Views of donors and recipients regarding disclosure to children following altruistic known oocyte donation

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Abstract This paper reports on a Canadian study of the views of 15 women who had altruistically donated oocytes to a friend or a relative for family building and 18 women who had received oocytes donated by a friend or a relative towards disclosure of the donation to both the donor-conceived child and the child(ren) of the donor. Semi-structured interviews were undertaken with participants either in person or by telephone. The vast majority of donors and recipients reported concordance regarding disclosure. There was a greater tendency towards disclosure than for non-disclosure, especially where the donation had resulted in the birth of a child. Nevertheless, participants expressed considerable ambiguity around the optimum time for disclosure. The study highlights unique characteristics in co-ordinating disclosure plans to children in both families when the donors also had young child(ren) and how the relationships between donors and recipients and their families may be expected to impact on, and be impacted by, their disclosure decisions. These include the psychological and social costs that may occur when donors and recipients disagree regarding disclosure. Findings from this study contribute to the currently limited research evidence on disclosure to children in both donor and recipient families following known oocyte donation.
Introduction

Research regarding parental disclosure to donor-conceived children of the nature of their conception has focused largely on families built using anonymous sperm donation (Becker et al., 2005; Blyth et al., 2010; Daniels et al., 2009; Hunter et al., 2000; Lycett et al., 2005; Rumball and Adair, 1999; Shehab et al., 2008) and open-identity sperm donation (Gottlieb et al., 2000; Jadva et al., 2009, 2010; Lalos et al., 2007; Lindblad et al., 2000; Readings et al., 2011; Scheib et al., 2003, 2005), as well as contacts among donor siblings and families with children who share the same sperm donor (Freeman et al., 2009; Scheib and Ruby, 2008).

Growing research attention has been directed to exploring disclosure practices in oocyte donation as this has become an increasingly available option for family building (see reviews in Purewal and van den Akker, 2009; van den Akker, 2006). Studies investigating disclosure preferences in families built using anonymous oocyte donation have identified differences in attitudes between donors and recipients. Most donors favour disclosure and endorse the child’s right to know their genetic origins and would not object to future contact with the offspring born as a result of their donation (Braverman and Corson, 2002; Jordan et al., 2004; Kalfoglou and Geller, 2000; Klock et al., 2003). Alternatively, many recipients remain ambivalent about, or are opposed to, disclosure (Baetens et al., 2000; Golombok et al., 2004, 2006; Greenfeld and Klock, 2004; Hersberger et al., 2007; Klock and Greenfeld, 2004; Murray and Golombok, 2003; Murray et al., 2006; Readings et al., 2011). Studies have also shown that recipients who do not intend to tell their child about their recourse to donor oocytes nevertheless may have informed others in their family and/or social networks (Golombok et al., 2004, 2006; Hersberger et al., 2007; Kirkland et al., 1992; Readings et al., 2011), thus exposing their child(ren) to the risk of accidental disclosure.

Previous studies exploring disclosure decisions in gamete donation have identified a range of cognitive-reasoning methods used by parents (Blyth et al., 2010; Hahn and Craft-Rosenberg, 2002; Hersberger et al., 2007; Hunter et al., 2000; Lindblad et al., 2000; Lycett et al., 2005; Murray and Golombok, 2003; Nachtigall et al., 1998; Shehab et al., 2008). Such reasoning strategies include: (i) rights-based reasoning, how to resolve tensions between the child’s right to know the means of his/her conception and parents’ rights to privacy; (ii) principled reasoning, how the decision is guided by personal values, moral and ethical principles such as the desire to be honest and open; (iii) welfare of the child reasoning, whether disclosure is in the best interest of the child and if knowing their genetic origins helps to consolidate self-identity and contribute to the child’s long-term welfare; (iv) family-wellbeing reasoning, how the disclosure decision would affect interpersonal family relationships and whether secrecy is inherently destructive to family functioning; (v) risks-benefits reasoning, to evaluate whether the disclosure decision is harmful or beneficial to the child based on family circumstances; and (vi) context-dependent reasoning, how the decision is made based on an imaginary context, such as the effects of the child accidentally learning of his/her genetic origins and feeling deceived or lied to.

In jurisdictions where commercial procurement of oocytes is prohibited (Jones Jr. et al., 2010), including in Canada under the Assisted Human Reproduction Act 2004 (House of Commons of Canada, 2004), oocyte donation is dependent on recruitment of altruistic donors, among whom donors already known to recipients may play a key role in service provision and service viability. To date, very few studies (Khamsi et al., 1997; van Berkel et al., 2007; Weil et al., 1994; Winter and Daniluk, 2004; Yee et al., 2007) have explored disclosure issues in known donation, and where both pre- and post-donation relationships between donors and recipients may be expected to impact on, and be impacted by, their disclosure decisions. Key factors impacting these decisions are: (i) at least some members of the donor’s and/or recipient’s family and/or social network are likely to know about the donation, including the identity of the donor and/or recipient; (ii) the donor and recipient share a familial or social relationship prior to the donation that is likely to continue into the future and will most likely include the donor-conceived child and any children of the donor; and (iii) where the donation takes place between family members, the donor-conceived child will share a family relationship as well as a genetic relationship with the donor and any of her children.

Given these unique characteristics, disclosure decisions include not only whether to disclose to the donor-conceived child the nature of his/her conception, but also whether to disclose the identity of the donor; and in situations where the donor also has children, whether to disclose to them also. Furthermore, since the donor—recipient relationship is likely to continue following donation, a decision to disclose none or only part of this information to the child(ren) may have implications for relationships both within and between the donor and recipient families.

This paper reports on the views of women involved in known oocyte donation either as a donor or as a recipient regarding disclosure to children in both donor and recipient families. It forms part of a wider study exploring participants’ experiences of and views regarding altruistic known oocyte donation in Canada.

Materials and methods

Women who had donated oocytes to a recipient known to them or had received oocytes from a known donor for family-building between January 2000 and February 2009 via a hospital-based IVF clinic in a Canadian city were recruited to participate in a semi-structured face-to-face or phone interview. Ethics approval was obtained from the hospital in which the study was undertaken and by the authors’ employing universities.

In total, 48 donors and 48 recipients were identified through chart review, of which 18 donors and 20 recipients had either relocated to an unknown address or were otherwise not contactable. All participants were offered the option to be interviewed in person at the IVF clinic or by phone at their choice. Nineteen of the 30 contactable donors agreed to participate. Among the potential participants, six resided in the same city where the IVF clinic
was located, 19 resided outside the city and two had relocated to another province, two were subsequently not contactable and one withdrew because of time pressure. Another donor was excluded because she had ‘donated’ to her same-sex partner and did not consider herself a donor.

Twenty of the 28 contactable recipients agreed to participate. Among the potential participants, five resided in the same city where the IVF clinic was located and 15 resided outside the city. One of these was subsequently not contactable and one was excluded from the study because she and her donor came to know each other only because of the donation and did not share a prior relationship. Analysis was therefore based on 15 donor and 18 recipient interviews, with six conducted in person and 27 by phone. The response rates were 50% for donors and 64% for recipients.

Of the 15 donors, seven were a friend, six were a sister, one was a niece of the recipient and one donor donated both to her sister and to a friend. Of the 18 recipients, eight were a sister, seven were a friend, two were a cousin and one was the aunt of the donor. Where these pairings occurred, the interviews were conducted independently.

Each participant was asked to indicate her own preference regarding disclosure (‘disclosure’, ‘non-disclosure’, ‘no preference’ or ‘undecided’) and the reasons for this, as well as her understanding of the donor’s or recipient’s preference. Interviews were audiotaped and transcribed verbatim. Transcripts were imported to N-VIVO version 8 software (QSR International) for coding and were thematically analysed. Investigator triangulation was achieved by members of the research team independently analysing transcripts through an iterative process of coding recurrent themes using constant comparative methods (Strauss, 1998). Anonymized extracts from interviews (including the case identification code D or R, indicating donor or recipient, respectively) are used to illustrate the major themes arising from this analysis.

Results

Demographics

The mean age of donors at the time of donation was 29.8 years (range 22–35). Ten (67%) donors were either partnered or married, three (20%) were single, one (7%) courting and one (7%) separated. Nine donors had children; seven (47%) had their own biological children, two (13%) through adoption or step-parenting. Five of these donors indicated that they had completed their family prior to donating. Two of the six donors without children indicated that they may choose a childfree life.

The mean age of recipients at the time of donation was 35.6 years (range 27–44). All were in a heterosexual relationship. Reasons for seeking egg donation included premature ovarian failure, advanced maternal age, poor oocyte quality and other medical conditions.

Table 1 Donors’ and recipients’ preferences regarding disclosure to the donor-conceived offspring.

<table>
<thead>
<tr>
<th>Successful and unsuccessful cases</th>
<th>Donor’s view</th>
<th>Recipient’s view according to the donor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donors (n = 15)</td>
<td>Prefer disclosure: 10 (67)</td>
<td>Prefer disclosure: 11 (73)</td>
</tr>
<tr>
<td></td>
<td>Prefer non-disclosure: 0</td>
<td>Prefer non-disclosure: 4 (27)</td>
</tr>
<tr>
<td></td>
<td>No preference*: 5 (33)</td>
<td>No preference*: 0</td>
</tr>
<tr>
<td>Recipients (n = 18)</td>
<td>Recipient’s view</td>
<td>Donor’s view according to the recipient</td>
</tr>
<tr>
<td></td>
<td>Prefer disclosure: 12 (67)</td>
<td>Prefer disclosure: 9 (50)</td>
</tr>
<tr>
<td></td>
<td>Prefer non-disclosure: 4 (22)</td>
<td>Prefer non-disclosure: 4 (22)</td>
</tr>
<tr>
<td></td>
<td>No preference*: 1 (6)</td>
<td>No preference*: 4 (22)</td>
</tr>
<tr>
<td></td>
<td>Undecided: 1 (6)</td>
<td>Undecided: 1 (6)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Successful cases only</th>
<th>Donor’s view</th>
<th>Recipient’s view according to the donor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donors (n = 9)</td>
<td>Prefer disclosure: 6 (67)</td>
<td>Prefer disclosure: 5 (56)</td>
</tr>
<tr>
<td></td>
<td>Prefer non-disclosure: 0</td>
<td>Prefer non-disclosure: 4 (44)</td>
</tr>
<tr>
<td></td>
<td>No preference*: 3 (33)</td>
<td>No preference*: 0</td>
</tr>
<tr>
<td>Recipients (n = 8)</td>
<td>Recipient’s view</td>
<td>Donor’s view according to the recipient</td>
</tr>
<tr>
<td></td>
<td>Prefer disclosure: 6 (75)</td>
<td>Prefer disclosure: 4 (50)</td>
</tr>
<tr>
<td></td>
<td>Prefer non-disclosure: 2 (25)</td>
<td>Prefer non-disclosure: 4 (50)</td>
</tr>
</tbody>
</table>

Values are n (%).

*The donor/recipient had no preference and wanted to respect the other party’s decision.
Disclosure preferences following both successful and unsuccessful donation

Table 1 summarizes the disclosure preference of all participants and their understanding of their donor’s or recipient’s preference.

Donors

Ten donors (67%) believed that donor-conceived offspring had the right to know about the nature of their conception: ‘we’re going to tell everybody. Just a matter of how we’re going to tell certain people’ (D21). Some donors placed themselves in the offspring’s position: ‘if I accidentally found out or, yeah, you would feel deceived or lied to, and I mean there’s nothing wrong with being adopted or being, you know, having donating egg or sperm’ (D26).

Notwithstanding their own views, five donors (33%) considered the decision whether or not to disclose belonged to the recipient. Deference to recipients was often couched in terms of parental responsibility and privilege: ‘it’s their child […] it’s their right to choose how they want to treat it’ (D35). However, most donors also considered that maintaining secrecy would be difficult and acknowledged that the risk of inadvertent disclosure was high when some family members and friends were aware of the donation and/or were involved during the donation process.

Recipients

Twelve recipients (67%) had decided to be open to their child: ‘it would not be a secret, that a child had been conceived through IVF using a donor egg’ (R22). The majority stated their belief that donor-conceived offspring had the right to know about their conception and genetic origins: ‘I think that it is absolutely right for every child should know their biological origin as well as who brings them up, and I just think that there is a fundamental mistrust that happens when you don’t fully disclose these types of things to children, and it’s not one of those things that it’s okay to find out when you’re twenty’ (R31).

In known donation, where the pre-existing relationship between donor and recipient will usually continue following the donation, disclosing donor conception is also likely to necessitate disclosing the donor’s identity to satisfy subsequent questioning by the donor-conceived child: ‘the child would have been told that mommy couldn’t have babies until she helped us’ (R34).

In contrast, prior to receiving donated oocytes, four recipients (22%) had already decided not to tell their child: ‘basically, nobody was going to know about it, not even the child. We didn’t feel that there was any reason for it’ (R26). These recipients anticipated disclosure becoming necessary only in the event of a medical emergency or life-threatening health issue.

Disclosure preferences following successful donation

Table 2 summarizes the combined disclosure preferences of nine donors whose donation resulted in a live birth and eight recipients who conceived successfully following oocyte donation. In five instances both the donor and recipient participated in the study, although their participation and interviews were independent of each other. At the time of interview, 11 live births and one ongoing pregnancy were reported by participants.

Table 2  Disclosure decision to the donor-conceived offspring in successful donation cases.

<table>
<thead>
<tr>
<th>Nature of donation</th>
<th>Interview participant</th>
<th>Donor has children</th>
<th>Age of the donor-conceived offspring</th>
<th>Donor’s preference regarding disclosure</th>
<th>Recipient’s preference regarding disclosure</th>
<th>Disclosure preference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intra-familial 1</td>
<td>Donor</td>
<td>Yes</td>
<td>7 years</td>
<td>Disclosure</td>
<td>Non-disclosure</td>
<td>Mismatched</td>
</tr>
<tr>
<td>Intra-familial 2</td>
<td>Donor</td>
<td>No</td>
<td>4 years</td>
<td>No preference</td>
<td>Non-disclosure</td>
<td>Recipient’s decision</td>
</tr>
<tr>
<td>Intra-familial 3</td>
<td>Recipient</td>
<td>Yes</td>
<td>3 years</td>
<td>No preference</td>
<td>Disclosure</td>
<td>Recipient’s decision</td>
</tr>
<tr>
<td>Intra-familial 4</td>
<td>Donor and recipient²</td>
<td>Yes</td>
<td>1 year</td>
<td>Disclosure</td>
<td>Disclosure</td>
<td>Matched</td>
</tr>
<tr>
<td>Intra-familial 5</td>
<td>Donor and recipient²</td>
<td>Yes</td>
<td>New born</td>
<td>Disclosure</td>
<td>Disclosure</td>
<td>Matched</td>
</tr>
<tr>
<td>Friend-to-friend 1</td>
<td>Recipient</td>
<td>Yes</td>
<td>5 years</td>
<td>Disclosure</td>
<td>Disclosure</td>
<td>Matched</td>
</tr>
<tr>
<td>Friend-to-friend 2</td>
<td>Donor and recipient²</td>
<td>Yes</td>
<td>3 years</td>
<td>No preference</td>
<td>Disclosure</td>
<td>Recipient’s decision</td>
</tr>
<tr>
<td>Friend-to-friend 3</td>
<td>Donor and recipient²</td>
<td>No</td>
<td>3 years</td>
<td>No preference</td>
<td>Disclosure</td>
<td>Recipient’s decision</td>
</tr>
<tr>
<td>Friend-to-friend 4</td>
<td>Donor</td>
<td>Yes</td>
<td>2.5 years</td>
<td>Disclosure</td>
<td>Non-disclosure</td>
<td>Mismatched</td>
</tr>
<tr>
<td>Friend-to-friend 5</td>
<td>Donor</td>
<td>No</td>
<td>1 year</td>
<td>Disclosure</td>
<td>Disclosure</td>
<td>Matched</td>
</tr>
<tr>
<td>Friend-to-friend 6</td>
<td>Donor and recipient²</td>
<td>No</td>
<td>New born</td>
<td>Disclosure</td>
<td>Disclosure</td>
<td>Matched</td>
</tr>
<tr>
<td>Friend-to-friend 7</td>
<td>Recipient</td>
<td>No</td>
<td>Pregnant</td>
<td>Non-disclosure</td>
<td>Non-disclosure</td>
<td>Matched</td>
</tr>
</tbody>
</table>

²Instances of multiple births are not indicated in order to protect participants’ confidentiality.

²Both donor and recipient participated in the study independently of each other.
Donors

Among the successful cases reported by the donors, four donations had taken place between family members, five between friends. Five donors had children of their own at the time of donation. In four instances the donor’s and recipient’s disclosure preferences were identical and with both parties favouring disclosure. Two donors reported disagreement with their recipient regarding disclosure, and in both instances the donor’s preference was for disclosure while the recipient favoured non-disclosure.

Where disclosure had been mutually agreed by both parties, some indicated how they had anticipated answering any future inquiry from the offspring: ‘Once [offspring] is old enough to understand, and if he wants to come meet me. But, again, he won’t be a baby then, so maybe the emotional connection isn’t as great. If [offspring] ever comes to me, I’ll tell him why I did it and, you know, I think it’s just, it helps with self-identity. It just helps you figure out who you are’ (D27).

Alternatively, the potential problems of non-disclosure within the context of known donation were also recognized, given the anticipated continuing contact between the donor and recipient families: ‘I have some issues with it just in terms of logistics because we know what actually happened, and so it’s like you have to watch what you say. It’s just hard to keep the secret’ (D23). In several instances where the recipient had no plan to disclose to the child, donors were concerned about accidental disclosure when other family members and/or friends already knew about the donation: ‘because there’re so many people in the family who already know. Children can sense when there’s something they’re not being told. It would be I think a shame for her to learn it from somebody else’ (D30). Another donor indicated the tensions accompanying non-disclosure: ‘We’re all pretending that [recipient] conceived this beautiful child. I think that’s really what was the hardest part was the closeness and just keeping it a secret […] but it certainly has its consequences’ (D31).

As previously noted, where the donor has a child prior to donation, decisions regarding disclosure affect not only the donor-conceived child but also the donor’s child(ren). Whenever disclosure was best considered to occur, the donor’s child(ren) would reach that age before the recipient’s child(ren) did so. Some donors had given thought to this: ‘I don’t know when. I’m going to wait until [recipient] decides. I know [recipient] is going to start lightly talking about it when [offspring] gets a little bit older, so [offspring] is not totally shocked by that […] when [offspring] knows, that’s when I’ll let my kids know’ (D33).

Donors expressed common concerns of only wanting their own children to learn about the donation from themselves: ‘if they find out another route, like if they find out from someone else, I’d feel pretty bad that it isn’t us that explained it to them’ (D33). One donor wanted to be proactive and had started sharing information with her own children as soon as her recipient initiated disclosure with her donor-conceived child: ‘[own children] know a little bit. They know that mommy helped [recipient] have a baby. We are not hiding anything from them and if they ask questions then I will tell them, and we’ve discussed that with [recipient] that we will be up front with all of our children in the family. The whole family knows, friends, everybody knows’ (D26).

One donor who subsequently learned that her recipient had changed her mind about telling her child had to alter her own plan for disclosure to ensure consistency with her recipient’s decision: ‘once I knew [recipient] wasn’t planning to tell [offspring] […] I decided to drop it and not talk to my kids anymore about it because I thought it would be uncomfortable for everybody if [donor’s own children] knew and [offspring] didn’t’ (D30).

Where non-disclosure had been agreed, where the donor and recipient children were relatively close in age, and where the donor and the recipient families had continuing contact, the possibility of friendship between the children and – later – romantic attachment between them concerned some donors: ‘I don’t know what it’s going to be like when [her own children and the offspring] are older’ (D24); ‘like in twenty-five years, what if [my own child] fell in love with [offspring], […] I would never want my child to go through that’ (D23); ‘if my son started dating [offspring] or you know what, I mean, they’re going to know each other their whole entire lives and they’re not that far apart in age’ (D29).

Recipients

Five donations had taken place between friends and three between family members. Five donations were from donors who already had young children. In five instances the donor’s and recipient’s disclosure preferences were identical (four for disclosure and one for non-disclosure).

Most commonly, recipients who had decided on disclosure had already told their friends and family about the use of oocyte donation: ‘I’m not going to hide and I’m not going to pretend that it didn’t happen […] and I, personally, I think it’s important that [offspring] knows the truth and as opposed to when [offspring] is twenty-five or thirty finding out by accident or hearing from a relative’ (R37). Recipients in general agreed that disclosure should be initiated before the child became a teenager, although there was no agreement among participants on what that age would be. Nonetheless, a few recipients expressed some anxiety of not being able to anticipate their child’s reaction to disclosure: ‘the one big hurdle left I can see is explaining to the children that the process in which we went through. We’re going to have to formulate a plan, ‘this is how much we love you, this is why we did what we did’ […] I’m hoping that they’ll understand’ (R33).

Some recipients found assurance in knowing about the availability of counselling and books related to donor conception to assist them with disclosure: ‘so it’s useful to know the process and know that there is, are, people, professionals out there that can help us through that’ (R21). Some recipients recalled earlier discussion with the counselor that had helped prepare them to think proactively about disclosure: ‘[counsellor] kind of presented both sides and she kind of gave us a way to sort of tell the baby and when he’s a little bit older and how to say, you know, ‘mummy’s eggs didn’t work and, you know, auntie X gave us one of her eggs, and that’s where you came from but you grew inside mommy’ (R37).
Some recipients spoke about using a 'small-talk' approach to introduce disclosure to the donor-conceived child slowly and gradually, according to the child's developmental age: ‘he [donor-conceived child] has started asking questions. He did make a comment one day that he really wished he had brothers and sisters, so we told him that he actually did have brothers and sisters, but they just had different mommy and daddy, because [donor] does have her own kids and he kind of looked at me and he said ‘well, how does that work?’ I said ‘well, you know [donor] helped us with this and that’s how we got to have you’, and he just kind of raised his eyebrow, he gave me a look and said ‘okay, well, can we go over there and play? So he hasn’t really asked a ton of questions yet, but we’re more than ready to be more than willing and open’ (R27).

Since there was no unified approach as regards when, what and how to disclose donor conception to the child, some recipients thought about using organ or blood donation as an analogy, that the recipient had a medical issue and the donor provided the help she needed: ‘we’re going to tell [offspring], and we’re going to talk to [offspring] about it [...] like almost when somebody needs an organ, and it will keep them alive and somebody would donate that organ to help them or donating blood’ (R33).

Where the donor had a child (or children) already, the decision regarding disclosure affected not only the donor-conceived child but also the donor’s child(ren). Several recipients spoke about the logistics of co-ordinating the disclosure timeline and plans jointly with their donor: ‘we’re going to have to start giving [donor-conceived child] little bits of information, and obviously, [my donor’s] children will have to have that little bit of information gradually over the years too’ (R21). Recipients thought it understandable that the donor’s children would be curious to know about the donor-conceived child because of their shared genetic relationship: ‘[donor’s children] [...] understand that [donor-conceived child] is a little bit different because he came from a different way. They were just kind of curious. Her daughter has asked a lot of questions about our son, and [my donor] has been pretty up front with her. So she understands that she does have another half-brother somewhere. Whether she’s put the two together that it’s our son, and she’s really gotten that concept, I’m not quite sure. But she does know that he’s here’ (R27).

In known donation where the family and/or friends are closely tied and connected, it was acknowledged that openness with others about the nature of the child’s conception might compromise the recipient’s personal and family privacy: ‘I am very comfortable with telling people what’s going on, so now [donor’s extended family] all know that my daughter is a donor egg, and sometimes it makes me feel a little bit uncomfortable, but I try not to think about it. Because I don’t want them looking at [my donor child] as my [donor’s] and some of them do’ (R21).

Discussion

Findings from this study contribute to the currently limited research on disclosure to children in both donor and recipient families following altruistic known oocyte donation. The study explores how disclosure decisions are reached and negotiated by donors and recipients, the ensuing dynamics of personal and inter-familial relationships and interactions, and the need for the timing and planning of disclosure to children in both families when the donors also had young child(ren) to be co-ordinated. The process-oriented approach is consistent with recent studies concerning parental disclosure following gamete donation (Blake et al., 2010; Blyth et al., 2010; MacDougall et al., 2007; Shehab et al., 2008).

Understandably, disclosure decisions in known donation are much more complex than in anonymous donation, where both donors and recipients are actively involved in negotiating their disclosure preferences to arrive at consensus. Participants in this study reported the use of one or more reasoning strategies in reaching their disclosure decision. The data show that a small number of donors and recipients had no preference either for disclosure or for non-disclosure and were willing to leave the decision to the other party. Where both donor and recipient had agreed on disclosure, the timing and ways of sharing information with children in both families had to be negotiated. Where they had agreed on non-disclosure, they had to devise strategies to keep the donation private, although of course the risk of accidental disclosure in such circumstances cannot be discounted. While the literature on gamete donation contains anecdotal information on the adverse consequences of unplanned or unintended disclosure, there are, as far as is known, no instances of this occurring following known donation.

This study’s findings provide evidence of general agreement in principle between donors and recipients with regards to disclosure to their children relating to the nature of their conception and the donor’s identity. Among the successful donations, discordance between the donor and recipient in disclosure preferences was reported in two instances only, each reported by a donor. In one, where disclosure had initially been agreed, the recipient changed her mind. In the other, non-disclosure had initially been agreed, but the donor later wished to disclose. In both instances, invariably the donor had to modify her plans for disclosure to her own children to support her recipient’s preference. Although apparently infrequent, such discrepancies may come at considerable psychological and social cost, ascertaining their full impact would require further, longer-term research. One donor, whose recipient decided to keep the donation secret from everyone, eventually felt the need to distance her children from the recipient family because the children in both families had become playmates and she worried about the possible implications of the children developing a romantic relationship in later years in ignorance of their genetic relationship.

Some recipients endorsing full disclosure expressed uncertainty regarding the appropriate age to initiate disclosure with their children, other than that this should occur before adolescence. Blake et al. (2010) and Solomon and Johnson (1996) suggest that children under 7 years of age have limited cognitive capacity to comprehend the disclosure information and therefore earlier disclosure might not be meaningful to them, although there is evidence of parental disclosure at much younger ages (Blyth et al., 2010; MacDougall et al., 2007). Since the ages of the donor-conceived children in this study ranged from newborn
to 7 years, and most recipients intending to disclose had yet to do so, it is impossible to state whether these intentions will be realized. Factors such as a change of mind, uncertainty of how to engage with the practicalities of disclosure or deciding that disclosure has been left too late may also play a part in influencing future disclosure decisions.

A further area of potential dissonance between donors and recipients who have agreed on disclosure is when to initiate disclosure with children in both families, bearing in mind first the previously-noted uncertainty regarding the most appropriate age at which disclosure should take place and second that — whatever age is agreed between the donor and recipient — the donor’s child(ren) would likely reach that age first. In this study, the timing of disclosure was centred around the donor-conceived child. The implication that donors would wait until the donor-conceived child had been told before initiating disclosure with their own children is that disclosure would most likely occur when the donor’s children are pre-adolescent or adolescent, a time when the young person has a well-developed understanding of family roles and relationships and when the receipt of new information challenging existing knowledge and understanding of family concepts may be especially problematic. The detrimental impact of late disclosure on offspring and family functioning has been well documented (Daniels and Meadows, 2006; Kirkman et al., 2007; Turner and Coyle, 2000). However, to date, no study has explored the impact of disclosure — whether ‘early’ or ‘late’ — on the donor’s children. Future research will be necessary to investigate the nature of such implications.

Notwithstanding uncertainties expressed by a number of participants in the study regarding the most appropriate time to initiate disclosure, a few donors and recipients had already started the disclosure process with their children, using the ‘seed-planting’ strategy that was geared to the developmental age of their child and the ‘right timing’ approach, relying on their own discretion to ascertain the most appropriate time to convey the information to their children (Blyth et al., 2010; MacDougall et al., 2007; Söderström-Anttila et al., 2010). For example, one recipient initiated the discussion of donor conception during regular family routines when her child expressed the wish to have a sibling. In another case, a donor had told her own child that she had helped a friend to have a baby using a ‘small-talk’ approach to initiate a conversation about oocyte donation. Some recipients thought about referring to the donor as a ‘helper’ to aid them to have a baby; others used organ and blood donation as an analogy to explain how the donor helped to resolve a medical problem. These data are consistent with the findings by MacDougall et al. (2007) that the ‘helper’ story was often the most common narrative approach used by recipients of donor oocytes to person-alize the donor and to acknowledge her instrumental contribution in helping to build their family. Furthermore, recipients also emphasized the importance of building a base of strong parental and family relationships that would withstand unforeseeable reactions from the child, such that disclosure would occur at a time concordant with family cohesion. These findings support the notion that disclosure is an interactive dynamic process in which the child is also an active agent in scripting the disclosure narratives together with their parents.

This study has several limitations when interpreting the results of disclosure to children and identifying potential implications. First, all donor and recipient participants were recruited via a single IVF facility. Second, as with all studies that recruit participants retrospectively, those who had positive experiences of oocyte donation, enjoyed a harmonious relationship with their donor or recipient following the donation or who had favourable attitudes towards disclosure may have been more willing to participate in the study. It was therefore not possible to make any comparisons between participants’ and non-participants’ attitudes towards disclosure. Third, the disclosure preference expressed by participants needs to be interpreted with caution due to the small sample size, with 15 of 30 reachable potential donor participants (50%) and 18 of 28 reachable potential recipient participants (64%) actually taking part. Fourth, the cross-sectional method represents a snapshot of the lives of both donors’ and recipients’ families at the time of data collection. Their perspectives may alter with changes in relationship dynamics and as the children grow up. While it is therefore not possible to predict longer-term disclosure decisions or the future relationships emanating from them, participants’ ability to reflect on their experiences over a period of up to 7 years prior to interview nevertheless sheds new light on the dynamics of disclosure in known oocyte donation. Finally, the data on which this paper is based were generated from both face-to-face and telephone interviews, the choice of which was made by the participants. This was unavoidable for pragmatic reasons given the geographical distance between some participants’ locations and those of the research team. However utilization of the two different methods may have generated some bias. It is recognized that visual clues and non-verbal communication are absent from telephone interviewing that may make interviewer—participant rapport less easy to establish. On the other hand, telephone interviews generally result in smaller interviewer effects and a reduced tendency on the part of participants to provide socially desirable responses, while direct comparisons of face-to-face and telephone interviewing generally conclude that both methods produce data of comparable quality (Carr and Worth, 2001).

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