

Disclosure behaviour and intentions among III couples following treatment with oocytes or sperm from identity-release donors: follow-up at offspring age 1–4 years

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STUDY QUESTION: Do heterosexual parents of young children following oocyte donation (OD) and sperm donation (SD) tell or intend to tell their offspring about the way he/she was conceived?

SUMMARY ANSWER: Following successful treatment with oocytes or sperm from identity-release donors in Sweden, almost all heterosexual couples intend to tell their offspring about the way he/she was conceived and some start the information-sharing process very early.

WHAT IS KNOWN AND WHAT THIS PAPER ADDS: Although the Swedish legislation on identity-release gamete donors has been in effect since 1985, there is a discrepancy between the behaviour of donor-insemination parents and the legal intention that offspring be informed about their genetic origin. The present study contributes data on a relatively large sample of oocyte and sperm recipient couples' intended compliance with the Swedish legislation.

DESIGN AND DATA COLLECTION METHOD: The present study constitutes a follow-up assessment of heterosexual couples who had given birth to a child following treatment with donated oocytes. Data collection was performed during 2007–2011; participants individually completed a questionnaire when the child was between 1 and 4 years of age.

PARTICIPANTS AND SETTING: The present study is part of the Swedish Study on Gamete Donation, a prospective longitudinal cohort study including all fertility clinics performing gamete donation in Sweden. For children conceived via OD, 107 individuals (including 52 couples and 3 individuals) agreed to participate (73% response). For children conceived via SD, the response rate was 70% ($n = 122$ individuals, including 59 couples and 4 individuals). Mean age of participants was 34 years (SD 4.4) and they reported a high level of education.

MAIN RESULTS: The majority of participants (78%) planned to tell the child about the donation, 16% had already started the information-sharing process and 6% planned not to tell their child about the donation or were undecided. Many were unsure about a suitable time to start the disclosure process and desired more information about strategies and tools for information sharing. Agreement on disclosure to offspring within the couple was related to the quality of the partner relationship.

BIAS AND GENERALIZABILITY: There is a risk of selection bias, with gamete recipients preferring secrecy and non-disclosure declining study participation. The results may be regarded as partly generalizable to heterosexual couples with young children following treatment with gametes from legislatively mandated identity-release donors in an established donor programme.

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Key words: gamete donation / assisted reproduction / psychology / disclosure / legislation

Introduction

Treatment with donated gametes is a technique for assisted reproduction used by infertile couples, and treatment with donated sperm is also an option for single women (not permitted in Sweden) and women in lesbian relationships. In Sweden, legislation gives children conceived through donation treatment the right to obtain identifying information about the donor when they are sufficiently mature. The legislation on identity-release donation is in compliance with the United Nations Children's Convention and has been in effect in Sweden since 1985 (SFS 2006:351). Parents of gamete donation children have no right to identifying information about the donor but are encouraged to start disclosing the nature of the conception to the child from an early age (The National Board of Health and Welfare, 2004). Despite this, previous studies of parents after donor insemination (DI) in Sweden have shown that disclosure to the child is not an obvious decision for the parents (Gottlieb *et al.*, 2000; Leeb-Lundberg *et al.*, 2006); <20% of parents had shared information about the donation with the child (aged 1–15 years). Although the majority intended to tell the child at a later time, about one-third stated they were unsure or planned not to tell the child about the donation. A follow-up of a self-selected sample of 19 couples from the Gottlieb study (2000) suggested an increase in disclosure behaviour among DI parents during the intervening period (Lalos *et al.*, 2007) but also found a prevailing discrepancy between the intentions of the Swedish legislation and the behaviour of DI parents.

According to Daniels (2005) and Daniels *et al.* (2001), disclosure should not be seen as a single occasion event but as an information-sharing process, where parents talk to their child about how their family was formed rather than about how the child was conceived. According to the Swedish guidelines for gamete donation, parents are advised to start talking with the child from an early age about how he/she was conceived (The National Board of Health and Welfare, 2004). These guidelines were developed based on research in the field of adoption, showing that children are not harmed by the truth about their genetic origin but by a withholding of the truth, and that children benefit from an open and honest relationship with their parents. This view on information sharing with offspring of gamete donation is supported by the American Society for Reproductive Medicine (2004) and European guidelines state that the child has a right to all known information about the donor and general information about the donation (ESHRE Task Force on Ethics and Law, 2002).

A common age for disclosure to donor-conceived offspring is when the child is about 5 years old (Gottlieb *et al.*, 2000; Lalos *et al.*, 2007; Söderström-Anttila *et al.*, 2010); some children are told from an earlier age (Hargreaves and Daniels, 2007), but some DI offspring are not told until their late teens or when they are adults (Jadva *et al.*, 2009; Mahlstedt *et al.*, 2010). Mac Dougall *et al.* (2007) found that mothers of DI offspring were generally more in favour of disclosure at an earlier age than were their male partners. Studies based on self-reports by DI offspring have shown that those who had known about the donation since a young age felt neutral about it (Scheib *et al.*, 2005; Jadva *et al.*, 2009), while those who had learned about their genetic origin during adolescence or adulthood found it more traumatic and difficult to cope with (Turner and Coyle, 2000; Jadva *et al.*, 2009; Beeson *et al.*, 2011).

Irrespective of type of donation and age of the child at disclosure, most parents reported a feeling of relief after disclosure and did not regret the disclosure decision (Hunter *et al.*, 2000; Lycett *et al.*, 2005; Lalos *et al.*, 2007; Mac Dougall *et al.*, 2007). Some parents expressed regret that disclosure had not taken place much earlier (Daniels and Meadows, 2006) and reported that postponing disclosure was connected with feelings of tension and discomfort (Mac Dougall *et al.*, 2007).

Most parents who decide to share information about the donation with the child provide reasons for their decision, such as that the child has a fundamental right to know the truth and that they would not want to live with a life-long lie (Hunter *et al.*, 2000; Lindblad *et al.*, 2000; Hahn and Craft-Rosenberg, 2002; Lycett *et al.*, 2005; Söderström-Anttila *et al.*, 2010). Commonly stated reasons for not sharing information with the child include that it is unnecessary and a fear of hurting the child, damaging the relationship and being rejected by the child (Lindblad *et al.*, 2000; Hahn and Craft-Rosenberg, 2002; Golombok *et al.*, 2004; Lycett *et al.*, 2005; Lalos *et al.*, 2007; Söderström-Anttila *et al.*, 2010). Irrespective of the decision to tell or not to tell the child about the donation treatment, most recipients of donated gametes talk to someone besides their partner about the treatment (Gottlieb *et al.*, 2000; Greenfeld and Klock, 2004; Schmidt *et al.*, 2005a; Daniels *et al.*, 2009).

Couples who have children with donated gametes should come to a joint decision regarding disclosure to offspring. In an interview study of 141 heterosexual couples who had conceived a child with donated oocytes or sperm, about half had the same views on the disclosure decision from the outset. Among couples with initially disparate disclosure attitudes, almost all had reached a joint disclosure decision after discussions and negotiations within the couple. In couples that decided in favour of disclosure, it was typically the woman who preferred disclosure and the man who deferred to his wife. In non-disclosing couples the opposite pattern was seen, i.e. the man preferred non-disclosure and the woman deferred to her husband (Shehab *et al.*, 2008). Couples who remained undecided about the issue of disclosure expressed distress about making the right choice and dealt with the situation by avoiding the topic. Open emotional sharing through behaviour, words and communication and the ability to solve problems and conflicts have been found to constitute a basic foundation in healthy and resilient families (Black and Lobo, 2008). Conversely, negative or unclear communication and ambiguity can lead to withdrawal, mistrust and insecurity within the family or relationship (Black and Lobo, 2008, Lavner and Bradbury, 2012). Thus, the level of agreement regarding disclosure issues may be related to the quality of the partner relationship in couples with donor offspring.

Previous results from the 'Swedish Study on Gamete Donation' demonstrated that heterosexual couples receiving donated oocytes and sperm were open about their treatment and supported being honest with the child about his/her genetic origin (Isaksson *et al.*, 2011). The aim of the present follow-up study was 2-fold: (i) to investigate disclosure behaviour and intentions for disclosure among heterosexual parents of children aged 1–4 years following gamete donation and, (ii) to study the association between agreement on disclosure to offspring and relationship satisfaction within the couple.

Materials and Methods

Participants and procedure

The present study is part of the prospective longitudinal Swedish Study on Gamete Donation. This multicentre study includes all fertility clinics performing gamete donation in Sweden, at the University hospitals in Stockholm, Gothenburg, Uppsala, Umeå, Linköping, Örebro and Malmö. During the 2005–2008 period, a consecutive cohort of heterosexual couples starting donation treatment was approached for participation. Exclusion criteria were not being able to speak and/or read Swedish and not having completed at least one round of donation treatment. Participants individually completed three questionnaires: in connection with treatment start (T1), follow-up 2 months after treatment (T2) and follow-up 2–5 years after treatment (T3).

The eligible sample for the present study comprised all women and men within heterosexual couples who participated at inclusion (T1) and who had given birth to a child following treatment with donated oocytes or sperm at Swedish clinics. Data collection was performed during 2007–2011 when offspring were 1–4 years of age. The questionnaires were distributed by mail together with a prepaid return envelope and a cover letter stating the purpose of the study and guaranteeing confidentiality. Non-responders were sent two reminders and participation was rewarded with gift vouchers (worth ~12€). Return of the completed questionnaire was regarded as providing informed consent. Couples who had conceived with oocytes or sperm from a donor that was known to them (e.g. a sister) were excluded. The study was approved by the Regional Ethical Review Board in Linköping, Sweden.

Of the 147 women and men (73 couples and 1 individual) with a child conceived via oocyte donation (OD), 107 individuals (including 52 couples and 3 individuals) agreed to participate (73% response). Of the 174 women and men (87 couples) with a child conceived via sperm donation (SD), one individual was not contacted owing to administrative failure and the response rate was 70% ($n = 122$ individuals, including 59 couples and 4 individuals). At inclusion (T1), the mean age of participants was 34 years (SD 4.4) and they reported a high level of education. At follow-up at child age 1–4 years (T3), all but four participants reported living with the same partner as during the donation treatment (Table 1).

Comparison of responders and non-responders at T3 showed a higher extent of university education among responders (55%) than among non-responders (38%; $\chi^2 = 6.90$, $P < 0.01$); no significant age difference was

detected. In addition, responders and non-responders were compared with regard to attitudes towards disclosure to offspring (six items) assessed 2 months after treatment (T2) (Isaksson et al., 2011). There were significant group differences for two items, with non-responders reporting less positive attitudes for the statements 'Parents should be honest with their children with regard to their genetic origin' ($U = 7331.5$, $P = 0.007$) and 'The child has the right to know that he/she was conceived through OD/SD' ($U = 7435.5$, $P = 0.002$).

Measurements

The data collection at follow-up 2–5 years after treatment (T3) included the following instruments.

'Disclosure to offspring' was measured by eight items developed by the research group and based on clinical experience and previous research. Each participant was asked to answer between two and four questions with an open-response format depending on his/her stage in the disclosure process. Participants who already had started the information-sharing process were requested to report (a) at what age they had started talking about the donation with their child, (b) how they talk about the donation (e.g. in what situations, alone or with the partner, with the help of any tool) and (c) what they say about the donation (e.g. about the treatment, what they know about the donor, the child's possibility to receive information about the identity of the donor). Participants who intended to tell the child about the donation when it was older were asked the same questions as above but formulated in the future tense. Participants who were undecided or planned not to tell their child about the donation were asked to report what they planned to tell their child about his/her conception (e.g. receiving help from the hospital).

'Desire for information on disclosure to offspring' was assessed by one study-specific question: 'Would you like more information about telling children conceived through donation treatment about their conception?' Parents were given three response alternatives (Yes, No, Don't know) and the option to elaborate on what type of information they desired.

'Couple agreement on disclosure to offspring' was assessed by one study-specific question: 'Do you and your partner agree on what to tell your child about how he/she was conceived?' There were four response alternatives (Yes, totally; Partly; No, not at all; Don't know).

'Relationship satisfaction' was assessed using the Evaluating and Nurturing Relationship Issues, Communication, and Happiness (ENRICH) scale, which is a valid and reliable instrument (Fowers and Olson, 1989). The

Table 1 Characteristics of participating parents following OD or SD.

	Total, $n = 229$ (%)	OD parents		SD parents	
		Women, $n = 55$ (%)	Men, $n = 52$ (%)	Women, $n = 63$ (%)	Men, $n = 59$ (%)
Age (years)	$M = 34.0$ (SD 4.4)	$M = 33.6$ (SD 3.5)	$M = 35.8$ (SD 4.6)	$M = 31.9$ (SD 3.9)	$M = 35.0$ (SD 4.6)
Education (highest level)					
Compulsory education (9 years)	9 (4)	2 (4)	2 (4)	1 (2)	4 (7)
Secondary education (11–12 years)	94 (41)	16 (30)	21 (40)	25 (40)	32 (55)
University education	124 (55)	36 (67)	29 (56)	37 (59)	22 (38)
Same partner ^a					
Yes	225 (98)	53 (96)	51 (98)	62 (98)	59 (100)
No	4 (2)	2 (4)	1 (2)	1 (2)	0

^aLiving with the same partner at T3 (i.e. at follow-up at 2–5 years after treatment) as at inclusion in study (T1).

ENRICH scale assesses perceptions of partner relationship in 10 categories comprising 10 items each. The subscales are personality issues (satisfaction with the partner's behaviours), communication (feelings and attitudes about communication in the relationship), conflict resolution (perception of the existence and resolution of conflict in the relationship), financial management (attitudes and concerns about how economic issues are managed within the relationship), leisure activities (preferences for spending free time; social versus personal activities, shared versus individual preferences and expectations about spending leisure time as a couple), sexual relationship (feelings about affection and sexual relationship), children and parenting (attitudes and feelings about having and raising children), family and friends (feelings and concerns about relationships with relatives, in-laws and friends), egalitarian roles (feelings and attitudes about various marital and family roles) and conception of life (the meaning of values, religious beliefs and practice and conception of life within the marriage/relationship). There are five alternatives for each item ranging from 'in total agreement' to 'do not agree at all'. Each subscale score can vary between 10 and 50 points and the total ENRICH score can vary between 100 and 500 points, with high scores indicating high satisfaction with the partner relationship. The reliability and validity of the Swedish version of the instrument have been established and are satisfactory (Wadsby, 1998).

'Disclosure to others' was assessed using five items. Two items adapted from Schmidt *et al* (2005a) concerned whether respondents had talked to others (beside their partner) about their problems with conceiving children and what kind of infertility treatments they used, including the donation treatment; response alternatives were none, family, friends, colleagues and most others. Three items had an open-response format (a) 'How did people react when you told them about the donation treatment?', (b) 'Do you wish you could talk about the donation treatment with more people than you already have? If so, with whom?' and (c) 'Do you regret having talked about the donation treatment with certain people? If so, with whom?'

'Participant characteristics' were assessed by self-report at inclusion (age and education) and 2–5 years after treatment (current partner status). Clinical data regarding time of birth of the donor-conceived children were obtained from the seven clinics participating in the multicentre study.

Data analysis

All statistical analyses were performed using IBM SPSS Statistics version 20. In all analyses, a *P*-value of <0.05 was considered significant. χ^2 test was used to compare differences in proportions between subgroups based on participant sex, type of treatment (OD versus SD) and sex/treatment (female/OD, male/OD, female/SD, male/SD). Differences between two independent groups were analysed using independent samples *t*-test or Mann–Whitney *U*-test depending on the level of measurement and distribution.

For analyses including the ENRICH scale, data from couples where only one partner participated and from participants who had separated from their partner were excluded (*n* = 9). Missing values were substituted with the mean of the subscale for the participant, provided at least half of the items had been answered; more missing values for one subscale resulted in the exclusion of the subscale for that participant.

Data collected in an open-response format were categorized according to content (e.g. planned timing/age for disclosure to offspring) by the first author. Quotes from participants are presented to illustrate and enrich the results.

Results

Disclosure to offspring

The majority of participants (78%) reported that they planned to talk to their child about the donation and 16% had already started the information-sharing process. Six percent stated that they planned not to talk to their child about the donation or that they were undecided (Table II). There were no statistically significant differences in disclosure behaviour/intention with regard to participant sex or type of treatment.

Early disclosers

Of the 35 participants who had already started the information-sharing process, 43% had started talking about the donation when the child

Table II Disclosure to the child among parents following OD and SD.

	Total, <i>n</i> = 215 (%)	OD parents		SD parents	
		Women, <i>n</i> = 55 (%)	Men, <i>n</i> = 48 (%)	Women, <i>n</i> = 59 (%)	Men, <i>n</i> = 53 (%)
Have already told	35 (16)	10 (18)	6 (13)	10 (17)	9 (17)
0–2 years	15 (43)	6 (60)	4 (67)	4 (40)	1 (11)
2–4 years	20 (57)	4 (40)	2 (33)	6 (60)	8 (89)
Plan to tell	167 (78)	41 (75)	37 (77)	47 (80)	42 (79)
2–4 years	28 (17)	4 (10)	7 (19)	11 (24)	6 (14)
4–6 years	35 (21)	9 (22)	7 (19)	9 (19)	10 (24)
6–10 years	10 (6)	1 (2)	4 (11)	2 (4)	3 (7)
10–16 years	8 (5)	2 (5)	2 (5)	1 (2)	3 (7)
16–20 years	2 (1)	0	0	0	2 (5)
When the child asks	28 (17)	13 (32)	3 (8)	8 (17)	4 (10)
Do not know/when the child understands	56 (33)	12 (29)	14 (38)	16 (34)	14 (33)
Do not intend to tell	5 (2)	1 (2)	1 (2)	2 (3)	1 (2)
Do not know	8 (4)	3 (5)	4 (8)	0	1 (2)

was 0–2 years old, and the remainder had started at the age of 2–4 years (Table II). According to the participants' open responses, information at this early age most often concerned the fact that the parents had received a seed from a kind woman or man at the hospital so that they would be able to have a child. Some participants used storybooks and some tried to make talking about the donation a normal part of daily life. One OD father who had started the information-sharing process when his child was 18 months old explained 'Since he's still so small, it's been mostly like "mum had no eggs, so she got eggs from a kind girl"'.

Planned disclosers

Among the 167 participants who planned to talk to their child about the donation, approximately half responded that they would do so when the child starts asking questions, when the child understands, or they were undecided about the timing (Table II). One OD father responded 'When the child begins to ask questions, becomes curious', and a SD father wrote 'Don't know today, but it feels like the child should have reached some level of maturity'. The remaining participants stated an age or age range at which they planned to start talking with the child about the fact that he/she was conceived with donated gametes; 38% planned to do so at age 2–6, 6% at age 6–10 and 6% at age 10–20 (Table II).

Common to participants who planned to disclose was their intention to tell the child all they knew or all that the child wanted to know about the donation, including the child's right to obtain identifying information about the donor. Most planned to start talking to their child about the donation together with their partner.

Non-disclosers and undecided

Thirteen participants stated that they would not talk to their child about the donation or that they were undecided (Table II). Among the five non-disclosers, three stated they would tell the child that they received some medical assistance to conceive, and the remaining two saw no need to tell the child anything at all. The five non-disclosers consisted of one non-disclosing SD couple, one SD mother whose partner did not participate, one OD mother whose partner was undecided and one OD father whose partner intended to tell the child.

The eight undecided participants consisted of two jointly undecided OD couples, one OD father with a non-disclosing partner and three participants (OD father, SD father and OD mother) whose partners were in favour of disclosing.

Desire for information on disclosure to offspring

Irrespective of type of treatment, more women (59%) than men (26%) reported a desire for more information about talking with donation offspring about their conception ($\chi^2 = 24.87$, $P < 0.001$). According to the open responses of 85 participants, many would like to have storybooks for children, advice on how and when to start telling the child, and to hear about the experiences of other parents who have already told their child about the donation. As one OD mother suggested: 'I want all kinds of information. Books, both storybooks and pure facts, good photos and illustrations. Maybe a movie and the opportunity for the kids to have a network of other children who were conceived through sperm or egg donation'.

Couple agreement on disclosure to offspring in relation to relationship satisfaction

All participants, irrespective of disclosure decision, were asked to individually assess to what extent they and their partner agreed on what to tell their child about how he/she was conceived. The majority of participants (76%) stated that they totally agreed with their partner, and the remaining stated that they did not agree, partly agreed, or that they did not know (Table III). On the basis of these responses, couples were categorized into two groups: 'perfect agreement' comprising those couples where both partners individually reported being in total agreement about what to disclose to their offspring about his/her conception, and 'deficient agreement' comprising all remaining couples. About a third of couples (OD 28%; SD 35%) demonstrated 'deficient agreement' and these participants reported lower scores on relationship quality for the ENRICH total score ($P = 0.025$) and for the subscales communication ($P = 0.017$), conflict resolution ($P = 0.001$) and family and friends ($P = 0.003$) than did the participants in the 'perfect agreement' group. Subgroup analyses demonstrated significant group differences among female SD mothers; those in 'deficient agreement' reported lower scores on the ENRICH total score ($P = 0.027$) and for the subscales personality issues ($P = 0.024$), conflict resolution ($P = 0.027$), family and friends ($P = 0.034$) and egalitarian roles ($P = 0.013$) than did those in 'perfect agreement' with their partner (Table IV).

Disclosure to others

Most participants had talked to other persons, besides their partner, about the fact that they could not have children ($n = 204/226$,

Table III Agreement on the disclosure decision among parents following OD and SD.

Do you and your partner agree on what to tell your child about how he/she was conceived?	Total, $n = 204$ (%)	OD parents		SD parents		P-value ^a
		Women, $n = 53$ (%)	Men, $n = 48$ (%)	Women, $n = 55$ (%)	Men, $n = 48$ (%)	
Yes, totally	155 (76)	42 (79)	36 (75)	37 (67)	40 (83)	NS
Partly	22 (11)	7 (13)	4 (8)	9 (16)	2 (4)	
No, not at all	5 (3)	0	1 (2)	2 (4)	2 (4)	
Do not know	22 (11)	4 (8)	7 (15)	7 (13)	4 (8)	

^aAnalysis showed that four cells had expected count < 5 , so an exact significance test was selected for Pearson's χ^2 .

Table IV Quality of relationship among couples in 'perfect agreement' or 'deficient agreement' on disclosure to offspring.^a

	Total		P-value ^b	OD parents				SD parents				P-value ^b
	Perfect agreement n = 126, M (SD)	Deficient agreement n = 58, M (SD)		Women		Men		Women		Men		
				Perfect n = 33, M (SD)	Deficient n = 13, M (SD)	Perfect n = 33, M (SD)	Deficient n = 13, M (SD)	Perfect n = 30, M (SD)	Deficient n = 16, M (SD)	Perfect n = 30, M (SD)	Deficient n = 16, M (SD)	
Personality issues	42.32 (6.11)	40.34 (6.88)	NS	42.42 (6.84)	41.08 (7.66)	41.82 (5.86)	41.23 (7.69)	43.93 (5.98)	39.44 (6.61)	41.13 (5.59)	39.94 (6.31)	0.024 ^c
Communication	41.60 (6.18)	38.85 (7.46)	0.017	41.13 (7.60)	39.27 (6.72)	40.67 (5.46)	40.20 (7.24)	42.51 (5.97)	38.75 (7.67)	42.24 (5.47)	37.52 (8.39)	NS
Conflict resolution	39.25 (5.43)	36.16 (6.88)	0.001	39.35 (5.44)	36.86 (7.18)	38.08 (6.35)	36.31 (6.68)	40.52 (5.49)	36.69 (5.19)	39.20 (4.06)	34.87 (8.69)	0.027 ^c
Financial management	42.53 (4.91)	41.89 (5.47)	NS	43.39 (4.83)	42.25 (6.62)	41.33 (4.99)	40.69 (5.84)	42.83 (5.52)	41.88 (4.59)	42.60 (4.20)	42.63 (5.43)	NS
Leisure activities	38.37 (6.42)	37.28 (5.89)	NS	38.61 (6.11)	37.58 (5.52)	36.88 (7.01)	38.85 (3.83)	40.53 (6.63)	37.75 (6.08)	37.60 (5.41)	35.31 (7.22)	NS
Sexual relationship	42.22 (6.25)	41.10 (5.96)	NS	42.70 (7.00)	43.54 (4.37)	40.70 (6.46)	39.62 (6.08)	43.21 (5.62)	41.25 (5.30)	42.43 (5.68)	40.19 (7.35)	NS
Children and parenting	40.98 (5.31)	40.92 (4.71)	NS	40.21 (5.72)	41.23 (4.21)	40.36 (5.14)	42.92 (5.14)	41.79 (9.34)	40.06 (4.25)	41.72 (4.92)	39.88 (5.03)	NS
Family and friends	44.00 (4.60)	41.07 (6.45)	0.003	44.16 (4.67)	41.15 (8.44)	43.48 (4.67)	40.77 (7.35)	44.72 (4.71)	41.38 (5.25)	43.70 (4.49)	40.94 (5.51)	0.034 ^c
Egalitarian roles	39.78 (4.59)	38.53 (5.10)	NS	39.61 (5.15)	39.31 (3.25)	39.00 (5.31)	39.46 (4.88)	39.83 (4.29)	36.13 (5.16)	40.77 (3.20)	39.56 (6.01)	0.013 ^c
Conception of life	38.71 (4.79)	37.76 (4.90)	NS	38.18 (5.92)	37.54 (4.72)	38.45 (4.37)	38.15 (3.78)	39.66 (4.64)	37.44 (4.66)	38.67 (4.05)	37.94 (6.33)	NS
Total score	410.06 (43.44)	393.98 (45.56)	0.025	410.28 (50.06)	397.43 (47.25)	400.78 (43.91)	398.20 (49.18)	420.38 (41.97)	390.75 (40.66)	410.06 (35.94)	391.00 (50.08)	0.027 ^c

^aData presented only for couples who both answered the question about agreement, excluding four individuals who had separated from their partner since treatment.

^bT-test.

^cP-value from t-test comparing scores between sperm recipient women categorized as 'perfect agreement' and 'deficient agreement', respectively, on disclosure decision to offspring.

90%) and about their infertility treatments, including the donation treatment ($n = 187/223$, 84%). There were no statistically significant differences in disclosure to others with regard to participant sex or type of treatment. According to open responses from 204 participants, they experienced almost entirely positive, understanding and empathetic reactions when telling others about the donation treatment.

A total of 216 participants responded to the open-response question on whether they wished they could tell more people about the donation treatment than they actually had done. The majority (81%) was satisfied with the people they had told but 13% would have liked to tell more people about the donation. Commonly stated reasons were to increase understanding about donation treatment and to remove some of the taboo concerning infertility. Several refrained from talking about the donation with persons outside the closest family and friends because they wanted the child to learn about the donation before other people did. One SD mother stated: 'Yes, friends. But we don't want things to be wrong when the child grows up. We want to be the ones talking about it, explaining'. Some mentioned concerns regarding the integrity of the child, e.g. one SD father wrote: 'No! I want my son to know and understand everything before he decides whether he wants to tell people outside the family'.

A total of 211 participants answered the question on whether they regretted telling anyone about the donation treatment. A majority (86%) were satisfied with the people they had told, but 14% (23 women and 6 men) reported some regret related to disclosure to other people. Reasons for regret included disappointment in persons who had not kept information about the donation to themselves, feelings of having been too 'private' with persons outside the close circle of family and friends, and fear that the child might learn about the donation from others before the parents themselves had started the information-sharing process with their child. One SD mother wrote: 'In the very beginning when we learned the reason for our childlessness I was extremely sad and needed to talk about it, told some close friends. Don't regret telling everyone, but told some friends who weren't part of the closest circle, who I fear may not keep it to themselves'.

Discussion

The present results indicate that, following treatment with identity-release donors, most parents planned to talk to their offspring about the way he/she was conceived, which is in line with the intention of the Swedish legislation. However, many participants were unsure about suitable timing for disclosure and expressed a desire for more information as well as strategies for disclosure to offspring. Agreement on disclosure to offspring was related to the quality of the partner relationship.

Sixteen percent of participants had already started talking with their young children about their conception via gamete donation and 38% intended to do so before the age of 6 years, which is in compliance with guidelines by the Swedish National Board of Health and Welfare and by the Ethics Committee of the American Society for Reproductive Medicine (ASRM) (American Society for Reproductive Medicine, 2004). Results from several studies indicate that disclosure at an early age is easier for donation offspring to cope with than

being told at an older age (Turner and Coyle, 2000; Scheib et al., 2005; Jadva et al., 2009; Beeson et al., 2011), while other studies have found no relationship between age at disclosure and offspring's attitude to their donor conception (Paul and Berger, 2007; Mahlstedt et al., 2010).

In the present study, half of the parents were either unsure about the timing of disclosure or they stated that they would start talking about the donation when the child understands or when the child starts asking questions about where babies come from. These findings are in line with the 'right-time strategy' used by disclosing parents following OD or SD and described by Mac Dougall et al. (2007). The present results can be interpreted in two different ways: on the one hand, they suggest that parents want to take into consideration the child's maturity and emotional readiness for the information, as recommended by the Ethics Committee of the ASRM (American Society for Reproductive Medicine, 2004). This approach may be interpreted as a sign of parents' sensitivity of the child's perspective and may be preferable to deciding a specific age irrespective of the child's developmental stage or what is happening in the child's life at that moment. On the other hand, not deciding on an age or age range for starting the disclosure process entails the risk of postponing the discussion to a later and more sensitive age as well as the risk that the 'right time' will never appear. According to previous findings on parents who did not share information about the donation with their offspring, the longer information sharing is postponed, the more difficult it becomes (Daniels et al., 2011).

A few study participants planned to start talking about the donation when the offspring were in their late teens, which must be regarded as challenging. Postponement until such a high age increases the risk that offspring will learn about the nature of their conception from someone else, by accident or through increased awareness about heredity. In their study on DI parents, Daniels and Meadows (2006) described how school lessons in biology resulted in offspring asking questions about whether their father really was their father, and how parents were unable to handle the conversation. DI offspring told about their conception by donation after the age of 18 years have also reported feeling more confused or shocked than those told at an early age (Jadva et al., 2009; Beeson et al., 2011).

More than half of the women and only one in four men expressed a desire for additional information about talking with the child about his/her conception. These findings are in line with previous results from the Swedish Study on Gamete Donation, where women undergoing donation treatment more frequently than men reported wanting more information about parenthood following donation treatment (Isaksson et al., 2011). One possible explanation for this finding is that women feel more responsibility for the information-sharing process concerning having children through donated gametes. In previous studies of heterosexual oocyte and sperm recipient couples, the initial information-sharing with the child was more often carried out by mothers than by fathers (Jadva et al., 2009; Blake et al., 2010; Mahlstedt et al., 2010). Our findings that an equal share of women and men had already started talking about the donation with their child may reflect the fact that Sweden is relatively a gender equal society, with men taking more responsibility for childcare now than during previous decades (The Swedish Social Insurance Agency, 2011).

About a third of the couples reported not being in total agreement about what to disclose to their offspring about his/her conception.

These couples reported lower satisfaction with several aspects of their partner relationship than did the couples who were in perfect agreement about disclosure, the latter group reporting similar mean scores on relationship satisfaction as did heterosexual couples undergoing traditional IVF treatment (Borneskog *et al.*, 2012). Our results are in line with research on family resilience, which stresses the ability to communicate and handle conflicts as important factors for family functioning (Black and Lobo, 2008). In addition, previous interview studies of DI parents have shown that inability to communicate about disclosure to offspring is associated with stress within the relationship (Hargreaves, 2006) and may even lead to a divorce (Daniels and Meadows, 2006). An interesting finding was that the level of couple agreement on what to disclose to their offspring about his/her conception was associated with significantly lower satisfaction with the partner relationship among mothers following SD but not in any other subgroup of participants. This finding indicated that women in SD couples are particularly vulnerable to deficient agreement regarding disclosure issues. These results may be related to men being less likely to talk about their infertility problems, even with their own partner (Throsby and Gill, 2004), along with the fact that DI women previously have been found to defer to their partner's wishes in an attempt to accommodate their partner's needs or desire (Daniels *et al.*, 1995). It is important to keep in mind that these results are based on the participants' individually perceived agreement on disclosure with their partner. For instance, it is possible that some couples in the deficient agreement group in fact share the same disclosure intentions but are not aware of it owing to a lack of communication. In conclusion, our findings lend further support to the notion that agreement on disclosure to offspring is related to the quality of the partner relationship in heterosexual couples.

Most participants had talked to other persons besides their partner about the donation treatment. Several reported limiting the group of persons they talked to out of respect for their child's right to be the first to know about the donation treatment or out of respect for their partner's wishes. Although most were satisfied with the people they had told, one in eight, and of these mostly women, reported some regrets about telling other people. Regrets concerned having been too open with private matters and were related to subsequent anxiety that the child would learn about his/her genetic origin from other people before the parents themselves had started the information-sharing process with the child. These results indicate that couples should be given the opportunity to discuss disclosure issues with health care professionals early in the donation process. Such discussions may promote couples' understanding of the short- and long-term consequences of disclosing information about their treatment to other people and to their offspring. Schmidt *et al.* (2005b) showed that a communication training programme for couples undergoing infertility treatment increased their competence in communication in different social arenas. Both women and men developed skills in moderating their communication patterns in relation to different social groups; for women this included limiting communication about their infertility to close colleagues. Thus, the present findings indicate that couples undergoing donation treatment could benefit from support regarding how to handle conversations related to their treatment with other people and how to plan for information-sharing with the future child.

Methodological considerations

The main strengths of the present study are the large population-based sample, including all fertility clinics performing gamete donation in Sweden, the prospective research design and the relatively high response rate. However, to the extent that gamete donation treatment is associated with secrecy and stigmatization, there is a risk of selection bias, i.e. recipients preferring secrecy and non-disclosure may decline participation in research studies. The prospective design of the present multicentre study allowed us to investigate attrition bias based on attitudes towards disclosure assessed 2 months after treatment (T2). Results showed that parents of donation offspring who dropped out of the study at T3 reported less positive attitudes towards disclosure to offspring than did responders. In addition, non-responders at T3 had a lower education level than responders. Brewaeys *et al.* (2005) as well as Salter-Ling *et al.* (2001) found that low education level was associated with a desire for secrecy and an intention not to tell the child about the donation. In addition, it is important to acknowledge that an unknown number of heterosexual couples from Sweden every year choose to undergo treatment in countries that allow anonymous donors, and no information is available for these individuals. While the present results indicate some attrition bias, study participants included both parents who reported that they planned to keep the conception a secret and parents who were undecided about disclosure, indicating that the study did not only attract couples in favour of disclosure. In view of the stated limitations, the present results may be regarded as partly generalizable to heterosexual couples with young children following treatment with gametes from legislatively mandated identity-release donors in an established donor programme.

The present findings suggest a trend towards openness in Sweden compared with earlier results on disclosure intention and behaviour among parents following DI treatment between 1985 and 1997 (Gottlieb *et al.*, 2000). One possible explanation for these findings is that acceptance of and compliance with new legislation takes time. Some support for this notion was reported in a recent study on attitudes towards disclosure among IVF doctors in the Nordic countries (Lampic *et al.*, 2009). Despite similar legislation on identity-release donors in Sweden 1985 and Norway 2003, Norwegian physicians reported significantly more negative attitudes towards disclosure to offspring than did participants from Sweden. Healthcare staff at IVF clinics play an important role in implementing legislative intentions in clinical practice, and staff attitudes towards disclosure may have an impact on the advice they give to couples undergoing donation treatment. A study of parents following DI treatment directly after the enactment of the Swedish legislation showed that a majority had not been encouraged by IVF staff to be open and honest with their child (Lalos *et al.*, 2007). Furthermore, staff attitudes and advice concerning disclosure appeared to have a significant impact on parents' disclosure decision.

Conclusion

In conclusion, following successful treatment with gametes from identity-release donors in Sweden, almost all heterosexual couples reported intending to tell their offspring about the way he/she was conceived and some had started the information-sharing process very early. While these results suggest increasing compliance with

the Swedish legislation on identity-release donors among parents of donation offspring, follow-up studies are needed to evaluate the outcome of their intentions. In addition, couples undergoing donation treatment may benefit from opportunities to discuss disclosure to other people as well as to offspring with health care professionals early on in the treatment process.

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Authors' roles

C.L., G.S. and A.S.S. planned and designed the study. S.I. was responsible for most of the data acquisition. S.I. and C.L. analysed the data and were primarily responsible for writing the paper. All authors were involved in drafting and revising the manuscript.

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Conflict of interest

None declared.

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