

# A longitudinal study of recipients' views and experiences of intra-family egg donation

V. Jadva\*, P. Casey, J. Readings, L. Blake, and S. Golombok

Centre for Family Research, Faculty of Politics, Psychology, Sociology and International Studies, University of Cambridge, Free School Lane, Cambridge CB2 3RF, UK

\*Correspondence address. Fax: +44-1223-330574; E-mail: vj227@cam.ac.uk

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**BACKGROUND:** For the past 10 years, we have been carrying out a longitudinal investigation of egg donation families in the UK; a subsample of recipients in these families had a child by egg donation from a sister or sister-in-law. In response to the current debate over the practice of intra-family donation, together with the general lack of available data on the consequences of donation between family members, we examined recipients' experiences of donation between sisters and sisters-in-law.

**METHODS:** We analysed data from a subsample of recipient mothers who were taking part in a larger investigation of gamete donation families. Mothers were visited at home and interviewed when their child was aged 1, 3, 7 and 10 years. Data from nine recipient mothers whose egg donor was either their sister or sister-in-law were examined to assess the nature of mothers', fathers' and the child's relationship with the donor, and whether mothers had disclosed the nature of their child's conception to others, including the child.

**RESULTS:** The majority of recipient mothers reported positive relationships between the donor and members of their family (themselves, their partner and their children). Most mothers were happy with the donor's level of involvement with the child and reported that they and the donor maintained their social roles within the family, i.e. as mother and aunt, respectively. By age 10, two children had been told that they had been conceived using egg donation, both of whom had been told the identity of the donor.

**CONCLUSIONS:** Although the sample was small, this study provides the first longitudinal data on the experiences of families created using donated gametes from a family member. Intra-family donation between sisters or sisters-in-law can be a positive experience for recipients during the first 10 years following the child's birth. Studies that are specifically designed to look at donation between family members are needed to better evaluate the practice.

**Key words:** intra-family / egg donation / family relationships / disclosure

## Introduction

In the UK, the Human Fertilisation and Embryology Authority (HFEA) is currently reviewing its policy on gamete donation between family members. Currently, there are no specific guidelines relating to how intra-family donation should be carried out. Instead, it is left to individual clinics to decide whether treatment should be offered. Intra-family donation, where the donor is a relative of the mother or father of the resultant child, includes intra-generational donation (e.g. between siblings or cousins), and inter-generational donation (e.g. between mother and daughter). There are no exact figures on the prevalence of intra-family donation in the UK. However, in a survey of UK clinics conducted by the HFEA (2010), it was found that >40% of clinics received a request for intra-family donation at least once a month, and that these requests were mainly for sister-to-sister donation. The survey found that inter-generational donation was

less common, with 29% of clinics reporting father-to-son donation and even fewer clinics reporting daughter-to-mother (11%) or niece-to-aunt (11%) donation.

Concerns have been raised over the use of family members as donors and these have mainly centred on the degree of autonomy that donors have when faced with a family member in need of gametes. Pressure to donate can be external, resulting from other family members or internal, when the relative feels obliged to donate (Vayena and Golombok, *in press*). However, concerns about the donor's autonomy are not restricted to intra-family donation and also apply to other cases where donors are known to the recipient couple (Vayena and Golombok, *in press*). Other concerns include whether intra-family donation may be consanguineous, that is, whether gametes of individuals who are closely related genetically are mixed together. The European Society for Human Reproduction and Embryology (ESHRE) Task Force (2011) differentiate between

two forms of consanguineous intra-family donation: donation between third-degree relatives, which—though very rare—may occasionally be reported and, donation between first- or second-degree relatives, which is ‘highly unlikely to occur in practice’ (European Society for Human Reproduction and Embryology (ESHRE) Task Force, 2011, p. 504). Inter-generational gamete donation raises additional concerns (Ethics Committee of the American Society for Reproductive Medicine, 2003) and case studies of sperm donation from father-to-son, and egg donation from daughter-to-mother or niece-to-aunt, have been particularly challenging for clinicians (Pierce et al., 1995; Marshall, 1998; Nikolettos et al., 2003). The ESHRE Task Force (2011) argued that these types of inter-generational donation raise additional concerns over whether donors make a voluntary decision to donate, particularly in cases where the donor is a dependent of the recipient, for example, in child-to-parent donation.

The present paper focuses on intra-generational egg donation, where the donor was either the sister or sister-in-law of the woman undergoing treatment—a form of intra-family donation that is more widely accepted and practiced (ESHRE Task Force, 2011). Studies of egg donors who had donated to a sister, cousin or sister-in-law have found that in all cases the donors had volunteered to do so (Winter and Daniluk, 2004; Yee et al., 2007). Yee et al. (2007) reported that all five donors in their study who had donated to either their sister or cousin had been motivated by altruism resulting from their knowledge of the effect of failed infertility treatment on the couple. The donors found the most rewarding aspect of egg donation was being able to offer help. Laruelle et al. (2010) found similar findings in their larger sample of 46 donors who had donated to a relative. A particular anxiety about intra-family donation centres on the welfare of the resultant child. Egg donation by a family member may cause the boundaries between the genetic, gestational and social parents to become blurred and, together with the emotional and physical proximity between the couple and the donor, may have a negative impact on the mother’s parental role. Winter and Daniluk’s (2004) study of three egg donors who had successfully donated to their sister found that all maintained their social role in the family, i.e. as the child’s aunt. Overall, all donors reported positive experiences of egg donation stating that it had enhanced their life and had made them feel proud and grateful.

Unlike anonymous donation, where the couple may be able to conceal the use of a donor egg, intra-family donation involves at least one member of the family i.e. the donor, being aware of the nature of the child’s conception. This is likely to make the concealment of egg donation from the wider family and the child more difficult. For those couples who wish to tell their child about the egg donation, having an egg donor who is a family member may cause additional complications. Lessor (1993) interviewed 14 couples and their donors who were undergoing sister-to-sister egg donation and found that recipient sisters were less open to telling others about the egg donation than their donor sisters. However, most couples and donors agreed that they would eventually tell the child about their donor origins. More recently, Van Berkel et al. (2007) reported the experiences of women who had had a child using egg donation from a known donor (47% of whom were members of the family) and found that 82% intended to tell their child about their biological origins although only two had done so at the time of the study, i.e. during early childhood. The egg donors in the study by Yee et al.

(2007) thought that the child should be told about their genetic origins although they also felt it was up to the parents to decide whether or not to disclose.

Positive attitudes towards sister-to-sister donation have been reported by infertile couples (Sauer et al., 1988) and found among the general public (Lessor et al., 1993). Women receiving eggs from a sister value the genetic connection with the child that donation by a sister provides (Lessor, 1993; Weil et al., 1994; Laruelle et al., 2010). Couples’ motivations for using related egg donors include preserving the family’s genetic inheritance and reducing the costs or waiting time for treatment (Ethics Committee of the American Society for Reproductive Medicine, 2003). In the UK, where there is a shortage of donor gametes, using gametes from a family member may be the only option available to some couples (HFEA, 2010).

The scarcity of studies on intra-family donation makes it difficult to draw conclusions about its impact. We know very little about the nature of the relationship between couples and the egg donor or, more importantly, between the child and the donor. Furthermore, we do not know how these relationships evolve over time or how the issue of disclosure is negotiated within these families.

For the past 10 years, we have been carrying out a longitudinal investigation of egg donation families in the UK (Golombok et al., 2004, 2005, 2006, 2011). A subsample of recipients in these families had a child by egg donation from a sister or sister-in-law. In response to the current debate over the practice of intra-family donation, together with the general lack of available data on the consequences of donation between family members, we extracted data relating to these families from our longitudinal study to examine recipients’ experiences of donation between sisters and sisters-in-law.

## Materials and Methods

### Participants

The recipient mothers in this study were a subsample of a larger sample of gamete donation families taking part in a longitudinal study of parenting and child development (Golombok et al., 2004, 2005, 2006, 2011). The initial sample of 51 egg donation families was recruited through nine fertility clinics in the UK. In each clinic, all two parent heterosexual families with a child aged between 9 and 12 months were invited to take part. The exclusion criteria were multiple births and severe congenital abnormalities. The response rate for the original study was 75%.

Tape-recorded interviews were carried out with mothers in their home when their child was aged 1, 2, 3, 7 and 10 years. Data on parents’ experiences of gamete donation were not obtained at age 2, and thus the present study reports findings from four time points (age: 1, 3, 7 and 10 years). Ethical approval for the first three phases of this study (ages 1, 2 and 3) were obtained from the City University London Ethics Committee, and ethical approval for phases 4 and 5 were obtained from the University of Cambridge Psychology Research Ethics Committee.

At age 1, there were nine mothers who had a child using egg donation from a family member [Due to a classification error, 10 families instead of 9 were reported as having used egg donation from a family member in Golombok et al. (2004)]. Six egg donors were sisters of the mother and three egg donors were sisters-in-law, where one was the wife of the mother’s brother, one was the wife of the father’s brother and one was the female partner of the father’s sister. Seven of the mothers were interviewed again at age 3, and 5 were interviewed at age 7 and age 10. Thus, 56% of the original participants took part in the study at age 10.

Of those who did not take part, two had actively withdrawn from the study and two had moved home and could not be contacted.

Sociodemographic details of the sample at age 1 are summarized in Table I. Occupational status was measured by the occupation of the parent with the highest ranking position according to a modified version of the Registrar General's classification (Office of the Population and Census Statistics and Employment Department Group, 1991) ranging from one (professional/managerial) to four (partly skilled or unskilled).

## Measures

A semi-structured interview was administered to mothers, a section of which included questions about mothers' experiences of egg donation. Information from the interview was rated according to a standardized coding scheme. The format of the questions and the coding criteria were drawn from previous investigations (Cook *et al.*, 1995; Lycett *et al.*, 2005).

### Relationship with the donor

At age 1, mothers were asked who had first suggested that the donor donate her eggs. Responses were coded as either 'mother', 'father', 'donor' or 'other'. They were also asked if they had discussed what role the donor would play in the child's life with responses rated by the interviewer as either 'maintain social role with the family' (i.e. as an aunt of the child), or 'play special role' (e.g. as a 'god-mother' or a 'special aunt'). At all four time-points, mothers were asked about the quality of their relationship with the donor and between the father and the donor. Data on the quality of the relationship between the donor and the child were also obtained from mothers at ages 7 and 10. The quality of these relationships were rated by the interviewer according to one of the four categories: 'Harmonious relationship' (characterized as a warm or friendly relationship with co-operation on both sides) 'Dissatisfaction/coldness' (when minor disagreements had arisen between the parties or when little communication or warmth was apparent), 'Major conflict/hostility' (where there was evidence of arguments or a breakdown in communication) and 'No contact' (no reported contact with the donor). Contact was defined as whether the recipient mother had been in any type of contact (i.e. telephone or face-to-face) with the donor during the past

year. The mother's feelings about the donor's involvement with the child was rated according to one of the four categories: 'Positive' (the mother was happy with the donor's involvement with the child and felt that this was good for the child), 'Ambivalent' (the mother was generally pleased that the egg donor was in contact with the child but had some doubts about whether contact was in the best interests of the child), 'Concerned' (where the mother expressed concern about the donor's involvement with the child because she felt that this may not be in the best interests of the child and 'No contact' (where there had been no contact with the donor).

### Disclosure about donor conception

At each time-point, mothers were asked whom they had told about their use of egg donation. Information was also obtained on whether mothers had told, or planned to tell, their child about the method of their conception and the reason(s) for their decision. Mothers who planned to tell but had not yet done so were asked at what age they intended to tell and their reasons for not having told so far.

In order to examine issues specific to intra-family donation that may not have been captured by the coding criteria, the interviews were later transcribed and relevant responses have been quoted for illustration.

## Results

### Relationship with the donor

In the majority of cases (five sisters and one sister-in-law), the suggestion that the donor donates her eggs was made by the donor herself. In two cases, the recipient mother had suggested that she donates and in one instance it was the recipient father. Although mothers were not directly asked why they had chosen to use a related donor, some commented on this during the interview. For example, one mother said that using a known egg donor meant that she did not have to wait long for treatment.

In terms of the role that donors would play, most mothers (7/9) reported that the donor would maintain their social role in the family, i.e. as the child's aunt, as summarized in the following comment:

'She's very, um, I don't know what the word is really, not detached, but just very much, you know, stepped back... If she sends a card she always sends it "to my nephew...'

Two mothers reported that the donor would play a 'special' role in the child's life, such as godmother.

Table II shows mothers' reports on the quality of their relationship with the donor, and between the father and the donor, at four time points, and between the child and the donor at ages 7 and 10. Most mothers reported a harmonious relationship with the egg donor, and none reported a relationship characterized by major conflict or hostility. These relationships remained stable over time—that is, those families who were rated as having a harmonious relationship at age 1 continued to have a harmonious relationship with the donor at age 10 and those who were rated as having a relationship characterized by dissatisfaction/coldness at age 1 continued to do so until age 10.

In terms of contact, at age 1, all except one mother reported that they were in contact with the donor. For subsequent ages, all mothers reported that they had been in contact with the donor during the past

**Table I** Socio-demographic information when child was aged 1.

	Mean	SD
Age of mother (years)	36.44	6.19
Child's sex	<i>n</i>	
Boy	4	
Girl	5	
Occupational status		
Professional/managerial	5	
Skilled non-manual	2	
Skilled manual	1	
Partly skilled or unskilled	1	
Ethnicity		
Caucasian	5	
Indian/Pakistani/Bangladeshi	2	
African/Afro Caribbean	1	
Other	1	

**Table II Mothers view of quality of relationship between the family and donor.**

	Age 1	Age 3	Age 7	Age 10
Mother's relationship with donor				
Harmonious relationship	7	6	4	4
Dissatisfaction/coldness	2	1	1	1
Major conflict/hostility	0	0	0	0
No contact	0	0	0	0
Total	9	7	5	5
Father's relationship with donor				
Harmonious relationship	8	6	4	3
Dissatisfaction/coldness	1	1	1	1
Major conflict/hostility	0	0	0	1
No contact	0	0	0	0
Total	9	7	5	5
Child's relationship with donor				
Harmonious relationship	—	—	5	5
Dissatisfaction/coldness	—	—	0	0
Major conflict/hostility	—	—	0	0
No contact	—	—	0	0
Total			5	5

year. The majority of mothers (8/9 at age 1; 6/6 at age 7, 4/5 at age 7 and 4/5 at age 10) were positive about the level of involvement their child had with the egg donor, with none stating that they were concerned about it.

### Disclosure about donor conception

In terms of telling other family members about the egg donation, at age 1, 6/9 mothers had told their parents, 5/9 had told their partner's parents, 8/9 had told their siblings and 7/9 had told their partner's siblings. However, not all mothers had told the whole story, two mothers commented that they had not told others that they knew the donor's identity and four had been open about using IVF but did not mention egg donation. For example, one mother said '... we've always been quite open about it, apart from the egg, I mean, only about IVF I don't mention egg donation'. Telling other family members remained stable over time. At age 10, of the 5 mothers who remained in the study, all had told their parents (5/5), 3/5 had told their partner's parents, 5/5 had told their siblings and 3/5 had told their partner's siblings. At age 10, two mothers were happy discussing IVF but not egg donation with others. One mother said that although her family were aware about the IVF she 'wouldn't go as far as to tell them that it was anything else'. The second mother was afraid of how people would react and went on to say that she did not think it was very important.

With regard to telling the child, when the child was 1 year old, the majority (6/9) of mothers planned to tell their child about the egg donation. The most common reason for planning to tell, given by four mothers, was that 'the child had a right to know'. Other reasons included 'to avoid disclosure from others' ( $n = 3$ ), 'to comply with the donors wishes' ( $n = 3$ ), and 'no reason not to tell'

( $n = 2$ ). One mother had said she wanted to tell to avoid intermarriage

'... imagine if she went out with one of her cousins or what ever and ... I think she should know where she came from and who helped me and everything, rather than hide it from them'.

Three mothers planned not to tell the child and their reasons included 'to protect the child' ( $n = 2$ ), 'to protect the mother' ( $n = 2$ ) or 'do not know what to tell' ( $n = 1$ ). One mother said she would tell only if the child asked about it:

'Um, we probably won't unless we have to and it works the same with my sister's children as well. We all agreed that if any, if ever any of them [the children] queried we would just come out and be straight and tell them all, but if they never query it then we would never tell them'.

In spite of the intention of most mothers to tell their child, by age 7, only one mother had done so. This mother had explained to her child that the egg had been donated by her sister (the child's aunt) but stressed her own connection to the child:

'... But we're always very clear that she grew in mummy's tummy and all of that so she knows that that connection is there... I don't want her to think that (egg donor) is her mummy... and I don't think to be fair that (egg donor) wants that either...'

The only mother who planned not to tell when the child was 7 years old revealed uncertainty over this decision saying '... I suppose sometimes I question myself as to whether we should be honest about it now'.

Two mothers who had not told their child were concerned about people noticing a resemblance between their child and their donor's children with one mother reporting that her mother-in-law (who was unaware of the egg donation) had commented that her child looked like her nephew and that this had been 'hard to swallow'.

The telling status at each time point can be seen in Table III. Mothers' views on telling the child remained stable over time—that is, those who planned not to tell at age 1 still planned not to tell at age 10. At age 7, three mothers were planning to tell the child, one at age 7, one at age 10 and one was unsure but thought that she would do so between 18 and 20 years. These mothers had not yet disclosed this information as they felt their child was too young to understand. By age 10, the mother who was planning to tell her child at age 7 had now done so. This mother reported feeling a sense of relief after telling the child and commented on how easy it had been:

**Table III Mothers telling status at each time point.**

	Age 1	Age 3	Age 7	Age 10
Told	0	1	1	2
Plan to tell	6	4	3	2
Uncertain	0	0	0	0
Plan not to tell	3	2	1	1
Total	9	7	5	5

'I just had a chat with him in bed one night and I think he just said, "Mummy, why didn't you have enough eggs yourself?", and I just said "just one of those things" and things like that, and I kind of brought it up maybe once a year since then, just to kind of remind him. . . . But um, it was all quite easy in the end. . . .'

The mother who was planning to tell her child at age 10 had told her child about the IVF treatment but had not mentioned egg donation. When asked if she will disclose the egg donation she replied '...he'll have to be told, yeah, because it's going to, it'll come out, too many people know'. While this mother was still intending to tell the child about the egg donation and about the identity of the donor, she was unsure about when she would do so.

## Discussion

Findings from this study suggest that intra-family egg donation where the donor is either the recipient mother's sister or sister-in-law does not have a negative impact on the relationship between the adults concerned, a finding similar to other studies of intra-generational donation between family members (Lessor, 1993; Weil *et al.*, 1994). Social rather than genetic connections were of greater importance in determining the nature of the adult's relationship to the child, with each adult maintaining their social role in the family, i.e. the recipient of the egg as the mother of the child, and the donor as the aunt.

By age 10, only two of the families that remained in the study had told their child that they were born using a donated egg from their aunt. In contrast, most mothers had told other family members about the egg donation, which may increase the chances of disclosure from somebody else. In addition, in situations where the donor and her family are in close contact with the recipient family, the child may notice a resemblance between themselves and the donor, or between themselves and the donor's children or the donor's children may notice a resemblance between themselves and the donor-conceived child. Resemblance between the child and the donor's children should be less of a concern for families where the donor is a sister, as similarities in appearance between cousins, or between the donor and the child, can be explained by the sharing of genetic material. However, this may be more problematic in cases where there is no perceived genetic relationship between the donor and the child, i.e. in cases where the donor is a sister-in-law of one of the parents. Similarly, this may also be problematic for couples whose donor is a close friend and who decide to keep the donor's identity a secret.

Another feature of disclosure within this sample was that of 'partial disclosure' where parents had told others that they had used IVF, but not disclosed the use of a donor egg, or where they had mentioned the use of egg donation, but not disclosed that the donor is a family member. Partial disclosure has also been found among parents of children conceived using gamete donation and surrogacy in our larger sample (Readings *et al.*, 2011), and may lead to the potentially problematic scenario where parents feel that they have been open and honest with the child, but where the child does not know the full story. The two mothers in the current study who had told the child the identity of the donor did not report any difficulties in telling the child and felt comfortable with their decision to tell. It is possible that children conceived using the gametes of family members may react more positively to the information that they are donor-

conceived because of the fact that they already know the donor. Their feelings may also depend on the quality of their relationship to the donor, that is, they may respond more favourably if the donor is someone they get on particularly well with rather than someone they dislike. That our study began over 10 years ago is noteworthy. Participants in our study conceived their child at a time in the UK when donor anonymity was still in place. While some of the clinics encouraged couples seeking treatment to be open with their child about the donation, this was not the case for all clinics. It is possible that current patients seeking gamete donation from a family member may have different counselling experiences compared with those seeking treatment in the past, which may have an impact on parents' decision to tell the child about their conception.

Some clinics now offer 'pooling schemes' where a relative of the recipient donates into a pool and in return the recipient receives gametes from an unknown donor. Such systems may offer an alternative to recipients and donors who may not be comfortable with direct donation within the family, and would also be an option in situations where direct donation would be consanguineous, for example, when a brother wishes to help his sister. One UK clinic which operates a 'pooling scheme' reported that around half of sisters donated to the pool and the other half donated directly to their sister (HFEA, 2010).

It is also worth noting the ethnic composition of the sample. Almost half the mothers belonged to an ethnic minority group (Asian, Black or mixed race), suggesting that intra-family donation may be more common among some cultures. In the Belgium study by Laruelle *et al.* (2010), it was also reported that 60% of couples who were of African origin had donors who were relatives, mostly sisters or cousins. In the UK, there is a shortage of donors from ethnic minority groups. Intra-family donation may be the only viable route for ethnic minority couples to access donor gametes.

A particular advantage of this study was its longitudinal design, enabling recipient mothers to be followed up until the child approached adolescence. In most cases, good relationships were maintained between the recipient mother and donor, and the quality of these relationships remained stable over time. Mothers were happy with the donor's involvement with their child and did not appear threatened by this. In the few instances where mothers reported dissatisfaction in their or their partner's relationship with the donor, this was not serious and did not appear to affect the relationship between the child and the donor. Thus, our overall findings suggest that recipient mothers have positive experiences of donation from a sister or sister-in-law.

This study has a number of limitations. Our investigation was not designed to look specifically at intra-family donation. While more general questions about known donation were included in the study, we did not ask questions specific to donation from a family member—for example, we did not ask if recipient mothers would have preferred to have used an anonymous donor instead of a related donor.

A second limitation of this study was its small sample size of nine families diminishing to five families by the 10 year follow-up. Some families were lost to follow up, which may suggest that certain types of families, for example, those who were particularly secretive or who were experiencing problems in their relationship with the donor, were less likely to participate. However, the study did not reveal a clear pattern between those families who dropped out and those who remained and the participation rates for this sample of recipient



mothers who had intra-family donation were similar to those of the remaining recipient mothers in our larger investigation, most of whom who had used an anonymous donor (56 versus 60%, respectively).

It should be emphasized that the donors themselves were not interviewed and therefore no conclusions can be drawn about their feelings and experiences. For example, we cannot comment on the extent to which donors felt under pressure to donate to a family member or how they feel about their relationship with the child. The fact that in some families, requests for a related donor to donate her eggs was made by the mother or the father does raise some concern about whether these women were free to make an autonomous decision to donate.

While this study sheds some light on the experiences of recipients of egg donation from a sister or a sister-in-law, and shows that such donations can work out well for recipient mothers, future studies with larger samples are needed to replicate and extend these findings. There is a need for investigations that are specifically designed to study intra-family gamete donation and which include different forms of donation—that is, inter-generational and intra-generational donation.

## Authors' roles

All authors contributed to the acquisition and interpretation of data for this study. V.J. drafted this manuscript and all authors contributed to its revision and have approved the final version for publication.

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