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ORIGINAL ARTICLE *Psychology and counselling*

Increasing openness in oocyte donation families regarding disclosure over 15 years

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BACKGROUND: Worldwide there is an increasing number of families created by oocyte donation (OD). The aim of this study was to gather information about parents' plans of disclosure to their child and to other people, as well as parents' attitudes and level of satisfaction up to 15 years after their OD treatment.

METHODS: A questionnaire with separate material for each partner was sent to all parents (167 mothers, 163 fathers) who had had a child after treatment with donated oocytes at Väestöliitto Fertility Clinics in Helsinki during 1992–2006. These parents had a total of 231 children aged 1–14 years. Parents were asked if they had told or intended to tell their child about his/her origin and how and when they had done so and about the reasons to disclose or not. Other questions were about openness towards other people, concerns about donor characteristics, counselling and feelings towards the child.

RESULTS: Of the mothers, 61.1%, and of the fathers, 60.0%, had told or intended to tell the child of his/her conception. Of children over 3 years of age, 26% had already been informed. There was a statistically significant difference between parental telling in different age groups of children ($P = 0.011$, χ^2). In the youngest age group (1–3 years), 83.3% of parents were inclined to disclosure compared with 44.4% in the oldest age group (13–14 years). A high proportion of mothers (86.7%) and fathers (71.0%) had told other people about the nature of their child's conception. The majority of parents did not have much concern about the characteristics of the donor. A higher proportion of the mothers (24%) compared with fathers (11%) thought that the psychological support had been insufficient. They thought that discussions with health professionals should be arranged routinely after delivery or when it was time to inform the child.

CONCLUSIONS: Parents with young OD children are clearly more inclined to disclosure compared with parents with older children.

Key words: children / disclosure / oocyte donation / openness

Introduction

Since the early 1980s, it has been possible for infertile women to conceive and become a mother with donated oocytes (Trounson *et al.*, 1983; Lutjen *et al.*, 1984). Over the years, oocyte donation (OD) has become a more accepted and widely used method of assisted reproduction leading to a high number of OD children being born every year worldwide. According to ESHRE statistics, 11 000 embryo transfers (ETs) from OD cycles were carried out in Europe in 2005 (Nybo Andersen *et al.*, 2009). In the USA in 2006, 15 500 OD–ET cycles resulted in almost 10 000 infants being born, half of them from multiple pregnancies (Sunderam *et al.*, 2009).

With thousands of OD infants being born every year worldwide, it is surprising that there are so few follow-up studies on these families. A few reports on OD families show no negative effects on the mother–child relationship, quality of parenting or emotional health of the children despite the absence of a genetic connection between the mother and the child (Golombok *et al.*, 1999, 2006). The existing literature on gamete donation families has mainly focused on disclosure plans among the parents, but mostly after donor sperm conception (Breways *et al.*, 1997; Nachtigall *et al.*, 1997; Rumball and Adair, 1999; Gottlieb *et al.*, 2000; Lycett *et al.*, 2005; Golombok *et al.*, 2006; Lalos *et al.*, 2007; Daniels *et al.*, 2009). Less is known about the parents' disclosure decisions in families formed after the use of donated oocytes. In these families, the parents may consider the disclosure differently from donor insemination (DI) families as the recipient woman is able to experience pregnancy and delivery (Hershberger *et al.*, 2007). The number of families included in previous OD studies has varied between 17 and 92, and the age of the children has mostly been under 8 years (Pettee and Weckstein, 1993; Weil *et al.*, 1994; Hahn and Craft-Rosenberg, 2002; Greenfeld and Klock,

2004; Klock and Greenfeld, 2004; Golombok et al., 2006; Murray et al. 2006; Mac Dougall et al., 2007; Van Berkel et al., 2007). These studies reported that 26–81% of the parents planned to tell their child about their conception, but very little is known about how many actually tell the child (Klock and Greenfeld, 2004; Golombok et al., 2006; Murray et al., 2006; Mac Dougall et al., 2007; Van Berkel et al.,2007).

In 1991, an OD programme was established at the Family Federation of Finland, Helsinki clinic, using altruistic, healthy volunteers as donors (Söderström-Anttila and Hovatta, 1995). Most of the donors have been anonymous women. The information on the donor available for the recipient couple has included ethnic background, age, height and colour of the eyes and hair. It has also been possible for a couple to have a known donor, for example a sister or a friend. Importantly, counselling has been included in the process from the beginning, and has been offered by either an experienced nurse or an independent psychologist. Openness and honesty regarding disclosure has been recommended by the professionals. In 1998, a follow-up study of the OD families who had undergone treatment at our clinic was carried out. The health and growth of the then 1–4-year-old children were found to be within normal ranges compared with standard IVF children (Söderström-Anttila et al., 1998). At the time, 38% of the parents intended to disclose the nature of the conception to their children.

On 1 September 2007, the Finnish Parliament enacted an Act on Assisted Fertility treatments (1237/2006) which states that gamete donors would have to register their identifying information in a donor register kept by the National Authority for Medico-legal Affairs in Finland. This makes it possible for the children born as a result of OD, DI or embryo donation to obtain identifying information of the donor at the age of 18 years.

The primary purpose of this study was to contact all OD parents treated at our clinic from 1992 to 2006 and collect information regarding disclosure issues (before the Finnish ART law came into effect). A second aim was to obtain data on OD parents' attitudes and level of satisfaction up to 15 years after their OD treatment regarding the treatment decisions, counselling and feelings towards their child. We also asked for a brief description of the current health of the child.

Materials and Methods

Study participants and procedure

A questionnaire, which was to be filled in separately by the mother and the father, was sent to all parents who had a child after treatment with donated oocytes at the Family Federation of Finland (Väestöliitto Fertility Clinics) in Helsinki between 1992 and 2006. During the years, the mean age of oocyte recipients was 34–35 years and approximately half of the OD recipients had primary or secondary ovarian failure, and in other cases repeated IVF failures, poor embryo quality, genetic disease or other medical conditions (Söderström-Anttila and Hovatta, 1995; Söderström-Anttila et al., 2003). The waiting time for anonymously donated oocytes was 1.5–2 years. Up to the end of 2007, 175 women had 206 deliveries leading to the birth of 243 children. There were 33 sets of twins and 2 sets of triplets (the proportion of multiple births of all deliveries was 17%). Six babies were stillbirths (2.9%), five of which were born from singleton pregnancies and one from a triplet pregnancy.

Before sending out the letters, addresses of the recipients were checked through the Finnish and Swedish address register centres. One mother and three fathers had died during the years. One couple refused all contact with the fertility clinic. One couple from Sri Lanka was excluded because of language problems. The addresses of two mothers and five fathers could not be confirmed. After excluding the couples with a perinatal death and no other OD child, a total of 167 questionnaires were sent to the mothers and 163 to the fathers. Altogether, these parents had 231 children aged 1–14 years. Of the recipient families, 139 (83%) were Finnish and 28 (17%) were Swedish residents. A reminder letter was sent out if no answer was received within 1 month.

Survey questions

The first part of the questionnaire assessed demographic data such as age, marital status, education and indication for OD treatment. In the next part, the parents were asked if they had told or planned to tell their children about their conception, at which age they had told them and why they thought this information should or should not be disclosed. Questions on openness of the nature of their fertility treatment in the delivery hospitals and to other people were included. Parents were also asked whether they felt that the decision to use donated oocytes had been a good decision, and if they felt that the child was their own, if they had concerns about the characteristics of the donor, and if they considered that the psychological support and counselling had been appropriate during their treatment process. Parents were asked to express their opinion about the new Finnish ART legislation and if they would be willing to participate in patient support groups for OD parents. Finally, the parents were asked to give a brief description of the health of their children and to report any malformations or medical disorders which might have been diagnosed.

The study was approved by the ethics committee of Gynaecology and Obstetrics, Pediatrics and Psychiatry, Hospital district of Helsinki and Uusimaa.

Statistics

All data analyses were done using SPSS version 17.0. Categorical variables were analysed by means of χ^2 tests and continuous variables by means of Student's t-tests. Values of $P < 0.05$ were considered significant.

Results

Demographics of the participants

The response rate among the mothers was 67.7% (113/167) and among the fathers 61.4% (100/163). The response rate was similar among parents with different ages of children, and the answers provided information on 70.9% of the children born (164/231). The mean age of the women respondents was 44 years (range 25–57 years) and that of the men was 45 years (range 25–61 years). Of the couples, 83% were married, 13% were cohabiting and 4% were living alone with their children. Eight couples had divorced and 11 had registered their relationship by getting married after having had an OD child. The educational background of the responding mothers was 26% academic, 66% vocational, 8% non-professional, and that of the responding fathers was 24% academic, 64% vocational and 12% non-professional.

A majority of the couples (85%) had received oocytes from an anonymous donor and 15% had a known donor (nine sisters, one niece, one sister-in-law, one cousin, two friends, two fellow workers, one donor through newspaper advertisement). In 51

women (45%), the indication of OD treatment was premature ovarian failure. There were 62 couples (55%) who had tried to conceive spontaneously and/or with conventional fertility treatments for 1–20 years (mean 5.6 years) before the decision to proceed with OD. Of the parents, 40 had two OD children, 13 had three OD children and 13 couples (12%) also had children born with their own oocytes. Of the OD children, 51% were boys and 49% were girls.

Disclosure to the child

The parents' decisions and opinions regarding secrecy issues are summarized in Table I. Of the mothers, 61.1% (69/113) reported that they had told or were planning to tell their child of his/her conception, and 60.0% (60/100) of the fathers responded similarly. There was no difference regarding openness between mothers with an anonymous donor (58/96, 60.4%) and those with a known donor (11/17, 64.7%), or between fathers with an anonymous (51/84, 60.7%) or known donor (9/16, 56.3%). There was no difference in disclosure intentions between parents with different educational backgrounds, marital status or indication for treatment (data not shown). Families with both genetically their own and OD children did not differ regarding openness from those with all children born from donated oocytes.

Among the respondents, there were 101 parents with children 3 years of age or older. Of them, 28 had already informed their child/children of their conception (27.7%). Altogether 38 of the 146 children (26.0%) aged 3–14 years had already been told. Seven children (18.4%) were informed at the age of 7–9 years and the others (76.3%) were informed when they were 3–6 years of age, except for two children (5.2%) who were told 'right from the beginning'. Most parents used the so-called seed-planting strategy, using words such as, 'we had a gift, an egg, or seed from a nice person, who helped us to get you'. In eight families (29%; 8/28), the parents reported that they read story books to their children describing different ways to create a family.

Interestingly, the disclosure intentions of the parents were clearly different between different age groups of the children (13–14 years, 10–12 years, 7–9 years, 4–6 years, 1–3 years, $P = 0.011$). Of the parents with children in the youngest age group, 83.3% intended to tell, whereas only 44.4% of parents of the oldest children had decided to disclose the information (Fig. 1). In 16 cases (16%), the mother and the father answered differently regarding the disclosure. Three mothers answered that they had told, but their spouses said they had not. In 13 cases one of the parents was uncertain whereas the partner had already decided what to do.

The reasons to disclose or not to disclose are summarized in Table II. For those parents who were inclined to disclose, the two most common reasons were 'it is natural to be open and honest' and 'the child has the right to know'. Among those who planned not to tell or could not say what they were going to do, ~70% of the reasons for not telling were either that it was 'unnecessary information' or 'it could be harmful for the child'. Three of these parents (4%) remarked that they would tell only if they were forced to do so because of some medical reason.

Disclosure to other people

A great majority of the parents informed medical professionals of the use of donated oocytes during pregnancy and delivery (Table I). A significantly higher percentage of mothers (86.7%) compared with the fathers (71%) had told someone else in addition to the medical team ($P < 0.05$, Table I). There was a strong correlation between intentions to tell their child and openness to other people (χ^2 test; $P < 0.005$). However, 71.4% (70/98) of the parents who had already told other people had not yet told their child. Ten mothers (11.4%) and two fathers (3.2%) regretted that they had told other

Table I Questions about openness and secrecy.

Question	Mother	Father	Significance
Have you told your child about his/her conception?	($n = 113$)	($n = 100$)	
Yes	28 (24.8%)	22 (22%)	ns
No, but I am going to tell	41 (36.3%)	38 (38%)	
No, and I am not going to tell	16 (14.2%)	15 (15%)	
No, and I am not sure what to do	28 (24.8%)	25 (25%)	
Had you told the medical team taking care of your pregnancy and delivery about the treatment?	($n = 113$)	($n = 98$)	
Yes	93 (82.3%)	70 (71.4%)	ns
No	20 (17.7%)	28 (28.6%)	
Have you told other people (except for the medical team) about your child's conception?	($n = 113$)	($n = 100$)	
Nobody	15 (13.3%)	29 (29%)	$P < 0.05$
Closest family members	23 (20.4%)	16 (16%)	
Friends and family	58 (51.3%)	41 (41%)	
Openly	17 (15.0%)	14 (14%)	
If you have informed other people, would you do it again?	($n = 88$)	($n = 61$)	ns
Yes	65 (73.9%)	48 (78.7%)	
No	10 (11.4%)	2 (3.2%)	
Do not know	13 (14.8%)	11 (18.0%)	

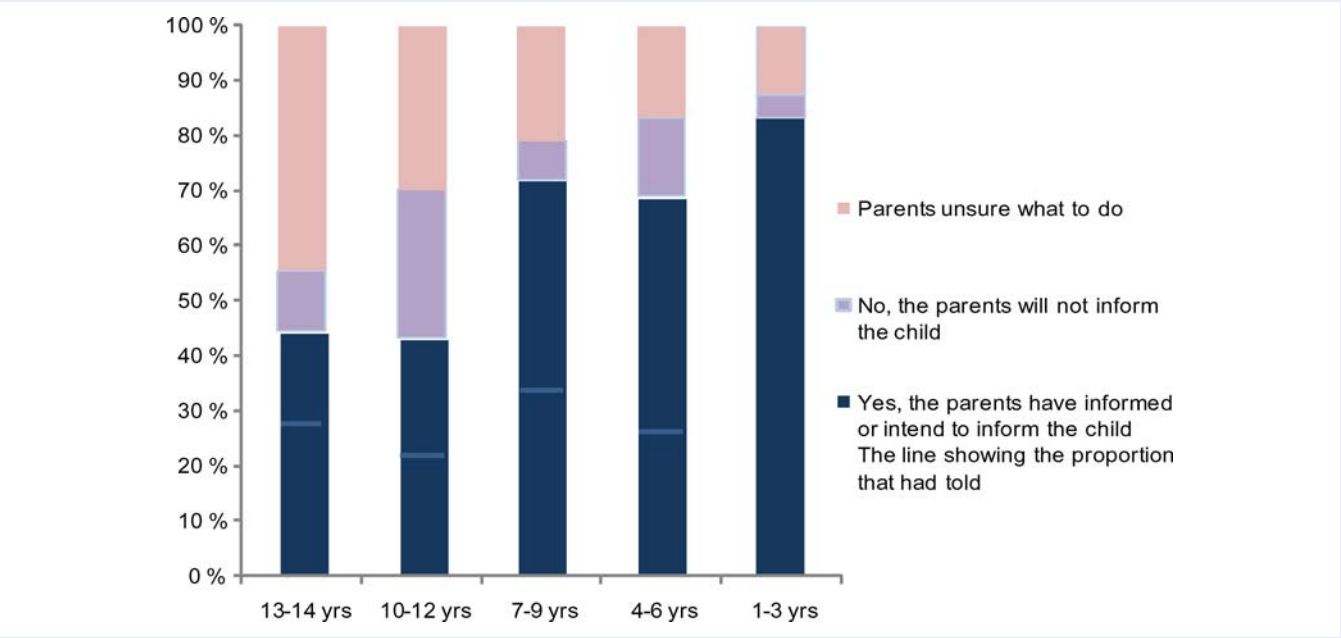

Figure 1 Disclosure decisions among 114 Finnish parents according to age of the OD children.

people about the OD treatment. These parents had been open about the conception during pregnancy, but when the child was born they saw the situation differently, more from the child's point of view. Four parents experienced that knowledge of the child's OD conception had spread to bystanders, and in one case a doctor had discussed the donor background in front of the child before the parents disclosed the information themselves.

Thoughts and feelings before and after treatment

The decision to use donated oocytes in the fertility treatment was easy for 88.5% of the mothers and for 81% of the fathers (Table III). Afterwards when the children were born, 100% of the mothers and 97% of the fathers thought that it was a right decision. Three fathers were not able to or did not want to answer this question. All parents felt that the child was their own. The majority of the parents who received oocytes from an anonymous donor had very few or no concerns about the background characteristics of the donor regarding her physical resemblance, personality, intelligence, or the risk that their child would fall in love with a half-sibling (Table IV). There were 37 mothers (39%) and 27 fathers (32%) who had some worries and only four mothers who had 'great' concerns about the genetic or medical background of the donor. In the 17 families in which the donor was known, one donor (6%) met the child every week, eight (47%) every month, six (35%) a few times a year, while one (6%) had met the child only once and one (6%) had never seen the child. None of the 17 mothers reported any kind of problems with the known donor.

Attitudes regarding counselling and support

Approximately half of the mothers (54%) and a few more of the fathers (59%) were satisfied with the amount of counselling and psychological support they had received during their treatment process. A higher proportion of the mothers (24%) compared with fathers (11%) thought that the psychological support was insufficient ($P < 0.05$). They felt that they would have needed more individual counselling, no pressure towards disclosure and more help to solve disagreements between the partners on disclosure issues. The most common comment on counselling was that before OD, infertility *per se* was so difficult and stressful that the origin of the gametes was less significant and psychological support would be needed primarily after the child was born. Twelve parents answered that discussions with a psychologist should be available routinely after delivery or at the time of disclosure. Mothers were more interested than fathers in participating in OD patient support groups, 42.5 and 22%, respectively ($P < 0.01$).

Views on the new art legislation

Of the mothers, 31%, and 24% of the fathers thought that it was good that the new Finnish ART law requires open-identity donation giving the future gamete donation children the possibility to contact their donor. One-third of the parents thought that it had been a poor decision to remove donor anonymity and approximately one-third were uncertain. Approximately 40% of the parents answered that the removal of donor anonymity is not going to impact the parents' disclosure intentions in the future. There were 15% who thought that a higher proportion of parents would tell in the future and 15% who thought that fewer parents would tell.

Health of the children

The parents were asked whether their children had had any birth defects or major medical problems. A birth anomaly was reported in seven children (4.3%). These included a cardiac defect, cleft sternum, hip luxation, amnion stricture of a foot, stenosis of pylorus, micro-ophtalmus, hydrotestis and skin haemangioma.

Table II What are the reason(s) for choosing to tell/not to tell your child of her/his conception?

Question	Mother	Father
What are the main reasons to inform the child*?	(*n* = 97)	(*n* = 82)
It is natural to be open and honest	66 (68.4%)	67 (81.7%)
The child has the right to know	77 (79.4%)	50 (61.0%)
To prevent the risk of accidental disclosure	54 (55.7%)	36 (43.9%)
Other	5 (5.2%)	
Secrecy creates tension within the family	2	
To prevent possible family conflicts when the child is a teenager	2	
Medical reasons	2	
To promote identity development	1	
What are the main reasons not to tell†?	(*n* = 39)	(*n* = 30)
Information is unnecessary	16 (41.0%)	16 (53.3%)
Information could be harmful for the child	18 (46.2%)	15 (50.0%)
Concern that the child will attach to the donor	4 (10.3%)	
Other	10 (25.6%)	5 (16.7%)
My partner does not want to tell	1	2
Will inform only if forced to because of medical reasons	2	1
It is the wish of the known donor	1	
Unnecessary to tell as the donor was anonymous	1	
Risk of inequality between the partners		1
A desire to keep equality between OD and genetically own children	1	
Grandparents would not understand	1	
Fear of confusing the child	1	
No clear reason	2	1

*Answers by those who are inclined to openness or are unsure.
†Answers by those who are inclined to secrecy or are unsure.

Table III Data about decision-making, counselling and feelings towards the child.

Question	Mothers (*n* = 113)	Fathers (*n* = 100)	Significance
The decision to use oocyte donation in fertility treatment was			
Very difficult	3 (2.7%)	3 (3%)	ns
Quite difficult	9 (8.0%)	13 (13%)	
Quite easy	52 (46.0%)	51 (51%)	
Very easy	48 (42.5%)	30 (30%)	
I cannot answer	1 (0.9%)	3 (3%)	
Did you get enough counselling and support regarding psychological and ethical aspects of the treatment?			0.046
Yes	61 (53.9%)	59 (59%)	
No	27 (23.8%)	11 (11%)	
I cannot answer	25 (22.1%)	30 (30%)	
Do you afterwards think that the decision to use donated oocytes was right and good?			
Yes	113 (100%)	97 (97%)	ns
No	0	0	
I cannot answer	0	3	
Does the child feel your own?			
Yes	113 (100%)	100 (100%)	ns
No	0	0	
I cannot answer	0	0	

Among severe illnesses, there was one child with Prader–Willi syndrome, two children with unknown neurological delays of development and one child with cerebral palsy. One of these children was born at 26 weeks of gestation from a triplet pregnancy, one child was a full-term twin and two were full-term singletons. The incidence of severe neurological disability was 1.8%. In addition, there were two children with slight neurological disabilities. Endocrine or autoimmune disease was reported in nine children (5.5%) including premature adrenarche, diabetes, growth delay, hypothyreosis, parathyroid disorder, juvenile rheumatitis and coeliac disease.

Discussion

In this questionnaire study, we examined the attitudes and decisions on the disclosure of the nature of conception to the child and other people among a total cohort of mothers and fathers in a Finnish OD programme. The response rate among all OD parents was high, 65%, particularly as many of the couples had not been in any contact with the clinic during the last 10 years. As a result, we were able to obtain information on 114 families including 164 children. Thus, to our knowledge this is the largest follow-up study performed on OD children, including 18 children as old as 13–14 years of age.

Of all respondents, 61% had already informed or intended to inform their child of his/her origin. The level of openness was in accordance with other studies reporting that 26–81% of OD parents have been inclined to disclosure (Pettee and Weckstein, 1993; Weil *et al.*, 1994; Hahn and Craft-Rosenberg, 2002; Greenfeld and Klock, 2004; Klock and Greenfeld, 2004; Golombok *et al.*, 2006; Murray *et al.*, 2006; Mac Dougall *et al.*, 2007; Van Berkel *et al.*, 2007). However, in many previous reports the response rate has either been low or the participating couples have actively expressed willingness to be contacted for research purposes (Rumball and Adair, 1999; Greenfeld and Klock, 2004; Shehab *et al.*, 2008). These factors may have impacted the previous results, as those parents who decide not to participate in a survey are probably less inclined to disclosure (Nachtigall *et al.*, 1997; Gottlieb *et al.*, 2000; Klock and Greenfeld, 2004). That was probably also the case for non-responders in this study. Our finding that 26% of all children aged 3–14 years had already been informed of their origin was comparable to or higher than in previous studies, in which the disclosure rate has varied between 5 and 24% (Klock and Greenfeld, 2004; Golombok *et al.*, 2006; Murray *et al.*, 2006; Mac Dougall *et al.*, 2007; Van Berkel *et al.*, 2007). This result, that every fourth child over 3 years of age

Table IV The parents' concerns regarding the anonymous donors.

Have you been worried about the following things regarding your donor?	Mother	Father	Significance
Medical or genetic background?	($n = 95$)	($n = 83$)	ns
Very much	4 (4%)	0	
A little	37 (39%)	27 (32%)	
Not at all	53 (56%)	56 (68%)	
Do not know	1 (1%)	0	
Looks	($n = 94$)	($n = 83$)	ns
Very much	3 (3%)	0	
A little	14 (15%)	16 (19%)	
Not at all	76 (81%)	66 (80%)	
Do not know	1 (1%)	1 (1%)	
Personality	($n = 94$)	($n = 83$)	ns
Very much	1 (1%)	0	
A little	15 (16%)	19 (23%)	
Not at all	77 (82%)	62 (75%)	
Do not know	1 (1%)	2 (2%)	
Intelligence	($n = 94$)	($n = 83$)	ns
Very much	1 (1%)	0	
A little	12 (13%)	17 (21%)	
Not at all	80 (85%)	65 (78%)	
Do not know	1 (1%)	1 (1%)	
That my child will fall in love with his/her genetic half-sister/brother	($n = 94$)	($n = 83$)	ns
Very much	1 (1%)		
A little	12 (13%)	5 (6%)	
Not at all	81 (86%)	76 (92%)	
Do not know	0	2 (2%)	

had already received information on his/her conception was well in line with our aim to encourage openness within the families.

An interesting finding was that parents with younger children (1–3 years) were more likely to tell their child compared with parents with older children (10–14 years) (Fig. 1). There could be several explanations for this. One could be that as long as the child is still very young, it is easier to plan the disclosure, and as the child grows, the threshold to begin to discuss the matter becomes higher. Another explanation could be that there has, in fact, been a real change in attitudes towards greater openness in women and men who have become parents using donated gametes over the years. Data published in 1998 from the same cohort of parents with OD children born 1992–1996 support this picture of change in disclosure attitudes over time (Söderström-Anttila *et al.*, 1998). Thirteen years ago when these children were 6 months to 4 years old, only 38% of the parents reported that they intended to tell and 29% planned never to tell the child (Söderström-Anttila *et al.*,1998). Now, according to the present study, 83% of parents with small children intend to disclose the information to the child, 13% could not say what they are going to do, and only 4% plan never to tell. Furthermore, the attitudes among the first OD recipients treated in the early 1990s, whose children are now 10–14 years of age, have not changed over time as only 44% report that they have told or plan to tell. To our knowledge, this is the first time parental decision-making after OD has been studied at two points of time—13 years apart. The reasons for growing openness regarding disclosure issues could be associated with changing attitudes towards gamete donation in general. OD has become an increasingly accepted method of assisted reproduction to overcome fertility problems. Another important factor affecting disclosure decisions is the nature of counselling provided by the medical team and psychologists. Over the years, knowledge has accumulated about the advantages of a gradual disclosure starting at a young age (Rumball and Adair, 1999). Consequently, the professionals have more and more actively encouraged the parents to inform their presumptive child of his/her conception.

OD parents have in general been more open towards their child compared with families with a DI child (Golombok *et al.*, 2006). Surveys among DI parents report that 30–54% of them intend to inform the child (Nachtigall *et al.*, 1997; Rumball and Adair, 1999; Gottlieb *et al.*, 2000; Lycett *et al.*, 2005; Golombok *et al.*, 2006; Daniels *et al.*, 2009). However, according to recent follow-up studies from Sweden and New Zealand, a similar change towards openness has been seen in the attitudes towards disclosure among DI parents (Gottlieb *et al.*, 2000; Lalos *et al.*, 2007; Daniels *et al.*, 2009). Likewise, it has been postulated that this change in attitudes has been a result of a more active role of the healthcare personnel to encourage openness and honesty among the parents (Lalos *et al.*, 2007). Other factors influencing parents' disclosure decisions are religious and cultural backgrounds, family relationships, personal beliefs and early life experiences (Shehab *et al.*, 2008).

Some investigators have observed differences in disclosure according to the type of donor, with greater willingness to inform the child if the donor has been non-anonymous (Weil *et al.*, 1994; Greenfeld *et al.*, 1998; van Berkel *et al.*, 2007). We did not observe any difference in disclosure patterns in families with a known compared with an anonymous donation. Furthermore, indication for treatment, level of education, marital relationship or difficulties in decision-making regarding the OD treatment itself did not affect parents' disclosure decisions. Those who decided to tell the child did it simply because they felt that it was the right thing to do, and that the child had the right to know. These results are in line with previous studies on gamete donation families (Rumball and Adair, 1999; Golombok *et al.*, 2006). On the other hand, those couples who had decided on non-disclosure were more strongly influenced by the opinions of family members, relatives and other people.

Most of the parents had told a third party of their child's conception, for example medical professionals, close friends, relatives or other people. Similarly to previous studies, the mothers were significantly more open compared with the fathers (Pettee and Weckstein, 1993; Klock and Greenfeld, 2004). According to our present study, 87% of mothers had told other people outside the medical professionals compared with 73% of the mothers 13 years ago (Söderström-Anttila *et al.*, 1998). Again, this can be seen as a step towards greater openness in parents using third-party reproduction. Previous studies have shown that parents talk to relatives and

friends before they inform their own child, and that ~60% of the parents regret having done so (Klock and Greenfeld, 2004; Daniels *et al*., 2009). On the contrary, we found that although a majority of mothers and fathers had told other people, very few regretted their decision.

For a great majority of the parents, the decision to proceed to OD had been easy and all parents felt that the child was their own after he/she was born. However, almost half of the parents felt that psychological support had been insufficient. Two issues regarding counselling were repeatedly brought up by the respondents. Firstly, OD parents expressed a desire to talk with a counsellor immediately after the child was born and also when it was time to tell the child about his/her OD origin. The parents felt uncertain about how to tell the child and wished for guidance and assistance. The importance of ongoing support for parents following the birth of the child has also been emphasized by others (Rumball and Adair, 1999). Secondly, almost half of the mothers expressed willingness to participate in patient support groups. Consequently, a support group for gamete donation families and couples planning for this type of treatment was founded in 2009 within The Finnish Association for infertile couples, Simpukka ry.

Our study shows that a high proportion of OD parents maintained their relationship in spite of a difficult infertility problem, repeated unsuccessful treatments and a 2 year waiting period to get donated oocytes. Only eight couples were divorced. This is in accordance with a recent study from Finland showing that the shared stress of infertility may stabilize marital relationships (Repokari *et al*., 2007). The low divorce rate could also indicate that couples with good spousal relationships are those capable of continuing assisted reproduction treatments despite disappointments and long-term stress of infertility. However, this theory does not seem to fit with DI families, in which separation rates of 15–46% have been reported (Lycett *et al*., 2005; Daniels *et al*., 2009).

A reassuring finding was that very few parents had any concerns about their anonymous donor. All four mothers who expressed clear concern about the donor's genetic background had a child with a medical problem. Klock and Greenfeld (2004) found that worries about the physical resemblance of the donor were significantly higher for women than for men. In this study, we found no difference in the concerns about the physical appearance of the donor between the mothers and the fathers. The parents did not seem to be uncomfortable with the loss of control regarding the child's physical resemblance to their mother, or any other donor characteristic.

There was no increase in congenital malformations in these OD children compared with the incidences reported in the literature in IVF children in general (Ericson and Källén, 2001; Koivurova *et al*., 2002). Furthermore, there was no specific pattern in the 14 children presenting health problems up to 14 years of age. The incidence of neurological disorders was comparable to that of previous reports on IVF children (Pinborg *et al*., 2003). However, in the total cohort of OD children, the perinatal mortality was higher than that of 0.5–0.7% in the general population at the same time in Finland (Finnish Birth Register). This indicates that there are increased risks, possibly related to maternal background factors such as age or health, or immunological factors, involved in OD treatment and resulting pregnancies (Söderström-Anttila, 2001). Consequently, more research on the long-term physical health of OD children will be needed.

To conclude, this is, to our knowledge, the largest follow-up study on disclosure decisions of OD families with children born over a 15 year time period. Our results show that 61% of the parents plan to inform their child of his/her origin, and 26% of the children between 3 and 14 years of age had already been told. There is a clear tendency towards greater openness in OD families, as parents with young children were more inclined to disclosure compared with parents with older children. In the future in Finland, open-identity donors will be the only option to parents wishing to use donated gametes to build a family. How this will impact parents' decisions remains to be seen. The majority of the OD parents in this study were either unsure or thought that the new legislation would not have any implication on the parents' disclosure decisions in the future. Experience from Sweden also shows a wide divergence between the intentions of the legislation and how parents act regarding secrecy issues (Lalos *et al*., 2007). Parents need continuous guidance and support on disclosure issues after the child has been born. At the same time, parents have very few concerns regarding the characteristics of their anonymous donor.

Authors' roles

V.S.-A.: study conception and design, execution, manuscript drafting. M.S.: statistical analysis of data, manuscript drafting, discussion. A.-M.S.: study design, execution, manuscript drafting, critical discussion.

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