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The child's best interest

Perspectives of gamete recipients and donors

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Abstract

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Background: An increasing number of couples turn to treatment with oocyte or sperm donation, but there is limited knowledge regarding the consequences of these treatments in a program using identifiable donors. *Aim:* The overall aim was to study information-sharing among heterosexual couples following identity-release gamete donation. A further aim was to study donors' attitudes towards future contact with donation offspring. *Methods:* The four studies were part of The Swedish Study on Gamete Donation; a prospective, longitudinal study of donors and recipients of donated oocytes and sperm. Study I and II had a quantitative approach with recipients of donated oocytes or sperm participating through questionnaires at start of treatment, two months after the first treatment and when their child was 1-4 years old. Study III was a qualitative interview study with 30 parents following sperm donation with school-aged children. Study IV had a quantitative approach with oocyte and sperm donors participating through questionnaires 5-8 years post-donation. *Results:* Study I revealed that the recipients of donated gametes in general were open about their treatment with the people around them and supported disclosure to offspring regarding his/her genetic origin. Study II reported that most of those who became parents following donor conception intended to share information about the donation with their offspring and some had already started the information-sharing process with their young child. Study III described information sharing with the offspring to be a process of several levels, revealing various amounts of information about the way of conception. The parent was seen to be the owner of the process and moving the process forward with different aspects and the reactions of the offspring serving as driving or impeding forces of the process. Study IV reported that a majority of the gamete donors seem to have a positive or neutral attitude towards a future meeting with a donation offspring. *Conclusion:* The present thesis suggests that there is a trend towards more openness among recipients of donated gametes in Sweden. It also points out that most recipients and donors within the Swedish gamete donation programme acknowledge the child's right to his/her genetic origin and have the best interest of the child in mind.

Keywords: Assisted reproduction, heterosexuals, sperm donation, oocyte donation, donor, disclosure, information-sharing, quantitative, qualitative

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*To
Olle, Melker and Svante*

‘If you don’t talk to kids about the difficult stuff, they worry alone’.

Meg Rosoff
The Guardian
21-09-2013

Front cover: illustration by Elin Wallin/Studio Elwa

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I Isaksson S., Skoog Svanberg A., Sydsjö G., Thurin-Kjellberg A., Karlström P-O., Solensten N-G., Lampic C. (2011) Two decades after legislation on identifiable donors in Sweden: are couples ready to be open about using gamete donation? *Human Reproduction*, 26(4): 853–860
- II Isaksson S., Sydsjö G., Skoog Svanberg A., Lampic C. (2012) Disclosure behaviour and intentions among 111 couples following treatment with oocytes and sperm from identity-release donors: follow-up at offspring age 1–4 years. *Human Reproduction*, 27(10): 2998–3007
- III Isaksson S., Skoog Svanberg A., Sydsjö G., Linell L., Lampic C. (2015) It takes two to tango. Reasoning and experiences of information sharing with offspring among heterosexual parents following identity-release sperm donation. *Human Reproduction*, accepted for publication 29-10-2015
- IV Isaksson S., Sydsjö G., Skoog Svanberg A., Lampic C. (2014) Preferences and needs regarding future contact with donation offspring among identity-release gamete donors: results from the Swedish Study on Gamete Donation. *Fertility and Sterility*, 102(4): 1160–1166

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Abbreviations

ART	Assisted reproduction technology
CBRC	Cross-border reproductive care
DSR	The Donor Sibling Registry
DT1	Timepoint for donors' baseline questionnaire assessment
DT2	Timepoint for donors' second questionnaire assessment
DT3	Timepoint for donors' third questionnaire assessment
DT4	Timepoint for donors' fourth questionnaire assessment
ENRICH	Evaluating and Nurturing Relationship Issues, Communication and Happiness
FSH	Follicle-stimulating hormones
HADS	Hospital Anxiety and Depression Scale
ICSI	Intracytoplasmic sperm injection
IUI	Intra-uterine insemination
IVF	In vitro fertilisation
OHSS	Ovarian hyperstimulation syndrome
RT1	Timepoint for recipients' baseline questionnaire assessment
RT2	Timepoint for recipients' second questionnaire assessment
RT3	Timepoint for recipients' third questionnaire assessment
RT4	Timepoint for recipients' fourth questionnaire assessment
SSGD	The Swedish Study on Gamete Donation
TCI	Temperament and Character Inventory
TPB	Theory of planned behaviour

Prologue

Working as a young nurse at the maternity ward, I met lots of new parents with their newborn child. Being a small part of their start of the journey of parenthood was amazing, especially since at that time I had not experienced parenthood myself. However, I soon realised that their journey was not always self-evident. I was sometimes amazed by their stories of struggling for years to bring this precious little child into the world. Some years later I had the opportunity to be a part of the Swedish Study on Gamete Donation through a position as a PhD student within the project. Through this project I had a chance to get closer to some of these parents, not as a nurse but as a becoming researcher. The precious collection of stories of couples struggling to achieve parenthood that I keep in my heart has grown, as has my admiration for all couples who are struggling to have a child.

A parent has the great privilege of being given the responsibility, with all the challenges that follow, of shaping the child's identity and helping them grow into a free, independent individual. Building a family through donor conception might imply even greater challenges as a parent.

This thesis describes the views on and experiences of information sharing among heterosexual couples building their family through donor conception. Furthermore, it describes the views of gamete donors regarding a potential future contact with the donor offspring. The thesis was written in light of the Swedish legislation on identity-release gamete donation and focuses on the offspring's right to information about his/her genetic origin.

Introduction

The desire for parenthood

Having a child is viewed as a natural form of progress and is, for most people, a part of their life plan. Motives for being a parent include expectations of happiness, positive effects on family relationships, life fulfilment, a strengthened identity, a wish to live on through the child and the fulfilment of a social expectation to have children.^{1 2} In most dictionaries as well as among the public in general, a family is most often defined as parents with children. For people to qualify in this definition of a family, children seem to be a required factor.

In Sweden, the view of parenthood and what a family or kinship consists of has varied over time. In former times, a childless woman could get a child from a woman who had delivered many children and was perhaps not able to nurture them all.³ The notion of a traditional kinship with two parents and their biological children was the norm in Sweden throughout the twentieth century. In contemporary Sweden, however, this notion has developed into a wider range of kinships, including cohabitation, marriage, families who live apart, same-sex families, single parents and separated families.⁴ All these family types are common and accepted, but they implicitly assume there is a child included, something which has never been achievable for everyone through a spontaneous pregnancy.

Involuntary childlessness

Involuntary childlessness is estimated to affect 10–15% of couples in the global population, about half of which seek medical help for their infertility.⁵ The definition of infertility is when a couple has been trying to get pregnant for a year without success. Medical reasons for infertility include female infertility due to reduced oocyte quality, hormonal disorder or reduced tubal function. Male infertility can be due to reduced sperm quality or azoospermia.⁶ Female and male infertility are equally common and occur relatively often in combination in a couple attempting to conceive a child. Sometimes, however, infertility remains unexplained.

However, infertility is not solely a medical condition. George L. Engel developed the biopsychosocial model from a need to broaden the biomedical

approach to disease by including the psychosocial aspect.⁷ The idea is that biological, psychological and social factors play a significant role in human functioning in the context of disease or illness. Ken Daniels⁸ applied this model to infertile couples in assisted reproduction treatment. When facing involuntary childlessness, the infertile couple is not only dealing with a medical condition. Involuntary childlessness, which involves grief, loss, self-image and identity, has an impact on the psychological wellbeing of both individuals and the relationship itself. It also includes a social aspect concerning the openness or secrecy of the couple in relation to their surrounding relationships and networks and with the potential future child. Each part of the model stands separately, but all parts interact and are essential for an understanding of the phenomenon.⁸

Infertility treatment

For an involuntarily childless couple, help through assisted reproduction technology (ART) is an option. ART includes intra-uterine insemination (IUI), where the sperm is injected in the uterus; in vitro fertilisation (IVF), where the oocyte is fertilised outside the body; and intracytoplasmic sperm injection (ICSI), which is an advanced form of IVF where one single sperm is injected directly into the oocyte's cytoplasm.⁹

The first baby conceived by IVF, Louise Brown, was born in 1978 in the United Kingdom (UK).¹⁰ There have been great advances in the field of ART since then. Today there are several different ARTs available for creating a family and hundreds of thousands of children are born every year after ART. Of the children born in Sweden every year, about 3% are born following IVF treatment.¹¹

When a couple's infertility is due to defects in their sperm or oocytes, treatment with donated gametes can be an option. The first reported case of donor insemination was in 1884,¹² and sperm donation through insemination has been performed in Sweden at least since the 1920s.¹³ However, it was not until the 1960s and 70s that the number of treatments began to increase successively. Oocyte donation has a more recent history, with the first baby born following treatment with a donated oocyte in 1984.¹⁴ This procedure has been performed in Sweden since 2003. The rate of successful treatment for oocyte donation is approximately 20%, while for sperm donation the rate is 30%.¹¹ In Sweden in 2012, 397 treatments with donated oocytes were carried out and 88 children were born; with respect to sperm donations, 555 treatments were carried out and 190 children were born.¹¹

The treatment procedure depends on which type of ART is performed. Donor conception through insemination is the least medically intrusive form of ART, by which the donor sperm is inseminated directly into the uterus of the woman. The insemination can be performed in an unstimulated cycle

without hormone supplements or in a stimulated cycle, i.e. when the woman receives follicle-stimulating hormone (FSH) therapy before the insemination in order to increase the production of oocytes.¹⁵ One insemination treatment cycle often requires 4–5 weeks from start to end.

IVF is an alternative to insemination in sperm donation treatment. In the case of sperm donation, one cycle of in vitro fertilisation typically requires nine to twelve days of self-injection with FSH to stimulate the production of oocytes. This is followed by the retrieval of oocytes via transvaginal ultrasound and fertilisation of oocytes and donor sperm in the laboratory through conventional IVF or through ICSI. IVF or ICSI is also used in the case of oocyte donation, in which the donor oocyte is fertilised with the man's own sperm. The recipient woman is then treated hormonally approximately three weeks before the transferral of the fertilised embryo. After 2–5 days of incubation, the couple return to the clinic and the embryo is transferred into the woman's uterus. After two to three weeks, a pregnancy test can confirm if implantation has succeeded and a pregnancy has occurred. An ultrasound examination is used to verify the result in the case of a positive pregnancy test.¹⁵

In Sweden, while the number of reimbursed insemination treatments differs between county councils, it is common for 6 inseminations to be reimbursed. If 2–3 insemination treatments do not result in a pregnancy, the couple is offered the opportunity to proceed with IVF treatment. In order to avoid the high risk of obstetric and neonatal complications in duplex pregnancies and births, the main principle of IVF in Sweden is transferral of only one embryo at each separate treatment cycle.¹⁶

Since couples also travel abroad for treatment in other countries (e.g. Finland or Denmark), i.e. cross-border reproductive care (CBRC), it is difficult to calculate how many children in total are born annually in Sweden following gamete donation. In addition, there are women and couples who choose to make private arrangements with a sperm donor in order to conceive, and these arrangements are not visible in any records. Oocyte donation is a more complex procedure than sperm donation, with the oocyte donor receiving hormonal medication before a surgical procedure of oocyte extraction. Pregnancies following oocyte donation treatment are also associated with more complications for the recipient than pregnancies after sperm donation, including a higher risk of high blood pressure and preeclampsia.¹⁵

This thesis is limited to research on heterosexual couples who build their families with the help of third-party reproductive treatment with donated gametes. This limitation is based on the fact that children born from heterosexual couples have a mother and a father and the nature of the child's conception is less likely to be questioned by the child or others. It is therefore possible for a heterosexual couple not to reveal the donor conception to the child or the people around them. In contrast, for single

women or lesbian couples, the absence of a father is obvious and requires an explanation to the child and other people around the parents. In addition, lesbian couples who build a family using sperm donation might face other issues, e.g. the negotiation of biological motherhood vs co-motherhood. Previous results from lesbian couples within the Swedish Study on Gamete Donation are presented elsewhere.¹⁷

A gender perspective on infertility

Gender refers to the social and cultural construction of femininity and masculinity while sex refers to the biological classification of females and males with regard to their biological differences and reproductive function.¹⁸ However, most gender researchers today do not see these two concepts of gender and sex as completely separated but instead view them as being related to each other.¹⁹ A central aspect of gender theories is the power relations between men and women in society, particularly how hierarchical power relations are built up and reproduced within the current gender system.²⁰ Additionally, gender is not seen as naturally given, but as constantly constructed. West and Zimmerman, for example, refer to gender as ‘something that one does and *does* recurrently, in interaction with others’.²¹

Connell has studied the construct of gender in Western society and argues that masculinity and femininity are contextually and relationally constructed and hierarchically ordered in relation to each other.¹⁹ The concept of hegemonic masculinity is one approach to describe the idealised form of masculinity, including power and authority, denial of weakness or vulnerability, emotional and physical control and the appearance of being strong and free from any need of help.²² When a man experiences illness or disability, this can reduce his status in masculine hierarchies, shift his power relations with women and raise uncertainty about his masculinity. To preserve their sense of masculinity, men with chronic illnesses have been seen to make significant efforts to hide their disabilities from others.²³ A physical condition such as male infertility might imply a particular challenge for a man’s image of his masculinity.²⁴ It has been asserted by researchers that manliness is related more to the ability to make a woman pregnant than to entering the role of a father. Furthermore, fatherhood for men is associated with masculinity, while for women motherhood is associated with fulfilment.²⁵ Fertility is central to the man’s gender identity and infertility is therefore a threat to his masculinity^{25 26} and a seedbed for infertility-related distress.²⁴ The stress of infertility has traditionally been thought of as being more noticeable for women.²⁷ However, more recent research indicates that men also experience feelings of sadness and anxiety and may feel unable to share this experience with their friends or family.^{28 29}

Men have been seen to place more importance on the genetic link between parent and child than women.³⁰ In gamete donation, there is an asymmetry between the parents of a child where one parent is genetically connected to the child and the other is not.³¹ There are also some differences between the infertile man and woman regarding the linkage to the child. When the donor conception is due to male infertility, i.e. sperm donation, the man only has a social link to the offspring. This is in contrast to conception through oocyte donation, where the woman lacks the genetic link with the child. However, the biological link to the offspring in conception through oocyte donation is intact through gestation, birth and breastfeeding.

Gamete donation—legal, ethical and practical aspects

A history of secrecy

Gamete donation has long been associated with secrecy throughout the world. During the twentieth century, infertile couples were encouraged by medical professionals not to talk about their infertility treatment and even to forget about the treatment once a pregnancy has been achieved.³²⁻³⁴ It has been reported that couples were encouraged by clinicians to have intercourse immediately after the insemination with donor sperm, creating ambiguity about the biological inheritance of the child.³⁵ The reasons for this have included a fear of stigma and a wish to protect the donor, the infertile half of the couple and the offspring born following gamete donation. In addition, physicians were often afraid that it would not be possible to recruit donors if the offspring obtained access to records about the identity of the donor.^{33 34} However, findings from the field of adoption reveal that an open approach is more beneficial to all parties involved and that family secrets put a particularly burdensome strain on the parents.³⁶ This was the basis for governments in several countries, with Sweden in the lead, to develop legislations and guidelines in favour of openness.

Sweden becomes a legislative pioneer

In December 1984, sperm donation through insemination in Sweden was regulated by law, and all donor offspring born from gametes donated after 1 March 1985 have the right to obtain identifying information about the donor when sufficiently mature.³⁷ Before the legislation in 1984, sperm donation treatment was performed unregulated in Sweden and under complete secrecy in order to resolve the problem of the childless couple. Records were kept hidden and most often were destroyed by the responsible doctor after treatment. No psychosocial investigation of the suitability of the prospective

parents was undertaken and the husband or the cohabitant of the woman receiving treatment was not legally and irrevocably bound to the offspring. When the number of treatments increased and up to 230 children were born annually following donor insemination, a need for legal regulation was raised to ensure the offspring's legal protection.

In 1981, the Swedish government appointed the Insemination Committee to investigate the issue of artificial insemination. In the pre-legislative ethical argumentation process, insemination with donated sperm was seen as a well-established technique to resolve childlessness, with the positive consequences outweighing the negative if treatment was performed under acceptable circumstances.¹³ However, the Insemination Committee concluded that the individual playing the lead role was not the childless couple but the offspring born following the treatment. The goal of the treatment was to cure childlessness, but it was argued that an offspring can never be treated as a method for this goal. The offspring growing as a free and independent individual in a healthy society was seen to be a goal in itself, not a way of removing the sorrow and disappointment of an unwanted infertility.¹³ The committee stated that offspring conceived following sperm donation cannot be asked. Therefore, the involved adults must create possibilities through their actions for the offspring to become a free and responsible individual, and hence the offspring's interests should be taken into greatest consideration. It was argued that the consequence of prioritising the interests of the offspring must be a greater openness and the offspring must not be denied the right to information. As the research had revealed that adoptive children have a need for information, there was nothing from an ethical perspective that would tell against the donor offspring to have the same need.¹³

The Insemination Committee commented that 'an open and honest relationship between parents and child certainly is an important prerequisite for the child's favorable development'¹³ (p. 212, author's translation), and that parents should therefore inform the child. According to the committee, health care personnel were to inform and educate the prospective parents about the importance of openness with the child. It was also recognised that when openness was promoted and parents were encouraged to talk with their offspring about his/her conception, it would not be reasonable to exclude the offspring from available information about the donor.¹³ The work of the Insemination Committee resulted in a proposal that records on the donor and on the woman receiving treatment should be kept for the future and the legal status of the non-biological parent should be ensured and irrevocable. Furthermore, the committee stated that a donor-conceived offspring has a right to knowledge about his/her origin.¹³

The consultant bodies during the legislation process were not unanimous and the legal regulation was not enacted without debate. The majority of the members of the National Board of Health and Welfare wanted to postpone

the legislative initiatives until the possibility of a united regulation among the Nordic countries had been investigated. Other consultant bodies wanted to prohibit the use of donor insemination due to the possible ethical difficulties surrounding donor insemination.¹³ Also, there was a fear among Swedish physicians that banning donor anonymity would reduce the access to donors and subsequently the number of treatments.^{38 39}

However, the legislative proposal that regulated donor insemination was executed and is today regulated in the Genetic Integrity Act³⁷ and in the subsequent Regulations and Guidelines.^{16 40} This included allowing heterosexual couples treatment with donor insemination and giving the offspring born following donor insemination the right to identifying information about the donor when mature enough.³⁷ The law demonstrated a change in attitude, moving away from secrecy and encouraging parents following donor insemination treatment to be open with their offspring. At the centre of this change was the child's right. The legislation was in compliance with the later implemented United Nations' Children's Convention on a child's right to knowledge about its origin (article 7).⁶

In the 1980s, the secrecy surrounding sperm donation treatment was the norm internationally and thus Sweden was a pioneer as the first country in the world to legislate on identity-release donations.⁴¹ In 2003, IVF treatment with donated sperm or oocytes was allowed. In 2005, lesbian couples were permitted to undergo sperm donation treatment in Sweden, and there is currently a government bill proposing single women to be allowed treatment in Sweden.⁴² It is not allowed for a couple to use both donated sperm and oocytes at the same time (i.e. embryo donation). Surrogacy is likewise not allowed in Sweden. Treatment with donated gametes was initially permitted only at the university hospitals in Sweden that are located in Malmö, Gothenburg, Linköping, Örebro, Stockholm, Uppsala and Umeå, but since 2015, treatment is also allowed at other Swedish fertility clinics after obtaining special permission. The couple has no right to identifying information about the donor, but the legislation gives the offspring following gamete donation the right to such information about the donor.

To sum up, in 1985 Sweden shifted away from unregulated gamete donation treatment and secrecy aiming to protect the childless couple. From this point on, the right of the offspring, both juridically and psychosocially, was accentuated in the legal regulation of treatment with donated gametes.

Legislations in other countries

Since Sweden's implementation of the legislation on identity-release donations, several countries have followed with slightly different regulations. Among the Nordic countries, Norway (2005) and Finland (2007) have legislations that accept only identity-release donors.⁴³ In Denmark and Iceland it is possible for both the donor and the recipient couple to choose

between anonymous and identity-release donation. Other countries with jurisdictions on identity-release donations include Austria, Switzerland, the Netherlands, the UK, New Zealand and three states in Australia.⁴³ However, a majority of countries in the European Union have legislations that permit anonymous donation and some countries still do not have any legislation that regulates donor anonymity/non-anonymity.⁴⁴ Italy, for example, banned any type of ART with donated gametes between 2004 and 2014 since gamete donation was seen as an intrusion of a third party in the privacy of a marriage. However, in 2014 the law was regarded as unconstitutional and removed by the Italian Constitutional Court.⁴⁵ In the United States (US), most of the states have either no or limited regulations regarding gamete donation. As a result, the medical professionals, market providers and consumers remain autonomous and the right of each participant in the process is rather uncertain if challenged in court.⁴⁶

The Swedish legislation in practice

The donor

The donor of oocytes or sperm has to be of legal age (at least 18 years) and give written consent that his/her gametes may be used for fertilisation.³⁷ Gametes from a dead person may not be used in treatment, and the importation of frozen gametes is not allowed without permission from the National Board of Health and Welfare. A medical examination of the donor is performed, including medical history, health status and infection markers. The donor is to be informed about the legal, psychological and social consequences of a donation and that the potential offspring can obtain identifying information in the future about the donor and contact the donor.

A donor has no obligations nor rights towards the offspring, neither socially nor legally, which is also declared in the written consent form.³⁷ However, the donor can obtain information from the fertility clinic on whether the donation resulted in a child or not. It is not regulated in law how many children a donor can generate. Nevertheless, the involved county councils have set the limit for a donor to donate to a maximum of 6–10 families. The donor is financially compensated with approximately 40–60 EUR per sperm sample for sperm donors and 400–600 EUR (1 100 EUR in one county council) as a lump-sum payment for oocyte donors (information about the sums are available on each county council website).

The recipient couple

The couple who is seeking treatment with donated gametes has to undergo an investigation of their medical, psychological and social situation performed by the physician and a psychologist or social worker. Treatment

is permitted only if it can be presumed that the prospective child will grow up under good conditions.¹⁶

The investigation includes an evaluation of the couple's age, health, their relationship, living conditions and attitude towards telling the child about its genetic origin, followed by individually adjusted information and counselling provided to the couple.¹⁶ The upper age limits for donation are 40 years for women and 56 years for men. The partner of the woman undergoing IVF or insemination with donated gametes is required to give written consent that donated gametes are used for fertilisation and that the partner is the legal parent of the prospective child.¹⁶

The offspring

A child born following gamete donation in Sweden has the legal right to obtain identifying information about the donor when sufficiently mature. 'Sufficiently mature' is not defined as a specific age in the law; instead, it is defined as the age of majority, i.e. 18 years, in the government advisement.⁴⁷ The law does not specify who is to tell the offspring about his/her origin and no information about the donation treatment is registered in the offspring's medical record or birth certificate. It is, however, postulated that the parents are the most suitable to tell their offspring about his/her origin.

An offspring of a mature age who wants access to identifying information can contact the fertility clinic or the social service in order to obtain information. At a personal meeting at the fertility clinic, the offspring has a dialogue with a physician and a psychologist or social worker and the requested amount of information is given to the offspring. If the offspring requests identifying information about the donor, a notification about the released information is made in the donor's record.

The donor

Donor recruitment

When donor anonymity was banned in Sweden in 1985, a fear was raised among physicians that recruitment of identity-release donors would be impossible.^{38 39} The access to available donors did initially decrease, but later went on to increase five-fold in 1997, twelve years after the law was implemented.⁴⁸ Nevertheless, there is still a shortage of donors which results in waiting times for the recipient couples before treatment.⁴⁹ Before the identity-release legislation, the majority of sperm donors were young men, often students or in the military service,⁴⁸ which is similar to the former tradition in the UK.⁵⁰ After the change of legislation, the recruitment of donors led to a change in donor characteristics in both Sweden and the UK,

and nowadays most donors, including both sperm and oocyte donors, are older, well-educated and often in a stable relationship with their own biological children.⁵¹⁻⁵⁴

Until 2010, there was a recommended limit in Sweden that every donor should not be used for pregnancies leading to more than six children, but in 2010 this recommendation was removed.¹⁶ International use of donor sperm is a common practice, but the international distribution of sperm is unregulated.⁵⁵ The lack of regulation regarding a maximum donor quota in international sperm distribution has recently been highlighted and debated.⁵⁵ A Swedish study calculating the optimal limit of offspring per donor in a country with 10 million inhabitants such as Sweden found that a limit of 10 donor offspring would present a risk for consanguineous matings of 0.9% per year, or only once every 100 years.⁵⁶ Another Swedish study among gamete donors revealed that a majority of donors expressed an opinion that the number of offspring from one donor should be limited to between one and 10. Oocyte donors were both more restrictive and more generous than sperm donors regarding their opinion on an acceptable donor quota; a higher percentage of women (33%) than men (13%) thought that the number of offspring should be limited to between one and five, and a larger group of women (16%) than men (3%) had the opinion that one should place no limit on the number of offspring.⁵⁷

The donation procedure

The donation procedure differs between sperm and oocyte donors for obvious reasons. A man donating sperm does not have to undergo any medical procedure since the sperm is delivered through masturbation. A woman donating oocytes undergoes a relatively complicated donation process. Birth control pills are often administered during the first few weeks of the egg donation process to regulate the menstrual cycle. This is followed by a series of injections which halt the normal functioning of the donor's ovaries. These injections are self-administered daily for one to three weeks. Next, follicle-stimulating hormones (FSH) are given to the donor to stimulate oocyte production and increase the number of oocytes produced by the ovaries. Blood tests and ultrasound exams are performed throughout the cycle to determine the donor's reaction to the hormones and the progress of follicle growth. When the follicles are mature, the donor gets an injection of HCG hormone approximately 36 hours before retrieval. The oocyte retrieval is a procedure lasting 20–30 minutes and performed under sedation. A small ultrasound-guided needle is inserted through the vagina to aspirate the oocyte follicles in both ovaries. After the donation the donor has to rest for a few hours at the fertility clinic, but most donors can perform regular activities by the next day. However, the oocyte donation is not free of risk. Beyond the negative side effects of the hormones (such as temperament

swings, swelling and sore breasts), there is a small risk (0,5–5%) of ovarian hyperstimulation syndrome (OHSS) and, albeit more rarely, liver failure.⁵⁸

Who is the donor?

Gamete donors can be categorised according to the relation between the donor and the recipient/offspring as follows: (1) known or personal donors who donate to a couple known to them or are recruited by an infertile couple;^{53 59} (2) anonymous donors;⁶⁰⁻⁶⁶ (3) donors who donated anonymously but later actively made themselves identifiable to the offspring, for example, through a voluntary contact register, e.g. The Donor Sibling Registry (DSR);^{67 68} and (4) identifiable donors who chose to donate through identity-release arrangements despite the option to donate anonymously⁶⁹ or who donate under identity-release jurisdictions.^{52 70-74} A review of studies on sperm donors⁷⁵ reported that altruistic reasons and financial compensation play a role in the decision to donate sperm, but an investigation of the donor's own fertility status and a wish to pass on their own genes were also revealed as reasons for donating.

A similar review of studies on oocyte donors revealed that oocyte donors, like sperm donors, have altruistic reasons for donating, but seem not to be driven by financial compensation or curiosity regarding their own fertility status to the same extent as sperm donors.⁷⁶ A Swedish study⁷⁰ reported that oocyte donors seem to be more driven by empathy towards the infertile couple than sperm donors. In some other countries, e.g. the United Kingdom (but not in Sweden), it is possible for a woman to donate oocytes through so-called 'oocyte sharing arrangements', when oocytes are donated during the woman's own fertility treatment. These donors are motivated by the feeling of helping another childless couple, but also by the access to their own fertility treatment and the reduced treatment cost that oocyte sharing helps make possible.⁷⁷

The experience of donation has been regarded as positive by the donors.⁷¹
^{76 78} The legislation in Sweden implies that a donor's involvement in a donation does not necessarily end with the donation since the donor offspring can learn the identity of the donor and seek contact. Irrespective of the type of donation, donors who are older, married and have their own biological children seem to be more open to contact with offspring.^{51 53 74} Also, donors performing identity-release donations seem to be more open to contact with offspring compared with anonymous donors.^{51 53 63 69 72} Jadva et al.⁶⁷ reported positive experiences of subsequent contact with donor offspring among anonymous donors who had made themselves open to contact with their donor offspring.

Family functioning in gamete donation families

The quality of partner relationship is important for family functioning in general.⁷⁹ While infertility is undoubtedly a stressful experience for the couple, it may also bring the couple together and strengthen the relationship.⁸⁰⁻⁸³ One main concern regarding families created through gamete donation has been that the absence of a genetic link between the offspring and one of the parents would have a negative effect on family functioning. Parallels have been drawn with adoptive families and stepfamilies where a more negative parent-child relationship, including more conflicts and less warmth, has been seen compared to families with naturally conceived children.^{84 85} However, this has not been found in studies of gamete donation families,⁸⁶⁻⁹³ even if only a few systematic studies on parents and children after gamete donation have been performed.

A UK research team conducted a longitudinal study of parent-child relationships and the psychological wellbeing in families after ART in the UK with five assessments at children's age 1, 2, 3, 7 and 10 years.⁸⁶⁻⁹² The study started in 2000 with 50 families after sperm donation (50% of eligible families), 51 families after oocyte donation (75% of eligible families), 42 families after surrogacy and a comparison group of 80 families after natural conception at nine UK fertility clinics. At the assessment when the children were 10 years old, 34 sperm donation families, 30 oocyte donation families, 33 surrogacy families and 55 natural conception families remained. Assessments included both questionnaires and standardised interviews. Findings from the UK study revealed that the children conceived by gamete donation were well-adjusted. The quality of the parent-child relationship in gamete donation families was similar or even better than parent-child relationships in families after a natural conception.^{86-89 91 92}

The European Study of Assisted Reproduction Families included data on families after sperm donation, conventional IVF, adoptive families and families with naturally conceived children from four European countries (the UK, the Netherlands, Italy and Spain) in 1996⁹⁴ with a follow-up in 2001.⁹⁵ Like the UK study, findings from The European Study of Assisted Reproduction Families presented well-functioning families that did not differ from families with naturally conceived children.^{94 95} These studies have provided a large amount of knowledge about families created by gamete donation using anonymous donors. However, these studies have some methodological problems with an initially relatively small sample that naturally has decreased over time, which results in a risk of selection as well as attrition bias.

To sum up, families built through donor conception seem to be well-functioning, but there is still a lack of larger longitudinal studies and studies on families created by gamete donation with identifiable donors.

Disclosure and sharing information with offspring

The decision regarding whether or not to disclose information about the donor conception to the offspring is an autonomous decision to be made by the parents. Nevertheless, it is one of the most challenging dilemmas couples in donor treatment face⁹⁶ and has been one of the most controversial and debated issues in assisted reproduction.⁹⁷⁻⁹⁹

The decision regarding disclosure or non-disclosure

The decision by parents to disclose information about the donor conception to the offspring is influenced by a range of factors. In several different studies, parents who disclosed such information unanimously stated that they believe the child has a fundamental right to know the truth, that they would not want to live with a life-long lie and that they disclose to avoid the risk of accidental disclosure.¹⁰⁰ The non-disclosure decision is often based on a wish not to move outside the norm by being different from the 'ideal' biological family and thus putting the family in jeopardy of stigmatisation.^{101 102} Other reasons for non-disclosure include that disclosure to the offspring would harm the relationship between the offspring and the non-genetic parent;^{86 103-107} uncertainty concerning how and when to tell the offspring about the donation; and/or the parents see no need to tell the child.^{104 106 108 109}

Lack of support and tools for disclosure have been reported to be determinants for non-disclosure.¹¹⁰ Couples receive counselling prior to treatment, but the content of counselling varies between countries, clinics and professionals.^{107 111} Furthermore, parents have expressed a wish for more individualised counselling.¹¹¹⁻¹¹³ Irrespective of the disclosure decision, most couples talk to someone outside the family about the donation treatment.^{32 104 105 107 114-117} If parents do not talk about the donation with the offspring or postpone disclosure to adulthood, the risk of accidental disclosure by someone else increases, which can be traumatic for the offspring.^{118 119} However, due to the secrecy that has been surrounding gamete donation, there is limited research on the experiences of offspring born following donation treatment and especially regarding offspring following oocyte donation.¹²⁰ Most research on the experiences of donation offspring concerns sperm donation offspring, since the history of oocyte donation is considerably shorter.¹²⁰ Also, research on donor offspring is mostly limited to self-selected groups, such as members of donor conception networks or voluntary contact registers (e.g. DSR).^{120 121}

The disclosure process

The disclosure process after treatment with identity-release gamete donors can be seen as a two-step process. The first step is sharing with the offspring

that he/she was conceived via donation treatment. The second step includes informing the offspring that he/she has a right to obtain identifying information about the donor when mature. The Swedish guidelines⁴⁷ for gamete donation recommend that parents should start the disclosure process at an early age. Disclosure at an early age creates a situation where the offspring has a sense of always having known about the donation.^{119 122} This is suggested to be preferable in contrast to offspring being told about the donation at an older age, which has been found to have negative consequences for family relationships and the offspring's sense of identity.¹¹⁸

Regardless of the various legal regulations in different countries, both European¹²³ and American¹²⁴ guidelines support that parents should share all known information about the donor and general information about the donation treatment with the offspring. However, many parents find it difficult to disclose the use of donor conception to their offspring.^{108 125} The prerequisites for disclosure and disclosure patterns may also differ due to several different aspects that will be presented further on.

Disclosure behaviour

Both Swedish^{32 115} and international^{114 126} studies have reported on small proportions of disclosure to the offspring among recipients of sperm or oocytes, regardless of policies and legislations.¹⁰⁰ The Gottlieb study in 1998³² was initiated by the National Board of Health and Welfare in Sweden to evaluate the outcome of the Swedish legislation. The study included 148 sperm donation families with children at age 1–15 years born between 1985 and 1997. It revealed that 89% of the couples had not told their offspring about the donation; while 41% intended to do so at a later time, 19% did not intend to disclose any information about the donation to the offspring. A follow-up study of the Gottlieb study was conducted in 2004.¹⁰⁷ Results from the semi-structured telephone interviews with 19 couples reported an increase in disclosure with 61% having told the offspring; however, 17% still intended not to disclose anything to the offspring.¹⁰⁷ The Swedish fertility clinics have reported that only 20 offspring have searched for information about the donor since legislation was implemented, although more than 500 offspring born after identity-release donations have reached the age of 18 (personal communication with G. Sydsjö 02-10-2015 and K. Wånggren 06-10-2015). This may indicate that a large number of offspring are not aware of their genetic origin.

The prerequisites for disclosure to offspring differ depending on the circumstances of the donation. A systematic review revealed that lack of donor information made parents worry about the child's development if told about the donor conception without the ability to get additional information about the donor.¹⁰⁰ It has been suggested that the more information recipient

couples have about the donor, the more they are inclined to disclose information about the donor conception to their offspring.¹¹⁰ When given a choice of an anonymous or identifiable donor, prospective parents in the Netherlands who preferred an identifiable donor were more in favour of disclosure than those who preferred an anonymous donor.¹¹³ Known donation is more common among oocyte donation than sperm donation; in fact, experiences from known sperm donation are reported in only one study from New Zealand.¹²⁷ It has been assumed that disclosure rates would be higher among recipients with known donors than with anonymous donors.¹²⁸ This has been seen in one US study,¹²⁹ while comparisons of other studies with oocyte recipients using known vs anonymous donors have not revealed any differences regarding the disclosure intention.¹⁰⁰

A review of research from the 1980s through the early 2000s revealed that, in general, oocyte recipient couples were more in favour of openness (26–70%) than sperm recipient couples (10–30%).⁷⁸ A US study among oocyte recipient couples demonstrated that even if 71% had chosen anonymous donation, the majority had disclosed or intended to disclose to their offspring.¹¹⁶ However, this study had a response rate of only 31% and the reliability is therefore limited. Criticisms have been raised about the lack of longitudinal studies.¹⁰⁰ Almost all published studies have been based on a cross-sectional design despite the knowledge that the disclosure decision process might change over time.¹⁰⁰

The academic vocabulary around disclosure about the gamete donation has changed in recent years. Earlier disclosure was presented in terms of secrecy or openness as a dichotomous either/or,³³ while the reality for couples undergoing gamete donation has been seen to be more complex. Research has revealed that couples, for example, tell their closest family members about their donation treatment, but only talk about getting help with ART to friends and more distant contacts; in other instances, parents talk about the donation with their family, but not with their offspring.^{105 107 114}¹¹⁶ This has lately been described as ‘layers of disclosure’³¹ or ‘selective disclosure’.¹³⁰ It has also been suggested that looking at disclosure as an issue of opposites with either ‘privacy’ or ‘disclosure’ should be replaced by the terms ‘information sharing’ or ‘information exchange’.¹³¹ As a result of information sharing, the story about how the family was built is shared rather than the story about how the offspring was conceived. This is an including way of recognising the child as a part of the family rather than of excluding and separating the conception of the offspring from the family building.¹³²

Research within the psychosocial field of gamete donation has been criticised for being methodologically inconsistent, incompletely presented⁷⁸ and lacking a theoretical framework.^{78 100} A model that could be used as an explanatory theoretical model serving as a basis for understanding the different aspects related to the disclosure decision and disclosure process among parents following donation treatment is the theory of planned

behaviour (TPB).¹³³ The TPB has been successfully used for predicting health-related behaviours. The TPB suggests that specific behaviours are strongly influenced by the intention to perform that behaviour and that behavioural intentions are predicted based on attitudes, subjective norms and perceived control.¹³³ Hence, according to the TPB, parents' intentions to disclose information about the donation to offspring are influenced by their attitudes towards disclosure, social pressure to disclose and impeding or facilitating factors regarding disclosure.

To sum up, the disclosure decision is an autonomous decision to be made by the parents. Despite guidelines supporting openness, research within the field of gamete donation has revealed relatively small proportions of disclosure among parents following donor conception. Oocyte recipient parents tend to be more inclined to share information with their child than sperm recipient parents. However, there is a lack of longitudinal studies related to disclosure to offspring.

Rationale for the thesis

Involuntary childlessness affects large groups of individuals and has led to an increased demand for ART with donated sperm or oocytes. Having a child through donor conception means that one of the parents will lack a genetic link to the child. In 1985, Sweden was the first country to legalise that donor offspring have the right to obtain identifying information about the donor once they reach a mature age. However, in order for the child to execute that right, the child must be informed about his/her conception. No information about the gamete donation is visible in the child's birth certificate or official medical records. Consequently, the child's only possibility of finding out about his/her genetic origin is if the parents (or someone else) reveal it to him/her or if it becomes obvious in connection with specific medical conditions or genetic tests. Previous research, however, has revealed that irrespective of identity-release legislation or not, a significant share of parents following gamete donation treatment does not inform or intend to inform the offspring about his/her conception.

Despite the fact that an increasing number of couples use treatment with oocyte donation and sperm donation, there is limited knowledge regarding the consequences of these treatments in a programme using identifiable donors. There is also a lack of longitudinal studies with representative samples of recipients as well as donors of oocytes and sperm.

The ambition of the present thesis is to gain enhanced knowledge about Swedish heterosexual gamete recipient couples and donors under the legislation on identity-release donations with a specific focus on disclosure to offspring. Knowledge about how donor conception within an identity-release donor programme is perceived is of great interest in order to be able

to develop and improve the health care of the persons concerned. This might contribute to an avoidance of potential negative consequences of gamete donation treatment for donors, recipients and the offspring.

Aim

The overall aim was to investigate information sharing with offspring among heterosexual couples following identity-release gamete donation. A further aim was to study donors' attitudes towards future contact with donation offspring.

Study I

The aim was to investigate heterosexual recipient couples' attitudes towards disclosure to offspring and towards genetic parenthood, disclosure behaviour to others and perceived need of information and support regarding parenthood after donation.

Study II

The main aim was to investigate disclosure behaviour and intentions for disclosure among heterosexual parents of children aged 1–4 years following gamete donation. An additional aim was to study the association between agreement on disclosure to offspring and relationship satisfaction within the couple.

Study III

The aim was to explore how heterosexual parents with school-aged children reason about and experience information sharing with offspring following identity-release sperm donation.

Study IV

The aim was to investigate 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 towards contact with an offspring and, on the other hand, their sociodemographic characteristics and pre-donation ambivalence.

Methods

Design

The studies in the present thesis are a part of the Swedish Study on Gamete Donation, which is a prospective, longitudinal study of donors and recipients of donated oocytes and sperm. An overview of the included studies is presented in Table 1.

Table 1.

Study design	Data collection	Study sample	Analyses
I. Cross-sectional	Questionnaire	564 recipients	Chi ² test Mann-Whitney <i>U</i> -test Kruskal-Wallis test
II. Cross-sectional	Questionnaire	229 parents	Chi ² test Mann-Whitney <i>U</i> -test Independent samples <i>t</i> -test
III. Explorative	Interview	30 parents	Qualitative content analysis
IV. Longitudinal	Questionnaire	210 donors	Chi ² test Fisher's exact test Independent samples <i>t</i> -test Mann-Whitney <i>U</i> -test Kruskal-Wallis test

The Swedish Study on Gamete Donation

The Swedish Study on Gamete Donation is a multicentre study that includes all fertility clinics performing gamete donation in Sweden; the university hospitals in Malmö, Gothenburg, Linköping, Örebro, Stockholm, Uppsala and at the IVF clinic in Umeå in collaboration with the university hospital in Umeå. The study sample consists of donors and recipients (both heterosexual and lesbian couples) of donated oocytes and sperm, and includes two comparison groups: couples undergoing standard IVF treatment (with their own gametes) and couples with a spontaneous pregnancy. In the present thesis, data only from donors and heterosexual recipients of donated oocytes and sperm are included. During 2005–2008, all couples that started treatment

with donated oocytes or sperm and all women and men who were accepted as donors of oocytes or sperm were approached at the fertility clinics regarding study participation. A general exclusion criterion was not speaking and/or reading Swedish. Recipient couples were required to have completed at least one round of donation treatment (i.e. insemination or transferral of ≥ 1 fertilised oocyte) and donors should have completed donation of oocytes or sperm. Recipients individually completed the following four questionnaires: in connection with treatment start (RT1), two months after treatment (RT2), 2–5 years after treatment (RT3) and 10 years after treatment, or for those who had given birth to a child following donation treatment, when the child was 7 years old (RT4). Recipients are also included in further planned quantitative and qualitative follow-up assessments. Donors completed the questionnaires once they had been accepted in the donor programme (DT1), two months after the donation (DT2), one year after the donation (DT3) and 5–8 years after the donation (DT4).

Participants and data collection

Study I

Participants in study I were heterosexual recipients of donated oocytes or sperm. All heterosexual couples who started treatment with donated oocytes or sperm from April 2005 to April 2008 were approached at the fertility clinics for study participation and were asked to individually complete two questionnaires. The first questionnaire was handed out at the clinic in connection with treatment start (RT1) and the second questionnaire was distributed by mail two months after the first treatment (RT2) to those who had completed the first questionnaire. Both questionnaires were distributed with a prepaid return envelope and a cover letter stating the purpose of the study and guarantee of confidentiality. Non-responders received two reminders and participation was rewarded with a gift voucher (worth 10 EUR).

Of 430 eligible individuals (215 couples) starting treatment with donated oocytes, 309 individuals (152 couples and 5 individuals) completed the first questionnaire (RT1) (72%). Among these individuals, 212 also completed the second questionnaire (RT2) (69%).

Of 316 eligible individuals (158 couples) starting treatment with donated sperm, 255 individuals (127 couples and 1 individual) completed the first questionnaire (RT1) (81%). Among these individuals, 215 completed the second questionnaire (RT2) (84%). A flowchart is presented in Figure 1.

Study II

The eligible sample in study II comprised all recipient women and men within heterosexual couples who had participated at inclusion (RT1) and who had given birth to a child following treatment with donated oocytes or sperm. Data collection was performed during 2007–2011 when the offspring was 1–4 years old (RT3). The distribution procedure was identical to that which was described for RT2 in study I. Couples who had conceived with oocytes or sperm from a donor who was known to them (e.g. a sister) were excluded.

At RT3, 147 women and men (73 couples and 1 individual) had given birth to a child following oocyte donation. Of these, 107 individuals (52 couples and 3 individuals) participated (73%). Of the 174 women and men (87 couples) who had conceived a child via sperm donation, 122 individuals (59 couples and 4 individuals) participated (70%). Due to administrative failure, one individual was not contacted. A flowchart is presented in Figure 1.

Study III

Parents (following sperm donation) participating in the Swedish Study on Gamete Donation were during February 2014 until March 2015, after participating in RT4, receiving an invitation letter for participation in an individual interview. A total of 51 parents were invited and 30 parents (19 women and 11 men), representing recipients from all fertility clinics in Sweden performing gamete donation, agreed to participate and signed a consent form. The interviews were undertaken at a time chosen by the informant. Since the informants were spread across the country, interviews were performed either face to face or through telephone interviews. The informants included nine couples cohabiting with their donor offspring and twelve parents (10 women and 2 men), in cases where only one parent agreed to participate. Five of the informants had separated from the other parent of the donor offspring and three of these lived in new relationships. The interviews lasted between 40 and 120 min.

Study IV

Participants in study IV were donors of oocytes or sperm and the study included data from the first donor assessment (DT1) and the fourth donor assessment (DT4). The recruitment of participants was performed as in study I.

Of 217 eligible women and 150 men approached, 181 (83%) women and 118 (79%) men agreed to participate in the study and completed the baseline assessment (DT1) prior to their donation. Of these, 30 women and 5 men reported donating to a known/specific couple and were therefore excluded from the present study. This resulted in a total of 151 women and 113 men

participating at DT1. The fourth assessment (DT4) was completed by 126 women (83% of participants at DT1) and 84 men (74% of participants at DT1).

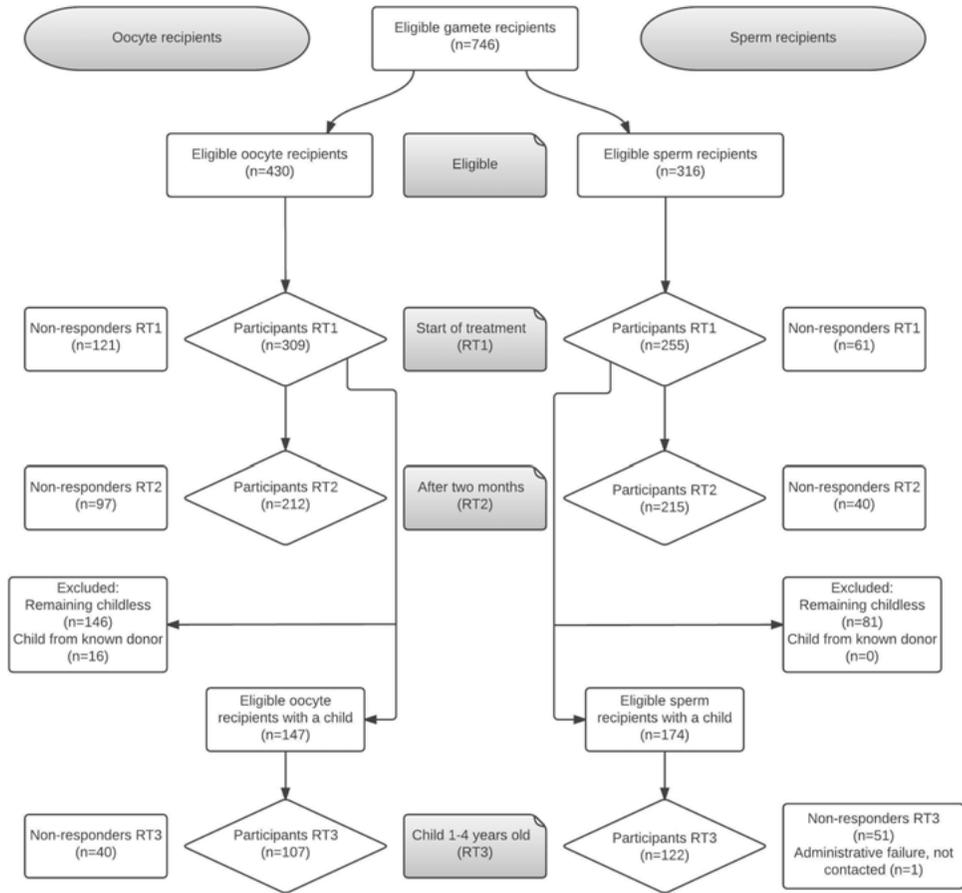


Figure 1. Flowchart of oocyte and sperm recipients participating in study I and II.

Measurements

Study I and II

The measurements used in studies I and II include a validated instrument for assessment of relationship satisfaction, two attitude scales developed for a previous study³⁰ and study-specific measurements for assessments of behaviour, behavioural intentions and perceived needs/desires and reactions. The study-specific items were developed by a multi-professional group of researchers/clinicians based on previous research and clinical experience and were pilot tested by recipient couples not included in the SSGD.

Participant characteristics regarding age, education and use of anonymous/known donor were self-reported at RT1 and current partner status was self-reported at RT3. Clinical data regarding the time of birth of the donor-conceived children were obtained from the fertility clinics.

Instruments

Study I

Attitude towards the importance of genetic parenthood (RT1)

Attitude towards the importance of genetic parenthood³⁰ is an instrument based on four items. Two items concern the importance of a genetic link between father/mother and child and the other two items concern the perceived importance of physical and behavioural resemblance. Responses are given on a five-point Likert scale from 'totally disagree' to 'totally agree' and the additional option 'cannot form an opinion'. The instrument was developed, pilot tested and validated by the research group in a previous study.³⁰ A satisfactory internal validity was found in the present study with a Cronbach's alpha value of 0.83.

Attitude towards disclosure to offspring (RT2)

Attitude towards disclosure to offspring^{30 134 135} is an instrument based on six items concerning whether or not the donation should be kept a secret and the potential impact of disclosure on family relationships. Responses are given on a five-point Likert scale from 'totally disagree' to 'totally agree' and the additional option 'cannot form an opinion'. The instrument was developed, pilot tested and validated by the research group in a previous study.³⁰ A satisfactory internal validity was found in the present study with a Cronbach's alpha value of 0.77.

Openness to others (RT2)

Openness to others was a study-specific instrument assessing whether or not the participant had told different groups of individuals (e.g. their own

parents, siblings and friends/acquaintances) about the donation treatment. This instrument also assessed the predominant reaction from these groups (positive, negative or neutral).

Need/desire for information about parenthood following donation (RT2)

Two study-specific questions asked whether the participant had received information about being a parent following oocyte/sperm donation. The first question was as follows: ‘Did you receive information about being a parent following oocyte/sperm donation?’ There were three response alternatives (Yes, all the information that I need; Yes but not enough; No). The second question was as follows: ‘Would you like additional information or support regarding the future parenthood?’ There were three response alternatives (Yes; No; Unsure).

Study II

Disclosure to offspring (RT3)

Participants were asked between two and four study-specific questions with an open-response format on disclosure to offspring, depending on the stage in the disclosure process. Participants who had already started the disclosure process were asked (a) at what age they had started talking about the donation with their child; (b) how they talk about the donation (e.g. in what situations, alone or with partner and/or with the help of any tool, e.g. a book) and (c) what they say about the donation (e.g. about the treatment, what they know about the donor and/or the child’s possibility to receive information about the identity of the donor). Participants who intended to tell the child about the donation when he/she was older were asked the same questions as above but formulated in the future tense. Participants who were undecided or planned not to tell their child about the donation were asked what they planned to tell their child about the conception (e.g. receiving help from the hospital). One final question assessed whether the participant and his/her partner agreed on what to tell the offspring about the conception.

Need/desire for information on disclosure to offspring (RT3)

One study-specific question concerned whether the participant would like more information on disclosure to offspring: ‘Would you like more information about telling children conceived through donation treatment about their conception?’ There were three response alternatives (Yes; No; Don’t know). In addition, participants were given the option to elaborate on what type of information they desired.

Relationship satisfaction (RT3)

Relationship satisfaction was measured using the Evaluating and Nurturing Relationship Issues, Communication and Happiness (ENRICH) scale,¹³⁶ with

a Swedish version found to have satisfactory validity and reliability.¹³⁷ Perceptions of partner relationship are assessed in 10 subscales comprising 10 items each. The subscales are personality issues, communication, conflict resolution, financial management, leisure activities, sexual relationship, children and parenting, family and friends, egalitarian roles and conception of life. There are five response alternatives for each item ranging from 'in total agreement' to 'do not agree at all'. Each subscale can vary between 10 and 50 points and the total ENRICH score can vary between 100 and 500 points, with high scores indicating high satisfaction with partner relationship.

Disclosure to others (RT3)

Disclosure to others was assessed using five items with two items concerning whether participants had talked to others beyond their partner about their problems with conceiving children and infertility treatments used (adapted from Schmidt et al.¹³⁸). In the other three items with an open-response format respondents were asked (a) how people reacted when they were told about the donation treatment; (b) if the respondent had a wish to tell more people about the donation treatment, and if so, to whom; and (c) if the respondent regretted telling somebody about the donation treatment, and if so, to whom.

Study III

An interview guide was developed by the research team which included the following topics: the treatment, talking with the child and others, the donor, genetic link and resemblance, parenthood after gamete donation and support from the fertility clinic. The interviews were semi-structured. When necessary, the informant was asked for clarifications or follow-up questions, including the following: 'Can you give an example?', 'What do you mean?' or 'Tell me more'. The interview guide was not pilot tested, but after the first interviews, minor changes in the interview guide were made. For this study, only data regarding information sharing with the child was analysed.

Study IV

Donor characteristics concerning biological children, educational level, partner status and knowledge of the outcome of the donation were collected at DT4; age at DT4 was calculated based on the baseline data (DT1).

Instruments

Attitudes regarding future contact with a donation offspring (DT4)

Attitudes regarding future contact with a donation offspring were assessed with two study-specific items developed by the research group and pilot

tested among oocyte and sperm donors not included in the study. The items concerned whether the participant was positive about being contacted by an offspring and their attitudes towards meeting an offspring from their donation. Participants were requested to indicate their responses on a 5-point Likert scale from 'Totally agree' to 'Totally disagree' and the additional option 'Cannot form an opinion.' In addition, participants were given the opportunity to elaborate on their answers.

Preferences regarding future contact with a donation offspring (DT4)

Preferences regarding future contact with a donation offspring were assessed with six study-specific items developed by the research group and pilot tested among oocyte and sperm donors not included in the study. Three items concerned the preferences regarding where to meet an offspring and one item concerned the attitude towards the offspring meeting the donor's own family. The response format was identical to that described above. Two items concerned whether they wanted to be notified by the clinic when an offspring searched for information about them (before vs after identifying information had been released to the offspring). Responses to these statements were described as positive, neutral or negative attitude towards receiving information about an offspring searching for their identity, regardless of timing. Here as well, the participants were given the opportunity to elaborate on their answers.

Need for counselling (DT4)

Need for counselling included one item concerning whether the participant wanted counselling regarding future contact with an offspring. The response format was identical to that described above.

Ambivalence towards donation (DT1)

Ambivalence towards donation was measured with a Swedish version of Klock et al.'s Donor Ambivalence Scale¹³⁹, presented in Skoog Svanberg et al.⁷⁰ Seven multiple-choice items measured mixed feelings about the donation and responses were added into 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 (cf. ⁷⁰).

Data analysis

All statistical analyses were performed using PASW Statistics version 18 or IBM SPSS Statistics version 20 and 22. The level of statistical significance was set to $p < 0.05$ in all analyses.

Study I

Kruskal-Wallis tests were used to analyse differences in attitudes between the four subgroups of female/male and oocyte/sperm recipients and Mann-Whitney *U*-tests were used for post hoc tests for group differences. For analysing differences in proportions between the subgroups, Chi² tests were performed.

Study II

Differences in proportions between the subgroups were measured with Chi² tests. Differences between two independent groups were analysed using independent samples *t*-tests or Mann-Whitney *U*-tests, depending on the level of measurement and distribution. For analyses on the ENRICH scale, data from separated couples or couples where only one half participated were excluded (*n* = 9). Missing values were substituted with the mean of the participant's responses on the subscale (*n* = 15), provided that at least half of the items had been answered; more than half missing values on a subscale resulted in exclusion of the subscale for that participant (*n* = 1). The agreement on disclosure decision within the couple was assessed with a question where participants individually answered to what extent they and their partner agreed on what to tell the child about the conception. Based on these answers, the couples were categorised into the following two groups: couples who both individually reported total agreement on what to tell the child about his/her conception, i.e. 'perfect agreement', and the remaining couples, i.e. 'deficient agreement'. Data collected in an open-response format, e.g. planned timing/age for disclosure to offspring, were manually categorised according to content.

Study III

The interviews were analysed with an inductive approach using qualitative content analysis. This approach involves analysing data where the data itself is used to reach a structure of analysis with no predetermined theory.¹⁴⁰

All interviews were digitally recorded, transcribed verbatim and analysed using latent content analysis, according to Burnard et al.¹⁴⁰ The transcriptions were read several times according to the aim of the study. This was followed by open coding, when what was said in the text was identified and summarized with notes or short phrases. In the next step, the notes or phrases were grouped together into categories with sub-headings according to content. To reduce and refine the number of categories, overlapping and similar categories were grouped together. Through discussions in the research group on the identified categories, a pervasive theme was

elaborated, which provided a deeper understanding of the participants' reasoning and experiences on a more latent level.

Study IV

Comparisons between the female and male donor characteristics were computed with Chi² tests or Fisher's Exact Tests, while comparisons for age were computed with independent samples *t*-tests. Mann-Whitney *U*-tests were used to analyse sex differences in attitudes, preferences and need (based on 1–5 scale scores). The relationship between the independent variables (sociodemographic characteristics and pre-donation ambivalence) and the dependent variable (attitude towards contact with an offspring) was analysed separately for male and female donors, comparing those with low/high levels of ambivalence (with Mann-Whitney *U*-tests) and comparing four groups of donors by age and biological children (≤ 39 /biological children, ≤ 39 /no biological children, >40 /biological children, >40 /no biological children) using Kruskal-Wallis tests.

Ethical considerations

Studies I–IV were approved by the Regional Ethical Review Board in Linköping, Sweden (Dnr M29-05, M29-05/1-06, 2012/356-31, 2014/52-31). The risk and burdens of the approached participants were estimated in relation to the importance of the studies' outcomes in accordance with the World Medical Association (WMA) Declaration of Helsinki.¹⁴¹

All approached participants in studies I–II and IV were given oral and written information about the study prior to inclusion at the fertility clinics and written study information was provided at each subsequent assessment occasion. Participants were also informed that they could withdraw from study participation at any time without giving any reason and that neither participation nor non-participation would have any effect on their treatment or donation. Return of the completed questionnaire was regarded as providing informed consent.

Regarding study III, all informants were given written and oral information about the study and signed an informed consent form prior to the interview. Parents were informed that participation was voluntary, that they were guaranteed confidentiality and that they could withdraw from the study whenever they wished without giving a reason. Permission to record the interview was obtained before each interview and the interviews were performed in an emphatic and non-judgmental manner. One aspect of performing interviews on issues related to informants' infertility is that the interview may bring them into a situation where emotional reactions can arise since infertility most often is connected to a range of different

emotions. However, emotional reactions are not necessarily negative. During some interviews the informant shared information or memories that made them feel emotional. They were then asked whether they wanted to continue the interview or not. After each interview, informants were given a chance to reflect over the interview and how it made them feel. Informants were also encouraged to make contact if they had any concerns and were given the e-mail addresses and telephone numbers of the researchers.

Results

Study I

Study I reported results from participants at treatment start and two months after treatment. A large majority of participants stated that parents should be honest with their child regarding his/her genetic origin (90%, $n = 350$) and that the child has the right to know that he/she was conceived by gamete donation (91%, $n = 354$). About half (56%, $n = 218$) regarded it to be in the best interest of the child to be able to know the identity of the donor as an adult. A minority (7%, $n = 29$) regarded contact with the donor as potentially harmful for the child or family, and 37% ($n = 144$) could not form an opinion on this issue. Responses from the men regarding future contact with the donor were more neutral and less favourable than those from the women ($p = 0.006$).

The majority (94%, $n = 393$) had told someone else about the donation treatment, with oocyte recipient women being the most open ($p < 0.000$), i.e. 84% ($n = 92$) telling family as well as friends/others about the treatment. Most participants (74%, $n = 313$) reported having received all the information needed about what it means being a parent after sperm/oocyte donation. Despite this, 35% ($n = 149$) would like more information or support concerning the future parenthood. Among sperm recipients, significantly more women (40%) than men (26%) wanted additional information/support ($p = 0.028$).

In total, less than a third of participants regarded the genetic link between the mother and child (27%) or the father and child (24%) to be of importance. Men placed significantly more importance on the genetic link between parent and child than did women regardless of type of donation ($p = 0.002$). When comparing male recipients of donated oocytes and sperm, sperm recipient men placed less importance on the genetic link between father and child and more importance on behavioural resemblance ($p = 0.034$). When comparing female recipients of donated oocytes and sperm, oocyte recipients regarded physical resemblance of their child less important ($p = 0.045$).

Study II

Study II revealed results from parents with a child aged 1–4 years old. A total of 78% (n = 167) of the parents reported planning to talk to their child about the donation and 16% (n = 35) had already started talking about the donation with their child. Participants could specify at what age they had started or planned to start to talk to their child about the donation (see Figure 2 for details). A total of 6% (n = 13) reported not planning to talk or were undecided about whether or not to talk to their child about the donation. As Figure 2 shows, the majority of the parents planning for disclosure at a certain age planned to start talking to the child when the child reached 2–6 years of age. However, there was a large variation in parents' plans regarding the age of offspring at disclosure (2–20 years). Half of the parents planning for disclosure did not specify a certain age for disclosure and reported being unsure about the time of disclosure or planned to start the information sharing when the child understands or starts asking about reproductive matters. No differences in disclosure behaviour or intention were seen with regard to participant sex or type of treatment.

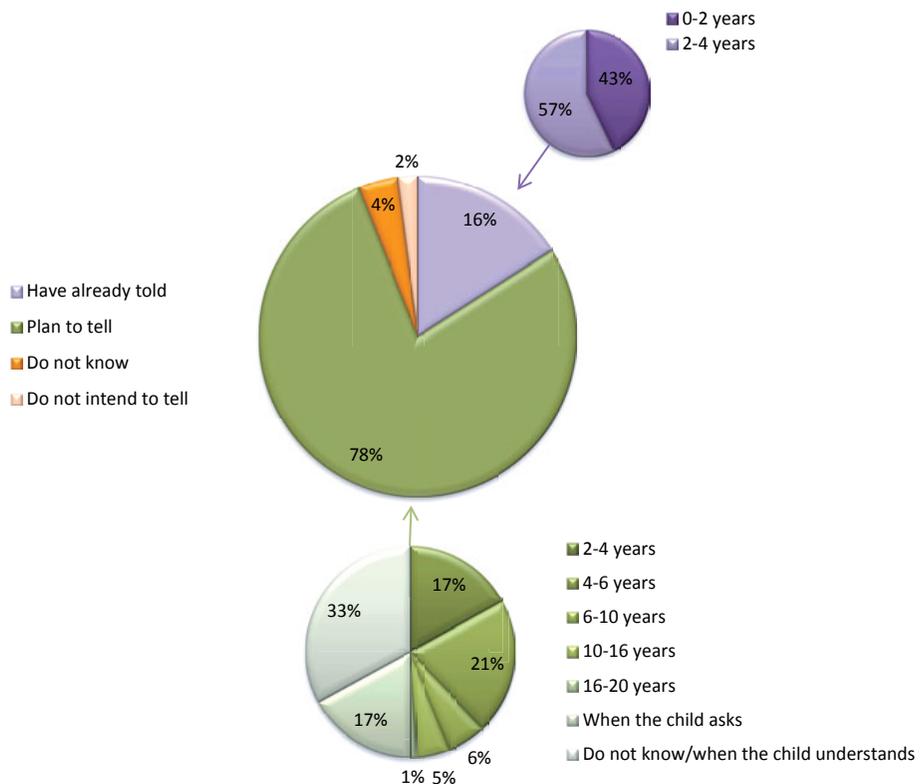


Figure 2. Disclosure to the child among parents following gamete donation

More women (59%, $n = 64$) than men (26%, $n = 25$), irrespective of type of donation, had a desire for more information about how to talk to their child about the conception ($\chi^2 = 24.87$, $p < 0.001$). Most participants had talked to other persons besides their partner about the fact that they could not have children (90%) and about their infertility treatment, including the donation treatment (84%). No differences were seen with regard to participant sex or type of treatment.

Regarding agreement on the disclosure decision, there were 92 couples where both parts had answered the question. Of these, 29 couples (32%) demonstrated deficient agreement and displayed lower scores on the relationship quality for the ENRICH total score ($p = 0.025$) and for the subscales communication ($p = 0.017$), conflict resolution ($p = 0.001$) and family and friends ($p = 0.003$) than did the participants in the 'perfect agreement' group.

Study III

Study III revealed results from interviews with parents following sperm donation when the child was 7–8 years old. One main theme was seen: *Information sharing is a process* with three sub-themes: *The parent as process manager*, *The child as force or friction* and *Being in the process*. The first two sub-themes include categories that describe driving or impeding forces on the information-sharing process.

The process of information sharing with a child about his or her conception deals with the fact that information sharing is not limited to one single occasion of disclosure when everything is revealed. In the present study four different levels in the process were seen, with the levels containing varying types of information: (1) the story of how babies are made; (2) that the parents needed help at the hospital; (3) that the parents got help from a sperm donor and (4) that the child will be able to obtain information about the donor when older. Most parents had started the information-sharing process but were on different levels in the process.

The two sub-themes *The parent as process manager* and *The child as force or friction* described how the information-sharing process is not about the parent *giving* information *to* the child but about the parent *sharing* information *with* the child. The driving forces within the process were the notion that the child had the right to know and that there would never be a better opportunity to start the process than talking with the child from the outset. The process is illustrated in Figure 3. Telling friends and family in their immediate environment was also a strategy that often appeared to act as a driving force for the information-sharing process. An impeding force for parents to move forward in the process was the notion that the child had to be mature enough to understand all the different aspects of the conception.

Also, the sense of losing control when talking with the child about his/her conception served as an impeding force for the process. The child's reaction to the information was perceived as either driving or impeding the information-sharing process. Neutral or curious reactions encouraged the parent to move forward with more information, while non-interest made the parent feel unsecure about how to move forward and bring up the topic again.

The last sub-theme, *Being in the process*, described how parents deal with different emotions and thoughts while in the process concerning how they have built their family and the consequences this might have. This included thoughts about the future and how to deal with the existence of a donor.

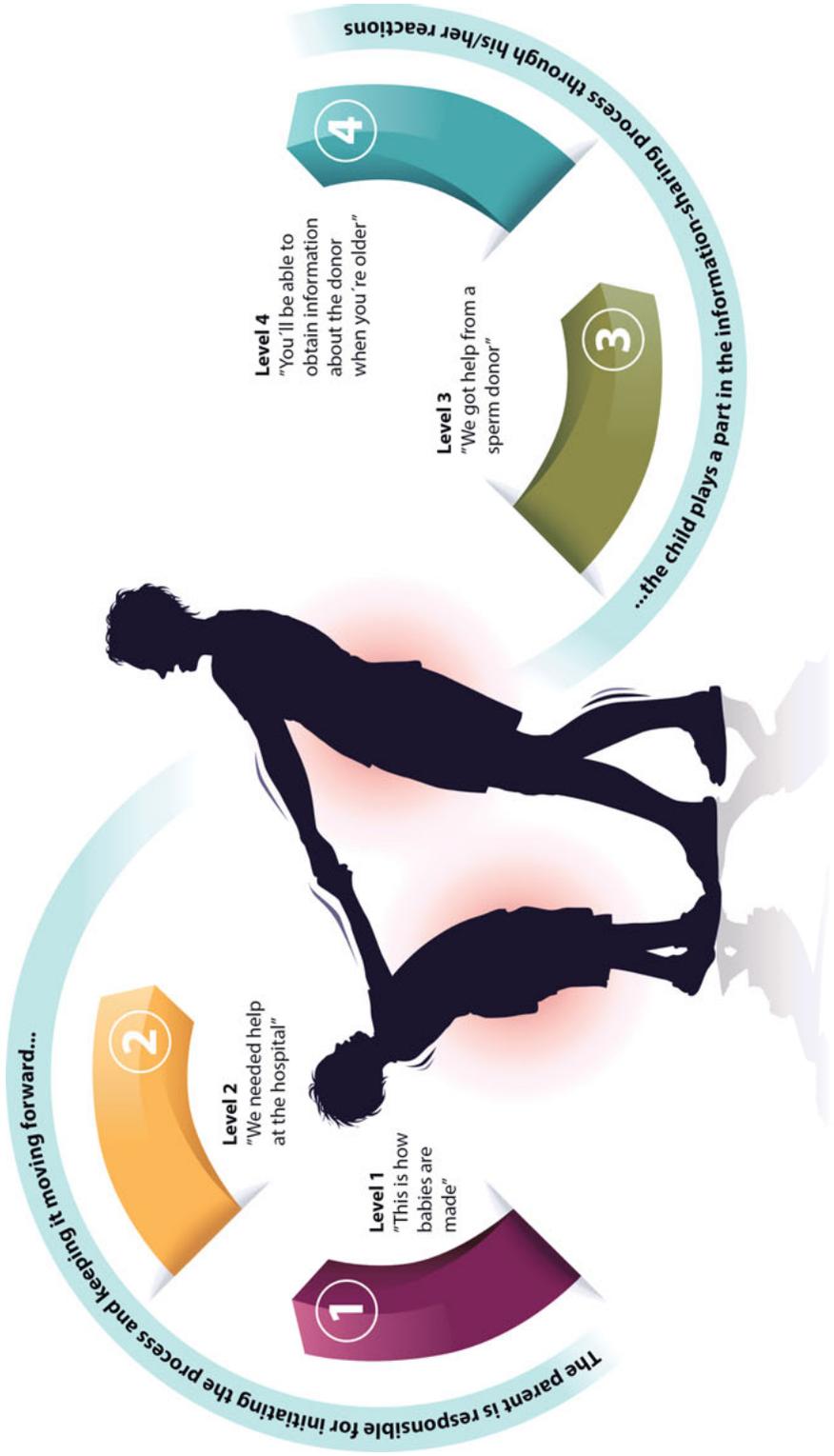


Figure 3. Illustration of the information-sharing process between parent and child.

Study IV

Study IV reported data from donors 5–8 years after donation. A majority of the women and men were positive (67%) or neutral (16%) towards being contacted by an offspring after 18 years; 10% were negative towards future contact. Few donors (4%, $n = 8$) reported not wanting to meet a child conceived from their donation. Several donors wrote in open comments that they had the best interest of the child in mind and wanted to support the child's wishes in case of a meeting. 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 towards being contacted by an offspring was not related to donor sex. Among oocyte donors, there was no difference between those with high and low levels of ambivalence ($p = 0.593$) nor between young/old donors with/without biological children ($p = 0.173$). Correspondingly, sperm donors' attitude towards being contacted by offspring was not related to level of pre-donation ambivalence ($p = 0.389$) nor with age and biological children ($p = 0.065$).

The majority of the donors (57%) reported that they wanted to receive information that a donation offspring was searching for information about them, while 29% did not want to receive such information. In total, 14% of the donors were neutral or could not form an opinion about this. No differences were seen between the female and male donors.

A few of the donors wanted a potential meeting with the offspring to take place at the fertility clinic (11%, $n = 22$) or in the donor's home (15%, $n = 31$), but most preferred a meeting at a neutral place, e.g. a café (35%, $n = 74$). More than half of the donors were also positive towards the possibility of an offspring meeting the donor's family, e.g. their own children (62%, $n = 129$).

Discussion

Summary of findings

In summary, the findings revealed that men and women undergoing fertility treatment with donated gametes in Sweden were open about their treatment with the people around them and supported disclosure to offspring regarding his/her genetic origin (study I). Those who became parents following gamete donation intended to share information about the donation with their offspring and some had already started the information-sharing process with their young child (1–4 years) (study II). Information sharing with the offspring was seen to be a process that involves several levels, revealing various amount of information about the way of conception. The parent was seen to be the owner of the process and the one moving the process forward with different aspects and the reactions of the offspring as driving or impeding forces of the process (study III). Swedish gamete donors were seen to have a positive attitude towards a future meeting with a donation offspring, but appeared to have different preferences for information and support regarding such a contact (study IV).

Discussion of the main findings

A trend towards more openness

This thesis revealed that recipients of donated gametes in Sweden support honesty and openness towards the offspring (study I and II). Most parents had the intention to share information about the donor conception with their child and some had already started the information-sharing process when the child was at age 1–4 years (study II). The informants in study III also expressed the wish to be honest with their offspring. In relation to previous results from Sweden,^{32 107} this must be seen as a trend towards more openness about the way of building the family. The results indicate that one of the main goals of the Swedish legislation, i.e. recognising the child's right to information about his/her genetic origin, has been reached to a certain extent. The legislation on identity-release donors not only presumes openness, it also puts a great emphasis on the child's best interest growing

up in a family built on honest relationships. The present findings are supported by recent studies from other countries with similar legislations which also have indicated a shift towards more openness regarding information sharing with offspring.^{31 112 142} From an international perspective, even if legislations differ between countries, the guidelines support openness and honesty in that the child has a right to all available information about the donor and donation.^{123 124} However, when conceived by anonymous donation, a limited amount of information can be revealed to a donor offspring in contrast to the information available for offspring conceived under the Swedish identity-release legislation.

An intention to share information

A large majority of participants with children aged 1–4 years reported an intention to share information about the donor conception with their offspring (study II). In a UK study by Golombok et al.,⁸⁶ when the donation offspring was one year old, 46% of sperm donation parents and 56% of oocyte donation parents reported an intention to share information about the donor conception with their child. A follow-up at age 7 revealed that only 28% and 41% of all parents respectively had disclosed the donor conception to their child, and 19% and 31% respectively had not gone any farther than the intention to tell.³¹ This might be supported by the findings from study III, i.e. that information sharing with donation offspring is not necessarily easy to carry out despite the parents' firm intentions to do so. The two previous Swedish studies on sperm donation^{32 107} reported data from two fertility clinics in Sweden. These studies revealed that 41% of parents following sperm donation intended to tell their child about the mode of conception at the time of the first study.³² At the follow-up 6 years later, 27% of participants in favour of disclosure still had not gone any farther than the intention to tell.¹⁰⁷ Up until now, more than 500 offspring following sperm donation in Sweden have reached the mature age that gives them the right to identifying information about the donor. However, only 20 offspring have contacted the fertility clinics in order to request identifying information about their donor (personal communication with G. Sydsjö 02-10-2015 and K. Wångren 06-10-2015). This might on the one hand be a result of offspring being aware of their donor conception but not feeling any need for identifying information about the donor. On the other hand, it might indicate that a considerable share of donor offspring is not aware of their donor conception and hence are not able to seek identifying information.

The information-sharing process

Study III indicated that information sharing with donor offspring is a process and highlighted the complex interplay within the information-sharing

process between parent and child. Parents reflected how depending on his/her reactions, the child either drives the process forward or impedes the process from moving forward to the next level in which more information is revealed about the child's genetic origin. In their study conducted in the UK, Readings et al.³¹ discussed layers of disclosure possible with parents engaging in different levels of openness with different people. This UK study suggested that parents engage in partial disclosure since IVF might be easier to talk about compared to the issue of genetic relatedness. Telling the child about the IVF may be a way for parents to avoid full disclosure.³¹ Readings et al. also suggested that these layers of disclosure were performed with the child's maturity and understanding taken into consideration, but they were also affected by the parent's own comfort or discomfort in discussing the subject.³¹ Similar findings were found in the present thesis where a considerable share of parents with the intention to share information about the donor conception with their offspring planned to do so when the child was mature enough and ready for the information (study II). Information sharing customised to the child's level of understanding may on the one hand indicate sensitivity to the child's maturity and understanding. However, this might on the other hand lead to a risk of postponing sharing the information about the use of a donor and the child's right to information about the donor. The longer information sharing is postponed, the more difficult it has been reported to find the right time for sharing information with offspring.⁹⁶

Men and the importance of a genetic link

Male recipients of donated gametes were found to place more importance on the genetic link between parent and child than women (study I). In addition, men were more neutral and less favourable regarding a future contact with the donor, which could support the notion that genes are more important for men than for women, i.e. that a subsequent contact could be perceived as more intrusive by men than by women. However, the sperm recipient men placed less importance on the genetic link between father and child and more importance on the resemblance in terms of behaviour between father and child (study I). This leads to the suggestion that when facing infertility, men adapt to what is accessible for them as a way of coping. A similar result was also presented in Belgian pre-treatment groups of gamete recipients, where the recipients focussed on 'passing on things' through education rather than through genes.¹⁴³

Couple agreement and need for support

Couples who were not in perfect agreement on the disclosure decision reported lower satisfaction with several aspects of their partner relationship

than the couples who were in perfect agreement about disclosure (study II). Communication has been shown to be an important factor within healthy and well-functioning relationships.¹⁴⁴ Here, the pre-treatment counselling within the fertility clinics plays an important role in encouraging the couple not only to talk with their prospective child, but also to communicate with each other. Several recipients reported a need for more information and support regarding parenthood following donor conception as well as strategies and tools for information sharing (study I and II). This indicates that the needs of the parents are specific and vary on an individual basis. It also highlights the important work done by the fertility clinics to identify and address the different needs of gamete recipients by providing individually designed counselling in order to meet these different needs.

Contact between donor and offspring

Research on subsequent contact between donor and offspring or donation parents is scarce and mostly relies on experiences from donation networks, such as The Donor Sibling Registry (DSR). These are self-selected samples representing specific interest groups with experiences predominantly from sperm donation.^{121 145 146} The key motivation for searching for the donor has been identified to be curiosity about the donor.¹⁴⁷ In the present thesis, offspring were still too young to have the possibility to seek for the donor's identity and make a subsequent contact with the donor. However, recipients (study III) as well as donors (study IV) highlighted that a potential identification of and meeting with the donor has to be made according to the offspring's wishes. One main aspect of the ethical reasoning that served as an important ground for the establishment of the Swedish legislation in 1985 was the notion that gamete donation should be performed prioritising the best interest of the child.¹³ The findings from study III and IV point out that this notion remains significant among recipients as well as among donors, which is reassuring.

The participants in the studies within this thesis were at least 10 years away from a potential contact between donor the offspring and the donor and thus this potential contact was seen to be rather abstract (study III). Nevertheless, parents had thoughts about the donor and about a potential contact with the donor (study III). A contact between the donor offspring and the donor is not solely a meeting between two people. It involves several other people as well, some of whom will likely have been involved in the decision to donate; however, some people who had no chance of impact on the decision may also be involved, e.g. a new partner of the donor or the donor's own children. Daniels et al.⁶⁸ have discussed the contact and relationship with the donor's own family to be the major challenge in a contact between the donor offspring and the donor. Within the Swedish

context, the experiences of a meeting between the donor and the offspring still remain to be investigated.

The majority of the donors were positive (67%) or neutral (16%) towards being contacted by an offspring after 18 years (study IV). The Swedish legislation gives the offspring the right to information, while the donor is given no right other than information (if wanted) about whether or not the donation resulted in any children. Gamete donors in Sweden must take into consideration a potential contact several years ahead when donating oocytes or sperm. Findings from a previous study from the late 1990s on Swedish sperm donors revealed that 44% of donors believed that they should have the right to remain anonymous.¹⁴⁸ The findings from this thesis indicate that Swedish gamete donors who donated between 2005 and 2008 are well aware of the circumstances under which they chose to donate. This is also underlined by the fact that the attitude towards contact with offspring was not related to donors' sex, age, own biological children or their pre-donation ambivalence (study IV). Interestingly, findings from another recent study on donors within the SSGD revealed that sperm donors reported a higher level of involvement with potential donor offspring compared with oocyte donors.¹⁴⁹ Oocyte donation is a far more intrusive and effortful procedure than sperm donation, which could lead to the assumption that women would feel a higher level of involvement in the donor offspring. One possible explanation for this finding could be that men in general have been seen to place more importance on the genetic link than women.³⁰

The applicability of results to a theoretical framework

As acknowledged in the introduction section, research within the psychosocial field of gamete donation has been criticised for being methodologically inconsistent, incompletely presented⁷⁸ and lacking a theoretical framework.^{78 100} According to the theory of planned behaviour (TPB)¹³³, parents' intentions to share information about the donation with offspring are influenced by their attitudes towards disclosure, social pressure to disclose and impeding or facilitating factors regarding disclosure. The intention for disclosure was highly prevalent and the studies within this thesis partly managed to address the factors within the TPB. The attitudes towards disclosure were addressed in study I, revealing positive attitudes among the gamete recipients. The social pressure regarding disclosure or non-disclosure was not measured. However, the pre-treatment counselling provided by the fertility clinics which provide information on the offspring's legal rights and encourage information sharing can be seen as a form of pressure from the society. Hence it can be assumed that parents following gamete donation treatment in Sweden may feel social pressure for disclosure, but this needs to be further examined. Perceived control is the third aspect of the TPB. Study III revealed information sharing to be a

process involving not only the parent but also the child as a driving or impeding force for the process. For example, parents expressed the sense of losing control when talking with the child about his/her conception with donor sperm to be an impeding factor for information sharing. The child's reaction to information sharing was also expressed as either driving or impeding the process. Some parents shared that information sharing with the child was not always an easy task despite their firm intentions to do so. The parent's efficacy in talking with the child about his/her genetic origins might in the end be the key to a successful information-sharing process. However, the use of TPB to explain behaviours related to parent's information sharing with their donor offspring needs further evaluation.

Methodological considerations

The overall aim of this thesis was to study information sharing among heterosexual couples following gamete donation. A further aim was to study donors' attitudes towards future contact with donation offspring. To answer the various research questions, information was gathered in four separate studies and analysed using both quantitative (study I, II and IV) and qualitative methods (study III). The use of a prospective cohort design, including recipients and donors recruited at all fertility clinics providing donation treatment in Sweden, along with the use of different methodologies strengthens the findings of this thesis. However, there are methodological considerations and limitations with the approaches used in this thesis that need to be discussed.

Study I, II & IV

External validity, or generalisability, refers to how well the results relate to the target population. The large population-based sample, including all fertility clinics performing gamete donation in Sweden, along with distinct inclusion criteria and relatively high initial response rates contribute to the external validity. No data regarding participants' or donors' ethnic origin was collected. One of the inclusion criteria were speaking and reading Swedish, which leads us to assume that participants with other ethnic and cultural backgrounds might be underrepresented. However, there is a lack of non-Caucasian Swedish donors (personal communication with G. Sydsjö, 25-09-2015). The donor recruitment involves a medical and psychosocial evaluation and information about the legal, psychological and social consequences of a donation which requires a certain comprehension of the Swedish language. It is therefore assumable that the study samples in this thesis reflect rather well the population of infertile couples seeking gamete donation treatment at Swedish fertility clinics.

Further, it is important to acknowledge that an unknown number of heterosexual couples from Sweden choose cross-border reproductive care (CBRC) every year in countries that allow anonymous donors, and no information is available for all these individuals. However, one of the major fertility clinics in Denmark states that approximately 75–80% of recipients within their donor programme actively choose the option with an identity-release donor (personal communication with I. F. Kristoffersen, 11-09-2015), which indicates support for the present findings on a trend towards openness with the offspring.

No information is available about the donors who chose not to participate in study IV, and thus it is possible that their views differ from the participating donors. To the extent that gamete donation treatment is associated with secrecy and stigmatisation, there is a risk of selection bias in study I and II. Recipients preferring secrecy and non-disclosure may have declined participation in these studies. No information is available about the recipients who chose not to participate in study I, and it is possible that they have a different view of the studied variables. In study I, there were a high percentage of non-responders at RT2 among oocyte recipients, but comparisons regarding age and educational level did not indicate any attrition bias. Instead, an examination of attrition rates on a clinical level indicated that the attrition among oocyte recipients was partly due to administrative failure. Attrition bias was investigated in study II based on attitudes towards disclosure assessed at RT2. Results revealed that parents of donation offspring who dropped out of the study at RT3 reported less positive attitudes towards disclosure to offspring than did responders. Non-responders at RT3 also had a lower education level than responders. Previous research has reported low education level to be associated with a desire for secrecy and an intention not to tell the child about the donation.¹¹³
¹⁵⁰ However, despite the fact that the results from study II indicate some attrition bias, study participants included both parents who reported that they planned to keep the conception a secret and parents who were undecided about disclosure. This indicates that the study did not only attract couples in favour of disclosure.

Data collection via questionnaires has some limitations. Answers on, for example, attitudes might not reflect the real views of the participants but instead the perceived desirable answer. Construct validity refers to the degree that an instrument measures the concepts under investigation.¹⁵¹ The instruments in study I, II and IV was a combination of established and validated instruments as well as instruments developed by the research group and not fully psychometrically tested, which must be considered regarding reliability.

Moreover, for the majority of parents study II only reflects an intention for disclosure and study IV reflects the views of donors when the scenario of being contacted by a donation offspring was still only hypothetical. Further studies are needed to follow up on the intentions of disclosure among parents

and elucidate the experiences of an actual contact between the offspring and the donor among identity-release donors, offspring and their respective families. Fortunately, the prospective longitudinal design used in the SSGD enables future follow-ups.

Study III

The quality criteria for discussing trustworthiness in qualitative research introduced by Lincoln and Guba¹⁵², i.e. credibility, dependability, confirmability and transferability, were taken into consideration in this study.

Credibility refers to what in quantitative studies is referred to as validity, i.e. the confidence in the truth of the data and the interpretations of such data.¹⁵¹ The recruitment of participants from all fertility clinics in Sweden performing sperm donation treatment provided a variety of informants from both urban and rural parts of Sweden. Informants were both men and women, from cohabitating and separated parent couples and living alone or in new relationships, which contributes to a richer variety of experiences. By the end of the data collection, no new information emerged, which can be seen as a sign of information saturation. To reduce the risk for researcher bias, investigator and analysis triangulation was used. Moreover, in order to further increase the credibility, representative quotations from the transcribed text was presented. However, it is important to bear in mind that we have no information about the sperm recipients who chose not to participate in the Swedish Study on Gamete Donation and the present interview study, and thus it is possible that their views differ from the present results. Parents' views, however, did not unanimously support the Swedish legislation and guidelines, which indicates that the participants felt they could speak freely about their opinions and experiences.

Dependability refers to the stability of data over time and over conditions.¹⁵¹ To achieve dependability, an interview guide developed by the research team was used in order to cover the same areas for all interviews.

Confirmability refers to the objectivity or neutrality of the data and interpretations.¹⁵¹ Data needs to represent the informant's views and not the biases or perspectives of the researcher. To achieve confirmability, the analysing process was systematic and rigorous. The researchers returned several times to the transcripts to confirm that data were analysed cautiously and the results were discussed in the research group.

Transferability refers to the extent to which the results can be transferred to other groups or settings.¹⁵¹ The present study was performed in the context of the Swedish legislation with donors that are identifiable for the donor offspring once they reach mature age. This fact must be taken into consideration since knowing that the child has a legal right to access knowledge about the donor is involved in the parents' reasoning on information sharing.

Concluding remarks and future research

Findings in the present thesis point out that most recipients and donors within the Swedish gamete donation programme acknowledge the child's right to his/her genetic origin and have the best interest of the child in mind. The subsequent questions this leads to are as follows: When are the disclosure rates high enough? When can the implementation of the child's right to his/her genetic origin be considered satisfactory? There were a number of parents who stated that they would not inform their child about his/her genetic origin. Also, there are most likely an unknown number of parents who did not participate in the studies within this thesis as a result of an unwillingness to reveal the donor conception to anyone. Offspring from these parents will either live their lives without knowing about their genetic origin or risk an accidental revelation of their donor conception with the potential trauma this may cause. Providing clinical care that is with the child's best interest in focus might be a challenge, but it is nevertheless of great importance for health care providers. In order to protect the right of the offspring of these couples, health care has a challenge in identifying these couples before treatment and providing them with sufficient support and encouragement to share how their family was built with their future child. For example, more active steps have been taken by the state of Victoria, Australia to increase the incentives for parents to inform their donor offspring about their genetic origin. Donor offspring born after 1 January 2010 who request a copy of their birth certificate as an adult receive an addendum which states that additional information about their birth is available. However, the potential effect on disclosure of this legislative change has not yet been evaluated.¹⁵³ The Swedish discretion surrounding reproductive treatment with separate and concealed medical records on the one hand acknowledges the integrity of the family. On the other hand it might signal to parents (as well as donor offspring) that the donor conception is something to be ashamed of and thus worth hiding.

The medical development of ART has been enormous during the last 40 years. Sweden has been rather careful in the implementation of new methods for treatment and for new groups of patients. Oocyte donation was first performed in 1984, but it was not until 2003 that it was allowed to be performed in Sweden. Sperm donation treatment for lesbian couples was accessible abroad (e.g. in Finland and Denmark) long before the change of the Swedish legislation in 2005 made it possible for this group of patients to

be treated with donated sperm in Sweden. Similarly, single women are not yet allowed to undergo treatment with donated sperm in Sweden and embryo donation and surrogacy are still not permitted in Sweden. With the lack of accessible treatment methods in Sweden, in the past couples with infertile women and lesbian couples have travelled abroad for CBRC with donated oocytes or sperm, and single women and couples in need of embryo donation or surrogacy still have to go abroad to try and become parents. In addition, long waiting times for treatment in Sweden due to lack of donors causes people to travel for CBRC. However, the rights of offspring born under jurisdictions abroad are not necessarily equal to offspring born under Swedish legislations, and the rights of these offspring to later have access to information about their origin are not always fulfilled. In addition, the routinely offered counselling that is performed before treatment in Sweden according to guidelines is not always given to persons seeking CBRC. The development of revised legislations related to ART in Sweden since the first legal regulation in 1985 has been performed with the child's best interest in mind. However, several ethical considerations have to be taken into account when developing legislative changes. The globalised world makes treatment abroad easily accessible for childless couples or women who are eager to have a child genetically connected to (at least) one of the parents. This may result in offspring conceived abroad lacking a right to knowledge about his/her genetic origin. The legislative carefulness in Sweden has resulted in donors and prospective parents becoming well informed about the legal consequences when entering gamete donation. However, it may also lead to CBRC if the identity-release legislation is undesirable, thereby causing a possible neglect of the offspring's potential interests and of prospective parents' potential need of support.

A study among parents following CBRC regarding these aspects would more thoroughly evaluate how the potential interests and needs of the Swedish parents and offspring after donor conception via CBRC are met. Moreover, the intentions of parents within the SSGD to share information with their offspring needs to be followed up. An examination of how many offspring actually seek to obtain information about the donor and how this eventual contact is perceived is needed. Lastly, the voices of those this issue concerns the most need to be heard, i.e. the donation offspring.

In conclusion, the present thesis adds to the body of research revealing a trend towards more openness and an intention among parents following identity-release gamete donation to share information with the child regarding his/her genetic origin. It also contributes with knowledge about the information-sharing process and the complex interplay between the parent and child within the process. Last but not least, the notion of the legislation, i.e. a consideration of the rights of the child and the child's best interest, seem to be highly prevalent among recipients as well as donors within the Swedish identity-release gamete donation programme.

Summary in Swedish - Sammanfattning på svenska

Ofrivillig barnlöshet förekommer i alla delar av världen och uppskattningsvis 10-15 % av befolkningen i reproduktiv ålder är drabbade. Provrörsbefruktning, sk. In-vitro-fertilisering (IVF) är den vanligaste metoden för behandling, men i de fall mannen är steril eller kvinnans ägg av någon anledning inte är brukbara, kan donation av spermier eller ägg vara en möjlig behandlingsform. År 1985 blev inseminationsbehandling med donerade spermier reglerat i lag i Sverige och sedan 2003 är IVF med donerade ägg/spermier tillåtet i Sverige. Sedan 2005 kan även lesbiska par behandlas med donerad sperma. Lagen innebär bl a att de barn som föds genom ägg- eller spermadonationsbehandling i Sverige har rätt att ta del av identifierbar information om donatorn vid mogen ålder. Sverige var det första landet i världen som lagstiftade om identifierbara donatorer, idag har ytterligare ett tiotal länder liknande lagstiftning som Sverige och diskussioner kring detta pågår i fler andra länder. Den svenska lagen säger dock inte vem som är skyldig att berätta för barnet om dess genetiska ursprung och uppgifter kring donationen finns inte tillgänglig i några officiella journalhandlingar eller i födelsebeviset. Enligt Socialstyrelsens riktlinjer bör föräldrarna börja berätta för barnet om dess tillkomst från tidig ålder, och barnet har sedan i mogen ålder rätt att ta del av uppgifter som finns om donatorn i sjukhusets särskilda journal.

Studier har visat att relativt få heterosexuella föräldrar berättar för sina barn att de blivit till genom donation. Däremot visar samma studier att majoriteten av föräldrarna berättat för andra personer om donationen. Därmed ökar risken att barnet får reda på sitt ursprung av någon annan än föräldrarna, vilket har visat sig vara en traumatisk upplevelse för många. Familjer som var öppna om donationen gentemot sina barn hade mer positiva relationer, medan familjer som inte berättat om donationen i större utsträckning upplevde barnet som en belastning och hade problem i föräldrarollen.

I Sverige har multicenterstudien ”The Swedish Study on Gamete Donation” i 10 år följt donatorer och mottagare av donerade ägg och spermier med syfte att följa och utvärdera de långsiktiga konsekvenserna av ägg- och spermadonation i Sverige.

Det övergripande syftet med avhandlingsarbetet var att undersöka hur recipienter av donerade ägg och spermier tänker och agerar om barnets rätt till sitt genetiska ursprung samt att undersöka hur donatorer ser på en eventuell framtida kontakt med ett donatorbarn.

Avhandlingsarbetet omfattar fyra delarbeten som ingår i multicenterstudien ”The Swedish Study on Gamete Donation”. Multicenterstudien inkluderar både donatorer och mottagare av ägg/spermier och har en prospektiv, longitudinell och komparativ design med två kontrollgrupper (par som genomgår traditionell IVF-behandling respektive par som blivit spontant gravida). Studien omfattar samtliga sju fertilitetskliniker som får bedriva ägg- och spermadonation i Sverige: universitetssjukhusen i Uppsala, Stockholm, Göteborg, Linköping, Malmö, Umeå och Örebro. Inklusionen av deltagare pågick under perioden april 2005 till april 2008. I denna avhandling inkluderas endast data från heterosexuella mottagarpar samt data från donatorer av ägg och spermier.

Syftet med *studie I* var att undersöka mottagarparens attityder och beteende avseende öppenhet om donationen till barnet och till andra personer, attityder till genetiskt föräldraskap samt uppfattningar om information rörande föräldraskap genom donationsbehandling. Under inklusionsperioden tillfrågades alla par som påbörjade donationsbehandling om deltagande i studien. Av 215 par som påbörjade behandling med donerade ägg accepterade 152 par (72 %) deltagande. Av 158 par som påbörjade behandling med donerade spermier accepterade 127 par (81 %) deltagande. Deltagarna besvarade individuellt två enkäter med studiespecifika instrument om öppenhet, genetiskt föräldraskap och information. Resultatet visade att omkring 90 % av deltagarna stödde öppenhet och ärlighet gentemot barnet kring dess genetiska ursprung och hade berättat för andra personer om donationsbehandlingen. Mellan 26 % och 40 % av deltagarna ville ha ytterligare information/stöd kring föräldraskap efter donationsbehandling.

Syftet med *studie II* var att undersöka huruvida föräldrar till barn födda efter ägg- eller spermiedonation berättar eller tänker berätta för sitt barn om dess tillkomst. Syftet var också att studera sambandet mellan föräldraparens enighet i att berätta/inte berätta för barnet och hur nöjda de var med parrelationen. En kohort av totalt 111 föräldrapar med barn mellan ett och fyra år deltog. Av dessa var 52 par med barn efter behandling med äggdonation (73 % svarsfrekvens) och 59 par med barn efter behandling med spermiedonation (70 % svarsfrekvens). Majoriteten (78 %) av föräldrarna tänkte berätta för barnet om dess tillkomst och 16 % hade redan börjat prata med barnet om det. Sex procent av föräldrarna tänkte inte berätta för barnet eller hade ännu inte bestämt sig. Många var osäkra vid vilken tidpunkt det var bäst att börja berätta för barnet om donationen och önskade mer information om strategier och hjälpmedel för att berätta om donationen. De föräldrapar som var helt överens om beslutet att berätta/inte berätta för

barnet om donationen skattade en högre relationskvalitet än de par som inte var helt överens om beslutet.

Syftet med *studie III* var att utforska hur föräldrar till barn i sjuårsåldern resonerar kring att berätta för sitt barn om dess tillkomst och vilka erfarenheter de har av detta. En explorativ intervjustudie med 30 föräldrar efter spermadonation genomfördes. Resultatet visade att berättandet sker genom en process i fyra steg; (1) hur barn blir till, (2) att man behövde hjälp på sjukhuset, (3) att man fick hjälp med donerade spermier samt (4) att barnet längre fram kan ta reda på donatorns identitet. Processen initieras och förs framåt av föräldern, men olika faktorer såsom t ex barnets nyfikenhet eller ointresse kan föra processen snabbare framåt eller bromsa den.

Syftet med *studie IV* var att undersöka attityden bland ägg- och spermadonatorer till framtida kontakt med barnet som tillkommit till följd av donationen och vilka preferenser de har för en eventuell framtida kontakt. Donatorerna som följts från det att de accepterades som donatorer besvarade en enkät 5-8 år efter donationen. 126 kvinnor och 84 män deltog (svarsfrekvens 83 % resp. 74 %) och majoriteten av dessa var positiva till en eventuell framtida kontakt med barnet. Fler än hälften ville få information från kliniken om ett barn sökte identifierbara uppgifter om dem, medan en tredjedel inte ville få denna information.

Sammanfattningsvis visar avhandlingen att heterosexuella par som genomgår ägg- eller spermadonationsbehandling i Sverige är relativt öppna om sin behandling och förespråkar öppenhet även mot barnet. Nästan alla hade intentionen att berätta för barnet om dess tillblivelse och en del av föräldrarna hade redan startat berättandeprocessen när barnet var i 1-4-årsåldern. Både föräldrar och donatorer satte barnets intresse främst vad gäller att få vetskap om sitt ursprung och ett eventuellt möte med donatorn i framtiden, vilket är i linje med lagens intention om donatorbarns rätt till sitt ursprung.

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