Preferences and needs regarding future contact with donation offspring among identity-release gamete donors: results from the Swedish Study on Gamete Donation

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Objective: To investigate the attitudes and preferences regarding future contact with donation offspring among identity-release donors of oocytes or sperm.
Design: Longitudinal cohort study.
Setting: University-based fertility clinics in Sweden.
Patient(s): A total of 210 women and men were questioned 5–8 years after their donation of oocytes or sperm.
Intervention(s): Questionnaires given to donors prior to their donation and 5–8 years after donation.
Main Outcome Measure(s): Donors' attitudes and preferences regarding future contact with their donation offspring.
Result(s): A majority of identity-release oocyte (65%) and sperm (70%) donors were positive toward being contacted by an offspring of mature age. More than half wanted to be notified by the clinic when an offspring requested information about them, but about a third were negative toward receiving this information. One in four reported a need for counseling regarding future contact with an offspring.
Conclusion(s): Several years after donation, a majority of identity-release oocyte and sperm donors show positive attitudes toward future contact with their offspring. Donors appear to have different preferences for information and support regarding such contact. Fertility clinics and health-care services should provide counseling regarding contact with an offspring to the donors who express a need for this. (Fertil Steril® 2014;102:1160–6. ©2014 by American Society for Reproductive Medicine.)
Key Words: Attitude, information disclosure, oocyte donor, sperm donor

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Third-party conception with donated gametes is an established form of assisted reproductive technology. From the 1980s and onward, there has been a shift from total anonymity toward more openness and an accentuation of the donation offspring's right to have knowledge about his or her genetic origin (1, 2). However, the legal regulation of donor conception varies, from mandatory donor anonymity in some countries to different forms of optional as well as mandatory identity-release donations in others (1). Donor conception is not regulated by law in all countries; in the United States, for example, donation programs vary in the information collected about the donor and whether information about the donor is released to recipients and offspring (3–5).

In 1985, Sweden became the first country to legislate on identity-release

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donation treatment, which gives offspring born from donated gametes the right to obtain identifying information about the donor when they are sufficiently mature (6). The couple who receives the donated oocytes or sperm has no right to identifying information about the donor, nor has the donor any right to identifying information about the potential offspring born after the donation. Donors in Sweden receive financial compensation for their donation to cover their expenses and loss of income during the donation. The compensation is approximately 350 Euro for one round (oocyte donors) and 10 rounds of donation (sperm donors), respectively.

Research on gamete donors can be categorized according to the relation between the donor and the recipient/offspring into: [1] known or personal donors who donate to a couple known to them or are recruited by an infertile couple (7, 8), [2] anonymous donors (9–15), [3] donors who donated anonymously but later actively made themselves identifiable to the offspring, for example, through a voluntary contact register such as the Donor Sibling Registry (DSR) (16, 17), and [4] identifiable donors who chose to donate through identity-release arrangements despite the option to donate anonymously (18) or who donate under identity-release jurisdictions (19–24). Studies have investigated donors' demographic characteristics (9, 15, 25), motives for donation (9, 12, 14–18, 20, 23, 25), attitudes toward anonymity/information-sharing (9, 12, 15, 18), and views concerning the offspring (9, 14). Irrespective of the type of donation, donors who are older, married, and have own biological children seem to be more open to contact with a donation offspring (7, 24, 26). As expected, identity-release donors tend to be more open to contact with an offspring compared with anonymous donors (7, 12, 18, 22, 26), but there is limited knowledge concerning donors' and offspring's preferences regarding how such contact should be initiated. In a study by Scheib et al. (27), offspring from identity-release sperm donation were hesitant to contact the donor and expressed a need for reassurance that the donor was positive toward contact.

Systematic reviews of research on sperm donors (28) as well as on oocyte donors (29) have highlighted the need for longitudinal studies on the long-term consequences of donation, especially for identity-release donations. During the last few years, the Swedish Study on Gamete Donation has provided information on men and women who participate as gamete donors in a donor program under the mandatory identity-release legislation. The results have revealed that Swedish gamete donors have stable, well-adjusted personalities (19, 30) and are mainly driven by altruistic motives (20). Sperm donors have reported more ambivalent feelings toward their donation than oocyte donors (20), and even though most sperm and oocyte donors expressed satisfaction with their contribution shortly after their donation, high predonation ambivalence was associated with low postdonation satisfaction (21).

Although identity-release donors before donation accept that offspring have the right to obtain identifying information about them, there is a lack of knowledge on how donors think about potential contact with an offspring several years later and whether specific characteristics of the donors are related to their attitudes toward future contact. Furthermore, there is a lack of knowledge on donors' preferences regarding the initiation of contact with an offspring. A donation offspring in Sweden searching for information about the donor is to contact the fertility clinic or the local social welfare board, whose responsibility it is to assist the offspring with identifying information (31). The guidelines by the Swedish Society of Obstetrics and Gynecology recommend that the clinics notify the donor when an offspring has requested identifying information.

The concept of "gift giving" may be relevant for understanding gamete donors' perceptions of their donation. Based on the work on oocyte donors by anthropologist Monica Konrad (32) and the review by Daniels (7), receiving knowledge about the outcome of the donation may be regarded as a "return gift" and may function as a validation of the donor's action to donate. Drawing on the findings that older, married donors with children are more positive toward future contact with offspring, Daniels (7) suggested that for these groups of donors the act of donation might be regarded as a gift from one "complete" family to another "would be" family. Also, having children of one's own may make a donor more aware of the perspective of the potential offspring from their donation and of the offsprings' possible need for information about their genetic origin (2). Thus, based on the findings from previous research (7, 26), our hypothesis was that older age and having one's own children are related to positive attitudes toward future contact with offspring. Also, previous results indicating that men place more importance on the genetic link between a parent and child compared with women (33, 34) could imply sex differences in attitudes toward contact with donation offspring. In addition, as donors who reported predonation ambivalence were less satisfied with their donation shortly afterward (21, 35), they may also be more hesitant or negative toward future contact with an offspring.

We investigated attitudes and preferences regarding future contact with a donation offspring, among identity-release donors of oocytes and sperm. A further aim was to study the relation between, on the one hand, the donors' attitude toward contact with an offspring and, on the other hand, their sociodemographic characteristics and predonation ambivalence.

MATERIALS AND METHODS

Participants and Procedures

The Swedish Study on Gamete Donation is a multicenter study that includes all seven infertility clinics performing gamete donation in Sweden and includes donors and recipients of donated oocytes and sperm. The present study includes data from participating donors who had donated oocytes or sperm to a recipient couple who were unknown to them.

During 2005–2008, all women and men who were accepted as donors of oocytes or sperm were approached at the infertility clinics regarding study participation. The exclusion criteria were not speaking and/or reading Swedish and not completing at least one round of donation. Donors completed the questionnaires once they had been accepted in the donor program (T1), 2 months after the donation (T2), 1 year after the donation (T3), and 5–8 years after the

donation (T4). The present study includes data from the first assessment (T1) and the fourth assessment (T4). The study was approved by the regional ethics review board in Linköping, Sweden.

Of 217 eligible women and 150 men approached for the study, 181 (83%) women and 118 (79%) men agreed to participate and completed the baseline assessment (T1) before their donation. Of these, 30 women and 5 men reported donating to a known/specific couple and were therefore excluded from this study, resulting in a total of 151 women and 113 men participating at T1. The fourth assessment (T4) was completed by 126 women (83% of participants at T1) and 84 men (74% of participants at T1). A dropout analysis between responders and nonresponders at T4 showed no differences in sociodemographic characteristics.

Instruments

Attitudes regarding future contact with a donation offspring were assessed at T4 with two study-specific items developed by the research group and pilot-tested among oocyte and sperm donors. The items concerned whether the participant was positive toward being contacted by an offspring and their attitudes toward meeting an offspring from their donation. Participants were asked to indicate their responses on a 5-point Likert scale from "totally agree" to "totally disagree" with an additional option of "cannot form an opinion." In addition, participants were given the opportunity to elaborate on their answers.

Preferences regarding future contact with a donation offspring were assessed at T4 with six study-specific items developed by the research group and pilot-tested among oocyte and sperm donors. Three items concerned preferences regarding where to meet an offspring, and one item concerned the attitude toward the offspring meeting the donor's own family. The response format was identical to that described previously. Two items concerned whether donors wanted to be notified when an offspring searched for information about them (before versus after identifying information had been released to the offspring). Responses to these statements are described as positive, neutral, or negative attitude toward receiving information about an offspring searching for their identity, regardless of timing. Here, too, the participants could elaborate on their answers.

The need for counseling was assessed at T4, with one item concerning whether the participant wanted counseling regarding future contact with an offspring. The response format was identical to that described previously.

Ambivalence toward donation was measured before donating (T1), with a Swedish version of the Donor Ambivalence Scale by Klock et al. (35), presented in Skoog Svanberg et al. (20). Seven multiple-choice items measured mixed feelings about the donation (e.g., "How difficult a decision was it for you to decide to donate?"), and the responses were added to derive a summary score between 0 and 7, with higher scores indicating more ambivalence. A score ≥ 4 was considered as demonstrating a high level of ambivalence (20). Donor characteristics concerning biological children, educational level, partner status, and knowledge of the outcome of the donation were collected at T4, and age at T4 was calculated based on the baseline data (T1).

Data Analysis

Analyses were performed using IBM SPSS Statistics version 22 (IBM Corporation). Because of skewness in the distribution of the data, nonparametric tests were used. In all analyses, $P<.05$ was considered statistically significant. Comparisons between the female and male donor characteristics were computed with chi-square tests or Fisher's exact test, and for age with an independent *t*-test. The Mann-Whitney *U* test was used to analyze sex differences in attitudes, preferences, and need (based on 1–5 scale scores).

Because of the small groups of observations of the dependent variable (few donors reporting negative attitudes toward being contacted by offspring), it was not possible to perform multivariate regression analysis to analyze the relationship between the independent variables (sociodemographic characteristics and predonation ambivalence) and the dependent variable (attitude toward contact with an offspring). Instead, the relationship between the independent and the dependent variables (based on 1–5 scale scores) was analyzed by separate analyses for male and female donors, comparing those with low/high levels of ambivalence (Mann-Whitney *U* test) and comparing four groups of donors by age and biological children (<40 years/children, <40 years/no children, ≥ 40 years/children, ≥ 40 years/no children) using Kruskal-Wallis tests. Quotes from the participants are presented to illustrate and enrich the results.

RESULTS

There were statistically significant differences in the background characteristics of the participating oocyte and sperm donors (Table 1). In comparison with the men, the women were younger ($P<.001$), less well-educated ($P=.009$), and to a higher extent had their own biological children ($P<.001$) and the same partner as during the donation ($P=.049$). A larger percentage of men (46%) than women (32%) reported that their donation had resulted in a child/children ($P<.001$); half of the women (50%) and men (51%) had no knowledge of the outcome of their donation.

A majority of the women and men were positive (67%) or neutral (16%) toward being contacted by an offspring after 18 years. Ten percent of donors were negative toward future contact, and 4% reported not wanting to meet a child conceived from their donation (Table 2). Open comments concerning attitudes, preferences, and need for counseling were given by 27% of the women and 21% of the men. One woman who was positive toward being contacted by an offspring commented, "I am positive toward the child contacting me for the child's own sake. Naturally, I have no rights or obligations to this child. But, of course, I wish all the best for the child!" Another woman who was neutral toward being contacted stated, "The child/children should have the right to know who I am, but I feel that I have only been a helping hand when their parents needed help." A man who was negative toward being contacted by an offspring explained, "Preferably, the children feel no need to meet me since they are

TABLE 1

Background characteristics of donors 5 to 8 years after the donation.

Characteristic	Oocyte donors n = 126	% 100	Sperm donors n = 84	% 100	*P* value
Age					
Mean (SD)	37.3 (4.74)		41.4 (7.54)		<.001
≤35	42	33	21	25	<.001
36–39	34	27	15	18	
40–43	43	34	11	13	
44≤	7	6	37	44	
Education					.009
Elementary	7	6	0	0	
High school	41	33	18	21	
University	78	62	66	79	
Partner status					.049
Single	24	19	22	26	
Same partner as before donation	70	56	32	38	
New partner since donation	31	25	30	36	
Other	1	1	0	0	
Biological children					.001
Yes	92	77	47	56	
No	29	23	37	44	
Knowledge of the outcome of the donation					<.001
I do not know	63	50	41	51	
I do not want to know	0	0	3	4	
The donation did not result in any children	22	18	0	0	
The donation resulted in children	40	32	37	46	

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happy in their real family. So in a way, it doesn't matter to me if they don't get in touch." Several donors wrote that they had the best interest of the child in mind and wanted to support the child's wishes in case of a meeting. For example, one woman commented, "I believe that if a child who has his/her origin from one of my eggs contacts me, you must take it as it comes, with great sensitivity and rely on your gut feeling."

Attitude toward being contacted by an offspring was not related to donor sex (see Table 2). Among oocyte donors, there was no difference in attitude between those with high and low levels of ambivalence ($P=.593$) nor between young/old donors with/without biological children ($P=.173$). Similarly, sperm donors' attitude toward being contacted by offspring was not related to level of predonation ambivalence ($P=.389$) nor with age and biological children ($P=.065$).

More than half of the donors (57%) reported that they wanted to receive information that a donation offspring was searching for information about them, and 29% were negative to receiving such information. Fourteen percent were neutral or could not form an opinion about this. No differences were seen between the female and male donors. Two women who wanted to receive the information commented, "One would like to be prepared for the possibility that the child might get in touch. At the same time, then you will wonder when the phone call will come," and "Maybe I would be disappointed if I knew that there were children who didn't want to contact me." One woman who did not want to receive information if an offspring requested information about her wrote, "Since I made the choice to donate, I also chose to be open to different scenarios. I think it's totally fine that the child receives information about me without my knowledge."

Some of the donors wanted a potential meeting with the offspring to take place at the fertility clinic (11%) or in the donor's home (15%), but most preferred a meeting at a neutral place such as a café (35%) (see Table 2). A majority of the donors (62%) were also positive toward the possibility of an offspring meeting the donor's family (e.g., their own children). However, as one woman commented, "I can't speak for if my own children (biological) want to do as I want, when (and if) a child makes contact. I think that my children should (and will) choose when (or if) such a meeting would occur." One in four donors (24%) reported a need for counseling regarding future contact with an offspring (see Table 2), and one woman commented, "Counseling should take place in connection with/after a child has made contact."

DISCUSSION

The present results indicate that a majority of donors were positive toward being contacted by a grown-up offspring and very few reported not wanting to meet an offspring from their donation. Attitudes toward future contact with offspring were not related to the donors' sex, age, own biological children, or predonation ambivalence toward donating oocytes or sperm. Donors had different preferences regarding being notified when an offspring from their donation requests identifying information about them, and one in four reported a need for counseling concerning how to handle potential future contact with offspring.

The present findings that a majority of donors were positive toward a future contact with an offspring differ from the previous results on Swedish sperm donors in a 1998 study (36) where 44% believed that they should have the right to remain anonymous. The Swedish legislation has been in force for 30 years, and it has been suggested that acceptance of a new legislation takes time (37). Recent results showing that Swedish IVF staff support the identity-release donation system (37) and that recipients of donated gametes intend to be open about their child's origin (38) may indicate an increased acceptance of donor conception and contribute to the overall positive attitude among donors toward contact with offspring. Contrary to expectation and previous research by Daniels (7, 26), the attitude toward contact with offspring was not related to the donors' sex, age, own biological children, or predonation ambivalence.

A majority of donors were positive or neutral toward an offspring contacting them and toward the offspring meeting the donor's family (e.g., their own children). Jadva et al. (16) reported on positive experiences from meetings between the donors and the offspring, which is comforting. However, Daniels

TABLE 2

Oocyte and sperm donors' attitudes 5 to 8 years after donation toward contact with an offspring.

	5–8 years after donation								
	Total		Oocyte donors			Sperm donors			
Attitude	N	%	N	%	Median	N	%	Median	*P* value[a]
I think it's positive that I might be approached by a child after 18 years.									
Agree	140	67	81	65	1	59	70	2	NS
Neutral	34	16	21	17		13	16		
Disagree	20	10	9	7		11	13		
No opinion	15	7	14	11		1	1		
I do not want to meet a child who was conceived after my donation.									
Agree	8	4	2	2	5	6	7	5	NS
Neutral	27	13	16	13		11	13		
Disagree	160	77	95	76		65	77		
No opinion	14	7	12	10		2	2		
If a child wants to meet me, I want that meeting to take place at the IVF clinic.									
Agree	22	11	19	15	4	3	4	5	.042
Neutral	60	29	35	28		25	30		
Disagree	107	51	56	45		51	61		
No opinion	20	10	15	12		5	6		
If a child wants to meet me, I want her/him and me to meet at a neutral location, such as at a café.									
Agree	74	35	42	34	3	32	38	3	NS
Neutral	78	37	43	34		35	42		
Disagree	33	16	22	18		11	13		
No opinion	24	12	18	14		6	7		
If a child wants to meet me, I wish for her/him to meet at my house.									
Agree	31	15	22	18	3	9	11	3	NS
Neutral	79	38	42	34		37	44		
Disagree	78	37	45	36		33	39		
No opinion	21	10	16	13		5	6		
I'm positive toward a child meeting my family (e.g., my children) if she/he wishes.									
Agree	129	62	76	61	2	53	64	2	NS
Neutral	27	13	13	11		15	17		
Disagree	25	12	14	11		11	13		
No opinion	26	13	21	17		5	6		
I wish to have counseling on how I should behave in any future contact with the child following my donation.									
Agree	49	24	30	24	4	19	23	4	NS
Neutral	37	17	19	15		17	20		
Disagree	107	51	63	51		44	52		
No opinion	16	8	12	10		4	5		

Note: NS, not statistically significant.
[a] Mann-Whitney *U* tests between women and men calculated on original 5-point scale.

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et al. (17) revealed that the major challenge in contact between donor and offspring was the contact and relationship with the donor's own family. Because the majority of donors in the present study were in a relationship and a considerable percentage of donors had moved on to a new partner since the donation, this can be also seen as a potential challenge here. Being a donor is not solely an individual contribution to giving a couple the opportunity to become parents because it may also lead to a wider constellation of relationships extended beyond the donor and the donation offspring, something that also has been highlighted in previous research (17).

Donors reported different preferences regarding receiving information when an offspring requests identifying information about them. More than half of the donors wanted to be notified about this by the clinic whereas about one-third were negative to receiving such information. These findings suggest that many donors want to be prepared for a potential meeting, which was also supported by the open comments given. However, comments by other participants revealed concerns that knowing that an offspring has obtained information about them may turn into a long wait for a phone call and a risk for disappointment if no contact is made. To avoid such a situation, some identity-release donors may prefer not to receive notification when an offspring requests identifying information about them. These findings are in line with previous results indicating that some donors worry about having children they will never know or can contact (16).

The counseling given by the fertility clinics before donation in Sweden includes information about the legal circumstances under which the donation is made and what the consequences might be in the long term—that is, the possibility of being contacted by an offspring in the future. Our results indicate that gamete donors are well informed about and comply with the legal circumstances under which they have donated. Although Swedish gamete donors have been reported to be satisfied with the information provided by the clinics before donation (21), donors are not routinely

offered additional counseling after the donation. In the present study, 5 to 8 years after the donation, one in four donors reported a need for counseling regarding future contact with an offspring. In view of the long-term consequences of identity-release donation for donors, offspring, and their respective families, it is of great importance to provide adequate resources within the health-care services. Counselors and psychologists with a family perspective and knowledge about gamete donation could play an important role to create the best circumstances for donors, recipients, and donation offspring and to avoid negative consequences in the long term.

The main strength of our study is the large population-based sample of both oocyte and sperm donors, recruited from all the fertility clinics performing gamete donation treatment in Sweden. The inclusion criteria were specific, and the response rates were relatively high, which contributes to the external validity. The prospective cohort study design also enables investigation of the donor situation and preferences over time. However, no information is available about the donors who chose not to participate in the study; thus, it is possible that their views differ from the participating donors. The results are only generalizable to countries with identity-release legislation; the views of donors in countries without such legislation or with other types of legislation may differ. In addition, the study reflects donors' views 5 to 8 years after donation, when the scenario of being contacted by a donation offspring is still only hypothetical. Further studies are needed to illuminate the experiences of an actual contact between offspring and donor among identity-release donors, offspring, and their respective families. The instruments used have not been fully psychometrically tested, which is a limitation and needs to be taken into consideration when drawing conclusions.

Our study reveals that oocyte and sperm donors who donated several years previously within identity-release programs have positive or neutral attitudes toward potential future contact with offspring. In view of the finding that one in four donors reported a need for counseling about future contact with offspring, it is of great importance to provide adequate resources within the health-care services to create the best circumstances for donors, offspring, and their respective families and to avoid negative consequences in the long term.

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