The right of the donor to information about children conceived from his or her gametes

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ABSTRACT: The field of gamete donation for medically assisted reproduction purposes is evolving. While anonymous gamete donation was long the preferred practice, a new focus on the rights and interests of donor-conceived children has led a number of countries to shift towards an open-identity system. However, this evolution appears to overlook whether information exchange could also be of interest to the other parties involved, in particular the gamete donors. In this article, we analyse the question whether donors should be granted a right to some information about the offspring conceived by their donations. We constructed five arguments which donors could use in support of such a claim: (i) It can be of great importance to the donors’ and their own children’s health that they receive medical information (in particular, evidence of an unsuspected genetic disease) about the donor offspring; (ii) basic information (such as whether any children were born) could be a way to acknowledge donors for their altruistic behaviour; (iii) general information (information about the child’s wellbeing) about the donor offspring could ease the donors’ potential concern about and sense of responsibility for the offspring; (iv) basic information could provide an important enrichment of the donors’ identities; (v) identifying information would be useful for donors who want to contact the donor offspring. No strong arguments in favour of granting donors the right to identifying information were found. An exchange of this type of information should only be accepted when all parties agree. Taken together, the four first arguments form a strong case for granting donors a right to several types of anonymous information about the donor offspring.

Key words: ethics / donors / rights / anonymity.

Introduction

Over the past two decades, there has been a remarkable trend towards more openness in the practice of gamete donation. While initially only anonymous donation was permitted, 11 jurisdictions, such as Sweden, Finland, The Netherlands, UK, New Zealand and a number of Australian states have shifted towards an open-identity system (Janssens et al., 2011). In these countries, donors are no longer allowed to donate anonymously. Instead, they have to consent to the release of their identity to the children conceived from their gametes if they request this once they become mature.

This shift towards open-identity donation is the result of a new focus on the rights and interests of donor-conceived children (Scheib and Cushing, 2007). However, this evolution appears to focus exclusively on this party. Policy-makers seem to overlook whether information exchange could also be of interest to the other parties involved, in particular the gamete donors. As it stands today, donors rarely receive information about the result of their donation. A few countries make an exception to this. In the UK, since 2009, donors are granted access to anonymous information about the number of children born from their donation, their sex and year of birth (Human Fertilisation and Embryology Authority, 2009). In Victoria and New Zealand, donors can even receive identifying information about their donor-conceived children, but only if the donor-conceived child consents (New Zealand Government, 2004; Victorian Registry of Birth Death and Marriages, 2008).

Apart from these exceptions, the possible interests and rights of donors are not taken into account. Therefore, it would be useful to scrutinize the donors’ perspective on the practice of gamete donation. We need to analyse the question, ‘do donors also have an interest in receiving some kind of information about the offspring conceived by their donations and do they consequently have a right to such information?’
Possible arguments in favour of the donor

As a first step of our analysis, we distinguish between various types of information that a donor could claim.

(i) Basic information: this would include information about the outcome of the donation, in particular the number and sex of the donor offspring.

(ii) Medical information: this would involve medical and genetic facts about the donor offspring.

(iii) Phenotypic information: this information type would contain a description of the general body characteristics of the donor-conceived children, such as hair and eye colour, length and weight.

(iv) Extended donor child profile: this is a counterpart of the extended donor profile and would consist of elements like a personality description, information about the child’s interests and hobbies, and perhaps a letter to the donor.

(v) Identifying information: the name and contact details of the donor. Such information would be given in addition to some of the information types mentioned above.

Whether a donor can claim one or several of these information types depends on two conditions. First, we have to take into account the weight of their interests in obtaining such information. Are these interests related to recognized needs of a person? After all, a mere wish for something does not necessarily point to important needs that must be addressed. Secondly, we must weigh these interests against the potentially conflicting interests of the other parties involved.

We identify five arguments on which donors could base their claim for a right to some type of information about the offspring conceived by their donations:

- Medical information, in particular evidence of an unsuspected genetic disease, about the donor offspring can be of great importance to the donors’ and their own children’s health.
- Donors should be acknowledged for their altruistic behaviour. Basic information is a minimal reward for their donation.
- General information about the donor offspring should be given as a means to ease the donors’ potential concern about and sense of responsibility for the offspring.
- Basic information can provide an important enrichment of the donors’ identities.
- The open-identity system creates a ‘new’ type of donor—one that desires contact with the donor offspring. Identifying information enables such contact.

In what follows, we will analyse these arguments and evaluate the weight of the underlying interests.

Analysis of the arguments

Medical information about the donor offspring for the benefit of the donors’ health

The importance of exchanging medical information became clear in the USA in 2009 when a sperm donor passed on a lethal genetic heart disease to some of the donor offspring. This condition was discovered when one of the offspring died of the disease. The medical information was then passed on to the other offspring so that they could be examined, and treated if necessary, and regular observation was made possible (Jones, 2009). The exchange of medical information from donor to donor-conceived children is now increasingly accepted as a means for securing their health (McGee et al., 2001; Ethics Committee of the American Society for Reproductive Medicine, 2009; Ravitsky, 2012). But this line of reasoning might be just as convincing for the donor.

We can identify at least three reasons why donors could claim an equal right to medical information about the donor offspring. The first reason has to do with their own wellbeing. If a donor-conceived child develops a genetic disease and this information is passed on to the donor, the donor can be tested for the disease. At best, adequate measures can then be taken to prevent the disease. If the donor were to develop the disease, at least appropriate treatment could be started timely. It goes without saying that this argument only applies to preventable diseases, or diseases for which early treatment is advantageous. The second reason has to do with the donors’ reproduction. With this information, donors could make informed reproductive decisions about whether or not they should have children of their own, and about the need for prenatal or preimplantation diagnosis. Finally, this information could also benefit the donors’ own children. They have an interest in this information for the same reasons as the donor: it could lead to a suitable treatment if needed and it could help them make informed reproductive decisions in the future.

In other donation contexts—for instance with blood and tissue donation—relevant medical information is already passed on to the donor. In these practices, there are international guidelines concerning the release of information that benefits the donor’s wellbeing (Knoppers et al., 2006). The current wisdom is that blood and tissue donors should be informed if tests reveal a relevant medical condition. It is unclear why the same reasoning should not apply for gamete donors, particularly because their interest in this type of information can be met without intruding the rights and interests of the offspring and their parents. After all, medical information can be made anonymous and be passed on by for instance the fertility centre or general practitioner. To conclude, it would be reasonable to provide gamete donors information about genetic disorders exhibited by the donor offspring.

Basic information as a way to reward the donors

The practice of gamete donation is often compared with the act of giving someone a gift. Donors are seen as altruistic helpers who do the recipients a favour. Particularly in those donation settings where they do not receive payment, the question arises whether donors do not deserve to be rewarded for this gift, on top of whatever social recognition they may receive. Particularly for oocyte donors, the physical burden they endure supports the idea of some kind of compensation. There are other comparable donation contexts in which the donors are rewarded for their altruistic behaviour by granting them relevant feedback. For instance, people who donate to charity usually receive information about how their money was put to use and what their donation has helped to achieve. Also, within scientific research, it is common practice that participants are informed...
about the results of the research (Fernandez et al., 2003; Knoppers et al., 2006). This appears to be a good way to acknowledge their role. For gamete donors too, information could be an appropriate form of reciprocity (Pennings, 2005). Given that the main motivation of donors is to help other couples have a child of their own, the minimum feedback they desire is information about whether, and if so, how many, children were born from their donation. Indeed, several studies show that both sperm and egg donors ask questions about the outcome of their donation, such as the number or sex of the offspring (Cook and Golombok, 1995; Kalfoglou and Geller, 2000; Frith et al., 2007; Purewal and van den Akker, 2009). By granting them this type of information, we would allow them to feel positive about their donation, because this way at least they would know whether or not they actually helped other couples.

There is a second reason why identifiable donors could have an interest in this basic information. The Ethics Committee of the American Society for Reproductive Medicine (2009) states that ‘This information can offer psychological closure to the donor, caution the donor that contact may later occur, and give donors who already have children the opportunity to consider the impact of future contacts on their children and/or partner’ (p. 26). A study conducted by Kalfoglou and Geller (2000) shows that some egg donors wish to receive information about the outcome of the donation precisely for this last reason. Therefore, it could be argued that basic information is also important for the psychological wellbeing of the donors.

**General information about the donor offspring’s wellbeing in response to the donors’ concerns**

Donors wonder about the wellbeing and whereabouts of the offspring conceived by their donations. One study on ‘egg-sharing’ donors reports that they often think about the donor offspring (Gürtin et al., 2012). Studies conducted by Jada et al. (2011) and Daniels et al. (2005) indicate that sperm donors too worry about the wellbeing of the donor offspring. Jordan et al. (2004) show that some egg donors feel somewhat responsible for the donor offspring and are worried about the parenting style of the parents. Jada et al. (2011) and Baetens et al. (2000) report that some donors would even feel morally obliged to help the child if this were to be necessary. These concerns can be explained by the fact that the donors helped create the child. Our society is in general highly sensitive to the needs and wellbeing of children and so it is not surprising that this concern heightens when it involves children who carry part of your genes.

Granting donors general information about the offspring conceived by their donations could be a way to reassure them about the children’s wellbeing. Indeed, based on this same motivation, during the 1970–1980’s, in the practice of adoption, arguments were raised in favour of allowing birth parents (often birth mothers) to participate in the choice of the adoption parents and to gain information about the development of the child (Wolfgram, 2008). Studies conducted in the USA have shown that birth parents are concerned about their adopted child and desired a more active involvement in the adoption process and life of the child (Wolfgram, 2008).

The question is, however, whether a donor needs identifying information to reduce these potential concerns. Although gamete donation is comparable to the practice of adoption in the sense that both birth parents and gamete donors have a genetic child that is raised in another family, there is also an important difference. Donors do not have to cope with negative feelings about giving up the child. Therefore, donors do not have the same interests in contact with the offspring as the birth parents and there is much less ground for granting them identifying information about the donor offspring. Nonetheless, it could suffice to give donors anonymous feedback on the general wellbeing of the donor offspring, for instance through a rating scale that covers various welfare issues. This information could be updated every 5–10 years. It should be noted that donors are not obliged to receive this kind of information. Information should only be passed on to those donors who ask for it. When a donor expresses an interest in this type of information, the possibility of bad news should be made clear. One should keep in mind that the provision of this type of information may require accompanying measures such as counselling of the donor when he/she is informed that, for instance, the child experiences familial difficulties.

**Phenotypic and extended information about the donor offspring for the enrichment of one’s identity**

One can easily imagine that a gamete donor may now and then wonder about his or her donor offspring, for instance about whether they share certain physical or personality traits. Some studies confirm that there is curiosity among donors about physical resemblances, and this appears to be a major motivation for them to inquire about the donor offspring (Kalfoglou and Geller, 2000; Scheib et al., 2005; Jada et al., 2010). A curiosity about resemblances in personality traits was also found in a study by Daniels et al. (2005). However, as explained above, mere curiosity about the donor offspring is not reason enough to pass information on to the donor. A right to information must be based on a significant interest. According to advocates of the current open-identity gamete policies, this is undoubtedly the case for donor offspring. Even though their wish to know more about the donor also appears to stem from mainly curiosity (Scheib et al., 2005; Jada et al., 2009; Jada et al., 2010), they do get the opportunity to fulfill this curiosity. They are granted phenotypic information, an extended donor profile or even identifying information because this is said to be important in terms of the development of their identity (Daniels, 1998; McWhinnie, 2001; Velleman, 2008).

With information about their second genetic parent, it is argued, they are able to gain a better insight in who they are, in particular in those aspects of their identity that are ‘unique’ and those that they have in common with one or both progenitors. If this is a valid reasoning, does a similar argument not apply equally for the donor? After all, donors too share 50% of their genes with the offspring conceived by their donations. They too could discover similarities and differences, both physically and behaviourally, and use this information for a more correct perception or an enrichment of their identity (Kaebnick, 2004). One could thus argue that donors should receive phenotypic information and extended profiles of the donor offspring. An obvious problem is that children change over time. A solution could be to collect the information when the donor-conceived child...
reaches the age of 18. At that age, his or her personality traits and physical characteristics will have reached a more or less stable point. Alternatively, we could update this information every 5 years. Since donors typically have more than one donor-conceived child, they would receive several extended profiles and various types of phenotypic information. This should make it easier for donors to discover similarities or differences between themselves and the donor offspring.

However, there appear to be more differences than similarities between both cases. First, contrary to the donor offspring, donors generally do know (about) both their parents and therefore have been able to develop a personal identity based on sufficient information about their genetic origin. This is what the donor offspring are looking for. Both parties are in effect seeking a different kind of feeding about their genetic origin. This is what the donor offspring are generally do know (about) both their parents and therefore have between both cases. First, contrary to the donor offspring, donors have similarities or differences between themselves and the donor offspring. Typic information. This should make it easier for donors to discover would receive several extended profiles and various types of phenotypic information. Donors typically have more than one donor-conceived child, they will receive several extended profiles and various types of phenotypic information. Even a request by a donor for contact could have disastrous consequences: these donors have a desire to receive identifiable information. By not receiving this information, they are not likely to be harmed. However, there is no obvious reason why it should be prohibited either. If all parties desire contact, the possibility of mutual identity exchange could be offered, while not granting a particular right to it. This could for instance be accomplished by creating an online register to which both the gamete donor and the offspring can subscribe if contact is desired. Only when the donor child also registers on his own initiative and consent, should the exchange of identifying information be made possible. This system is already being used in the UK in the form of the UK Donor Link.

Nonetheless, a particular danger must be brought to attention. It is possible that the donors have high expectations about the contact which the donor offspring and their parents may not be willing to meet up to. There are at least two ways to prevent this kind of situation. For one, we could screen donor candidates in advance in terms of their personality, expectations, coping skills and perspective on donation. According to Sydsjø et al. (2012) and Sydsjø et al. (2011)
who conducted a study on the personality traits of current identifiable donors in Sweden, preventive screening resulted in the recruitment of mature and stable donors. However, this screening can only partially filter the donors’ motivations. An additional solution would be to offer psychological counselling to those donors who wish to contact the donor child so that unrealistic expectations can be identified and dealt with in time.

**Conclusion**

Our analysis shows that gamete donors have good reasons to claim a right to certain types of information about the offspring conceived by their donations. Information about genetic disorders can be important for the donors’ and their own children’s health. Basic information about the offspring can also be regarded as an appropriate reward for their altruistic behaviour. Such information can also play a role in the enrichment of their identity by confirming their procreation. Moreover, general information about the child’s wellbeing can be an important way to reassure concerned donors. Finally, it can be argued that a possibility to get in touch should be offered when all parties involved agree. While the provision of various degrees of anonymous information about the donor offspring should thus be considered, we have not found strong arguments in defence of a right to identifying information about the donor offspring.

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I.R. performed the literature research, drafted the manuscript and approved the final version for publication. A.R. and G.P. made substantial contributions to conception and design, critically revised the manuscript for important intellectual content and approved the final version for publication.

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