to donors].

b. I like the comment on nature versus nurture it does not work here. Maybe make it about the entire process of donation. However, intending parents are not choosing a marital partner they are getting a product unknown to them (whether it is an altruistic donation or in the US and UK a commercial product). Selecting a donor is different.

Future genetic screening:
I think this is the most interesting part of the paper. Donors will be willing to undergo testing but they do not necessarily want to know the results.

While this paper is descriptive there is an important point here:

The donor can not really change his or her potential illness (and its diagnosis) so why worry about this and allow genetic testing to be a "crystal ball" for them. If they have to undergo further genetic screening it would create an ethical dilemma, as the medical profession would have information about a person they would not have.

But the recipient who is receiving this product (that is in lieu of partner’s gametes) might want more information to make a better informed decision (or choose between donors). -- even if the respondents say they don't need more genetic information and they look to the "essay side " or whatever more humanistic material is provided.

Discussion:

I gather from this discussion section indirectly that what exactly is genetic and what further kinds of genetic testing [which seems to be about more extensive testing ] is not well-understood or perhaps vague. Put differently, exactly what were the respondents told.

(1) The authors write "sperm donors ranked health information as the second most important form of donor information, behind donor physical characteristics (lines 44-49 page 18)

Physical traits are not purely genetic (such as height). Not to be nitpicking

(2) What exactly do the respondents and donors understood "designer babies" to mean? And perhaps mention what is understood by these two parties about genetics overall.

I do think the findings are interesting and worth publishing especially since an earlier study based upon a US sample did not find the same results. I have also indicated what I think is new especially about research on donors.

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