

# Two decades after legislation on identifiable donors in Sweden: are recipient couples ready to be open about using gamete donation?

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**BACKGROUND:** Two decades after the introduction of Swedish legislation that allows children born as a result of gamete donation access to identifying information about the donor, a nationwide multicentre study on the psychosocial consequences of this legislation for recipients and donors of gametes was initiated in 2005. The aim of the present study was to investigate recipient couples' attitudes and behaviour regarding disclosure to offspring and others, attitudes towards genetic parenthood and perceptions of information regarding parenthood after donation.

**METHODS:** The present study is part of the prospective longitudinal 'Swedish study on gamete donation', including all fertility clinics performing donation treatment in Sweden. A consecutive cohort of 152 heterosexual recipient couples of donated oocytes (72% response) and 127 heterosexual recipient couples of donated sperm (81% response) accepted participation in the study. In connection with the donation treatment, male and female participants individually completed two questionnaires with study-specific instruments concerning disclosure, genetic parenthood and informational aspects.

**RESULTS:** About 90% of participants (in couples receiving anonymous donated gametes) supported disclosure and openness to the offspring concerning his/her genetic origin. Only 6% of all participants had not told other people about their donation treatment. Between 26 and 40% of participants wanted additional information/support about parenthood following donation treatment.

**CONCLUSIONS:** Two decades after the Swedish legislation of identifiable gamete donors, recipient couples of anonymously donated sperm and oocytes are relatively open about their treatment and support disclosure to offspring. Recipient couples may benefit from more information and support regarding parenthood after gamete donation. Further studies are required to follow-up on the future parents' actual disclosure behaviour directed to offspring.

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

## Introduction

Since 1985 all offspring in Sweden born from donated gametes have had the right to obtain identifying information about the donor when they are sufficiently mature (Stoll, 2008). 'Sufficiently mature' is not defined as a specific age in the law. However, in the government advisement, it is defined as the age of majority, i.e. 18 (SOSFS, 2007). Several countries have followed and currently 11 jurisdictions allow

only identifiable donors (Blyth and Frith, 2009). Donation treatment with identifiable donors entails a two-step disclosure process: sharing with the child that he/she was conceived with donated oocyte or sperm and informing the child of his/her legal right to obtain identifying information about the donor. In Sweden, The National Board of Health and Welfare recommend the physicians to make sure that couples applying for donation treatment will tell the offspring about his/her genetic origin.

However, legislation is not a guarantee for offspring to access knowledge about their genetic origin (Stoll, 2008). Two Swedish studies on parents of donor insemination-conceived children (conducted since the introduction of the 1985 legislation) found that <20% of parents had told their children (age: 1–15 years) about the donation (Gottlieb et al., 2000; Leeb-Lundberg et al., 2006). In a follow-up of the Gottlieb study, more than half of the parents had told their offspring (first child aged 5–15 years) about the donation, but it was less common to inform the child about his/her right to obtain information about the donor's identity (Lalos et al., 2007). In a recent study from New Zealand, where clinics have encouraged disclosure since 1985 and legislation on identifiable donors has been in place since 2004, 35% of donor insemination offspring aged 17–21 years had been told about their conception (Daniels et al., 2009). According to a review on gamete donation (van den Akker, 2006), oocyte recipients are, in general, more favourable towards disclosure (26–70%) than are sperm recipients (10–30%).

One common aspect among oocyte and sperm recipients is that most couples talk to someone outside the family about the treatment. In Swedish (Gottlieb et al., 2000; Leeb-Lundberg et al., 2006; Lalos et al., 2007) as well as international studies (Hahn and Craft-Rosenberg, 2002; Murray and Golombok, 2003; Klock and Greenfeld, 2004; Daniels et al., 2009), a considerable percentage of parents (28–70%) had told other persons about the donation, but had not informed their child. This increases the risk that the child finds out about his/her genetic origin by accident or from someone other than the parents, something that has been reported to be a traumatic experience for the offspring (Turner and Coyle, 2000; Jadva et al., 2009).

The most common reasons for parents' non-disclosure to offspring are the wish to protect the non-genetic parent and his/her relationship with the child and an uncertainty about how and when to disclose. Parents have reported being anxious of the social stigma associated with infertility and expressed a fear that the child would be upset and not see the non-genetic parent as the real parent if he/she found out about the donation (McWhinnie, 2000; Hahn and Craft-Rosenberg, 2002; Murray and Golombok, 2003; Golombok et al., 2004; Lycett et al., 2005; Lalos et al., 2007). Procreating a genetically related child is considered a basic human drive and infertile couples have been reported to prefer interventions where both parents have a genetic link to the child (Halman et al., 1992). In the general Swedish population, men have been found to place more importance on the genetic link between parent and child than have women (Skoog et al., 2003). Similarly, in a US study where participants were asked to hypothetically choose between a genetic or gestational relationship between woman and child, significantly more men than women preferred the genetic relationship (Ravin et al., 1997). These differences in attitudes may be related to the fact that a man can only be biologically related to a child through his genes, while a woman can also be related to a child through gestation. The absence of a genetic link to the prospective child may have importance for issues related to secrecy/openness regarding the donation among recipient couples.

Another common reason for nondisclosure is uncertainty regarding how and when to tell the child about the donation (Hahn and Craft-Rosenberg, 2002; Lycett et al., 2005; Lalos et al., 2007; Mac Dougall et al., 2007; Crawshaw, 2008). While counselling prospective

donors and recipients about psychosocial aspects of gamete donation, including disclosure, is required by authorities in several countries (Hammarberg et al., 2008; Daniels et al., 2009), studies on parenthood after gamete donation indicate deficiencies in the counselling offered by the fertility clinic (Mac Dougall et al., 2007; Shehab et al., 2008) and the existence of a need for more information and guidelines about disclosure (Shehab et al., 2008).

In view of the fact the Swedish legislation on identifiable donors has now been in force for 25 years, we decided to perform a nationwide multicentre study on the psychosocial consequences of this legislation for recipients and donors of sperm, as well as of oocytes (allowed since 2003). The present study constitutes the first report from this longitudinal study. The aim of the present study was to investigate heterosexual recipient couples' attitudes towards disclosure to offspring and towards genetic parenthood, disclosure behaviour to others and perceived need of information and support regarding parenthood after donation. The following specific research questions were posed:

- (1) What are the attitudes towards disclosure to offspring among recipients of donated oocytes or sperm and are these attitudes related to recipients' gender and type of donation?
- (2) To what extent do recipients of donated oocytes or sperm disclose undergoing donation treatment to individuals within and outside the family?
- (3) How do recipients of donated oocytes or sperm perceive the received information about parenthood after donation and their need for additional information or support?
- (4) Are recipients' attitudes towards the importance of genetic parenthood related to their gender and type of donation?

## Materials and Methods

### Participants and procedure

The present study is a part of the Swedish study on gamete donation, a prospective, longitudinal study of donors and recipients of donated sperm and oocytes. This multicentre study includes all infertility clinics performing gamete donation in Sweden—i.e. clinics located at the University hospitals in Stockholm, Gothenburg, Uppsala, Umeå, Linköping, Örebro and Malmö.

During the 2005–2008 period, a consecutive cohort of couples starting donation treatment were approached regarding participation. In the present study, only data for heterosexual recipients of donated sperm and oocytes are included. All couples who started treatment with oocyte or sperm donation were approached at the infertility clinics for study participation. Persons who did not speak or read Swedish were excluded, as were couples who did not complete at least one round of donation treatment (i.e. insemination or transferral of  $\geq 1$  fertilized oocyte). All participants were asked to individually complete two questionnaires. The first questionnaire was handed out at the clinic in connection with the treatment start, and the second questionnaire was distributed 2 months after treatment to those who had completed the first questionnaire. Both were distributed together with a prepaid return envelope and a cover letter stating the purpose of the study and guaranteeing confidentiality. Two reminders were sent out to non-respondents and participation was rewarded with gift vouchers (worth ~12 euros). The present study was approved by the Regional Ethical Review Board in Linköping, Sweden.

## Instruments

Data collection at treatment start included self-report of participant characteristics (age, education, use of anonymous/known donor) and attitude towards genetic parenthood.

Attitude towards the importance of genetic parenthood was assessed by four items previously used by this research group (Skoog Svanberg *et al.*, 2003). Two items concern the importance of a genetic link between father/mother and child, and two items concern the perceived importance that 'my child resembles me physically' and that 'my child resembles me in terms of behaviour'. Recipients were requested to indicate their responses on a five-point Likert scale from 'Disagree totally' to 'Agree totally'. In addition, respondents could choose the option 'Cannot form an opinion'. In the present sample, Cronbach's alpha was 0.83. The two positive and two negative responses were collapsed into 'Agree' versus 'Disagree'.

Data collection 2 months after treatment included one question about pregnancy status as well as the following instruments:

Attitude towards disclosure to offspring was assessed by six items previously used by this research group (Skoog Svanberg *et al.*, 2003, 2008; Lampic *et al.*, 2009). Response format was identical to that described for 'Attitude towards the importance of genetic parenthood' (above). Cronbach's alpha was 0.77.

Disclosure to others was assessed by a study-specific instrument requesting respondents to indicate whether they had told different groups of individuals (e.g. own parents, siblings and friends/acquaintances) about their undergoing donation treatment, and to report the predominant reaction (positive, negative and neutral) from these groups.

Need of information about parenthood following donation was assessed by two study-specific questions: 'Did you receive information about being a parent following oocyte/sperm donation?' with three response alternatives (Yes, all the information that I need; Yes, but not enough; No) and 'Would you like additional information or support regarding the future parenthood?' with three response alternatives (Yes; No; Unsure).

## Data analysis

All analyses were performed using PASW Statistics version 18. Due to skewness in the distribution of data, non-parametric tests were used for all analyses. Kruskal–Wallis tests were used to analyse differences in attitudes between the four subgroups (female/OD, male/OD, female/SD and male/SD). Mann–Whitney *U*-tests were used as post hoc tests for group differences between (i) men and women (without regard to treatment type) and (ii) between men (women) participating in oocyte versus sperm donation treatment. Differences in proportions between the four subgroups (see above) were measured with  $\chi^2$  tests. In all analyses, a *P*-value of  $<0.05$  was considered significant. The potential impact of using a known donor (8% of recipients) was investigated by control analyses excluding these participants. Since omission of participants with known donors altered results of attitude data, we chose to present results regarding attitudes towards disclosure and genetic parenthood based only on participants with anonymous donors.

## Results

### Recruitment and retention rates

#### Oocyte recipients

Of 215 eligible heterosexual couples ( $n = 430$  individuals) starting treatment with donated oocytes, 152 couples accepted participation and completed the first questionnaire. In five couples, only one partner

chose to participate, resulting in a total of 309 individuals participating in the study (72% response). Of these individuals, 212 also completed the second questionnaire, i.e. 49% of the eligible oocyte recipients.

#### Sperm recipients

Of 158 eligible heterosexual couples ( $n = 316$  individuals) starting treatment with donated sperm that were approached, 127 couples accepted participation and completed the first questionnaire. In one couple, only one partner chose to participate, resulting in a total of 255 individuals participating in the study (81% response). Of these individuals, 215 also completed the second questionnaire, i.e. 68% of the eligible sperm recipients.

Responders and non-responders to the second questionnaire did not differ in age and level of education but there was a marked variation in attrition rates for the participating clinics.

### Characteristics of the sample

The mean age of participants was 34.2 years (SD 4.7) and they were well educated, with 48% of participants reported to have completed university studies (Table I). A majority of recipient couples received gametes from anonymous donors. At the completion of the second questionnaire, 38% of the couples experienced a current pregnancy.

### Attitudes towards genetic parenthood

Table II presents data for 516 participants collected in connection with treatment start with oocytes/sperm from anonymous donors. Overall, less than half of the recipients agreed with the statements regarding the importance of genetic parenthood. Men placed significantly more importance on the genetic link between parent and child than did women. When comparing male recipients of donated oocytes and sperm (i.e. men with versus those without the potential for genetic offspring), sperm recipients placed less importance on the genetic link between father and child and more importance on 'that my child resembles me in terms of behaviour'. When comparing female recipients of sperm and oocytes (i.e. women with versus without the potential for genetic offspring), oocyte recipients regarded physical resemblance of their child less important.

### Attitudes towards disclosure to offspring

Table III presents results for 389 participants 2 months after receiving oocytes/sperm from anonymous donors. About 90% of the participants stated that parents should be honest with their child regarding his/her genetic origin and that the child has the right to this information. Few regarded that knowledge about the donation could harm the child's relationship with the non-genetic parent. About half of participants regarded it to be in the best interest of the child to be able to learn about the donor's identity and disagreed with the statement that contact with the donor can be harmful for the offspring or the family. Men's responses regarding future contact with the donor differed significantly from those of women, with men giving more neutral and less favourable responses. A considerable percentage of all participants could not form an opinion about possible future contact with the donor.

### Disclosure to others

Table IV presents the results for all study participants, including recipients of oocytes/sperm from anonymous and known donors. While

**Table I** Characteristics of participants.

	Total, <i>n</i> = 564 (%)	Oocyte recipients		Sperm recipients	
		Women, <i>n</i> = 157 (%)	Men, <i>n</i> = 152 (%)	Women, <i>n</i> = 128 (%)	Men, <i>n</i> = 127 (%)
Age	<i>M</i> = 34.2 (SD 4.7)	<i>M</i> = 33.7 (SD 3.6)	<i>M</i> = 35.6 (SD 4.5)	<i>M</i> = 32.2 (SD 4.1)	<i>M</i> = 35.0 (SD 5.6)
Education (highest level) <sup>a</sup>					
Compulsory education (9 years)	39 (7)	13 (8)	13 (9)	2 (2)	11 (9)
Secondary education (11–12 years)	250 (44)	59 (38)	78 (51)	48 (38)	65 (51)
University education	270 (48)	84 (54)	60 (40)	76 (60)	50 (40)
Donation					
Anonymous	519 (92)	135 (86)	131 (86)	127 (99)	126 (99)
Known	45 (8)	22 (14)	21 (14)	1 (1)	1 (1)
Current pregnancy at second questionnaire <sup>b</sup>	156 (38)	40 (39)	39 (42)	38 (36)	39 (37)

<sup>a</sup>Missing data for five persons.<sup>b</sup>Percentages of individuals who completed the second questionnaire.**Table II** Attitudes towards genetic parenthood among recipients of oocytes or sperm from anonymous donors.

		Total, <i>n</i> = 516 (%)	Oocyte recipients <sup>a</sup>				Sperm recipients <sup>a</sup>				<i>P</i> -value <sup>c</sup>
			Women, <i>n</i> = 135 (%)	Median <sup>b</sup>	Men, <i>n</i> = 128 (%)	Median <sup>b</sup>	Women, <i>n</i> = 127 (%)	Median <sup>b</sup>	Men, <i>n</i> = 126	Median <sup>b</sup>	
The genetic link between father and child is important	Agree	121 (24)	28 (21)	4	41 (32)	3	22 (17)	4	30 (24)	3	0.002 <sup>d, e</sup>
	Neutral	134 (26)	31 (23)		39 (31)		31 (24)		33 (26)		
	Disagree	226 (44)	65 (49)		41 (32)		64 (50)		56 (45)		
	No opinion	32 (6)	10 (8)		6 (5)		10 (8)		6 (5)		
The genetic link between mother and child is important	Agree	140 (27)	27 (20)	4	34 (27)	3	29 (23)	4	50 (40)	3	0.002 <sup>d</sup>
	Neutral	121 (23)	31 (23)		41 (32)		27 (21)		22 (18)		
	Disagree	220 (43)	69 (52)		43 (34)		61 (48)		47 (37)		
	No opinion	34 (7)	7 (5)		10 (8)		10 (8)		7 (6)		
It is important that my child resembles me physically	Agree	132 (26)	25 (19)	4	38 (30)	3	37 (29)	3	32 (25)	3	0.045 <sup>f</sup>
	Neutral	120 (23)	28 (21)		30 (23)		26 (21)		36 (29)		
	Disagree	258 (50)	82 (61)		58 (45)		62 (49)		56 (44)		
	No opinion	5 (1)	0		2 (2)		1 (1)		2 (2)		
It is important that my child resembles me in terms of behaviour	Agree	194 (38)	46 (34)	3	44 (34)	3	45 (35)	3	59 (47)	3	0.034 <sup>e</sup>
	Neutral	139 (27)	33 (25)		36 (28)		37 (29)		33 (26)		
	Disagree	180 (35)	54 (40)		47 (37)		45 (35)		34 (27)		
	No opinion	2 (0)	1 (1)		1 (1)		0		0		

<sup>a</sup>There was an internal drop-out of one person for each item.<sup>b</sup>Median values calculated on original data (five-point scale) for each item.<sup>c</sup>Kruskal–Wallis test calculated on original data (five-point scale).<sup>d</sup>Mann–Whitney *U*-test: Male versus female (with no regard to type of donation).<sup>e</sup>Mann–Whitney *U*-test: Male OD versus male SD.<sup>f</sup>Mann–Whitney *U*-test: Female OD versus female SD.

almost all participants had disclosed their use of donation treatment to others, with only 6% not telling anyone there were significant differences between groups with regard to disclosure behaviour. Women undergoing oocyte donation treatment were most open, a great

majority having disclosed this to family, friends and/or others. In comparison to the oocyte recipients, sperm recipients—to a higher extent—kept information about the treatment within the family. Among those who had told others about undergoing donation

**Table III** Attitudes towards disclosure to offspring among recipients of oocytes or sperm from anonymous donors.

		Total, n = 389 (%)	Oocyte recipients <sup>a</sup>				Sperm recipients <sup>a</sup>				P-value <sup>c</sup>
			Women, n = 89 (%)	Median <sup>b</sup>	Men, n = 85 (%)	Median <sup>b</sup>	Women, n = 108 (%)	Median <sup>b</sup>	Men, n = 107 (%)	Median <sup>b</sup>	
It is in the best interest for the child that he/she should never be informed of his/her genetic origin	Agree	15 (4)	4 (5)	5	4 (5)	5	3 (3)	5	4 (4)	5	NS
	Neutral	13 (3)	3 (3)		3 (4)		2 (2)		5 (5)		
	Disagree	342 (88)	81 (91)		72 (85)		98 (91)		91 (85)		
	No opinion	19 (5)	1 (1)		6 (7)		5 (5)		7 (7)		
Parents should be honest with their children with regard to their genetic origin	Agree	350 (90)	79 (89)	1	78 (92)	1	100 (93)	1	93 (87)	1	NS
	Neutral	6 (2)	0		1 (1)		2 (2)		3 (3)		
	Disagree	26 (7)	6 (7)		5 (6)		5 (5)		10 (9)		
	No opinion	7 (2)	4 (5)		1 (1)		1 (1)		1 (1)		
The child's relationship with the mother/father (non-genetic parent) could be damaged if he or she learns of the donation	Agree	15 (4)	2 (2)	5	5 (6)	5	2 (2)	5	6 (6)	5	NS
	Neutral	21 (5)	4 (5)		7 (8)		4 (4)		6 (6)		
	Disagree	300 (78)	71 (81)		64 (75)		92 (85)		73 (69)		
	No opinion	51 (13)	11 (13)		9 (11)		10 (9)		21 (20)		
The child has the right to know that he/she was conceived by oocyte/sperm donation	Agree	354 (91)	85 (96)	1	75 (88)	1	100 (93)	1	94 (88)	1	NS
	Neutral	8 (2)	0		3 (4)		2 (2)		3 (3)		
	Disagree	15 (4)	1 (1)		4 (5)		3 (3)		7 (7)		
	No opinion	12 (3)	3 (3)		3 (4)		3 (3)		3 (3)		
It is in the best interest of the child to be able to learn (as an adult) the identity of the donor	Agree	218 (56)	59 (67)	1	46 (55)	2	56 (52)	2	57 (53)	2	NS
	Neutral	36 (9)	9 (10)		8 (10)		9 (8)		10 (9)		
	Disagree	58 (15)	10 (11)		15 (18)		16 (15)		17 (16)		
	No opinion	75 (19)	10 (11)		15 (18)		27 (25)		23 (22)		
Contact with the donor (as an adult) can be harmful for the offspring and/or for the family	Agree	29 (7)	7 (8)	5	9 (11)	4	5 (5)	5	8 (8)	4	0.006 <sup>d,e</sup>
	Neutral	46 (12)	8 (9)		12 (14)		6 (6)		20 (19)		
	Disagree	168 (43)	42 (48)		38 (45)		53 (49)		35 (33)		
	No opinion	144 (37)	31 (35)		25 (30)		44 (41)		44 (41)		

<sup>a</sup>There was an internal drop-out of one person for each item.<sup>b</sup>Median values calculated on original data (five-point scale) for each item.<sup>c</sup>Kruskal–Wallis test calculated on original data (five-point scale).<sup>d</sup>Mann–Whitney U-test: Male versus female (with no regard to type of donation).<sup>e</sup>Mann–Whitney U-test: SD male versus SD female.**Table IV** Disclosure to others concerning the donation treatment among recipients of oocytes or sperm (from anonymous and known donors).

		Total, n = 420 (%)	Oocyte recipients		Sperm recipients		P-value <sup>a</sup>
			Women, n = 109 (%)	Men, n = 101 (%)	Women, n = 105 (%)	Men, n = 105 (%)	
Who have you told about the donation treatment?	Only the family	76 (18)	8 (7)	17 (17)	15 (14)	36 (34)	<0.000
	Friends/others (but not family)	31 (7)	6 (6)	8 (8)	7 (7)	10 (10)	NS
	Family and friends/others	286 (68)	92 (84)	67 (66)	77 (73)	50 (48)	<0.000
	Not anyone	27 (6)	3 (3)	9 (9)	6 (6)	9 (9)	NS

<sup>a</sup> $\chi^2$  test.



**Table V** Need for information about parenthood following donation among recipients of oocytes or sperm (from anonymous and known donors).

		Total, n = 425 (%)	Oocyte recipients		Sperm recipients		P-value <sup>a</sup>
			Women, n = 109 (%)	Men, n = 102 (%)	Women, n = 107 (%)	Men, n = 107 (%)	
Have you received information about parenthood after oocyte/sperm donation?	No	30 (7)	7 (6)	8 (8)	8 (8)	7 (7)	NS
	Not enough	82 (19)	23 (21)	21 (21)	28 (26)	10 (9)	
	All the information I need	313 (74)	79 (73)	73 (72)	71 (66)	90 (84)	
Would you like more information or support about the future parenthood?	No	129 (31)	29 (27)	28 (28)	25 (23)	47 (44)	0.028
	Yes	149 (35)	40 (37)	39 (39)	43 (40)	27 (26)	
	Unsure	145 (34)	40 (37)	34 (34)	39 (36)	32 (30)	

<sup>a</sup>χ<sup>2</sup> test.

treatment, 96% reported positive or neutral reactions and 4% (n = 16) had received negative reactions from at least one person.

Need for information about parenthood following donation

Table V presents results for all study participants, including recipients of oocytes/sperm from anonymous and known donors. Of the respondents, 74% stated having received all the information they needed about being a parent following donation treatment, while 7% reported not having received any such information. Overall, about a third of recipients had a desire for more information or support concerning future parenthood. Among sperm recipients, a significantly lower percentage of men (26%) than women (40%) reported a desire for additional information/support. One-third of the recipients indicated being unsure regarding this question.

Discussion

The results from the present study indicate that Swedish gamete recipients support honesty to offspring and have an open attitude towards their offspring getting to know his/her genetic origin. This is in line with the Swedish legislation and what the fertility clinics are instructed to recommend their clients. The child's right to know how he/she was conceived was stated clearly among the recipient couples, a view that confirms similar findings among gamete recipient couples who are in favour of disclosure (Brewaeys et al., 2005) as well as among the general population in Sweden (Skoog Svanberg et al., 2003).

Brewaeys et al. (2005) reported a distinction between a positive attitude to disclosure to offspring among recipient couples, and their interest in having contact with the donor in the future if their offspring would seek contact. Similar results were seen in the present study, where less than half of the recipients disagreed with the statement that contact with the donor could be harmful for the offspring and/or the family. Many respondents gave neutral responses or could not form an opinion on this topic, which might be interpreted as an uncertainty among the gamete recipients about what to expect of a future meeting between offspring and donor. Also, this item may have been regarded as too abstract, especially for those not pregnant

after the treatment. It is important to consider that these results concern only recipients of oocytes/sperm from donors who were anonymous at treatment, but identifiable for offspring in the future. While only 8% of participants used gametes from a known donor, their responses did influence results for the whole sample and were therefore excluded from analyses regarding attitudes towards disclosure and genetic parenthood.

Almost all participants had told someone about the donation treatment, which is on an increased level compared with earlier reports from Sweden (Gottlieb et al., 2000; Lalos et al., 2007). This may be interpreted as a change towards more openness concerning donation treatment. However, there were differences between subgroups of participants, with women undergoing oocyte donation treatment being the most open. Men in couples undergoing sperm donation treatment were the most secretive and also least interested in receiving additional information/support about parenthood following donation. Among couples seeking infertility treatment, men have been reported to be less likely to talk about infertility problems with others (Hjelmstedt et al., 1999) or even with their own partner (Throsby and Gill, 2004) and to use more distancing coping strategies than women (Peterson et al., 2006), which could explain the present findings.

While a majority of participants were satisfied with the information they had received about being a parent following gamete donation, one in four reported having received none or not enough information, which is similar to recent study results from Finland (Söderström-Anttila et al., 2010). These findings indicate that the support and guidance given by the clinics does not meet up to the need among gamete recipient couples. While the fertility clinics' psychosocial work-up prior to donation treatment includes discussion of specific aspects of donation parenthood, the clinics' responsibility usually ends when the treatment succeeds. In Finland, a support group for gamete donation families was founded in 2009 as a consequence of the parents' wish for support and guidance both before treatment and after the birth of a donor offspring (Söderström-Anttila et al., 2010). Another possibility is to incorporate support to gamete donation families within general child healthcare services, although this may entail that individual staff members have limited professional experience of donation families and may have opinions that are not

entirely in line with national legislation (Sydsjö *et al.*, 2007). Regardless of who should provide counselling to parents and offspring following gamete donation, these professionals need to have knowledge of psychosocial aspects as well as of the national legislation on gamete donation.

The present results on the importance of genetic parenthood are in line with previous findings of the general Swedish population (Skoog Svanberg *et al.*, 2003), with men placing more importance on the genetic link between parent and child than women do. The present study also allowed comparison of attitudes between groups of individuals with and without the potential of a genetic link to offspring. While female oocyte recipients will not have a genetic but a gestational link to their prospective child, male sperm recipients will altogether lack a biological/genetic link to offspring. The finding that this group of men regarded the genetic link between father and child as less important than did male oocyte recipients suggests that male sperm recipients cope with infertility by adapting their values to what is accessible to them. Interestingly, the low importance placed on the genetic father–child link in this group seems to be compensated by a high importance placed on the child resembling them in terms of behaviour.

Taken together, the present results suggest that the existence/absence of a genetic link to the prospective offspring is related to attitudes and behaviour concerning donation issues. In particular, male sperm recipients appear to differ from remaining groups with regard to keeping information about donation treatment within the family, limited desire for more support/information regarding donation parenthood and apprehensiveness regarding future contact with the donor. These findings may be related to the fact that this group is the only one who does not have a genetic or biological/gestational link to the prospective child. Future studies of female co-mothers in lesbian couples using sperm donation treatment may further illuminate this issue.

The main strength of the present study is the large population-based sample, including all fertility clinics performing gamete donation in Sweden. Distinct inclusion criteria and relatively high initial response rates contribute to the external validity. However, no information is available about the recipient couples who chose not to participate in the present study, and it is possible that they have a different view of the studied variables. There was a high percentage of non-responders to the second questionnaire among oocyte recipients, but comparisons regarding age and educational level did not indicate any attrition bias. Instead, inspection of attrition rates on the clinical level indicated that attrition among oocyte recipients was partly due to administrative failure. Nevertheless, the fact that only half of eligible oocyte recipients completed the second questionnaire limits the conclusions that can be drawn from the findings concerning this group. While the instruments assessing attitudes have been shown to have satisfactory face validity and reliability, the questions used to assess recipients' disclosure behaviour and need for information have not been validated. Finally, one methodological strength is that questionnaires were completed individually and not by the couples together.

In conclusion, two decades after the Swedish legislation of identifiable gamete donors came into force, couples undergoing gamete donation are relatively open about their treatment and agree that donation offspring have the right to know about their genetic origin.

Follow-up studies will be able to show if the recipient couples' favourable attitudes towards disclosure are translated into practice.

## Authors' roles

C.L., A.S.S. and G.S. planned and designed the study. C.L., A.S.S., G.S., A.T.K., P.O.K. and N.G.S. contributed to the acquisition of data. S.I. and C.L. analysed the data and were primarily responsible for writing the paper. All authors were involved in drafting/revising of the paper and approved the final version of the manuscript for submission.

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