

# Parents' knowledge about the donors and their attitudes toward disclosure in oocyte donation

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**BACKGROUND:** Oocyte donation is a popular treatment option among women with ovarian dysfunction. Little is known about the amount of information recipients have about their donors and if the amount of information the couple has relates to their plans to disclose. The purpose of this study was to assess the amount of information recipients had about their donors and their disclosure plans. **METHODS:** Sixty-two sets of oocyte donation parents from five programmes completed a self-report questionnaire. **RESULTS:** Ninety percent of both men and women knew their donor's age, ethnicity, hair colour, eye colour, height, weight, education and medical history. Significantly more women than men told others about using a donor to conceive, but two-thirds of women and men would not tell others if they had to do it over again. Fifty-nine percent of women and 52% of men planned to or had told their child; 34% of women and 41% of men do not plan to tell. The amount of information known about the donor was related to plans to tell the child for men only. **CONCLUSION:** Approximately half of couples plan to tell their child of their oocyte donor origin and a majority have told others but many regret having done so. Knowledge about the donor is related to disclosure for men only.

*Key words:* disclosure/oocyte donation/parenting/psychological factors

## Introduction

Oocyte donation has been used to help women with impaired ovarian functioning have children since it was first reported 20 years ago (Lutjen *et al.*, 1984). The increasing application of oocyte donation in the USA is evident in the Society of Assisted Reproductive Technology (SART) summary statistics (Centers for Disease Control, 1995, 2001; American Society for Reproductive Medicine, 2002). In 1995, the first year that statistics were reported, there were 3352 embryo transfers using fresh donated oocytes, with a live birth rate of 35%. In 2001, the most recent year for which data are available, 7722 embryo transfers using fresh donated oocytes resulted in a 47% live birth rate. As the use of oocyte donation increases, so too do the concerns about the psychological and social impact of oocyte donation on the children created in this manner. Parents of donor oocyte children face important decisions during treatment that ultimately may have a bearing on the development of their child. These decisions include selecting a donor, telling others and telling the child about the child's oocyte donation origin.

In many oocyte donation programmes, couples considering oocyte donation meet with a mental health professional prior to beginning treatment. During the consultation, the couple may discuss how they will select a donor and the traits they want the donor to have. Couples also discuss who they have told about using an oocyte donor, the long-term implications of the

disclosure to others and their thoughts and feelings about disclosure to the child. In the mental health consultation, differences in partner's attitudes can become apparent. These discussions highlight the fact that the use of a donor gamete in the conception of a couple's child poses unique decisions for the infertile couple.

Couples' attitudes about donor gamete use and their plans for disclosure have been well studied in donor sperm conceptions (Klock *et al.*, 1994; Gillett *et al.*, 1996; Nachtigall *et al.*, 1998). Much less is known about couples' attitudes when oocyte donation is used. A qualitative study of anonymous oocyte donation parents found that among the 58 respondents, 56% planned to disclose, 18% were not planning to and 24% were undecided (Hahn and Craft Rosenberg, 2002). Pettee and Weckstein (1993) in a sample of 31 oocyte donation parents found that 70% of respondents planned to inform their child about their oocyte donation origin. In a Finnish study, 51 parents of oocyte donation children were asked about their intentions toward telling the child about their oocyte donation origins (Soderstrom-Antilla *et al.*, 1998). The investigators found that 38% of the parents planned to tell their child. While these studies represent an important first step in describing the experiences of donor oocyte parents, additional research is needed to clarify the degree of agreement within couples about disclosure, the information known about the donor and how knowledge about the donor may be related to disclosure.

Additionally, as Broderick and Walker (1995) have pointed out, previous studies have been limited by small sample size and reliance on only one programme for subject recruitment.

In the USA, there is no legislation addressing donor gamete use in terms of information sharing. Guidelines from the American Society for Reproductive Medicine (2002) for gamete donation recommend that, 'A mechanism must exist to maintain these records as a future medical resource for any offspring produced.' The guidelines also recommend that the records be kept as long as local requirements stipulate. The clinic-by-clinic variation in terms of information storage and availability and enactment of new legislation may have a bearing on the couple's disclosure plans (Gottlieb *et al.*, 2000).

It has been posited by Scheib *et al.* (2003) that the disclosure decision is determined by a combination of factors, one of which may be the amount of information the couple has about the donor. Other factors may include the recommendations from treatment providers, the cultural context around female infertility and the degree of agreement between partners about the disclosure decision (Daniels *et al.*, 1995). As these authors reported, 29% of their donor insemination couples disagreed with one another about disclosure. Daniels *et al.* (1995) noted that in most cases the woman acquiesced to the man's wish to not disclose, but it is unclear whether this was due to general gender differences in disclosure behaviour or was based on the male factor fertility problem.

The purpose of the current study was to survey a large, multicentre sample of oocyte donation parents to determine: (i) the amount of information they have about their donor; (ii) the couples' attitudes toward disclosure and their agreement with one another about disclosure; and (iii) to determine if there is a relationship between information about the donor and disclosure.

This paper focuses on couples' responses only. Data from all women respondents, comparing known versus anonymous donor recipients, has been reported elsewhere (Greenfeld and Klock, in press).

## Methods

Five programmes from across the USA (one on the east coast, two in the Midwest, and two on the west coast) were included. Charts were reviewed to identify women who were married or cohabiting who had become pregnant via oocyte donation during the past 12 years. A total of 287 couples were identified from the five programmes (programme 1,  $n = 24$ ; programme 2,  $n = 51$ ; programme 3,  $n = 54$ ; programme 4,  $n = 98$ ; and programme 5,  $n = 60$ ). Covering letters, questionnaires and return envelopes were sent to 262 couples (25 couples were excluded because it was unclear if a live birth took place), with separate material for each partner.

The covering letter described the purpose of the study, instructions for completing the questionnaire and the investigators' contact information. The covering letter was sent by a person on the treatment staff at the programme who the couple knew during the course of their treatment in order to minimize concerns about breeches in confidentiality. Questionnaires were coded numerically by programme and had no other

identifying information, therefore analyses comparing responders with non-responders could not be completed. The study was approved by the Human Subjects' Review Board.

The four-page questionnaire contained 12 multiple choice items assessing demographic information such as age, marital status, ethnicity, education, occupation, income and religion. Thirteen multiple choice and open-ended items ascertained information about infertility diagnosis, length of treatment, matching time, status of the donor (known or anonymous), concerns about the physical resemblance, personality, medical history and intelligence of the donor, contact with the donor by self and child, and compensation (Klock and Maier, 1991).

Recipients were also asked what characteristics they knew about the donor, and were instructed to check off as many of the 15 characteristics that they knew about the donor (age, hair colour, eye colour, ethnic background, height, weight, blood type, number of children, religion, education, medical history, profession, hobbies, reason for donating and photograph). Two open-ended questions were included to find out what else the recipients would have liked to have known about the donor and what they felt were the three most important characteristics about the donor.

The last section of the questionnaire dealt with disclosure. Respondents were asked five multiple choice questions about counselling about disclosure prior to treatment, telling others about using oocyte donation and their opinions about whether a donor registry should be developed. The question regarding a donor registry specifically queried subjects regarding their opinion of creating a national registry in which information about the donor could be kept for the child; no other registry alternatives were included. Two open-ended questions were used to determine the parents' intentions regarding telling the child and telling others about oocyte donation.

Data from the questionnaires were coded and used in  $\chi^2$  analyses for categorical variables and  $t$ -tests for continuous variables. Results of  $P < 0.05$  were considered statistically significant.

## Results

Questionnaires were sent to 262 couples (524 individuals); 12 sets were undeliverable and 157 questionnaires (92 women and 65 men) were returned, yielding a response rate of 31.4% (157 out of 500). Response rates from the five programmes varied from 7.5 to 51.9%. Within this sample, a total of 62 sets of couples' data were identified. The analysis of these responses is the focus of this paper.

The demographic make-up of the sample is given in Table I. The couples were married an average of 9.8 years, with an average of 1.8 children with an average age of 2.8 years (range 2 months to 8 years). Ninety-two percent of women and 87% of men reported having no older ( $>10$  years older than the donor child) children, and 76% of both men and women reported that all their children were donor oocyte children.

In terms of the oocyte donation itself, the diagnosis necessitating oocyte donation was premature ovarian failure for 24 (38%) women, advanced age for 30 (50%) women, surgical removal of ovaries for two (3%) and 'other' for four

**Table I.** Demographic characteristics of the sample (%)

Variable	Women	Men
Age	44.7 ± 5.1 years	45.1 ± 7.3 years
Ethnicity		
Caucasian	55 (88.7%)	56 (90.3%)
Asian	3 (4.8%)	3 (4.8%)
African American	2 (3.2%)	2 (3.2%)
Hispanic	1 (1.6%)	1 (1.6%)
Other	1 (1.6%)	
Education		
High school graduate	2 (3.2%)	2 (3.2%)
High school + some college	8 (12.9%)	5 (7.9%)
College graduate	21 (33.9%)	19 (30.2%)
Master's degree	18 (29.0%)	20 (31.7%)
Doctoral degree	13 (21.0%)	16 (27.0%)
Religion		
Catholic	15 (24.2%)	12 (19.7%)
Jewish	14 (22.6%)	10 (16.4%)
Other Christian	25 (40.3%)	27 (44.3%)
Other	7 (11.3%)	12 (19.7%)
None	1 (1.6%)	
Hours/week worked outside the home		
None	13 (21.3%)	
1–10	10 (16.4%)	1 (1.6%)
11–20	5 (8.2%)	
21–30	4 (6.6%)	2 (3.3%)
31–40	18 (29.5%)	11 (18.0%)
41–50	7 (11.5%)	27 (44.3%)
50+	4 (6.6%)	20 (32.8%)
Household income (per couple)		
\$30 000–50 000	1 (1.7%)	
\$51 000–70 000	6 (10.0%)	
\$71 000–90 000	5 (8.3%)	
\$91 000–110 000	28 (46.7%)	
\$110 000+	20 (33.3%)	

(7%) of the women. Twenty-five (40%) women and 27 men (44%) reported that choosing to undergo oocyte donation was 'not at all' difficult, but nine (14%) women and five (8%) men reported that it was 'very difficult'. Couples began oocyte donation treatment between 1988 and 2001, with the largest percentage (22%) undergoing treatment in 2000. The average time to wait until matched to a donor was 6 months, with a range of 1 month to 4 years. Forty-four couples (71%) used an anonymous donor, 12 (19%) had a known donor and six (10%) had a donor that they had met once in the donation process. All but one donor (both known and anonymous) were compensated, with the average amount of US\$3939.53, mode US\$5000 and range US\$1000–25 000.

We were interested in determining how much each partner knew about the donor, what else, if anything, they wished to know, and the relative importance of donor characteristics. The percentage of mothers and fathers knowing various donor characteristics is given in Table II. There were no significant differences in the knowledge of various donor characteristics between women and men. When asked in an open-ended question, 'What else would you have liked to have known about your donor?', 32% of women and 39% of men stated 'nothing'; 25% of women and 35% of men did not respond; 11% of women and 6% of men would have liked to have seen a photograph, and 8% of women and 6% of men wished to know more medical history details. When asked to list the three most important donor characteristics, 50% of women stated appear-

**Table II.** Percentage of mothers and fathers knowing various donor characteristics<sup>a</sup>

Characteristic	Women	Men
Age	98.3%	98.3%
Ethnicity	98.3%	96.8%
Hair colour	96.7%	95.2%
Height	95.0%	91.9%
Education	95.0%	98.4%
Medical history	93.3%	95.2%
Eye colour	91.7%	90.0%
Weight	91.7%	88.7%
Number of children	86.7%	77.0%
Reason for donating	86.7%	83.6%
Profession	82.8%	86.9%
Blood type	80.0%	80.0%
Hobbies	62.7%	65.6%
Religion	60.3%	65.0%
Saw a photograph	45.8%	45.8%

<sup>a</sup>No significant differences in women's and men's knowledge about their donor.

ance, 42% health and 38% intelligence. For men, when asked to list the three most important characteristics, 51% listed appearance, 50% health and 37% intelligence. Other factors that were of interest but listed by a minority of respondents were donor availability, blood type and proven fertility.

When asked about their concerns about the donor, both men and women were most concerned about the genetic and medical background of the donor, with a mean score of 6.2 for women and 5.9 for men on a scale of 1 to 7, with 1 indicating 'not at all' concerned and 7 indicating 'extremely' concerned. The second highest mean levels of concern were for the intelligence of the donor, with women having a mean score of 5.4 and men 5.2. Concern about the personality and physical resemblance of the donor had lower mean scores. Concern about the physical resemblance of the donor were significantly higher for women than men ( $\bar{X}_w = 4.5$ ,  $\bar{X}_m = 3.7$ ,  $t = 2.3$ ,  $P < 0.01$ ).

In terms of disclosure, a summary of disclosure behaviours by gender is provided in Table III. A gender difference was found in telling others, with a significantly higher percentage of women (82%) telling others than men (66%). When asked if they were to do it again, would they tell others, 60% of women and 62% of men stated that they would not. In the open-ended comments, respondents cited concerns over the privacy of the information and the right of the child to be the first to be told as the primary considerations in their regret over telling others. In terms of the consistency of disclosure to others, we found that for 39 (63%) couples, both had told others, in eight couples (13%) neither partner had told and 15 couples (24%) were inconsistent, with one partner telling others and the other not telling.

Fifty-nine percent of women and 52% of men had disclosed or intended to disclose to the child. In terms of the consistency within the couple in telling the child, we found that for 12 (19%) couples, both partners stated they had told, 21 couples (34%) that both partners intended to tell, in 18 couples (29%) that both partners were not going to tell and for 11 couples (18%) the partners were inconsistent. The inconsistency

**Table III.** Disclosure to others and the child

Variable	Women	Men
Had told others	81.7%	66.7% <sup>a</sup>
Told family members	64.4%	55.6%
Told friends	48.3%	41.3%
Told obstetrician	62.7%	50.8%
Told paediatrician	50.0%	41.3%
If you had to do it again would you tell others?		
Yes	36.2%	37.9%
No	60.3%	62.1%
Undecided	3.4%	
Have you told your child?		
Yes	11.5%	7.9%
Plan to	47.5%	44.4%
No	34.4%	41.3%
Undecided	6.6%	6.3%

<sup>a</sup>Significant gender difference ( $\chi^2 = 3.6$ ,  $P < 0.05$ ).

between partners was evenly split, with in five couples the woman saying she would not disclose and the husband saying he would, and in six couples the wife intended to tell and the husband did not. The correlation between telling others and telling the child were positive and significant ( $r_w = 0.39$ ,  $P < 0.002$ ,  $r_m = 0.59$ ,  $P < 0.001$ ). There was no relationship between the age of the female recipient, her diagnosis and her disclosure to the child or others.

We asked respondents if they were in favour of the establishment of a national donor registry to maintain information about the donor. We found a significant gender difference, with 32% of women and 21% of men in favour of a registry; 32% of women and 54% of men were opposed and 35% of women and 24% of men were undecided ( $\chi^2 = 6.3$ ,  $P < 0.04$ ).

Finally, the relationship between the amount of information the couple had about the donor and the plans to disclose to the child was explored. The number of characteristics known about the donor were recoded into three categories (0–5, 6–10 and 11–15 characteristics known) and used in a  $\chi^2$  analysis with plans to disclose to the child. We found that the amount of information known by the recipient parent was related to disclosure to the child for men ( $\chi^2 = 14.16$ ,  $P < 0.02$ ) but not for women ( $\chi^2 = 1.8$ , NS), with men who knew relatively more about the donor being more frequently categorized in the 'have told' or 'plan to tell' disclosure groups.

## Discussion

This study examined donor oocyte parents' information about their donors and plans to disclose to the child and others. Our sample was from five different oocyte donation programmes with the respondents in their mid-forties parenting children between 2 months and 8 years of age. When examining the demographic and reproductive histories of the parents, we were surprised to find that half of the women in our study were using oocyte donation because of advanced age, not premature ovarian failure or other medical conditions. This appears to support the observation made by Becker and Nachtigall (1994) that, 'seeking medical care for unwanted childlessness reflects

an increasing tendency in American society to turn to biomedicine for solutions to social problems.'

Both women and men reported knowing quite a bit about their donor and being satisfied with the amount of information they had. Over 90% of both partners knew their donor's age, ethnicity, hair colour, eye colour, height, weight, education and medical history. Eighty percent knew blood type and 45% had seen a photograph of the donor. Even though the majority of recipients described their donors as 'anonymous', the fact that almost half of them had seen a photograph seems to diminish the sense of anonymity. We speculate that recipients want to see a photograph prior to treatment to get reassurance about physical similarity and connection to the donor. The long-term impact of seeing a photograph and/or retaining the photograph for the child is unexplored but worthy of further study.

We did not find a gender difference in the amount of information known about the donor, indicating that both women and men are attuned to the information available about the donor. Approximately one-third of both men and women indicated that they did not want any more information about the donor, one-third had other specific information they wanted about the donor and one-third did not respond to the question. Among the third that wished for more information, the type of information they wanted ranged from seeing a photograph, to medical history details, to knowing how the donor felt about donating, a wish specific only to the recipient mothers.

Women were more concerned over the physical resemblance of the donor to themselves than men were concerned about the resemblance of the donor to their wives. Oocyte donation recipients may need to form an attachment to the donor and begin identifying with the donor before treatment can begin. Women's concern about the resemblance of the donor may be an indirect expression of their concern about their ability to attach to the child. Alternatively, the retrospective recollection of concern about the physical resemblance of the donor may also be interpreted as concern about whether the parents would be able to keep the oocyte donation private via the physical appearance of the child, i.e. does the child look enough like the mother to be thought of as her genetic offspring.

More women tell others, but equal percentages of women and men regret having told others. Similar to Pettee and Weckstein (1993), we found that >80% of women told others about using an oocyte donor to conceive. Similar to findings among sperm donation recipients (Klock *et al.*, 1994), we found that a significantly higher percentage of women than men told others about using an oocyte donor to conceive. There was not, however, a significant difference in the percentage of men and women who, if they had to do it again, would tell others, with ~60% of men and women stating that if they had to do it again they would tell no one. The decision to tell others is an important decision and is interrelated to the decision to tell the child. The finding that a majority of couples regretted telling others indicates that couples are uncomfortable with the loss of control over the information. Comments such as 'It's no one's business except our own' and 'I'm afraid they will find out from someone else' may reflect the belief that the child has the right to be the first to be informed and the concern that the child might inadvertently find out from someone else. Couples

who have felt that they have already lost control over their fertility may intensify their efforts to retain control over the information about their child's donor origin.

The results of our study indicate that the majority of couples are consistent with one another about their disclosure plans. There were, however, 24% of couples who differed from one another in terms of telling others, and 16% were inconsistent with one another in relation to telling the child. For example, in one couple, the partner's dissimilar views are evident, with the wife stating 'She is too young now, but it is information that she should have at some point' while the husband remarked 'I see no reason to have the child go through life wondering who her real mother was'. Another mother noted 'I conceived them, carried them to term and if they knew anything different they might start to feeling insecure', while the father stated 'I see no reason not to tell them'. These findings are similar to those of Daniels *et al.* (1995) in their study of sperm donation parents. They pointed out the need for thorough counselling of couples prior to treatment so they can come to a preliminary agreement about how to handle disclosure decisions. Couples may benefit from discussing the disclosure decision from the separate perspectives of telling others and telling the child, with emphasis on the meaning of the information over time. The importance of therapist neutrality and allowing the couple to process the decision themselves is highlighted by one respondent's comments, 'I would never disclose because I think it introduces a major complication in the child's life, and I think that it is okay to keep a secret like that but my husband felt strongly that it was better to tell, so I agreed, but I still don't think that it is better for the child...I think if the therapist had been neutral my husband would have thought harder about what would be good for the child, not what prevailing societal views thought—which of course, are always changing.'

There were no significant differences between men and women in terms of the plans to tell the child. Our data, as with most data of this type, are flawed by the intention to tell and the age of the child. The modal age of the subjects' children was 2 years. It is impossible to know if those who plan to tell actually do tell as the child grows up. The percentage intending to tell the child is lower than the 70% reported by Pettee and Weckstein (1993) and similar to the 56% reported by Hahn and Craft-Rosenberg (2002) in their studies of oocyte donation parents.

In support of the proposition of Scheib *et al.* (2003), we found that knowledge about the donor was related to plans to disclose to the child for men only. Examination of these data indicated that men who knew more about their donor were more often in the group of men planning to tell their child. This relationship between information about the donor and plans of disclosure to the child was not present for women. Other variables, such as strongly held beliefs that 'honesty is the best policy' or 'what the child doesn't know won't hurt him/her', may be more salient to women as they consider disclosure.

This study is limited by the self-report nature of the data and the 30% response rate. It may be that the results over-represent the percentage of couples that will disclose because couples

who are maintaining privacy may not participate in a study such as this. Future studies should focus on longitudinal designs that could increase the response rate and provide a picture of the change in disclosure attitudes over time. A strength of this study was the use of five geographically diverse programmes to recruit subjects instead of the reliance on one clinic for subjects (Broderick and Walker, 1995). Additionally, obtaining information from both husbands and wives provides a more thorough picture of the oocyte donation experience than reliance on the mothers' experience alone. Future studies should aim to understand the underlying causes of differential disclosure attitudes within couples and if disclosure status has an impact on the developmental and emotional health of oocyte donation children.

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