

Why it is important that we understand the information that gamete donors provide about themselves to recipients

Author: John B Appleby (Lecturer in Medical Ethics)

Affiliation: Lancaster Medical School, Lancaster University

Email: j.appleby@lancaster.ac.uk

In the UK, when someone donates eggs or sperm at a clinic, they can leave behind a personal description of themselves and a goodwill message. This information, is made available to donor conceived persons at the age of 16 and their parents. Anyone donating gametes in the UK after April 1st, 2005, is by law an identity release donor, which means that they must provide their name and last known address at the time of donation. However, by the time donor-conceived offspring reach the age of 18, there are no guarantees that their address will still be accurate or that it will be possible to locate the donor to make contact (for example there is even a small chance that the donor may not still be alive). Therefore, despite the availability of identifying information, the donor's description and goodwill message may be some of the only information a donor-conceived person or their parents may ever get about what they were like or why they donated. When it comes to the satisfaction of the informational interests of donor-conceived children and their parents, a lot seems to ride on these key pieces of information that the donors do (or don't) leave behind.

The paper by Tohme et al. (2023) in this issue takes aim at better understanding this area of donor information. This paper is significant because among all the areas of donor-conception that are studied (including disclosure of donor conception, family functioning in donor-conception families), the nature of the information that donors leave behind in their personal descriptions and goodwill messages is among the least well researched and remains poorly understood.

There are additional reasons why further research in this area is important. First, by shedding light on the communication of the donor, we can potentially get a more intimate glimpse into why they chose to donate and how they explain this to the recipients. As it stands, much of the standard narrative about why donors donate still revolves around evidence suggesting they want to pass on their genes, gain financial benefit and/or be altruistic (among other reasons) (Tohme et al, 2023). While this evidence is helpful, there is still a demand in the academic community for research that reveals additional nuance and complexity on this topic. However, the evidence from the Tohme et al. study does help to enrich this picture by providing further detailed explanation, such as donors wanting to help another family avoid the suffering of infertility and giving to others the feeling of love you get from creating a family (Tohme et al, 2023).

Second, this research provides insights into how clinics can better support their donors via education and counselling. With further assistance it could be possible that they can write personal descriptions and goodwill messages that are more likely to address the questions or curiosities of those who will receive their donation. Not only is this written communication possibly going to be more satisfying for the recipient, but it also helps to take the guesswork out of the process for the donor; thus, potentially leading to a more satisfying donation experience as well. Third, this research also highlights differences between what egg donors and sperm donors say in the information they provide (for instance, sperm donors were more likely than egg donors to provide a personal description of themselves) (Tohme et al., 2023). Far too often in research on reproductive donation - especially

historically – egg and sperm donors were treated the same in the analysis of the study data and how they were reported on.

Finally, this study also highlights the interesting point that only 25% of donors discussed the topic of future contact when writing their goodwill messages (Tohme et al, 2023). It is hard to know exactly why this is, but it may seem curious given how the donors are of the open-identity variety. Why would a donor not mention making contact? Tohme et al. speculate that perhaps the donor may want to leave the decision to make contact up to the recipients, or perhaps the donors excluded any mention of making contact because they simply do not want any. However, there is a third possible reason that donors simply had not actually thought that far ahead. Perhaps the donors did not know how they would feel about any contact in 18 years and thought they would try to leave it ambiguous for now. While we still do not have a complete picture at this point of exactly why donors do what they do, this study does reveal helpful Human Fertilisation and Embryology Authority based data that raises new research questions. For example, could the data gathered in this study help to improve recruitment of donors now that we know a bit more about their motivations? Similarly, it would be interesting to find out in more detail what donors choose to leave out of their personal descriptions and goodwill messages and why (for instance, maybe they do not know if the recipients want to hear it or how best to say it).

Despite all the advances modern society has made in linking people together to communicate with greater ease than ever before, it remains the case that the information provided by donors to recipients via clinics may be minimal, extensive, or random and unpredictable. Whatever the case may be, the recipients have limited recourse to further information through their clinic. This raises the question of to what extent donor recipients will resort to using tools like the internet (beyond simply using ancestry tracing and donor matching websites) to dig up information about their donors, above and beyond what they donor originally chose to share. Furthermore, to what extent will new developments in AI expedite the capacity of donor recipients to do this? Needless to say, researchers will likely be kept busy with work in this area for the foreseeable future.

References

Tohme, N., Cutting, R., Gurtin, Z. and V. Jadvá (2023). A comparative study of sperm and egg donors' personal description and goodwill messages. *Reproductive BioMedicine Online*.