

National survey of donor-conceived individuals who requested information about their sperm donor—experiences from 17 years of identity releases in Sweden

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Submitted on June 09, 2021; resubmitted on November 22, 2021; editorial decision on November 30, 2021

STUDY QUESTION: What characterizes the group of donor-conceived (DC) individuals who request information about their identity-release sperm donor in Sweden, and what are their experiences of disclosure, information receipt and donor contact?

SUMMARY ANSWER: Following three decades of identity-release donation in Sweden, few DC individuals have requested donor information with varying experiences of information receipt and donor contact.

WHAT IS KNOWN ALREADY: In 1985, Sweden was the first country worldwide to enact legislation that gave DC individuals the right to obtain identifying information about their donor. Since then, identity-release gamete donation has become available in many countries but there is limited knowledge about the individuals who request donor information.

STUDY DESIGN, SIZE, DURATION: A nation-wide cross-sectional survey study was performed at all seven University hospitals that provided donation treatment in Sweden during 1985–2002. During this period only donor insemination to heterosexual couples was permitted. Inclusion criteria were being 18 years of age or older, conceived with donor sperm and having requested information about the donor by December 2020. Recruitment was performed during 2016–2020.

PARTICIPANTS/MATERIALS, SETTING, METHODS: A total of 60 individuals had requested information about their donor. Of these, 53 were approached and 40 individuals, representing 34 families, accepted study participation (75% response rate). Participants completed a postal survey with the WHO-10 well-being index and study-specific questions about experiences of disclosure, motivations for requesting donor information, receipt of information, as well as intentions and experiences of donor contact. Independent t-test and chi-square tests were used to compare ratings of participants with early and late disclosure.

MAIN RESULTS AND ROLE OF CHANCE: Of ~900 DC individuals who had reached adult age, a total of 60 (≈7%) had requested information about the donor. Most of the 40 study participants (78%) made their requests within 2 years after reaching 18 years of age, or following disclosure at later ages (up to 32 years). Several participants had adult DC siblings in the family who had not requested any donor information. All except five participants received identifying information about the donor from the clinic. However, some donors had died or lacked contact information. Among those participants who were able to contact their donor, 41% had done so at the time of the study, while a third of the participants were unsure about potential contact. Several had met the donor in person and a few were in regular

contact. About half of the participants had been informed about their donor conception in adolescence or adulthood (age 12–32), and there were significant differences between participants based on age at disclosure. Compared to those with early disclosure, participants with late disclosure were significantly more likely to be dissatisfied with the timing of their disclosure ($P=0.021$), to react with negative emotions ($P<0.001$), and to subsequently contact the donor ($P=0.047$).

LIMITATIONS, REASONS FOR CAUTION: The limited population available for inclusion resulted in a small sample size, despite a high response rate. In addition, men's lower participation rate must be taken into consideration when interpreting the results.

WIDER IMPLICATIONS OF THE FINDINGS: The small number of individuals requesting information about their identity-release sperm donor is surprising. While not all DC individuals appear to be interested in donor information, it is reasonable to assume that some are unaware of their donor conception and thus unable to make informed decisions regarding their genetic origins. During the coming years, young women and men in many countries will become eligible to access identifying information about their donor. In order to meet the needs of these individuals, and to support positive outcomes for all involved parties, it is essential that adequate protocols and resources are developed.

STUDY FUNDING/COMPETING INTEREST: Financial support from The Swedish Research Council. There are no conflicts of interest to declare.

TRIAL REGISTRATION NUMBER: N/A.

Key words: donor conception / donor insemination / disclosure / identity release / donor

Introduction

Donation treatment has historically been performed with sperm from anonymous donors. However, during the past decades there has been an increased availability of identity-release donation treatment that typically provides the recipient couple or single woman with some (non-identifying) information about the donor, while identifying information is released only to the donor-conceived (DC) individual at a mature age. Currently, 14 jurisdictions worldwide permit only identity-release gamete donation, and programmes in many countries offer treatment with gametes from both anonymous and identity-release donors (Indekeu *et al.*, 2021). Despite the increasing use of identity-release donation, there is limited knowledge about the individuals who request information about their donor. In part, this is due to the fact that identity-release donation has not been available for an extended period of time in most countries. As a result, there are relatively few programmes where DC individuals have reached, or soon will reach, an age when they are eligible to obtain identifying donor information, e.g. in Sweden (2002), the Netherlands (2020), New Zealand (2022), the UK (2023) and Norway (2024).

A recent systematic review on factors associated with searching for donor-related individuals (Indekeu *et al.*, 2021) identified only two studies reporting on DC individuals' experiences of searching for or contacting their identity-release donor. The first study reported on the outcomes of the first 10 years of identity releases at the Sperm Bank of California, when about one-third of eligible DC individuals were found to request their donor's identity (Scheib *et al.*, 2017). Requests were significantly more common among female offspring, and among individuals from single-mother and lesbian-couple families compared to heterosexual-couple families. Most DC individuals made their request within a few years of their 18th birthday and hoped to gain knowledge about the donor and any shared characteristics. A majority planned to contact the donor, but there was no information about their actual behaviour or the outcomes of such contact. The second study concerned the sixth wave of the US National Longitudinal Lesbian Family Study and reported on young adult offspring's experiences of contact with their donor (Koh *et al.*, 2020). Of those with an open-identity

sperm donor, a third had made contact with him since they turned 18 and a few reported having an ongoing relationship.

In December 1984, Sweden was the first country worldwide to introduce legislation on identity-release donation that gave individuals conceived with donor sperm the unconditional right to obtain the donor's identity when sufficiently mature (Stoll, 2008). The law further mandated that donor insemination be performed only at public hospitals, be permitted only for heterosexual couples and performed with sperm from donors who consented to have their identity released to mature offspring. Later legislative changes have made IVF-treatment with donor oocytes or sperm available for heterosexual couples (2003), and permitted sperm donation treatment for lesbian couples (2005) and single women (2016). In Sweden, an individual's donor conception is not visible in any official records (e.g. birth certificate) and national guidelines instruct physicians to ensure that the prospective parents are aware of their responsibility to share this information with their child (The National Board of Health and Welfare, 2004). However, among heterosexual couples who had conceived with donor sperm in the first years following the legislation (1985–1997) about half were unsure or negative towards disclosing the donor conception to their child (Gottlieb *et al.*, 2000). In contrast, heterosexual couples following conception with donor sperm or oocytes in later years have reported predominantly positive attitudes towards disclosure (Isaksson *et al.*, 2011), a large majority planned to share information about the donor conception with their child (Isaksson *et al.*, 2012) and about half had disclosed when the child had reached age 7 (Lampic *et al.*, 2021). A similar trend towards openness regarding oocyte donation was seen in Finland (Söderström-Anttila *et al.*, 2010; Sälevaara *et al.*, 2013), and it has been suggested that this may be related to changes in the attitudes of health care staff providing donation treatment (Isaksson *et al.*, 2012) and in society at large (Lampic *et al.*, 2021). Disclosure is increasingly perceived to be in the best interest of the DC child, which is reflected in official publications advising parents to start sharing information about the donor conception from an early age, e.g. (The National Board of Health and Welfare, 2004; Ethics Committee of the American Society for Reproductive Medicine, 2018; Human Fertility and Embryology Authority, 2019).

Despite the increasing availability and use of identity-release donation, there is limited knowledge about those individuals who request information about their donor, including their plans for and experiences of contact with the donor. Of those children conceived with gametes from identity-release donors since 1985, many have reached adult age and are eligible to request information about the donor. The present study constitutes a unique opportunity to follow-up on the implementation of the Swedish legislation and the long-term consequences of identity-release donation. The aim of the present study was to investigate the characteristics of DC individuals who request information about their identity-release sperm donor and describe their experiences of disclosure, information receipt and contact with the donor.

Materials and methods

Regulations of identity-release donation in Sweden

According to the Act on Insemination (SFS 1984:1140), individuals conceived with sperm donated after 1 March 1985 are entitled to obtain the information that is documented in the special medical record created for each donor, including the donor's identity (Stoll, 2008). This information is to be stored for 70 years at the clinic that provided the treatment. DC individuals who have reached sufficient maturity are to contact the clinic where he/she was conceived to obtain information about the donor and can, if needed, request assistance from the social services. In 2009, a working group of the Swedish Society of Obstetrics and Gynecology published short, specific guidelines for the process of identity releases (Gottlieb and Fridström, 2009). These specify that a DC individual who requests information about his/her donor shall be invited to a scheduled meeting with a physician and a counsellor or other professional. At this meeting, the staff should inquire about what information the individual desires and customize the conversation accordingly. For DC individuals who have not reached 18 years of age, an individual assessment of maturity shall be performed before any information is released. Requested information about the donor is retrieved from the donor's special medical record and shall be provided to the individual. The guidelines do not specify any additional support that should be provided by the clinic, nor do they mention any required or recommended contact between the clinic and the donor whose information has been requested.

The present study concerns all DC individuals with an identity-release sperm donor, who had reached adult age by 2020, and thus were eligible to obtain information about their donor. This group includes individuals conceived with sperm donated from March 1985, who were born between 1986 and 2002, and who had reached age 18 between 2004 and 2020, the first 17 years of possible identity releases in Sweden. Based on reports by the National Board of Health and Welfare (available at <https://www.socialstyrelsen.se/>), the number of live-born children following donor insemination in 1989–2002 was 802. Corresponding data for 1986–1988 are lacking, but could be presumed to be similar to the reported numbers for 1989 ($n=37$) and 1990 ($n=26$), i.e. about 30 live-born children per year. Consequently, the estimated eligible sample consisted of 892 individuals.

Design

A cross-sectional survey targeting a national sample of DC individuals.

Recruitment

Recruitment was performed at the Reproductive Medicine Centers (RMCs) of all University hospitals that provided sperm donation treatment during the time period 1985–2002. During this period only donor insemination to heterosexual couples was permitted, not IVF, and treatment was provided almost exclusively at University hospitals. Inclusion criteria were being 18 years of age or older and having requested donor information at the RMCs of the University hospitals in Stockholm, Uppsala, Gothenburg, Umeå, Malmö, Linköping or Örebro. Recruitment was performed during 2016–2020 and included all offspring who had requested donor information. Eligible offspring were approached regarding study participation by staff at the RMCs. Those who were interested in receiving more information were then contacted by the principal investigator (C.L.) and received written information about the study and a postal survey. Non-responders received one reminder. No compensation was provided for participation.

Data collection

Participants completed a survey with study-specific questions and a validated instrument for psychological well-being. The development of the study-specific questions was based on the literature (e.g. Scheib et al., 2017) and clinical experience, and concerned four areas.

Participant characteristics

Participants completed items regarding gender, age and family situation, including their parents' current relationship status and age of any DC siblings in the family.

Disclosure of donor conception

Questions regarding experiences of disclosure included: person(s) that disclosed (Mother, Father, Both parents, Other person), age at disclosure and perceived suitability of disclosure at that age (Yes; No, earlier; No, later). Participants were also asked to assess their emotional reactions to initial disclosure by indicating one or several response alternatives. For the data analysis, seven of these were categorized into 'Positive' (Relieved, Happy) and 'Negative' emotions (Shocked, Confused, Sad, Anxious, Angry) based on a categorization of emotions (Shaver et al., 1987). Remaining six response alternatives (Surprised, Curious, Feeling special, Feeling different, No particular emotion, Other) did not indicate any distinct positive or negative emotion and formed the category 'Neutral'.

Request of donor information

Participants completed items regarding their experiences of requesting and obtaining information about the donor. First, they reported their motivations for searching donor information by indicating one or several response alternatives (Physical resemblance, Resemblance of non-physical traits, Information about heritage, Information about medical background, Relevance to own identity, Contact with donor, Contact with donor's family, Other). Secondly, they reported their age at request, and if the decision to request donor information was related to any specific event. Third, participants reported what information about the donor they received (Background information, Letter, Photo,

Name and personal identity number, Contact information) and assessed their level of satisfaction with information and support at the RMC on a 0–100 visual analogue scale (endpoints: 0 = not at all satisfied, 100 = highly satisfied). Finally, participants reported if their parents knew about their request of donor information (Both parents, Mother, Father, No), the parents' reaction to their desire for donor information (Supportive, Hesitant, Understanding, Anxious, Angry) and could provide comments to this (open-response format).

Contact with donor

Participants indicated if they had attempted to contact their donor (Yes, No). Those who had not attempted any contact, were asked if they planned to do so (No, Yes, Uncertain) and to provide reasons/comments for their stance (open-response format). Those who had attempted to contact the donor were asked to indicate what form of communication they had used (Postal letter, E-mail, Text message, Telephone). They indicated what type of contact (if any) they had had with the donor (Written, Oral, Physical meeting) and could give a short description of their contact (open-response format). In addition, participants were asked to indicate if they had had any contact with the donor's family (Donor's children, Donor's partner, Other family members, No contact).

Psychological well-being

The Swedish version of the WHO well-being index (Löve et al., 2014) was used to assess psychological well-being. This scale consists of 10 items scored on a four-point Likert scale ('all the time' to 'never'). A sum score of all ratings is calculated (range 0–30), with higher scores indicating better subjective well-being. This Swedish version was reported to have excellent internal consistency and good construct validity (Löve et al., 2014).

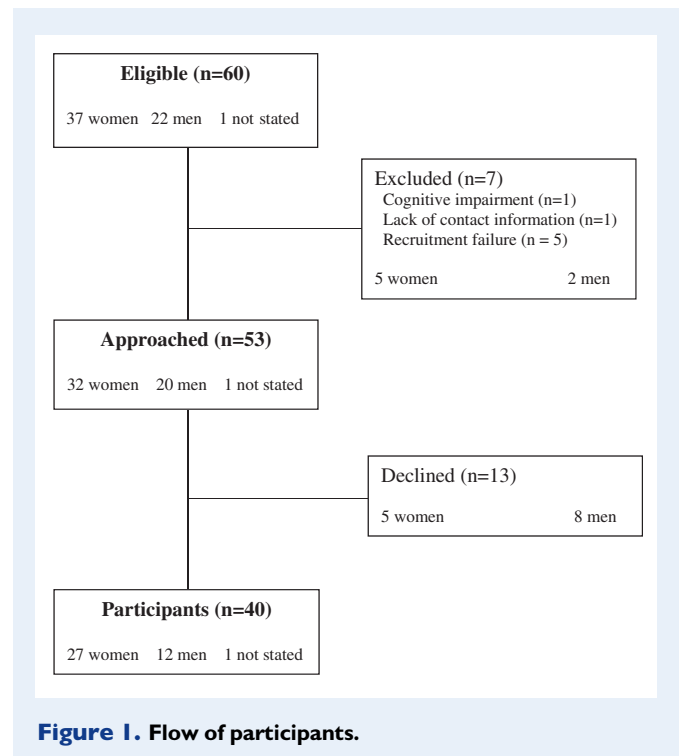
Data analysis

Descriptive statistics were used to identify characteristics of the study sample. Age at disclosure was dichotomized at transition to adolescence (<12 years, ≥12 years) after which issues of identity become more salient (Golombok et al., 2002) and disclosure may be experienced as more challenging for parents and offspring. Independent *t*-test and chi-square tests were used to compare participants with early and late disclosure with regard to background variables, psychological well-being, reactions to disclosure, motivations for information request, and contact with the donor. Due to skewed distribution of age at study, age at information request and years between request and study participation, Mann–Whitney *U*-test was used for group comparison of these variables. Visual analogue scores (0–100) assessing satisfaction with information/support from the RMC were categorized into low (<30), moderate (30–79) and high (≥80) satisfaction. Analyses were performed with IBM SPSS Statistics 26.0 and the significance level was set at $P < 0.05$.

Results

Who requested information about their sperm donor?

Of ~900 DC individuals who had reached adult age by 31 December 2020, a total of 60 (~7%) had requested information about their



donor. Requests had been made at five of seven University hospitals. Seven individuals were excluded due to cognitive impairment, lack of contact information at the time of study or staff failure to approach eligible individuals regarding study participation. In total, 53 were approached regarding study participation and 40 accepted (75% response rate; Fig. 1). Participants had requested information about their donor between 2010 and 2020, and responded to the survey between 1 month and 7 years after their request.

Study participants were 27 women, 12 men and 1 individual who preferred not to state gender identity (Table 1). Their median age at study was 21.5 years and they reported moderately high scores of subjective well-being. Participants with early disclosure (0–11 years of age) and late disclosure (≥12 years of age) were similar in terms of background characteristics. Both groups were between 18 and 33 years of age at time of study participation and were born during similar time periods (early disclosure 1987–2002; late disclosure 1987–2000; $P = 0.109$). Those with early disclosure were significantly younger when they contacted the RMC to obtain information about the donor ($P = 0.028$), but the groups did not differ with regard to time between possible request for donor information (i.e. at age 18 or later age at disclosure) and actual request, nor with regard to time between request and study participation.

Participants included six sibling-pairs, thus a total of 34 families were represented. In these families, the parents were still married/co-habiting ($n = 18$), divorced/separated ($n = 13$) or one/both parents had died ($n = 3$). Table 2 shows the composition of the 34 families in terms of DC-children's age and study participation. In about half of families, there was only one DC-child (study participant) and remaining families had two or three DC-children. In six of these families, both siblings had requested donor information (and were study participants). Participants from nine families reported having adult DC

Table I Participant characteristics by age at disclosure.

	Total (n = 40)	Early disclosure age <12 (n = 21)	Late disclosure age ≥ 12 (n = 19)	P
Age at study	21.5 (18–33)	21.0 (18–33)	24.0 (18–33)	0.527
md (range)				
Age at info request	20.0 (18–32)	19.0 (18–30)	21.0 (18–32)	0.028
md (range)				
Years between age 18/disclosure and info request	1.0 (0–12)	0.0 (0–12)	1.0 (0–8)	0.806
md (range)				
Years between info request and study	1.0 (0–7)	0.0 (0–4)	1.0 (0–7)	0.826
md (range)				
WHO well-being index^a	18.9 (5.2)	19.5 (5.6)	18.3 (4.8)	0.482
m (SD)				
	n (%)	n (%)	n (%)	
Gender				0.339
Women	27 (68)	16 (76)	11 (58)	
Men	12 (30)	5 (24)	7 (37)	
Declined to state	1 (2)	0	1 (5)	
Parents' relationship status^b				0.184
Married/co-habiting	23 (58)	10 (48)	13 (68)	
Divorced	17 (42)	11 (52)	6 (32)	
Siblings^c				0.855
Yes	30 (75)	16 (76)	14 (74)	
No	10 (25)	5 (24)	5 (26)	
Living arrangements				0.822
With parents	13 (32)	7 (33)	6 (32)	
With partner	12 (30)	5 (24)	7 (37)	
Alone	10 (25)	6 (29)	4 (21)	
With other people	5 (13)	3 (14)	2 (10)	

Bold text indicates statistical significance.

^aMissing data for one participant. Reference values of a randomized general population cohort (Löve et al., 2014): women, m = 17.4; men, m = 18.7.

^bRelationship status at time of study or at time of death of one/both parents.

^cSiblings in the family: donor-conceived siblings, half-siblings, adoptive siblings.

siblings in the family, and these had not requested donor information within the recruitment period for the present study. Thus, in more than half of families with several adult DC-children, not all siblings had requested donor information.

Disclosure of donor conception

There was a wide variation in age at disclosure, from participants who commented that they had 'always known' to finding out at age 32. Except for one participant, who was told by a close relative, all had been informed by one or both parents. About half had become aware of their donor conception before age 12, and half were told during adolescence or adulthood. Participants indicated a range of emotional responses to the initial disclosure, from positive emotions (relieved, happy) and neutral emotions (e.g. surprised, curious) to negative emotions (e.g. shocked, confused; Table III). Negative emotions were significantly more frequent in connection with late disclosure (84%) than with early disclosure (14%; $P < 0.001$).

Participants with early and late disclosure differed significantly in their assessment of the timing of their disclosure. A majority (84%) of those who had become aware of their conception with donor sperm before age 12 assessed this as a good age for disclosure, while this was true for only 50% of those with later disclosure ($\chi^2 = 7.716$, $P = 0.021$). Participants' assessments are presented for five age groups at disclosure (Table IV) and show that all with disclosure before age 7 supported this timing. For remaining age groups, half believed that their age at disclosure was adequate and the other half would have preferred earlier or later disclosure. One participant, who was content with finding out about the donor conception after age 30, commented that individual life circumstances were important for this assessment.

Requesting donor information

The most frequently stated motivations to request information about the donor were to see if there were any similarities in appearance (70%) or non-physical characteristics (65%; Table III). In comparison

Table II Composition of 34 families represented by participating adult donor-conceived (DC) individuals.

34 Families with DC-children				
Families	16 Families with only one DC-child		18 Families with more than one DC-child	
		Six families: both adult siblings requested donor info	Nine families: only one adult sibling requested donor info	Three families: one adult child that requested donor info and minor (<18 years) siblings
Adult DC-children	Study participants (n = 16) 10 women 6 men	Study participants (n = 12) 8 women 4 men	Study participants (n = 9) 7 women 1 man 1 not stated	Study participants (n = 3) 2 women 1 man
		Siblings who had not requested donor info (n = 10) 5 women 5 men		

Table III Circumstances of disclosure and motivation for requesting donor information, by age at disclosure.

	Total (n = 40)	Early disclosure age 0–11 (n = 21)	Late disclosure age ≥ 12 (n = 19)	P
	n (%)	n (%)	n (%)	
Emotions at disclosure^a				
Neutral	33 (82)	16 (76)	17 (89)	0.270
Surprised	17 (42)	4 (19)	13 (68)	
Curious	17 (42)	8 (38)	9 (47)	
Special	9 (22)	5 (24)	4 (21)	
Different	8 (20)	3 (14)	5 (26)	
No particular emotion	8 (20)	7 (33)	1 (5)	
Other	7 (18)	2 (10)	5 (26)	
Negative	19 (48)	3 (14)	16 (84)	<0.001
Shocked	15 (38)	2 (10)	13 (68)	
Confused	14 (35)	1 (5)	13 (68)	
Sad	8 (20)	1 (5)	7 (37)	
Anxious	4 (10)	1 (5)	3 (16)	
Angry	2 (5)	0 (0)	2 (10)	
Positive	6 (15)	2 (10)	4 (21)	0.308
Relieved	4 (10)	1 (5)	3 (16)	
Happy	3 (8)	1 (5)	2 (10)	
Motivation for requesting donor info				
Physical resemblance	28 (70)	13 (62)	15 (79)	0.240
Resemblance of non-physical traits	26 (65)	13 (62)	13 (68)	0.666
Information about heritage	20 (50)	7 (33)	13 (68)	0.027
Information about medical background	19 (48)	6 (29)	13 (68)	0.012
Relevance to own identity	17 (42)	9 (43)	8 (42)	0.962
Contact with donor	15 (38)	7 (33)	8 (42)	0.567
Contact with donor's family	8 (20)	1 (5)	7 (37)	0.011
Other	11 (28)	6 (29)	5 (26)	0.873

Bold text indicates statistical significance.

^aParticipants could select one or several response alternatives (emotional reactions). Responses were categorized into 'Negative' and 'Positive' emotions based on Shaver et al. (1987), and responses indicating no distinct positive or negative emotion formed the category 'Neutral'.

Table IV Assessment of suitability of age at disclosure in relation to participants' own age at disclosure.

After stating own age at disclosure, participants answered the question	Participants' own age at disclosure				
	<7	7–11	12–19	20–29	≥30
	n (%)	n (%)	n (%)	n (%)	n (%)
Was this a good age to learn about one's origins?^a					
Yes	13 (100)	3 (50)	5 (50)	3 (50)	1 (50)
No, better with earlier disclosure	0	1 (17)	4 (40)	3 (50)	1 (50)
No, better with later disclosure	0	2 (33)	1 (10)	0	0

^aMissing data for three participants.

with participants who had known about their donor conception from a young age, those with late disclosure reported significantly more interest in information about their heritage and medical background, and in contact with the donor's family.

Participants had requested information about their donor when they were between 18 and 32 years old, and those with early disclosure did so at a significantly younger age than those with late disclosure (Table 1). The majority of participants (78%) requested this information within 2 years of possible request, i.e. their 18th birthday or time of disclosure in adult age. For five participants the decision to request donor information was related to a specific event: pregnancy, decision to donate gametes, therapy prompting questions about identity, depression or a sibling's decision to request donor information.

The majority of participants reported that both of their parents knew about their request of donor information ($n=26$, 65%), and a third had told only the mother ($n=12$, 30%). In the remaining two cases, the parents were not informed due to the participant's desire to protect the father and the parents' death, respectively. Parents were described as being supportive (84% of mothers, 58% of fathers) and/or understanding (45% of mothers, 50% of fathers) regarding the participant's desire to obtain information about the donor. A third of informed fathers also, or solely, reacted with anxiousness ($n=9$, 35%), while this was reported for few mothers ($n=3$, 8%). In addition, some parents' reactions included hesitation (three mothers and two fathers) and/or anger (one father). Comments provided by six female participants primarily concerned fears and difficulties communicating with the father, for example 'I haven't dared to tell dad, don't know if he wants to know', 'dad doesn't know because he would get hurt/angry' and 'dad has had a hard time communicating about this'.

Receipt of information about the donor

Participants reported receiving different types of information about the donor from the RMC, including background information such as age and occupation ($n=32$), a photo ($n=7$) or letter ($n=5$) provided at the time of the donation, and contact information (e.g. postal address; $n=13$). The majority had received identifying information about the donor, i.e. his full name and personal identity number, but five participants had not (Fig. 2). Among these five participants, one described that staff were unable to find any information about the donor in the RMC's records. Another was informed that staff had attempted but failed to reach the donor with information about the request for his

identity and would not release this until they did. In the remaining three cases, the RMC staff had contacted the donor to inquire his attitude towards contact, and had subsequently refrained from providing participants any identifying information. Participants' satisfaction with received information and support from the RMC was high (56%), moderate (20%) or low (23%). Comments from participants who reported low satisfaction scores indicated frustration about the lack of information about the process of identity release on the clinic website, having to explain their request to multiple ignorant persons, and staff's apparent inexperience in handling requests of donor information.

Contact with the donor

Among the 35 participants who had obtained the donor's identity, some found that the donor had died ($n=4$) or that contact information was unavailable in the Swedish national population registry ($n=2$; Fig. 2). Of the 29 participants who had access to the donor's identity and contact information, 17 had not made any attempts to contact the donor at the time of study. Four stated that they planned to do so in the future, 11 were uncertain about potential contact and 2 did not plan to contact the donor. According to participants' free-text comments, many did not perceive a current need of contact and some were unsure about a suitable way to contact the donor and/or were afraid of being rejected. One participant had been informed at the RMC that the donor was not open for any contact and commented 'I think the donor's own children should be told that they have a half-sibling'.

Among those who knew who their donor was and had his contact information, 12 participants (41%) had contacted the donor. Half had written a postal letter and the remainder sent an e-mail or text message (to mobile phone or via Facebook), or phoned him. At the time of the study, seven had met the donor in person and an additional two had a scheduled meeting with the donor in the near future. Five participants (four women and one man) reported being in regular contact with the donor and members of the donor's family. Having contacted the donor was more common among those who found out about their donor conception at an older age (≥ 12 years; 62%) than among those informed before age 12 (25%; $\chi^2=3.948$, $P=0.047$). Initiating contact was not significantly related to offspring gender, age, sibling status, parents' relationship status or time elapsed between information request and study participation (data not shown).

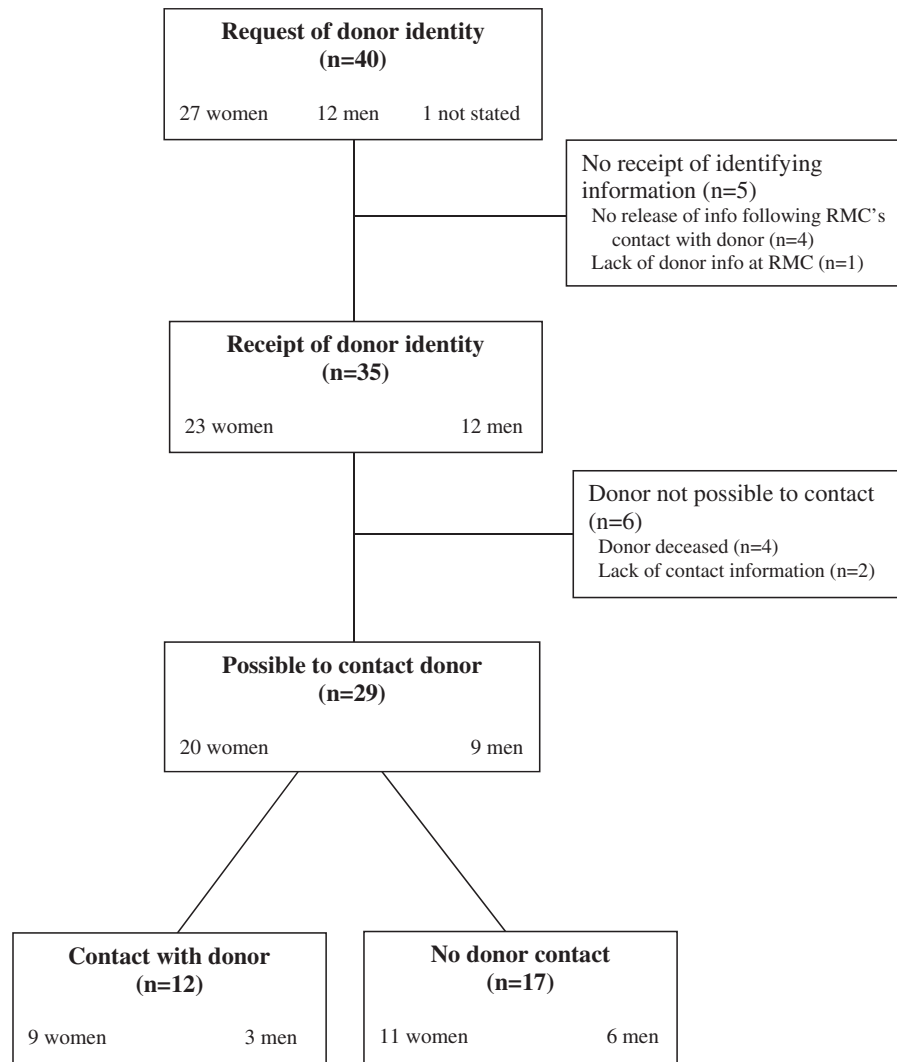


Figure 2. Participants' donor information and contact. RMC, Reproductive Medicine Center; info, information.

Discussion

This research aimed to provide insight into the long-term outcomes of the Swedish legislation on identity-release donation, with a focus on the individuals who made requests for their donor's identity. During the first 17 years of possible releases, <10% of eligible individuals had exercised their legal right to obtain identifying information about their sperm donor. While we know little about those who have not made such requests, the present results suggest that adult DC siblings in the same family may differ in their interest of donor information. Those who had requested their donor's identity were predominantly women and most had made their request soon after their 18th birthday or time of disclosure at later ages. Not all had obtained their donor's identity and a few were unable to obtain contact information or found that the donor had died. Among those who could contact their donor, less than half had done so at the time of the study and many were uncertain about a potential future contact. Being told about one's donor

conception in adolescence or adulthood was associated with more negative experiences of the disclosure, stronger interest in information about the donor and greater likelihood to contact the donor.

Low percentage of information requests

Only ~7% of those DC individuals who were eligible to obtain their sperm donor's identity had requested such information in the first 17 years of identity releases in Sweden. Likewise, in the only other study of offspring from heterosexual-couple families following identity-release sperm donation (Scheib *et al.*, 2017), relatively few (23%) of eligible offspring had requested donor information. In view of the low disclosure rates among heterosexual couples who used donor conception in the 1980s and 1990s (Gottlieb *et al.*, 2000; van den Akker, 2006), is it reasonable to assume that some of the individuals who were eligible to make requests were unaware of their donor conception. However, it is also possible that the low rate of requests is due

to other factors such as limited interest, hesitance or ambivalence among some DC individuals in obtaining their donor information. Indeed, nine of the study participants reported having adult DC siblings in the family who had not made any requests for donor information at the time of data collection. More knowledge is highly warranted about the perspectives of those DC individuals who are aware of their donor conception and do not actively seek information about their donor or other genetically related persons. However, such research is hampered by difficulties recruiting this population, as it is only ethically permissible to approach individuals who know about their donor conception.

Circumstances and experiences of disclosure

About half of the participants had become aware of their donor conception before age 12. This group did not differ from those with later disclosure with regard to year of birth, ranging from 1987 to 2002. As such, the present results did not reflect previous research indicating a trend towards greater openness about using donor conception among heterosexual couples in Sweden and Finland (Gottlieb et al., 2000; Söderström-Anttila et al., 2010; Isaksson et al., 2012; Sälevaara et al., 2013).

Participants reported a range of emotional reactions to becoming aware of their origins with donor sperm. A majority of all participants recalled feeling surprised and curious, but reports of negative emotions were significantly more frequent among participants with disclosure in adolescence or adulthood. These results support earlier reports about the benefit of early disclosure (Jadva et al., 2009; Blyth et al., 2012; Freeman, 2015; Ilioi et al., 2017). However, half of the participants with late disclosure still assessed their own age at disclosure as suitable. This finding was unexpected and may be related to differences in sample selection, where recruitment via e.g. interest groups for DC individuals may increase the risk of selection bias. At the time of the study, participants' subjective well-being was in line with that reported for a general population sample in Sweden (Löve et al., 2014) and did not differ between participants with early and late disclosure.

Requesting donor information

Those who had requested their donor's identity were predominantly women, as also shown for offspring in heterosexual-couple and single-mother families (Scheib et al., 2017), while an equal gender distribution of requesting individuals has been found in same-sex female families (Scheib et al., 2017; Koh et al., 2020). The most common motivation to seek information about the donor was to see any similarities in appearance or other characteristics, and many stated that they wanted to better understand themselves. These findings are in line with a recent systematic review on factors associated with searching for people related through donor conception (Indekeu et al., 2021). DC individuals may want to get in contact with the donor for various reasons, but they do not commonly desire to start a relationship with him/her (Scheib et al., 2017; Indekeu et al., 2021). In fact, contact with 'same-donor peers' or with the donor's own children may be preferred as such relationships are perceived as more reciprocal, while still being able to provide insights into their shared origins (Scheib et al., 2020). Compared to those who were aware of their origins from an early

age, those with later disclosure were significantly more interested in information about their heritage and medical background, and of contact with the donor's family. These findings partly support previous results of adolescents and adults conceived with sperm from predominantly anonymous donors (Jadva et al., 2010; Hertz et al., 2013). However, differences between studies with regard to participants' age range and family type, categorization of age at disclosure/study and confounding between these variables, makes it difficult to draw firm conclusions about the role of age at disclosure for DC individuals' motivation to search information about their donor.

Most participants had received information about the donor's identity and his characteristics at the time of donation, and a third had also received contact information. However, five of participants had not obtained their donor's identity, which was a surprising finding. In one case, the staff had been unsuccessful in finding any information about the donor in the RMC's records, which suggests a serious administrative failure. In the remaining four cases, it appears that identity release was conditional to the donor's consent or awareness of the request, which is not supported by the Swedish legislation or the guidelines issued by Swedish Society of Obstetrics and Gynecology (Gottlieb and Fridström, 2009). All donors in an identity-release program do consent that identifying information about them will be released to mature offspring at request, but they are under no obligation to engage in contact with offspring from their donation. Notifying donors about requests for their identity may enable them to prepare for potential future contact (Isaksson et al., 2014). Similarly, providing offspring with information about the donor's attitude and preferences for potential contact may be helpful and prevent awkward situations, although information that the donor is not open to contact may be disappointing and upsetting for the DC individual (Scheib et al., 2017). In summary, the present findings indicate that the intentions of the Swedish legislation, that all DC individuals have the unconditional right to identifying information about the donor, were not fully implemented during the first 17 years of identity releases. It is essential that clinics abide to legislation and guidelines as failure to do so may lead to court-cases with consequences for all involved parties.

Contact with the donor

Of those who had obtained the donor's identity and contact information, about half had already contacted him or planned to do so and a third were unsure about potential contact. A desire to contact or even meet with the donor is common among DC individuals, irrespective of donor type and possibility to achieve such contact (Jadva et al., 2010; Hertz et al., 2013). Focusing on DC individuals with identity-release donors, our results are in line with previous reports of wishes for donor contact before (Scheib et al., 2005; Bos and Gartrell, 2011) and after having obtained identifying information (Scheib et al., 2017). At the time of the present study, on average 1.5 years since their request, about 40% of those participants who could do so had already contacted the donor and five reported having an ongoing relationship with him and members of his family, which is in line with results for DC individuals from lesbian-couple families (Koh et al., 2020). There is limited knowledge about how parents experience their adult children's search for and contact with the donor. In the present study, a majority of participants were open about their search for donor information with both of their parents, who were predominantly supportive and

understanding. However, a third told only their mother and free-text comments suggest that this decision may have been related to worry that it might upset the father. Indeed, findings from a recent interview study with sperm donation parents indicate that adult offspring's interest in the donor's identity could challenge the father's position, and trigger emotions related to his infertility (Widbom *et al.*, 2021). Further studies are needed to explore parents' as well as identity-release donors' experiences of contact between the donor and offspring from their donation.

Methodological considerations

The main strength of the present study is its national scope, including the RMCs at all seven University hospitals that provided sperm donation in Sweden during 1985–2002. As donor insemination during that period was almost exclusively performed at these University hospitals, we were essentially able to include the whole population of DC individuals who were eligible to request information about their donor during the first 17 years of identity releases. Our estimation of the number of eligible DC individuals is based on official reports of the number of live-born children following donor insemination during 1989–2002 and estimated numbers for the period 1986–1988 (due to lack of official data for this period). While this introduces some uncertainty, the number of donor inseminations and subsequent births in the first years following the change in legislation is believed to be relatively small due to an initial drop of sperm donors (Daniels *et al.*, 1998). Based on the high response rate the results are considered to be largely representative of the population. However, men's lower participation rate must be taken into consideration when interpreting the results. In addition, some caution is recommended when interpreting our results concerning DC individuals who did not request donor information. These numbers are based on participants' reports of any DC siblings in the family. All adult siblings were born 1986 or later and were relatively close in age to the study participant (± 6 years), but it is possible that not all siblings were conceived with an identity-release donor and thus eligible to identifying information. In addition, we did not ask if participants shared the same donor with any siblings in the family, which is a limitation since siblings who share the same donor would have no need to request his information.

Clinical implications

The present findings provide information with relevance for clinical practice in connection with donation treatment and subsequent identity releases. First, the markedly greater percentage of information requests to a US sperm bank than found in the present study, suggests that providing patients after successful treatment with recurrent updates and educational material about disclosure may be beneficial to promote disclosure and enable identity release to offspring (Scheib *et al.*, 2017). Secondly, clinics need to make careful preparations for future identity releases in order to meet the specific informational and emotional needs of DC individuals. Such preparations should be informed by practice experiences of clinics providing identity-release donation (Scheib *et al.*, 2017), and voluntary donor linking services (Crawshaw *et al.*, 2013; Kelly *et al.*, 2019) as well as policy and practice recommendations by professional groups (Wilde *et al.*, 2014). Preparations should include setting up clear protocols, guidelines and/

or checklists concerning the process of identity release. Both the DC individual and the donor may benefit from clinic staff notifying the donor of requests for his/her identity, inquiring the donor's preferences regarding potential contact with DC offspring, and conveying these preferences to the DC individual. Such a process enables the donor to prepare for potential contact, which may include informing their family about their donation. For DC individuals, knowledge of the donor's acceptance and preferences of contact could mitigate fears of being rejected, and increase the chances of establishing contact in a considerate and respectful way. Adequate training of staff is essential to provide appropriate information and support to DC individuals, and training courses on issues related to donor identification and contact are organized by infertility counselling associations such as the BICA in the UK and the BKID in Germany. In the present sample of only 40 DC individuals, five found that the donor was deceased or did not want to be contacted, which could be distressing and raise questions about contacting the donor's family members, who may or may not know about his donor status. Such issues may require careful counselling and guidance to protect the rights and well-being of all involved individuals. At the very least, clear information about the process of releasing a donor's identity and the long-term aspects of identity-release donation should be made available to DC individuals as well as to donors. Websites providing such information have been developed by national or state authorities such as the Human Fertilisation & Embryology Authority (HFEA) in the UK and the Victorian Assisted Reproductive Treatment Authority (VARTA) in Australia, by state subsidized organizations such as the FIOM in the Netherlands, and by non-profit organizations such as the Donor Conception Network (DCN). These may serve as inspiration to authorities and clinics when developing informational resources that are based on their specific legislative, regulatory and cultural contexts.

Conclusion

The intention of the Swedish legislation, to give all DC individuals access to identifying information about their donor, appears to be implemented only to a limited degree. While our results indicate that not all DC adults choose to request such information, it is reasonable to assume that some of those eligible to receive information about their donor are unaware of their conception with donor sperm. During the coming years, young women and men in many countries will become eligible to access identifying information about their donor. In order to meet the needs of these individuals, and to support positive outcomes for all involved parties, it is essential that adequate resources are developed. Information about the process of identity release and long-term psychosocial aspects of identity-release donation should be made available to all DC individuals and donors, as well as to their families.

Data availability

The data underlying this article will be shared on reasonable request to the corresponding author.

Acknowledgements

We are grateful to all participants who took part in the study and to staff at the RMC's for assistance in recruitment.

Authors' roles

C.L., G.S. and A.S.S. conceived of the design. C.L. conducted the data collection and performed the data analyses. All authors contributed to the interpretation of results and revision of the manuscript, and approved the final manuscript.

Funding

The project was supported by grant 2013-2712 from the Swedish Research Council.

Conflict of interest

The authors have no conflict of interest to declare.

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