

# Attitudes towards disclosure and relationship to donor offspring among a national cohort of identity-release oocyte and sperm donors

C. Lampic<sup>1,\*</sup>, A. Skoog Svanberg<sup>2</sup>, and G. Sydsjö<sup>3,4</sup>

<sup>1</sup>Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, SE-141 83 Huddinge, Sweden <sup>2</sup>Department of Women's and Children's Health, Uppsala University, SE-751 85 Uppsala, Sweden <sup>3</sup>Division of Obstetrics and Gynecology, Department of Clinical and Experimental Medicine, Faculty of Health Sciences, Linköping University, SE-581 85 Linköping, Sweden <sup>4</sup>Department of Obstetrics and Gynecology in Linköping, County Council of Östergötland, SE-58183 Linköping, Sweden

\*Correspondence address. E-mail: claudia.lampic@ki.se

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**STUDY QUESTION:** What are oocyte donors and sperm donors' attitudes towards disclosure and relationship to donor offspring?

**SUMMARY ANSWER:** Oocyte and sperm donors in an identity-release donor programme support disclosure to donor offspring and have overall positive or neutral attitudes towards future contact with offspring.

**WHAT IS KNOWN ALREADY:** There is a global trend towards open-identity gamete donation with an increasing number of countries introducing legislation allowing only identifiable donors. While women and men who enrol in identity-release donor programmes accept that they may be contacted by donor offspring, there is limited knowledge of their attitudes towards disclosure to donor offspring and how they perceive their relationship to potential donor offspring.

**STUDY DESIGN, SIZE AND DURATION:** The present study is part of the 'Swedish study on gamete donation', a prospective cohort study including donors at all fertility clinics performing donation treatment in Sweden. During a 3-year period (2005–2008), donors were recruited consecutively and a total of 157 oocyte donors and 113 sperm donors (who did not donate to a specific 'known' couple) were included prior to donation. Participants in the present study include 125 female (80%) and 80 male donors (71%) that completed two follow-up assessments.

**PARTICIPANTS/MATERIALS, SETTINGS AND METHODS:** Participants completed two postal questionnaires 2 months after donation and 14 months after donation. Attitudes towards disclosure to donor offspring were assessed with an established instrument. Perceptions of involvement with donor offspring and need for counselling was assessed with study-specific instruments. Statistical analyses were performed with non-parametric tests.

**MAIN RESULTS AND THE ROLE OF CHANCE:** A majority of oocyte and sperm donors supported disclosure to donor offspring (71–91%) and had positive or neutral attitudes towards future contact with offspring (80–87%). Sperm donors reported a higher level of involvement with potential donor offspring compared with oocyte donors ( $P = 0.005$ ). Few donors reported a need for more counselling regarding the consequences of their donation.

**LIMITATIONS, REASONS FOR CAUTION:** While the multicentre study design strengthens external validity, attrition induced a risk of selection bias. In addition, the use of study-specific instruments that have not been psychometrically tested is a limitation.

**WIDER IMPLICATIONS OF THE FINDINGS:** The positive attitudes towards disclosure to offspring of female and male identity-release donors are in line with previous reports of anonymous and known donors. While our results on donors' general positive or neutral attitudes towards future contact with potential donor offspring are reassuring, a subset of donors with negative attitudes towards such contact warrants concern and suggests a need for counselling on long-term consequences of donating gametes.

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**Key words:** oocyte donation / insemination / artificial / heterologous / disclosure / psychology

## Introduction

There is a global trend towards open-identity gamete donation with an increasing number of countries introducing legislation allowing only identifiable donors (Blyth and Frith, 2009). In addition, programmes offering donors that are identifiable to offspring have become more common, as shown in an investigation of donor insemination programmes in the USA (Scheib and Cushing, 2007). While donation treatment with identifiable donors aims at providing donor offspring the right to information about his/her genetic origin, legislation is not a guarantee for offspring to access knowledge about their genetic origin. International studies have shown that increasing percentages of recipient couples choose to share with their offspring that they were conceived using donated gametes (Gottlieb *et al.*, 2000; Leeb-Lundberg *et al.*, 2006; van den Akker, 2006; Lalos *et al.*, 2007; Daniels *et al.*, 2009; Isaksson *et al.*, 2012). More hesitation has been reported regarding the benefits of offspring obtaining identifying information about their donor (Isaksson *et al.*, 2011); among parents using an identifiable donor, future contact with the donor may be regarded as a threat to the family, and especially to the non-genetic parent.

Despite the increasing availability of programmes using identity-release donors, there is limited knowledge of donors' attitudes towards disclosure issues and relationship to potential donor offspring, particularly for oocyte donors. A systematic review of oocyte donors (Purewal and van den Akker, 2009) predominantly included studies on commercial, volunteer and patient donors that had donated anonymously and women that had donated to specific 'known' recipients. The results on anonymous donors indicate that most were interested in the outcome of their donation and significant proportions of commercial donors would be willing to have contact with offspring. Two studies concerned volunteer donors' attitudes towards disclosure and donor offspring (Söderström-Anttila, 1995; Fielding *et al.*, 1998). These studies were based on relatively small samples of anonymous oocyte donors and reported inconsistent results. More recently, Jadva *et al.* (2011) performed an online survey with 11 women and 69 men who had donated anonymously but later had taken active steps to be identifiable to offspring by joining the Donor Sibling Registry (DSR). The oocyte donors predominantly viewed their relationship with offspring as 'a genetic relationship only' (45.5%) or as 'a distant member of the family' (27.3%) and few reported worries about the well-being of offspring. A majority of both oocyte and sperm donors stated that they accepted contact with offspring and, among those who had already had contact with offspring, all reported this to be a positive experience. There is an apparent lack of studies investigating attitudes towards disclosure and relationship with offspring among women who donate oocytes within an open-identity system.

A recent systematic review of sperm donors (Van den Broeck *et al.*, 2013) indicates a wide variation regarding male donors' interest in the outcome of their donation and their attitudes concerning disclosure of information and potential contact with offspring. The researchers suggest that sperm donors who are older and married are more positive towards being contacted by offspring from their donation, which is in line with previous reviews concerning sperm donors (Daniels, 2007a) and oocyte donors (Daniels, 2007b). Two studies have been conducted with sperm donors that had donated anonymously and, through

membership in the DSR, had shown interest in making information about themselves known to offspring (Jadva *et al.*, 2011; Daniels *et al.*, 2012). Almost all men reported thinking about the offspring they had helped to create, including thoughts about the number of offspring, their health and well-being and possible physical resemblance between the donor and offspring (Daniels *et al.*, 2012). One in four reported worries about the well-being of their donor offspring (Jadva *et al.*, 2011). In both studies a majority of men reported being open to contact with the offspring, and almost a third was open to establishing a parent-child relationship (Daniels *et al.*, 2012).

Few studies have investigated the attitudes towards disclosure and relationship to offspring among donors within open-identity donor programmes (Scheib, 2004; Daniels *et al.*, 2005; Ekerhovd *et al.*, 2008). Questionnaire studies with 30 newly recruited sperm donors (Ekerhovd *et al.*, 2008) and 30 previous sperm donors (Daniels *et al.*, 2005) at Swedish clinics (i.e. under legislation on identity-release donation) found that a majority of the men were positive regarding future contact with potential donor offspring but 13% were negative. Daniels *et al.* (2005) discussed that older men that had donated between 1 and 3 years previously expressed more positive feelings regarding contact with offspring than younger men who had been donors < 1 year. According to results from an interview study with 27 men that had donated in an open-identity programme in the USA 10–18 years previously (Scheib, 2004), donors were generally positive about the upcoming identity releases and many were looking forward to meeting adult offspring. However, more than half also expressed concerns related to future contact with offspring, including the impact on their lives and families.

Sweden was the first country to introduce legislation that gives offspring conceived by donation treatment the right to obtain identifying information about his/her donor at the age of majority. The hospitals are required to keep a registry of the donors for 70 years and to provide offspring with information about the donor upon request. During the recruitment period for the Swedish study on gamete donation (2005–2008) all clinics performing gamete donation in Sweden followed the same principles for screening of oocyte and sperm donors, i.e. criteria for being accepted as a donor were being physically and psychologically healthy with no known hereditary disease, being ~25–35 years of age (women) or up to 50 years of age (men), and preferably having biological children of their own. All donors were evaluated regarding their physical status by a physician and their psychological status by a psychologist/counsellor; these evaluations were performed in one-to-one sessions. The physician informed the donor about the legislation on donation treatment and the donor signed a legal document confirming that the donor has neither responsibilities nor demands on any resulting offspring. Pre-donation counselling was not mandatory but was available for those who requested it. The clinics followed the principle that each donor may contribute to offspring in a maximum of six families. Donors received compensation of ~350€ for 1 round (oocyte donors) and 10 rounds of donation (sperm donors), respectively. Those donors that actively requested information about the outcome of their donation from the clinic could receive information about the number of live children.

Systematic reviews on oocyte donors (Purewal and van den Akker, 2009) and sperm donors (Van den Broeck et al., 2013) concluded that there is a need for longitudinal studies on long-term psychosocial consequences of donating gametes, particularly for donors who are identifiable to potential offspring. Recent results from the nationwide longitudinal 'Swedish study on gamete donation' have shown that female and male identity-release donors present with mature and stable personality characteristics (Sydsjö et al., 2011; Sydsjö et al., 2012), donate for altruistic reasons (Skoog Svanberg et al., 2012) and that pre-donation ambivalence is related to lower satisfaction with their contribution 2 months post-donation (Skoog Svanberg et al., 2013).

The aim of the present study was to investigate and compare attitudes towards disclosure and relationship to donor offspring and need for counselling among identifiable oocyte and sperm donors soon after donation and 1 year post-donation.

## Materials and Methods

### Participants and procedure

The present study is a part of the Swedish multicentre study on gamete donation, a prospective, longitudinal study of donors and recipients of donated sperm and oocytes, with the overall goal to investigate psychosocial aspects of gamete donation. The 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. Donors, recipient couples and one comparison group undergoing standard IVF treatment (with own gametes) were recruited prior to donation/treatment and are followed over time; data are collected in questionnaires, medical charts and interviews.

During the period 2005–2008, a consecutive sample of oocyte and sperm donors was approached at the infertility clinics regarding study participation. Participating clinics followed the same protocol for study recruitment (with clear inclusion and exclusion criteria) and distribution of questionnaires. Persons who did not speak or read Swedish were excluded, as were donors who did not complete at least one round of donation. Donors completed two questionnaires postdonation: 2 months after successful oocyte retrieval (females) or successful sperm cryopreservation (males), and the next questionnaire about 12 months later. Questionnaires were labelled with a unique identification number for each participant, necessary for longitudinal data assessment. 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. Two reminders were sent out to non-respondents. Participation was rewarded with gift vouchers (worth ~12€).

**Oocyte donors:** Of 217 eligible women that were approached a total of 181 women (83%) accepted participation in the multicentre study and completed a baseline questionnaire prior to donation (not included in the present study). For the present study, women that reported donating to a specific/known recipient couple were excluded ( $n = 24$ ) leaving 157 oocyte donors at baseline, of which 141 (90%) completed the questionnaire 2 months post-donation and 125 (80%) also completed the questionnaire 14 months post-donation.

**Sperm donors:** Of 156 eligible men that were approached 118 men (76%) accepted participation and completed a baseline questionnaire prior to donation (not included in the present study). For the present study, men that reported donating to a specific/known recipient couple were excluded ( $n = 5$ ) leaving 113 men at baseline, of which 93 men (82%) completed the questionnaire 2 months post-donation and 80 men (71%) also completed the questionnaire 14 months post-donation.

### Instruments

Attitudes towards disclosure, perceived involvement with potential donor offspring and need for counselling were assessed with identical instruments at both assessments (2 months and 14 months after donation).

#### *Attitudes towards disclosure to offspring*

Attitudes towards disclosure to offspring were assessed by six items developed and previously used by the research group with couples receiving donated gametes (Isaksson et al., 2011) and in adapted forms with gynaecologists, obstetricians and the general population (Svanberg et al., 2003, 2008; Lampic et al., 2009). Donors were requested to indicate their responses on a 5-point Likert scale from 'Agree totally' to 'Disagree totally'; in addition, respondents could choose the option 'Cannot form an opinion'. This scale has been found to have high-internal reliability among male and female heterosexual recipients of donor oocyte and sperm ( $\alpha = 0.77$ ) (Isaksson et al., 2011) and, in an adapted version, in men and women of the general population ( $\alpha = 0.80$ ) (Svanberg et al., 2003). In the present sample, Cronbach's alpha values for the six items (computed on the 5-point scale) were acceptable for both groups at the 2 months assessment (women:  $\alpha = 0.72$ ; men:  $\alpha = 0.72$ ) and for the women at the 14 months assessment ( $\alpha = 0.71$ ), whereas alpha values for the men at the 14 months assessment ( $\alpha = 0.48$ ) indicated low internal consistency. A disclosure index was formed by computing the individual's mean value for the six items, with high mean values indicating positive attitudes towards disclosure to donor offspring.

#### *Involvement in potential donor offspring*

Involvement in potential donor offspring was assessed with five items developed on the basis of earlier research (Söderström-Anttila, 1995; Fielding et al., 1998; Svanberg et al., 2003). One item concerns interest in the outcome of the donation and four items concern thoughts and feelings about potential offspring, including a sense of responsibility for offspring if anything happened to his/her parents, and feelings about being contacted by offspring in the future. The response format was identical to that described for 'Attitude towards disclosure' (above). Cronbach's alpha values (computed on the 5-point scale) for the four items assessing thoughts and feelings towards potential offspring were acceptable at 2 months (women:  $\alpha = 0.76$ ; men:  $\alpha = 0.76$ ) and 14 months post-donation (women:  $\alpha = 0.64$ ; men:  $\alpha = 0.85$ ). An involvement index was formed by computing the individual's mean value for the four items, with high mean values indicating a high level of involvement in donor offspring.

#### *Need for counselling*

Need for counselling was assessed with one item 'I want more counselling regarding the consequences of the donation'. The response format was identical to that described for 'Attitude towards disclosure' (above).

Additional data collected in the questionnaires included age, highest level of education, marital status, biological children and knowledge of the outcome of the donation.

### Data analysis

All analyses were performed using PASW Statistics version 18. Two indexes were formed by computing each individual's mean value for disclosure (six items) and involvement (four items), respectively, with high mean values indicating positive attitudes towards disclosure to donor offspring and strong perceived involvement with potential donor offspring. Characteristics of female and male donors were compared with  $\chi^2$ -tests for nominal scale variables and, for age, with an independent  $t$ -test. Analyses of attitudes towards disclosure, perceived involvement and the need for counselling were based on ordinal data (5-point scale scores) and were computed with Mann–

Whitney *U*-tests for comparison between sexes and with Wilcoxon signed rank tests for comparison between assessments. All tests were two tailed.

## Ethical approval

The study was approved by the Regional Ethical Review Board in Linköping, Sweden. Return of the completed questionnaires was regarded as providing informed consent.

## Results

In comparison to sperm donors, oocyte donors were younger (women mean = 30.4 years, s.d. = 4.5; men mean = 34.0 years, s.d. = 7.5;  $t = 4.096$ ,  $P < 0.0001$ ), had a lower level of education and to a greater extent were cohabiting/married and had biological children (Table I). Oocyte donors also more frequently had obtained information about the outcome of their donation compared with sperm donors.

### Attitudes towards disclosure to donor offspring

A large majority of the female donors (88–91%) and male donors (71–76%) agreed that offspring have the right to know that they were conceived using donation treatment and that parents should be honest about this (Table II). About two-thirds of donors agreed that it is in offspring's best interest to be able to obtain information about the donor's identity (at mature age) and believed that contact between offspring and donor would not be harmful for offspring or his/her family. Group comparisons with Mann–Whitney *U*-test showed consistent differences between female and male donors at both assessments, with females reporting stronger support of disclosure to offspring. This was evident when comparing disclosure index scores at the 2 months assessment ( $U = 4131.5$ , males  $n = 88$ , females  $n = 134$ ,  $P < 0.0001$ ) and at the 14 months assessment ( $U = 3017.5$ , males  $n = 76$ , females  $n = 117$ ,  $P < 0.0001$ ), as well as for all but one of single items (Table II). Overall, support for disclosure to offspring was stable over time for both females and males, with only one difference for sperm donors indicating increased concerns regarding the benefits of offspring learning the identity of the donor (Wilcoxon signed rank test,  $z = 2.046$ ,  $N$ -ties = 27,  $P = 0.041$ , two tailed).

### Involvement with donor offspring

At both assessments, a large majority of female donors (2 months: 94%; 14 months: 86%) and male donors (2 months: 86%; 14 months: 84%) agreed (totally or partly) that they wanted to know if their donation resulted in a child. Many donors stated that they would think about any offspring from their donation (36–49%) and were positive towards the possibility that an adult offspring might contact them in the future (56–66%) (Table III). There were significant differences between female and male donors, with males reporting more involvement with potential offspring at both assessments. This was evident in male donors' higher values on the involvement index at 2 months post-donation ( $U = 5039.5$ , males  $n = 92$ , females  $n = 140$ ,  $P = 0.005$ , two tailed) and at 14 months post-donation ( $U = 4008.5$ , males  $n = 79$ , females  $n = 123$ ,  $P = 0.035$ , two-tailed). In comparison to women, the men reported more interest regarding how a potential offspring fares in life (2 months:  $P = 0.002$ ; 14 months:  $P = 0.005$ ) and feeling more responsibility for a potential offspring (2 months:

$P < 0.0001$ ; 14 months:  $P = 0.003$ ) (Table III). Involvement with offspring was stable over time for both female and male donors, with only one within-group difference for oocyte donors indicating an increased feeling of responsibility for potential offspring (Wilcoxon signed rank test,  $z = 2.225$ ,  $N$ -ties = 41,  $P = 0.026$ , two tailed).

There were no differences between sexes or assessments with regard to future contact with donor offspring. Fourteen months post-donation, a majority of donors were positive (females 56%; males 66%) or neutral (females 24%; males 14%) towards the possibility that an adult offspring might contact them in the future. Significant subsets of female (13%) and male donors (17%) were not positive towards future contact and remaining participants had no opinion. Open comments made by the donors (4 females and 3 males) who chose the most negative response alternative to the item on future contact, showed that two of the women strongly regretted donating oocytes due to subsequent fertility problems and altered life values. Both donated at a young age (at age 22 and 26 years, respectively), had no biological children and commented that they believed that the age limit for donors was set too low.

Perceived involvement in potential donor offspring (index) was not related to experience of biological parenthood among female and male donors. There were no differences in involvement in donor offspring between oocyte donors with and without biological children at the 2 months assessment ( $U = 1406.0$ , mothers  $n = 87$ , non-mothers  $n = 38$ ,  $P = 0.184$ , two tailed) and at the 14 months assessment ( $U = 1611.0$ , mothers  $n = 81$ , non-mothers  $n = 42$ ,  $P = 0.630$ , two tailed). Similarly, there were no differences in involvement in donor offspring between sperm donors with and without biological children at the 2 months assessment ( $U = 604.0$ , fathers  $n = 31$ , non-fathers  $n = 49$ ,  $P = 0.123$ , two tailed) and at the 14 months assessment ( $U = 601.5$ , fathers  $n = 24$ , non-fathers  $n = 55$ ,  $P = 0.531$ , two tailed).

### Need for counselling

Few donors reported a need for more counselling regarding the consequences of their donation, and there was no change over time. At 14 months post-donation, expressed need for counselling was more common among males ( $n = 5$ , 7%) than females ( $n = 3$ , 2%) ( $U = 4083.5$ , males  $n = 77$ , females  $n = 119$ ,  $P = 0.043$ , two tailed).

## Discussion

The present results indicate that oocyte and sperm donors in an identity-release donor programme support disclosure to donor offspring and have overall positive or neutral attitudes towards future contact with offspring. Interestingly, male donors reported a higher level of involvement with potential donor offspring than did oocyte donors.

The present results of donors' positive attitudes towards disclosing information about the conception to donor offspring are in line with previous findings on oocyte and sperm donors (Purewal and van den Akker, 2009; Van den Broeck et al., 2013) predominantly including research with anonymous donors and may reflect a general support of honesty and human rights. However, as the present study was conducted within the context of open-identity legislation, informing offspring about their conception also entails the first step towards the opportunity to obtain identifying information about the donor. As such, the present findings support previous findings from the Swedish context reported for heterosexual recipients of donated gametes (Isaksson et al., 2011),

**Table 1** Characteristics of oocyte donors and sperm donors at the assessments 2 months post-donation and 14 months post-donation.

2 months post-donation	Oocyte donors		Sperm donors		$\chi^2$	P
	N = 141	%	N = 93	%		
Education					10.848	0.006
Elementary	28	19.9	8	8.6		
High school	47	33.3	22	23.7		
University	66	46.8	63	67.7		
Civil status					6.246	0.044
Single	36	25.5	35	37.6		
Steady company	18	12.8	16	17.2		
Co-habiting/married	87	61.7	42	42.2		
Biological children					17.218	<0.0001
Yes	92	65.2	35	37.6		
No	49	34.8	58	62.4		
Do you know if your donation has resulted in a pregnancy? <sup>a</sup>					66.631	<0.0001
I do not know	58	41.1	85	94.4		
Pregnancy	40	28.4	4	4.4		
No pregnancy	43	30.5	1	1.1		
14 months post-donation	125	100	80	100	$\chi^2$	P
Biological children					19.005	<0.0001
Yes	87	69.6	31	38.8		
No	38	30.4	49	61.3		
Do you know if your donation has resulted in a pregnancy? <sup>a</sup>					21.394	<0.0001
I do not know	50	40.3	48	60.0		
Pregnancy	48	38.7	32	40.0		
No pregnancy	26	21.0	0			

Comparisons between female and male donors were computed with  $\chi^2$ -test.

<sup>a</sup> Regarding the knowledge of donation outcome, there were missing data for three male donors at 2 months post-donation and one female donor at 14 months post-donation.

gynaecologists and obstetricians (Svanberg et al., 2008) and the general population (Svanberg et al., 2003), indicating overall positive attitudes towards disclosure to donor offspring in Sweden, and particularly so among women. The present results are also in line with findings from sperm donors within an open-identity programme, expressing that offspring should have the option to know their identity and were looking forward to identity releases (Scheib, 2004). Only one previous was found that compared male and female donors' attitudes towards disclosure to offspring, the results indicating no significant differences within anonymous sperm ( $n = 34$ ) and oocyte donors ( $n = 39$ ) (Fielding et al., 1998). As in previous studies (Svanberg et al., 2003; Isaksson et al., 2011), significant subsets of participants could not form an opinion regarding consequences of future contact between donor and offspring, suggesting a need for information and counselling for donors and recipient couples.

A great majority of female and male donors wanted to know if the donation resulted in a pregnancy, which supports previous reports (Purewal and van den Akker, 2009; Van den Broeck et al., 2013). Providing gamete donors with basic information about the outcome of their donation (e.g. the number of donor offspring) has been argued to provide positive feedback (Raes et al., 2013). In addition, information about the number and

age of offspring also enables the donor to prepare for potential future contact with donor offspring, as stated by the Ethics Committee of the American Society of Reproductive Medicine (Ethics Committee of the American Society for Reproductive Medicine, 2009): 'This information can provide psychological closure to the donor, caution the donor that contact may later occur, and give donors who already have children the opportunity to consider the impact of future contacts on their children and/or partner' (p. 26).

While our findings that almost half of sperm donors would think about offspring from their donation is in line with earlier research on male donors that had taken active steps to being identifiable to offspring (Jadva et al., 2011; Daniels et al., 2012), our results of identity-release oocyte donors' perceptions contribute new and unique knowledge. Interestingly, female donors reported lower levels of involvement with potential donor offspring compared with males. This was a surprising finding considering the fact that donation of oocytes is a more time-consuming and invasive procedure than sperm donation. One possible explanation for this finding is related to previous findings that men place more importance on the genetic link between parent and child compared with women, both among heterosexual recipients of gametes (Isaksson et al., 2011) and in the general population (Svanberg



**Table II** Oocyte and sperm donors' attitudes towards disclosure to donor offspring at 2 months and 14 months post-donation.

	2 months post-donation				U	P	14 months post-donation				U	P
	Oocyte donors		Sperm donors				Oocyte donors		Sperm donors			
Attitudes towards disclosure	N = 141 <sup>a</sup>	%	N = 93 <sup>a</sup>	%			N = 125 <sup>a</sup>	%	N = 80 <sup>a</sup>	%		
It is in the best interest of the child that he/she never be informed of his/her genetic origin					4799.5	0.003					3891.5	0.374
Agree	3	2.1	5	5.4			5	4.1	3	3.8		
Neutral	7	5.0	8	8.7			8	6.5	10	12.7		
Disagree	122	87.1	73	79.3			103	83.7	58	73.4		
No opinion	8	5.7	6	6.5			7	5.7	8	10.1		
Parents should be honest with their children with regard to their genetic origin					4252.0	<0.0001					3336.0	0.001
Agree	123	87.9	69	75			111	89.5	56	70.9		
Neutral	7	5.0	9	9.8			4	3.2	11	13.9		
Disagree	2	1.4	10	10.9			4	3.2	6	7.6		
No opinion	8	5.7	4	4.3			5	4.0	6	7.6		
The child's relationship with the mother/father (non-genetic parent) could be damaged if he/she learns of the donation					3008.0	<0.0001					2402.5	<0.0001
Agree	2	1.4	3	3.3			3	2.4	7	8.9		
Neutral	5	3.6	11	12.0			3	2.4	10	12.7		
Disagree	122	87.1	63	68.5			103	83.1	52	65.8		
No opinion	11	7.9	15	16.3			15	12.1	10	12.7		
The child has the right to know that he/she was conceived by oocyte/sperm donation					4371.5	<0.0001					3332.0	0.004
Agree	127	90.7	69	75.0			110	88.7	60	75.9		
Neutral	4	2.9	11	12.0			2	1.6	11	13.9		
Disagree	2	1.4	7	7.6			4	3.2	1	1.3		
No opinion	7	5.0	5	5.4			8	6.5	7	8.9		
It is in the best interest of the child to be able to learn (as an adult) the identity of the donor					4203.5	0.744					3517.0	0.339
Agree	93	66.4	69	75.0			85	68.5	48	61.5		
Neutral	22	15.7	12	13.0			20	16.1	10	12.8		
Disagree	12	8.6	3	3.3			9	7.3	9	11.5		
No opinion	13	9.3	8	8.7			10	8.1	11	14.1		
Contact with the donor (as an adult) can be harmful for the offspring and/or for the family					3594.5	0.015					2805.0	0.019
Agree	1	0.7	1	1.1			0	0.0	1	1.3		
Neutral	11	7.9	13	14.1			10	8.1	13	16.7		
Disagree	101	72.1	62	67.4			91	73.4	53	67.9		
No opinion	27	19.3	16	17.4			23	18.5	11	14.1		

The two positive and two negative response alternatives of the 5-point Likert scale were collapsed into 'Agree' versus 'Disagree'. Comparisons between female and male donors were computed on the 5-point scale (excluding responses 'No opinion') with Mann-Whitney U-test.

<sup>a</sup>There are missing data for one female and one male donor on all items at the 2 months and 14 months assessments; in addition, 14 months post-donation data are missing for one additional female donor on one item and one additional male donor on two items.

**Table III** Oocyte and sperm donors' perceived involvement with donor offspring at 2 months and 14 months post-donation.

	2 months post-donation				U	P	14 months post-donation				U	P
	Oocyte donors		Sperm donors				Oocyte donors		Sperm donors			
Involvement with offspring	N = 141 <sup>a</sup>	%	N = 93 <sup>a</sup>	%			N = 125 <sup>a</sup>	%	N = 80 <sup>a</sup>	%		
If my donation did result in a child I would												
Think about the child					5093.0	0.145					4025.5	0.254
Agree	56	40.0	45	48.9			44	35.5	36	45.6		
Neutral	24	17.1	11	12.0			16	12.9	14	17.7		
Disagree	52	37.1	31	33.7			57	46.0	26	32.9		
No opinion	8	5.7	5	5.4			7	5.6	3	3.8		
Like to know how the child fares in life					4388.5	0.002					3392.5	0.005
Agree	36	25.7	38	41.3			24	19.4	33	42.3		
Neutral	16	11.4	15	16.3			25	20.2	15	19.2		
Disagree	82	58.6	33	35.9			66	53.2	29	37.2		
No opinion	6	4.3	6	6.5			9	7.3	1	1.3		
Feel responsible for the child if anything happened to his/her parents					3798.0	<0.0001					2265.0	0.003
Agree	10	7.1	27	29.7			17	13.7	22	28.2		
Neutral	10	7.1	9	9.9			12	9.7	13	16.7		
Disagree	104	74.3	48	52.7			84	67.7	41	52.6		
No opinion	16	11.4	7	7.7			11	8.9	2	2.6		
I welcome the possibility of being contacted by an offspring after 18 years					5856.0	0.889					4223.5	0.685
Agree	85	60.7	58	63.0			69	55.6	52	65.8		
Neutral	28	20.0	22	23.9			30	24.2	11	13.9		
Disagree	20	14.3	9	9.8			16	12.9	13	16.5		
No opinion	7	5.0	3	3.3			9	7.3	3	3.8		

The two positive and two negative response alternatives of the 5-point Likert scale were collapsed into 'Agree' versus 'Disagree'. Comparisons between female and male donors were computed on the 5-point scale (excluding responses 'No opinion') with Mann–Whitney *U*-test.

<sup>a</sup>There are missing data for one female and one male donor on all items at the 2 months and 14 months assessments; in addition, there are missing data for one male donor on one item (2 months post-donation) and two items (14 months post-donation).

*et al.*, 2003). Thus, male donors may be more likely to regard donor offspring as their genetic children and feel responsibility for their well-being. This notion is in line with previous results on perceptions among sperm donors open to identity release, understanding sperm as a symbol of genetic relatedness (Riggs and Russell, 2011), regarding their relationship to donor offspring as 'special' or 'like my own child' (Jadva *et al.*, 2011) and being open to establishing a parent–child relationship (Daniels *et al.*, 2012). While there is a lack of research on women that donate oocytes within open-identity programmes, the study by Jadva *et al.* (2011) included 11 oocyte donors that had donated anonymously but subsequently had taken active steps to being identifiable to offspring. These women predominantly viewed their relationship with offspring as 'a genetic relationship only' or as 'a distant member of the family'. Another explanation may be related to men and women's motives for donating gametes, with sperm donors more frequently stating that they want to share their good genes (Skoog Svanberg *et al.*, 2012) and some men being motivated by a desire to procreate (Riggs and Russell, 2011). While it has been suggested that having own children among donors is related to being open to contact with donor offspring

(Daniels, 2007a,b), the present findings did not support that personal experience of parenthood was associated with perceived involvement with donor offspring among oocyte nor sperm donors.

In view of the fact that study participants voluntarily enrolled in an identity-release donor programme, the finding that a majority of donors welcome the possibility that donor offspring might contact them in the future is reassuring and in line with previous results of identity-release sperm donors in Sweden (Daniels *et al.*, 2005; Ekerhovd *et al.*, 2008) and in the USA (Scheib, 2004). However, at 14 months post-donation, 17% of the sperm donors and 13% of the oocyte donors in the present study were not positive towards future contact with offspring and sperm donors reported increased concern regarding the benefits of offspring learning the identity of the donor. According to previous research of sperm donors in identity-release donor programmes (Scheib, 2004; Daniels *et al.*, 2005) and sperm donors who had taken active steps to make themselves identifiable to offspring (Daniels *et al.*, 2012), men may gradually understand that contact with donor offspring will have consequences not only for the donor and the offspring but also for their respective families. These results suggest that identifiable donors may

benefit from counselling regarding the consequences of their donation and it was somewhat surprising that few participants in the present study stated a need for such counselling. While ~40% of donors 14 months post-donation knew that their donation had resulted in a pregnancy, it is probable that contact with donor offspring was regarded as a potential event in the distant future. Future research should investigate identifiable oocyte and sperm donors' needs for counselling and support regarding future contact with donor offspring a longer time after donation.

The main strengths of the present study are its prospective cohort design, including consecutive samples of female and male donors recruited at all fertility clinics providing donation treatment in Sweden. This enables investigation of donors' attitudes not restricted to the cultural context of single clinics (Daniels, 2007a,b), changes over time and comparison of data provided by female and male donors in the same programme. While the initial response rates to the study were high (>75%), attrition induced a risk of selection bias. The low internal consistency for the sperm donors' disclosure index at the 14 months assessment constitutes another limitation and warrants caution when drawing conclusions from these data, as does the fact that the instruments used have not been fully psychometrically tested.

## Conclusion

The present study reports the views of a growing group of oocyte and sperm donors not much studied, namely those that participate as volunteers in identity-release donor programmes. Their positive attitudes towards disclosure to offspring are in line with previous reports of anonymous and known donors. While our results on donors' general positive or neutral attitudes towards future contact with potential donor offspring are reassuring, a subset of donors with negative attitudes towards such contact warrants concern and suggests a need for counselling on long-term consequences of donating gametes.

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## Authors' roles

C.L., A.S.S. and G.S. planned and designed the study and contributed to the acquisition of data. C.L. analysed the data and was primarily responsible for writing the paper. All authors were involved in revising of the paper and approved the final version of the manuscript for submission.

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## Conflict of interest

The authors declare that there are no conflicts of interest.

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