

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 pre-donation ambivalence was associated with low post-donation 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 pre-donation 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 pre-donation 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

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