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BUILDING A FAMILY WITH GAMETE DONATION – PERSPECTIVES OF PARENTS AND OFFSPRING

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Building a family with gamete donation – Perspectives of parents and offspring Thesis for Doctoral Degree (Ph.D.)

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Till min familj

Popular science summary of the thesis

Background: Most Swedish men and women want to have a child. However, 10–15% of couples are infertile. In such a case, couples can use medically assisted reproduction (e.g. in-vitro fertilization). These reproductive techniques can be used with the prospective parents' own gametes (i.e. eggs or sperm), or with gametes from a donor. When using a male donor, the father will not be genetically related with the prospective child. When using a female donor, the mother will not be genetically related with the prospective child but will have a biological bond with the child from pregnancy and breast-feeding. By such, these reproductive techniques enable new family compositions with varying genetic relations within and outside the family. In 1985, Sweden was the first country in the world to introduce a law stating that the donor conceived person (DCP) has the right to obtain identifying information about the donor when sufficiently mature (i.e. around the age of 18). Still, most other countries perform treatments with donated gametes using anonymous donors. Previous research that has investigated psychosocial well-being based on whether the parents have told their child about donor conceived or not indicate that there are more similarities than differences between the two groups. That is, telling the child or not about his/her genetic origins does not seem to be related to the child's, or the parent's, psychological well-being, or how well the family is functioning. However, most of these studies only concern sperm donation families, and tend to only include the mothers' perspectives. Moreover, studies often include few participants and have usually been conducted when the child is relatively young. When considering the child's age, a more comprehensive understanding of genetic inheritance is not developed until the child is older. Adolescence, i.e. the ages of 10–19, is also a period when the child start to develop a personal identity and find it more important to fit in. Thus, it is possible that negative psychosocial consequences of gamete donation appear later. In terms of those DCPs who are old enough to search for information about their donor, studies suggest that this is usually a positive experience, but one that may also include challenges, both for DCPs and their parents. Previous research investigating this experience is however very limited.

While there is an increasing accessibility and demand of medically assisted reproduction, the long-term psychosocial consequences of these treatments in

the context of identifiable donors are largely unknown. This also implies a lack of knowledge about what happens when the intention of the Swedish legislation is fulfilled, i.e. when DCPs obtain donor information.

Aim: The aim of this thesis was to investigate the long-term psychosocial consequences for heterosexual couple families following oocyte donation (OD) and sperm donation (SD), in the context of the Swedish legislation. An additional aim was to explore how heterosexual couple families following SD experience the process of obtaining identifying information about the donor.

Methods: This thesis includes four studies, where two studies investigated psychosocial well-being among donor conception families using a quantitative research method. These two studies were part of a larger study that have followed heterosexual parents using treatment with donated eggs and sperm at five points, from the start of treatment until their child was 17 years old. The studies in this thesis analyzed data from when the child was seven years old (Study I), and from when the child was 13–17 years old (Study II). Moreover, two qualitative interview studies explored the experiences of DCPs who search for information about their donor (Study III) and the parents of these DCPs (Study IV). Data from the qualitative studies were analyzed using reflexive thematic analysis.

Results: Study I showed that donor conception families' psychosocial well-being is within normal ranges at the time when the child is about seven years old. Further, Study I showed that the well-being of the families is not related to whether or not the parents have disclosed the use of donor conception to their child. Study II revealed that donor conception families' psychosocial well-being is within normal ranges also when the child is 13–17 years old. Also, the results from Study II showed that donor conception families report similar levels of well-being as a reference group of parents using IVF with their own gametes. However, when comparing OD to SD families, results showed that SD mothers to a significantly higher extent reported symptoms of anxiety indicating clinically relevant levels (31%) compared to OD mothers (7.5%). Study III described that searching for donor information could fill varying needs for the adult DCP, and that the process of obtaining donor information meant having to balance interests of both parents, the donor, and the clinic. Study III pointed to that the process of finding information about the donor thereby could be challenging for the DCP. Lastly, Study IV identified that parents' experiences of when their child

was searching for information about for their donor were influenced by how they perceived parenthood in the context of nature and nurture, and how they thereby experienced their own role as parents, which was related to how they managed the presence of the donor.

Conclusions: Donor conception does not appear to have negative consequences to the psychosocial well-being of families. However, both parents and their adult children face several challenges in the process of obtaining identifying information about the donor, which should be acknowledged by healthcare to assure that families are offered adequate support related to the use of these treatments in a long-term perspective.

Abstract

The aim of this thesis was to investigate the long-term psychosocial consequences for heterosexual couple families following oocyte donation (OD) and sperm donation (SD), in the context of the Swedish legislation. An additional aim was to explore how heterosexual couple families following SD experience the process of obtaining identifying information about the donor. *Methods:* As part of a prospective longitudinal study, two cross-sectional studies assessed aspects of psychosocial well-being among OD and SD families with seven-year-old children (Study I) and 13 to 17-year-old adolescents (Study II). Two qualitative interview studies explored the experiences of obtaining identifying information about the donor from the perspective of 29 adult children (Study III) and 23 parents (Study IV). *Results:* Study I showed that donor conception families' psychosocial well-being is within normal levels and is not related to whether or not the parents have disclosed the use of donor conception to their seven-year-old child. Study II revealed that donor conception families' psychosocial well-being is within normal levels and similar to a reference group of parents using IVF with own gametes, but that SD mothers to a significantly higher extent reported symptoms of anxiety indicating clinically relevant levels (31%) compared to OD mothers (7%) ($p=.018$). Study III described that searching for donor information could fill varying needs for the adult donor conceived person and that the process of obtaining donor information meant having to balance interests of different stakeholders. Study IV showed that parents' experiences were influenced by how they perceived parenthood in the context of nature and nurture, which was related to how the parents managed the presence of the donor. *Conclusions:* Donor conception does not appear to be detrimental to the psychosocial well-being of families. However, both parents and their adult children face several challenges in the process of obtaining identifying information about the donor.

List of scientific papers

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

- I. Widbom, A., Sydsjö, G., and Lampic, C. (2022). Psychological adjustment in disclosing and non-disclosing heterosexual-couple families following conception with oocytes or spermatozoa from identity-release donors. *Reproductive Biomedicine Online*, 45(5), 1046–1053. <https://doi.org/10.1016/j.rbmo.2022.06.011>
- II. Widbom, A., Paulin, J., Sydsjö, G., Skoog Svanberg, A., & Lampic, C. Comparison of heterosexual couples with adolescent children following oocyte donation, sperm donation or standard IVF with regard to psychological distress, family functioning, and parent-child relationship – a long-term follow up study (*manuscript*).
- III. Widbom, A., Isaksson, S., Sydsjö, G., Skoog Svanberg, A., and Lampic, C. (2023). The motives and experiences of donor-conceived persons requesting the identity of their sperm donors. *Reproductive Biomedicine Online*, 103413–103413. <https://doi.org/10.1016/j.rbmo.2023.103413>
- IV. Widbom, A., Isaksson, S., Sydsjö, G., Svanberg, A. S., and Lampic, C. (2021). Positioning the donor in a new landscape—mothers' and fathers' experiences as their adult children obtained information about the identity-release sperm donor. *Human Reproduction (Oxford)*, 36(8), 2181–2188. <https://doi.org/10.1093/humrep/deab146>

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List of abbreviations

DCP	Donor conceived person
MAR	Medically assisted reproduction
OD	Oocyte donation
ICSI	Intracytoplasmic sperm injection
IUI	Intra-uterine insemination
IVF	In-vitro fertilization
SD	Sperm donation

Introduction

As a psychologist with a psychodynamic perspective, I view the understanding of adult life as an exploration of one's life history, connecting the past with the present. Not seldom, patients seeking therapy intuitively identifies the problem they seek help for as having its emotional roots in the deeply complex social organization we call family. Psychologically, our family members are a group of individuals in relation to which I have become who I am today. They are in a fundamental way the ones who have introduced us to the interpersonal world in which we have developed our experience of being an individual among- and separated from- other individuals. Still, the boundaries between us and our family remain porous. We can spend our whole life trying to establish emotional closeness and distance to our parents, sometimes even long after they are gone. This thesis is not about mortality- the cognizance of life's finitude. It is about nativity- the knowledge of how we came about, and how we bring a child into life, which we do in increasingly various ways. In an attempt to disentangle genetic and social bonds, I wonder what it means to us knowing how we came into being. What part does genes have to play in identity development, kinship and family building? Does the event of being donor conceived simply belong to the past?

1 Literature review

1.1 The wish for a child

The majority of Swedish men and women wants to have a child (Delbaere et al., 2021; Svanberg et al., 2003; Statistics Sweden, 2017) and for a majority, it is considered “the most important thing in life” (Svanberg et al., 2003). A significant number of men and women may even consider it “the whole purpose of life” (Svanberg et al., 2003). However, for some there are medical and/or social reason for not being able to conceive. Infertility, defined as the inability to “achieve a pregnancy after 12 months or more of regular unprotected sexual intercourse” (World Health Organization, 2018), affects 10–15% of couples globally (Boivin et al., 2007), and is recognized by the World Health Organization as a public health issue (World Health Organization, 2018).

1.2 Infertility and treatment

Male factor infertility is largely identified from suboptimal quality of sperm (i.e. concentration, and/or motility and/or morphology), or an absence of sperm in the seminal plasma (i.e. azoospermia) (Kumar & Singh, 2015), but may also be idiopathic (Practice Committee of the American Society for Reproductive Medicine, 2015).

In women, infertility may be due to suboptimal quality of the oocytes, tubal function, or hormonal disorder. About half of couples that are unable to achieve a spontaneous pregnancy seek medical care (Boivin et al., 2007) such as medically assisted reproduction (MAR). This treatment may be used with the prospective parent’s own gametes (i.e. sperm or oocytes) in in-vitro fertilization (IVF), intra-uterine insemination (IUI), and intracytoplasmic sperm injection (ICSI). MAR may also be used with donor gametes. For a heterosexual couple achieving pregnancy with donated sperm, the mother will have a genetic bond with the prospective child whereas the father will not. For a heterosexual couple achieving pregnancy with donated oocytes, the father will have a genetic bond with the

prospective child whereas the mother will not. The oocyte receiving mother, however, still has a biological bond with the prospective child through gestation and lactation.

1.3 Swedish legislation

Swedish legislation on identity-release donation mandates that donor conceived persons (DCPs) are entitled to know who their donor is when they are sufficiently mature (i.e. around the age of 18) (Stoll, 2008). All recipients of donated gametes meet with a counsellor and a physician for a psychosocial evaluation and to receive information about the psychosocial, practical, and legal aspects of the treatment, including that the resulting child is entitled to know about the donor conception. The legislation was enacted in 1985, and initially applied only to heterosexual couples using donor insemination. Subsequently, legislation has granted IVF-treatment with donor oocytes or sperm to heterosexual couples in 2003. Sperm donation treatment to same-sex female couples was legislated for in 2005, and for single women in 2016, as well as embryo donation to same-sex female couples, heterosexual couples, and to single women in 2019 (Lampic, 2019). However, a recent study from the research group showed that only about 7% of DCPs have requested information about their donor (Lampic et al., 2021). Comparing this to a US-based study (Scheib et al., 2017), it appears that some Swedish DCPs are unaware of their donor conception, which further implies that the intention of the Swedish legislation has not been adequately fulfilled. That is, that the child should have the possibility to search for donor information. New Swedish legislation introduced in 2019 aims to further ensure that DCPs are given access to information about their genetic origin by specifying that parents are obliged to inform their children.

1.4 Identity-release donations vs. anonymous donations

Most medically assisted gamete donations are performed with anonymous donors. However, treatment with oocytes/sperm from identity-release donors is available in an increasing number of countries and jurisdictions (Glennon, 2016). Legislation on identity-release donations entitles DCPs to

identifying information about their donor when sufficiently mature (Indekeu, Maas, et al., 2021). Generally, identifying information about the donor is restricted to DCPs who obtain the information by a formal request to the clinic or a central registry. In some jurisdictions that have abolished anonymous donation, there are efforts to also make donor information available to offspring born prior to the legislation. For example, in the UK (Crawshaw et al., 2015) and in Victoria, Australia (Dempsey et al., 2019), persons who had donated anonymously can voluntarily register to make their identity available to offspring from their donation. Nevertheless, in terms of policy-making and clinical practice, there are diverging views about whether DCPs should be entitled to information about their donor, and why that information may be considered important. From the perspective of DCPs, it has been argued that entitling the DCP to information about one's genetic origin is in the child's best interest (American Society of Reproductive Medicine, 2018).

1.5 New family compositions in a world that is already old

New technologies such as MAR and new legislation enable new family compositions. Today, assisted reproduction is available to single mothers, same-sex female couples, and heterosexual couples in Sweden. That is, treatment with donated gametes is a method of family building. By such it involves a range of psychological needs of and between the donor, receiving parents, and the DCP (Daar et al., 2019). These treatments are carried out in a world with notions about what parenthood entails, how families are built, and how identities are formed in relation to genetic connectedness. For example, the vast majority of prospective parents wants genetic children (Hendriks et al., 2017). In a sample of 195 heterosexual infertile men and women at a Belgian fertility clinic, 98% favoured genetic over non-genetic parenthood and considered genetic relatedness with their child a necessity in order to fulfil nearly all of the motivations for parenthood, whereas one-third stated they would only consider parenting a genetically related child (Hendriks et al., 2017).

One reason for the ascribed importance to genetic relatedness could be that there are cultural interpretations suggesting family bonds are built on genetic relatedness. "We are born into a world that is already old" (O'Byrne,

2010, pg. 5) implies that we cannot decouple human biology from social contexts and culturally based beliefs. Such beliefs can be challenged by new family compositions, where genetic links vary both within and outside the family unit (Nordqvist, 2010; Wyverkens et al., 2015). A tension between genes and kinship may thus arise for those parents who lack a genetic link with their offspring, as having the role of a parent is contradicted by the absence of genetic relatedness. For men, the inability to reproduce may imply a particular challenge as fatherhood and fertility have a significant role in forming gender identity, and male infertility is perceived as more stigmatizing than female infertility (Wischmann & Thorn, 2013).

1.6 Implications of secrecy and disclosure in gamete donation families

One of the arguments behind disclosure is that knowledge about one's genetic origin is important for identity development (Frith et al., 2018), while others have argued that there is not sufficient robust evidence of anonymous donations being harmful to DCPs to advocate identity-release donations (Raes et al., 2016). It has also been emphasized that legislation entitling DCPs to identifying information about their donor does not respect parents' autonomy, and that undergoing anonymous donations may be an expression of desired privacy that both donors and receiving parents should respect (Pennings, 2019). Meanwhile, there has been a rapidly growing popularity of direct-to-consumer DNA testing, which may increase the risk of inadvertent disclosure. Thus, it is questioned whether anonymous donations can be guaranteed at all (Crawshaw, 2018; Harper et al., 2016).

Parents' disclosure to their children of using donor conception is associated with a number of factors, and it has been suggested that disclosure attitudes and behaviour is associated with family type. For example, as single women and same-sex female couples undergo treatment without a father present, they need to explain the absence of a father in the family and thus tend to be open with their children about their conception with donor sperm (Appleby et al., 2012). In comparison, heterosexual couples disclose their use of sperm donation to their children to a lesser degree, which has been related to worry about disclosure having

a negative impact on the parent–child relationship, particularly concerning the relationship with the non–genetic father (Golombok et al., 2002; Scheib et al., 2003). Thus, in view of the challenges for heterosexual donor conception families, and the ongoing debate about whether disclosure should be encouraged or not, the psychosocial consequences of disclosure in heterosexual couple families should be considered.

Previous research comparing disclosing and non–disclosing heterosexual couple families with DCPs between pre–school and early adolescence (i.e. four–14 years) indicate more similarities than differences in terms of psychosocial well–being. However, most of these studies only concern sperm donation or do not differentiate between donation type (i.e. OD, SD, and surrogacy with/without the parents’ own gametes), tend to include only the mothers’ perspectives, and samples typically include few disclosing families. One exception is a longitudinal study by Blake et al. (2014), which presented separate results for mothers and fathers in sperm donation (SD) and oocyte donation (OD) families (Blake et al., 2014).

1.6.1 Psychological distress

Concerning psychological distress among parents, a study by Kovacs et al. (2015) did not find any differences between disclosing and non–disclosing SD mothers, while other studies have found that disclosure of donor conceptions has a tendency towards having more positive outcomes for mothers (Blake et al., 2014), and more negative outcomes for fathers when the child was seven and 10 years old (Blake et al., 2014). Among mothers, disclosure was overall associated with similar (Blake et al., 2014) or lower levels of psychological distress (Blake et al., 2014; Golombok et al., 2013). In contrast, fathers in disclosing families have reported more psychological distress than fathers in non–disclosing families, particularly among SD families. That is, disclosing SD fathers have reported higher levels of parenting stress when the child was seven years old, and higher levels of symptoms of depression when the child was 10 years old, compared to non–disclosing fathers. Among OD fathers, a reverse pattern was seen, where disclosure was associated with lower levels of parenting stress and symptoms of depression compared to non–disclosing families (Blake et al., 2014).

1.6.2 Relationship satisfaction, parent–child relationship, and family functioning

So far, only three studies have compared the difference between disclosing and non–disclosing families in terms of parents’ satisfaction with partner relationship, and no differences have been found (Freeman & Golombok, 2012; Kovacs et al., 2015; Lycett et al., 2004). However, these three studies only concern SD families and the impact of disclosure on relationship satisfaction in OD families have yet to be investigated.

Concerning the impact of disclosure on parent–child relationship and family functioning, studies predominantly include the mothers’ perspectives and concern only SD families or do not differentiate between donation type in analyses. While the majority of results indicate that disclosure is not associated with parent–child relationship or family functioning, some studies report disclosure being associated with positive outcomes. Disclosing mothers have reported lower levels of conflict with their sons (Freeman & Golombok, 2012), less frequent and less severe disputes with their child (Golombok et al., 2002; Lycett et al., 2004), less strict discipline (Golombok et al., 2002), and their child being less of a strain and feeling more competent as a mother (Lycett et al., 2004), compared to non–disclosing mothers. The only significant results among fathers showed that disclosing SD fathers reported feeling more competent as a parent (Lycett et al., 2004), but that their adolescent child reported less warm father–child relationships (Freeman & Golombok, 2012).

1.6.3 Child’s psychological adjustment

Studies comparing disclosing and non–disclosing families in terms of the child’s psychological adjustment predominantly includes SD families or do not differentiate between different types of treatment, and samples typically include few disclosing families. In line with previous studies on the implications of disclosure, the majority of studies have not found any associations between disclosure and child adjustment assessed by parents, teachers, the child, and in clinical interviews (Freeman & Golombok, 2012; Golombok et al., 2013; Golombok et al., 2002; Ilioi et al., 2017; Kovacs et al., 2015; Lycett et al., 2004). However, disclosure has from

the perspective of mothers been associated with their children having lower levels of conduct problems (Lycett et al., 2004). While Golombok et al. (2013) found a reverse pattern, where disclosure was associated with greater child adjustment difficulties, this finding was suggested to be due to the high proportion of surrogacy families among disclosing families.

Moreover, few studies have investigated the association between disclosure and the child's psychological adjustment among DCP's in late adolescence, which may influence the findings. The DCP's age is an important aspect when investigating the psychosocial consequences of gamete donation. During adolescence, children develop a more comprehensive understanding of genetic inheritance, and may be better able to grasp the implications of donor conception than younger children (Blake et al., 2010). Consequently, identity issues and parent-child relationship conflicts may be more prevalent among adolescents (Freeman & Golombok, 2012). For example, mothers in oocyte donation couples (i.e. lacking a genetic link with their child) reported lower family functioning and less acceptance of their adolescent child as well as less positive family relationships, compared to mothers in sperm donation couples (Golombok, 2017; Golombok et al., 2017; Golombok et al., 2023). Thus, it is possible that the psychosocial implications of gamete donation are not prevalent until the child is old enough to form an understanding of what treatment with donated gametes entails, and until the knowledge of this information may be rendered important.

1.6.4 Summary

In summary, there is inconclusive evidence about the association between parents' disclosure of donor conception and psychosocial well-being. While most results indicate that psychosocial well-being is not influenced by disclosure, there is some indication of greater psychosocial well-being in disclosing families, and that disclosure may have negative outcomes for SD fathers. However, the majority of studies include only the mothers' perspectives, concern sperm donation using anonymous donors, does not include DCP's in late adolescence, and are hampered by methodological limitations such as not differentiating between donation types, small sample sizes, few disclosing parents, and high attrition in longitudinal

studies. Finally, many of the studies investigating the association between disclosure and psychosocial well-being were conducted around 20 years ago, and it is possible that attitudes to disclosure have changed in more recent years. Considering the debate about the benefits and risks of disclosure, the increasing risk of inadvertent disclosure and not being able to guarantee anonymity due to the increasing popularity of direct-to-consumer DNA tests, as well as the specific challenges for heterosexual donor conception couples, it is important to consider the implications of parents' disclosure on psychosocial well-being.

1.7 Experiences of searching for and obtaining donor information

Families created with the assistance of third-party reproduction, i.e. single mothers, same-sex female couples, and heterosexual couples, have been found, overall, to be overall well-functioning (Golombok, 2020). However, they are confronted with specific challenges. One such challenge concerns how to manage the existence of the donor and potential same-donor offspring, which may become increasingly apparent as the donor conceived child obtains information about the donor.

In the case of anonymous donations, matching services such as the Donor Sibling Registry (DSR) may be used by DCPs and parents to find and establish contact with same-donor offspring and/or the donor (Jadva et al., 2010). The limited research available on the experiences of identifying and establishing contact with genetically-related individuals outside the family among DCPs (Scheib & McCormick, 2020) suggests that relationship and contact outcomes are generally positive. According to survey studies based on the DSR, the majority of DCPs reported contact with their donor and/or same-donor offspring as a very positive experience (Jadva et al., 2010) and described the donor as a friend (Beeson et al., 2011). Qualitative studies indicate that learning the identity of the donor and same-donor offspring was an emotionally charged event that was sometimes described as a redefining moment in terms of personal identity, as new knowledge about genetic kin was interpreted as new knowledge about the self (Blyth et al., 2012; Frith et al., 2018; Scheib et al., 2020). Also, interacting with newly found genetic kin could extend the family, and thus also extend the support network for these offspring (Blyth et al., 2012), as well as reinforce a

sense of belongingness (Scheib et al., 2020). Negative experiences related to identifying or contacting the donor or same-donor offspring have also been reported by DCPs (Beeson et al., 2011; Blyth, 2012; Frith et al., 2018; Indekeu, Bolt, et al., 2021; Jadva et al., 2010; Koh et al., 2020; Scheib et al., 2020). These reports include mismatched expectations of the relationship between the donor and the DCP, causing conflicted feelings, and an emotional strain from the friction in meeting a person who is genetically close while simultaneously being a 'total stranger'.

From the perspective of parents of DCPs, there are less reports available on the experiences of contact with the donor or same-donor offspring. Moreover, the studies conducted mainly concern single mothers and same-sex female couples who had themselves actively established contact with the donor or same-donor families (Freeman et al., 2009; Scheib & Ruby, 2008). Among these parent groups, contact with the donor was reported as being a moderately to very positive experience, while the perceived role of the donor varied from merely being a donor to that of a father. Overall, contact with same-donor families was described in positive terms, but some parents reported difficulties with mismatched opinions about how open one should be about the child's origin and how close contact the families should have. Related to this, it has been suggested that parents should have access to support in order to manage family life following donor conception both in the short- and long-term (Boivin, 2003; Isaksson et al., 2019; Raes et al., 2016).

Previous research indicates that donor conceived individuals want to have information about their donor and same-donor offspring (Beeson et al., 2011; Bos et al., 2019; Indekeu, Bolt, et al., 2021; Jadva et al., 2010a; Scheib et al., 2005; Scheib et al., 2017). However, given various limitations, such as many of the studies being based on self-selected groups, it is not known to what extent these results are generalizable to the whole population of DCPs (Skoog Svanberg et al., 2019; Zadeh, 2016). A recently published study from our research group indicates that few offspring have exercised their right to obtain identifying information about their sperm donor (Lampic et al., 2021). Out of the approximately 900 DCPs who were eligible to obtain donor information (i.e. who had reached adult age), only 60 (about 7%) had contacted any of the RMCs in Sweden to obtain this information. In terms of the long-term consequences of identity-release donation, there is

limited knowledge about how the process of obtaining identifying information about the donor or meeting the donor is experienced by parents and their adult children.

1.8 Rationale for the thesis

While there is an increasing accessibility to and demand for MAR, and an increasing number of countries are introducing legislation on identity-release donations, the long-term psychosocial consequences of these treatments are still largely unknown, particularly in the context of identifiable donors. This also includes a lack of knowledge about the DCPs' experiences of searching and finding donor information, and its implications to the whole family. Knowledge about the psychosocial consequences of donor conception and obtaining donor information for parents and children is important in order for the clinics to provide adequate support to families using these treatments.

2 Research aims

Overall aim of the thesis

The aim of the thesis was to investigate the long-term psychosocial consequences for heterosexual couple families following oocyte donation (OD) and sperm donation (SD), in the context of the Swedish legislation. An additional aim was to explore how heterosexual couple families following SD experience the process of obtaining identifying information about the donor. The specific aims of Study I-IV were:

Study I: To investigate if there is a relationship between disclosure of donor conception and psychological adjustment in families following OD and SD when the child is seven years old.

Study II: To compare psychological adjustment and family functioning in families with adolescent children following OD, SD and in-vitro-fertilization (IVF) with their own gametes.

Study III: To explore the motives and experiences of adult donor conceived persons who search and receive information about their sperm donor.

Study IV: To explore how parents experience identity-release donation when their adult children have obtained information about their sperm donor.

3 Materials and methods

3.1 Design

The present dissertation project is based on two multicentre studies; a prospective longitudinal study of recipients of donated oocytes and sperm (Study I & II), and a qualitative interview study of families with adult offspring who have searched for identifying information about their sperm donor (Study III & IV). An overview of the characteristics of the included studies are presented in table 1.

Table 1. *Study design, data collection, study sample, time of data collection, and analyses in Study I-IV.*

Study design	Data collection	Study sample (n)	Time of data collection	Analyses
I. Cross-sectional data from a longitudinal cohort	Questionnaires (self-rating and proxy for children) from fourth wave	196 parents (OD and SD)	Child seven years old	Factorial Analysis of Variance (ANOVA)
II. Cross-sectional data from a longitudinal cohort	Questionnaires (self-rating) from fifth wave	205 parents (OD, SD, and IVF)	Child 13-17 years old	Kruskal-Wallis test, Mann Whitney U-test, χ^2 test, post hoc test
III. Qualitative	Semi-structured interviews	29 DCPs (SD)	After DCP contacting fertility clinic to obtain donor information (DCP age 18-29)	Reflexive Thematic Analysis
IV. Qualitative	Semi-structured interviews	23 parents (SD)	After DCP contacting fertility clinic to obtain donor information	Reflexive Thematic Analysis

Note. OD= oocyte donation, SD= sperm donation, IVF=in vitro fertilization with own gametes, DCP= donor conceived person

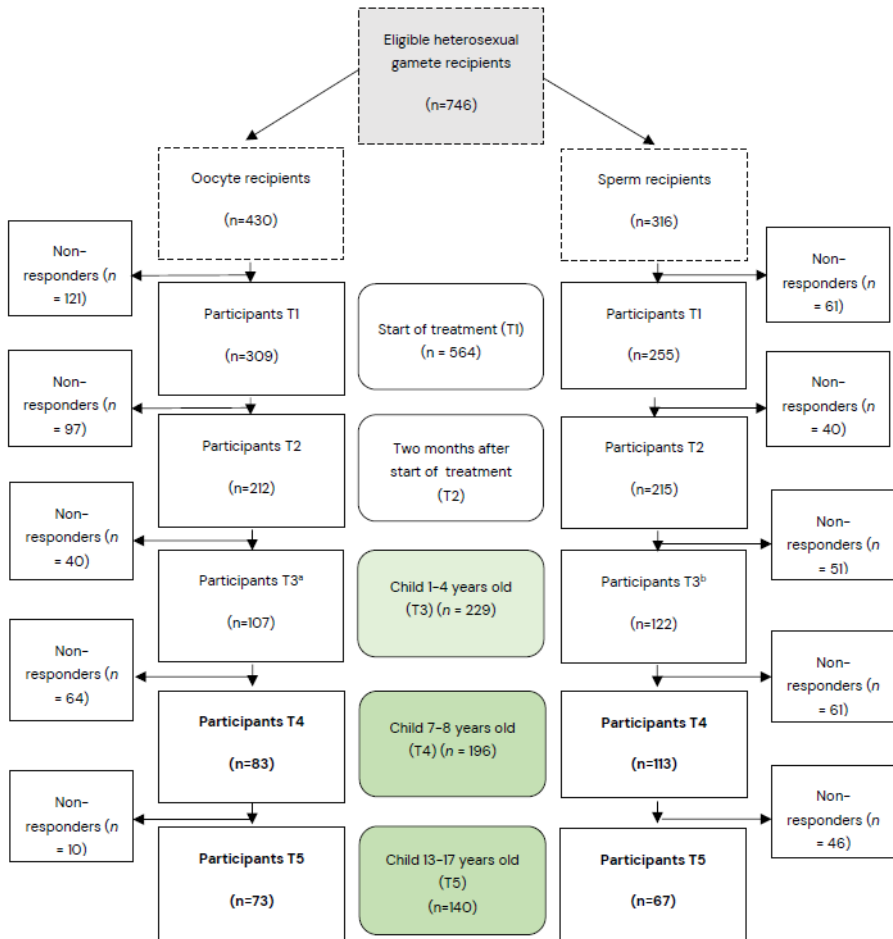
3.2 The Swedish study on gamete donation (Study I and II)

The Swedish Study on Gamete Donation (SSGD) is a prospective longitudinal multicentre study of recipients of donated oocytes and sperm (heterosexual and lesbian couples), donors of oocytes and sperm, and a comparison group of couples undergoing standard IVF treatment with their own oocytes and sperm. Data collection was conducted at all University hospitals' fertility clinics providing gamete donation in Sweden; Malmö, Linköping, Örebro, Gothenburg, Stockholm, Uppsala, and Umeå. All couples starting treatment with donated gametes, own gametes, and individuals accepted as gamete donors were approached between 2005 and 2008 and were recruited consecutively. Exclusion criteria were not speaking and/or reading Swedish and having completed at least one round of treatment (i.e. donor insemination, at least one transfer of fertilized oocyte, or IVF treatment with own gametes).

Five waves of data collection have been conducted, where recipients have been approached individually: in connection with treatment start (T1), two months post-treatment (T2), two to five years post-treatment (T3), seven years post-treatment (T4), and 15–18 years post-treatment (T5). For the first wave of data collection, questionnaires were given at the clinic in connection with the start of treatment, and for subsequent waves questionnaires were distributed via mail with a prepaid envelope, including a cover letter informing recipients about the study purpose and the confidentiality of participation. Non-responders were sent two reminders and participants received a gift voucher (≈10 EUR). Participants at T5 were not offered any compensation for participation. In the SSGD, the first child born to a participating couple following conception in 2005–2010 is considered the target child. As participating couples could have had several children, the target child's year and month of birth was indicated during each follow-up to assure participants completed items with the target child in mind.

The present thesis concerns data only from heterosexual recipients of donated oocytes and sperm, and of couples undergoing standard IVF treatment with their own oocytes and sperm. A flowchart of data collection is presented in figure 1.

Figure 1. Flow chart of data collection in SSGD



Note:

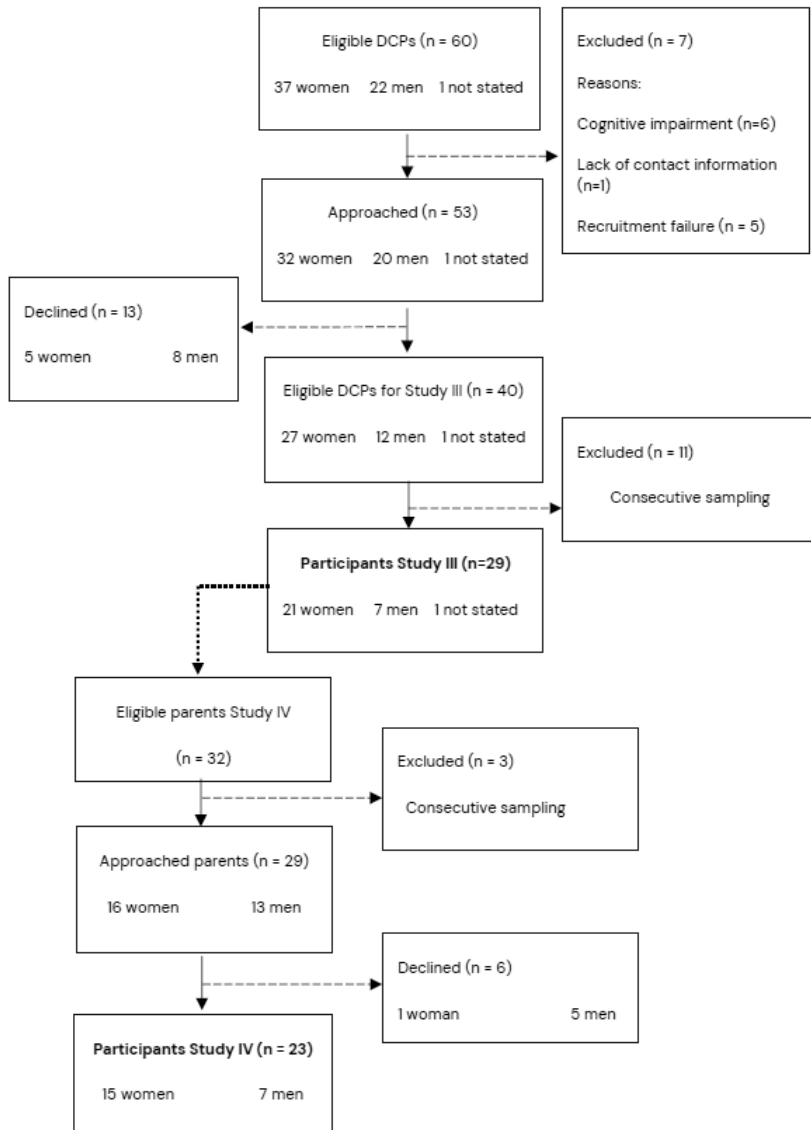
^a147 individuals had given birth to a child following OD and were eligible at T3

^b174 individuals had given birth to a child following SD and were eligible at T3

3.3 National study on release of donor information (Study III and IV)

This multicentre study targeted the first group of families in which the donor conceived child had requested information about his/her identity-release sperm donor. Donor conceived persons were recruited at all the university hospitals' fertility clinics providing sperm donation treatment in Sweden during the time period 1985–2002; the university hospitals in Malmö, Linköping, Örebro, Gothenburg, Stockholm, Uppsala, and Umeå. Inclusion criteria were having requested donor information at any of the fertility clinics and being at least 18 years old. Recruitment was conducted 2016–2020. As legislation granting access to donated oocytes was not implemented until 2003, DCPs in OD families had not yet reached a mature enough age to request donor information at the time of the study. Thus, the present study concerns data only from offspring following sperm donation (Study III) and recipients of donated sperm (Study IV). Eligible participants who had contacted the RMCs to obtain identifying information about their sperm donor (n=53) were approached by hospital staff regarding study participation and were subsequently contacted by the principal investigator. Eligible participants were given written information about the study and a postal survey with a pre-stamped return envelope. Non-responders were given one reminder, and no compensation was given for participation. A total of 40 DCPs completed the postal survey and were consecutively recruited for Study III, where semi-structured interviews were conducted with 29 DCPs. A purposive sample of participants in Study III (n=25) were asked for permission to contact their parents (Study IV). Following permission from the DCPs, parents to DCPs who had searched for identifying information about their sperm donor were recruited (n=23), and semi-structured interviews were conducted between 2018 and 2019. A flowchart of data collection is presented in figure 2.

Figure 2. Flow chart of data collection in National study on release of donor information



3.4 Participants and data collection

3.4.1 Study I

Study I concerned a cohort of parents from the fourth wave of data collection of the SSGD, i.e. following the DCP's seventh birthday. Inclusion criteria were being part of a heterosexual couple and having given birth to a child following treatment with OD or SD. Parents who had used a known donor (e.g. a friend or a sister) were excluded. A total of 196 participants were included: 83 parents following oocyte donation (response rate 56%), and 113 parents following sperm donation (response rate 65%). The 196 participants represented a total of 110 couples, where 86 couples were represented by both parents, and 24 couples were represented by one parent. The large majority of participants were living with the co-parent of the donor-conceived child.

3.4.2 Study II

Study II concerned a cohort of parents from the fifth wave of data collection of the SSGD, conducted between 2022 and 2023 when the donor conceived child was 13–17 years old. At this assessment point, responders at previous waves of data collection who had declined to participate in future follow-ups were not approached, as well as parents who had not participated in any waves of data collection since T2. Inclusion criteria were being part of a heterosexual couple at treatment start and having an adolescent child (age 13–17) conceived following gamete donation or standard IVF. A total of 205 participants were included: 73 parents following oocyte donation (response rate 70%), 67 parents following sperm donation (response rate 60%), and 65 parents following IVF with own gametes (response rate 69%). The 205 participants represented a total of 131 couples, where 74 couples were represented by both parents, and 57 couples were represented by one of the parents.

There was an equal gender distribution between the groups of OD, SD, and IVF. The only significant group difference in terms of demographics concerned the age of the donor conceived child, where the comparison

group of IVF parents had marginally older children. The majority of participants were still living with the co-parent of the target child, and the vast majority were working full-time or part-time. Most OD and SD parents had conceived using an identity-release donor, except nine participants in oocyte donation couples (five women and four men) who conceived with a known donor.

3.4.3 Study III

Participants in Study III included 29 DCPs who had searched for identifying information about their sperm donor (21 women, seven men and one “not stated”). Participants were born to heterosexual couple parents and were between 18–29 years old (median age 21). A total of 25 families were represented, with four participating sibling pairs. Semi-structured interviews were conducted between a few weeks and five years after the DCPs’ request for donor information, and most interviews (n=18) were conducted within the first year.

3.4.4 Study IV

Participants in Study IV included 23 heterosexual parents who had undergone sperm donation treatment over 18 years ago, and whose donor conceived offspring had contacted the fertility clinic to obtain identifying information about the donor. The 23 participants represented a total of 15 families, eight of which were represented by both parents and the rest were represented by only the mother. Most participants were still married to the co-parent at the time of the donor conception, and eight participants were in a relationship with a new partner or were single. Participants were between 50 and 64 years old and had varying educational and professional backgrounds.

3.5 Measures

3.5.1 Study I and Study II

In Study I, participants completed a questionnaire including sociodemographic characteristics and validated instruments measuring parents' symptoms of anxiety and depression, perceived relationship satisfaction, and ratings of the child's emotional and behavioral problems. Parents also answered items regarding disclosure intention/behaviour. In Study II participants completed a survey including sociodemographic characteristics and validated instruments measuring parents' symptoms of anxiety and depression, family functioning, parent-child relationship, and study-specific items concerning donor conception issues and disclosure intention/behaviour. The following specific measures are described in detail below.

Symptoms of depression and anxiety (Study I and II)

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was used to assess parents' symptoms of anxiety and depression. HADS includes 14 items divided in two subscales assessing symptoms of anxiety and depression, respectively. Subscale scores range from 0 to 21, with higher scores indicating more severe symptoms. A subscale score of ≥ 8 was used to indicate clinically relevant levels of anxiety and/or depression, respectively (Bjelland et al., 2002). HADS has demonstrated good psychometric properties, being a reliable a valid instrument for assessing symptom severity of depression and anxiety with good internal consistency and concurrent validity (Bjelland et al., 2002). In the present study, internal consistency was good for both depression (Cronbachs $\alpha = 0.77$) and anxiety (Cronbachs $\alpha = 0.81$).

Relationship satisfaction (Study I)

Parents' relationship satisfaction was assessed using the ENRICH (Evaluating and Nurturing Relationship Issues, Communication, Happiness) marital inventory (Fournier et al., 2013) including 10 subscales: Personality issues, Communication, Conflict resolution, Financial management, Leisure activities, Sexual relationship, Children and parenting, Family and friends,

Egalitarian roles, and Conception of life. Scores on each subscale range from 10 to 50, and add up to a total score that varies between 100 and 500. A higher score represents greater relationship satisfaction. For the Swedish version of the inventory, acceptable reliability and validity has been demonstrated (Wadsby, 1998). In the present study, Cronbach's alpha was 0.94 for the total score.

Stress associated with parenting (Study I)

The Swedish Parenthood Stress Questionnaire (SPSQ) (Östberg et al., 1997), which is the Swedish version of the Parenting Stress Index, Form 6, Parent Domain (Loyd & Abidin, 1985), was used to assess stress associated with parenting. The SPSQ includes five subscales: Incompetence, Role restrictions, Social isolation, Spouse relationship problems and Health problems. The mean score of the five subscale yields a total score ranging from 1 to 5, where a higher score indicate more stress (Östberg et al., 1997). The SPSQ has proven a reliable and valid instrument for assessing parenting stress, has demonstrated good psychometric properties with good internal consistency ($\alpha = 0.89$) and test-retest reliability (0.89) (Östberg & Hagekull, 2000), as well as concurrent, construct, predictive and discriminant validity (Östberg, 1998; Östberg et al., 2007; Östberg et al., 1997). In the present study, the total score showed a good internal consistency (Cronbachs $\alpha = 0.72$).

Child's emotional and behavioral problems (Study I)

The parents' perception of their child's emotional and behavioral problems was assessed using the Swedish version of the Strengths and Difficulties Questionnaire (SDQ-Swe) (Goodman, 1997; Smedje et al., 1999). The questionnaire includes five subscales measuring Emotional symptoms, Conduct problems, Hyperactivity/inattention, Peer relationship problems and Prosocial behaviour. The sum of four of the subscales (omitting Prosocial behaviour) yields a total difficulties score ranging from 0 to 40, where higher scores indicate greater difficulties. Borderline or abnormal range of psychological problems was defined as indicated by scores ≥ 14 (Malmberg et al., 2003; Smedje et al., 1999). The SDQ-Swe has

demonstrated good psychometric properties, being a reliable and valid instrument for assessing emotional and behavioural problems among children aged 4–16 with an acceptable to good internal consistency ($\alpha=0.84$ and 0.76) (Malmberg et al., 2003; Smedje et al., 1999). In the present study, internal consistency was good (Cronbachs $\alpha=0.80$).

Disclosure intention/behaviour (Study I and Study II)

Disclosure of donor conception was assessed by asking parents if they had started talking with their child about being conceived with oocyte/sperm donation. Participants were given five response alternatives and were categorized into 'Disclosers' (Yes, I have started talking about it) or 'Non-disclosers' (No, I intend to do it later on; No, I intend to do it if/when the child raises the question; No, I am uncertain/hesitant; No, I will not tell the child about the donor conception. Parents who had disclosed treatment with donated gametes to their child were asked to indicate the child's age when this occurred (open-ended question). In Study II, based on the five response alternatives and the open-ended question, participants were categorized as 'early disclosers' (< 7 years), 'late disclosers' (>7 years), or 'non-disclosers' (not yet disclosed treatment to their child).

Family functioning (Study II)

Parents' perception of their family functioning was assessed using a Swedish short version of the General Functioning Subscale (GF12), which is based on the McMaster Family Assessment Device (FAD) (Epstein et al., 1983). The short version used in the present study (GF6+) includes the six positive items (omitting negative items) from the GF12 subscale, e.g. "In times of crisis, we can turn to each other for support", "We can express feelings to each other", and "We feel accepted for what we are". Items are measured on a four-point Likert-scale, where higher scores indicate worse functioning. A total score was calculated as the mean average of values on all six items, and indication of unhealthy family functioning was defined as a cut-off score greater than 2 (Boterhoven de Haan et al., 2015). Any instances of missing data were handled by replacing missing items with the given participants mean total score. The GF6+ has demonstrated good psychometric properties and has been determined reliable and valid

instrument to assess family functioning (Boterhoven de Haan et al., 2015). The GF6+ and has demonstrated equivalent psychometric properties to the GF12 (Boterhoven de Haan et al., 2015). While there are no studies on the psychometric properties of the Swedish version of the GF6+, the Swedish version of the GF12 has demonstrated satisfactory reliability and acceptable validity in a bariatric sample (Bylund et al., 2016). In the present study, internal consistency (Cronbach's α) was 0.91.

Parent-child relationship (Study II)

Aspects of the parent-child relationship were assessed using two items developed by Goisis and Palma (2021), measuring closeness and conflict frequency. Closeness between the parent and the child was assessed with the question "Overall, how close would you say you are to your child?", and conflict frequency was assessed with the question "Most parents have occasional quarrels with their children. How often do you quarrel with your child?". The two items were measured on a four-point Likert-scale ranging from "not at all close" to "very close", and "most days" to "almost never", respectively. This measure of closeness and conflict between parent and child have previously been described as important predictors of child development (Driscoll & Pianta, 2011) and are frequently used to describe parent-child relationships during adolescence.

Sociodemographic characteristics (Study I and Study II)

Sociodemographic characteristics included age, gender, relationship with the co-parent of the adolescent child (co-habiting, or separated/divorced), and main occupation (employed, unemployed, or other). Items regarding which type of treatment had been used (OD, SD, or IVF with own gametes) were also included. Participants having used OD or SD were also asked which type of donor they had used (identity-release or known/directed donor).

3.5.2 Study III

In Study III, semi-structured qualitative interviews were conducted with DCPs using an interview guide that was developed by the research team. The interview guide covered the DCP's thoughts and feelings when learning about being donor conceived and the potential impact this event had on the DCP's family. Furthermore, the interview guide covered the DCP's thoughts, feelings and motives related to searching for donor information, and thoughts and feelings related to contacting/meeting the donor. Finally, the interview guide covered the DCP's views on family composition (i.e. who they considered as family members) and relationships between members of the family. When necessary, follow-up questions were probed, e.g. asking the participant to give an example. Interviews were conducted individually, face-to-face or via telephone (by C.L.), and lasted on average 62 minutes (range 31-106 minutes).

3.5.3 Study IV

Qualitative interviews in Study IV were performed with parents face-to-face or via telephone by two of the authors (A.W. and S.I.) trained in interview techniques. Individual interviews were conducted to decrease the risk of the participants taking their partners emotions into account, for example, not mentioning issues they may perceive as upsetting to their partner (Wyverkens et al., 2017). The interview guide was developed based on research and clinical experience, and covered the participants' thoughts and feelings in relation to having used sperm donation treatment, having talked with their child about the donor-conception, their adult child's searching for and obtaining information about the donor, and contact with the donor. Interviews were semi-structured, using open questions and probing follow-up questions, and lasted an average of 60 minutes (range 34-108 minutes).

3.6 Data analyses

3.6.1 Study I

A factorial analysis of variance (ANOVA) was conducted to investigate whether or not there were any effects of disclosure status (disclosing versus non-disclosing) and family type (SD versus OD) on the outcome measures (ENRICH, HADS, SPSQ, SDQ-Swe). Interaction effect of disclosure status and family type was also analyzed using a factorial ANOVA. Analyses were conducted for mothers and fathers separately since there was a dependency in the data. Furthermore, attrition bias was investigated by comparing responders and non-responders at T4 with regards to disclosure intentions and behaviour assessed by parents at the previous wave of data collection (when the child was 1-4 years old) (*Isaksson et al., 2012*). All analyses were performed using IBM SPSS, version 25 (IBM, USA). A P -value <0.05 was considered statistically significant.

3.6.2 Study II

Non-parametric statistical tests were used for all analyses due to distribution of data being negatively skewed and leptokurtic. Due to dependency in the data, participants were divided by gender, comparing mothers and fathers separately. The outcome measures (HADS, GF6+, Closeness, and Conflict) was compared based on family types (OD/SD/IVF) using the Kruskal-Wallis test. The potential impact of having used a known donor was investigated by comparing results when these participants were omitted in the analyses. Family types were further compared based on cut-off values on HADS and GAF6+ using χ^2 tests to identify clinically relevant levels of symptoms of anxiety and depression and to identify families with indication of unhealthy family functioning. Statistically significant differences were explored using post hoc tests. Furthermore, attrition bias was investigated by comparing responders and non-responders at T5 with regards to their responses at the previous wave of data collection (when the child was seven years old): disclosure of donor conception to their child (yes/no), psychological distress (HADS), and relationship with the co-parent of the target child (living together/divorced/separated). All analyses were

performed using IBM SPSS version 28. A P-value <0.05 was considered statistically significant.

3.6.3 Study III and Study IV

The interviews were transcribed verbatim, which included non-verbal communication such as pauses (indicated with three punctuations) and expression of emotions (indicated in square brackets), by A.W. and a research assistant in the research group. Interviews were analyzed using reflexive thematic analysis (Braun & Clarke, 2006, 2019) and the same procedure for the analysis was followed in Study III and Study IV. A complete coding was conducted whereby each dataset in Study III and IV was coded inductively based on the semantic and latent meaning of the data, with each code representing a singular idea relevant to the research aim (Braun & Clarke, 2013; Terry et al., 2017). The codes and themes were developed based on the first author's repeated engagement with the data in six phases as outlined by Braun and Clarke (2019), and then discussed within the research group (A.W., S.I., G.S., A.S.S., and C.L.). These discussions entailed going back-and-forth between themes, sub-themes, codes, and transcripts to ensure codes were representative of the data, and to highlight subjectivity (Braun & Clarke, 2019), using our professional backgrounds (nurse, nurse/midwife, psychotherapist, psychologists) and varying perspectives (e.g. in terms of gendered experiences of fertility and parenthood). Sub-themes were constructed by clustering codes to create patterns of underlying ideas, i.e., central organizing concepts, and themes aimed to capture latent meanings of sub-themes from a contextualist perspective (Braun & Clarke, 2019). That is, the analyses in Study III and IV aimed to explore how the participants experienced the process of identity-release, how the broader social context had an effect on these experiences, while still acknowledging the 'limits of reality' (Braun & Clarke, 2006) such as genetic inheritance.

An example from Study IV illustrates how this process of moving from a semantic meaning to more latent meanings, could occur. At an initial stage the code 'physical resemblance feels good' captured participants' comments that physical resemblance between the parents and their offspring was regarded as something positive, i.e. based on the semantic meaning of the data. However, based on repeated engagement with the data, the code 'physical resemblance

feels good' seemed to have this positive connotation of resemblance in the context of the parents meeting other people, and to specifically concern the ability to conceal the lack of a genetic bond between father and child. Thus, based on a recursive process of going back and forth between the codes and the data, the code was renamed 'resemblance as a mask', emphasizing resemblance being important for social approval, and thus capturing more latent meanings within the data. During the process of coding, it also appeared that some parents described resemblance having a more negative connotation, for example, a lack of resemblance between parent and offspring could evoke thoughts about the donor. Thus, the sub-theme 'resemblance as an asset/liability' was constructed to capture the dichotomy of resemblance, being both an asset as a mask, and a liability in that non-resemblance could confront parents with the absence of a genetic bond.

Braun and Clarke highlight that Reflexive Thematic Analysis is a method that is theoretically flexible. Thus, the theory underlying the analysis should be made explicit (Braun & Clarke, 2021). The results in Study IV were described using subject positioning (Davies & Harré, 1990). The theory of subject positioning suggests that people try to move from troubled to less troubled positions (Wetherell, 1998). However, what is considered troubling or untroubling depends on the person's specific context (Magnusson & Marecek, 2010), and which discursive practices are available (Davies et al., 2001). Thus, moving between different contexts and situations can lead to contradictions in how people act or speak (Davies et al., 2001). For example, positioning oneself as a parent may not be troubling for a non-genetic father until the father is confronted with beliefs that fatherhood is contingent on genetic inheritance, for example, someone mentioning the physical resemblance between the father and the child. Drawing on these assumptions, the analysis resulted in the themes "Navigating (in)visible markers of parenthood" and "Positioning the donor in a new landscape", highlighting that parents actively try to move from troubling to less troubling positions. By such means, the coding process aimed to initially derive on the semantic meaning of the data, and over time, in a reflexive process with a more interpretative lens, inductively construct themes that captured implicit meanings within the data from a contextualist perspective. Finally, Representative quotes from the interviews were translated from Swedish into English by a professional translator and checked for accuracy by two of the authors (A.W. and C.L.).

3.7 Ethical considerations

The potential risk, burdens, and benefits related to participating in the four constituent studies have been considered in accordance with the Declaration of Helsinki ("World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects," 2013) and are discussed in detail below.

3.7.1 Study I and Study II

Study I was approved by the Regional Ethical Review Board in Linköping, Sweden (Dnr: M29/05; M29/05/1-06; 2013/299-31), and Study II was approved by the Swedish Ethical Review Authority (before 2019 referred to as the Regional Ethical Review Board) in Linköping, Sweden (Dnr M29/05; M29/05/1-06; 2013/299-31; 2022-03739-01). All participants were given written and oral information about the study and signed an informed consent before inclusion at the fertility clinics. For each subsequent wave of data collection, participants were given written information about the study, including the voluntary nature of participation, confidentiality and the right to withdraw without stating any reason for doing so. Return of a completed questionnaire was considered as giving an informed consent. In terms of beneficence, participation did not involve any direct benefits for the study subjects. However, in previous waves of data collections, participants have expressed positive emotions related to participating in research that focuses on their specific circumstances.

In terms of non-beneficence, the risk of psychological harm (e.g. worry or negative emotions) associated with participation was considered small. To reduce the potential burden, the written information about the study informed participants that the questionnaire could potentially evoke emotions such as worry or a low mood. Participants were offered the opportunity to contact the principal investigator of the study (a licensed psychologist) if they felt a need for support. Further, the risk that answering questionnaires on psychosocial well-being may infer worries about negative consequences related to donor conception was considered. However, considering research on disclosure being

hampered by inconclusive evidence about its potential benefits and harms, and the scarce research on donor conception families within the context of identity-release donations, increased knowledge can contribute to develop clinical care and guide policymakers' decision-making within the field. Thus, the study may benefit the larger patient group.

Considering the low rates of disclosure reported at previous waves of data collection, and that the questionnaires were sent to the participants' home addresses, recruitment involved a risk of violating the participants' integrity by accidentally revealing the use of treatment with donated gametes to the participants' family members, who may not have known about the treatment. However, considering the participants had given consent to previous data collections and indicated they were willing to be contacted again, it is argued that they were familiar with the data collection and aware of such risks. Moreover, in terms of integrity, data were presented so that no single participants could be identified.

3.7.2 Study III and Study IV

Study III and Study IV were approved by the Regional Ethical Review Board in Linköping, Sweden (Dnr 2015/1465-31/5, 2016/1325-32, 2017/2370-32). All participants were given written and oral information about the study and signed an informed consent before the interview. Participants were informed about the voluntary nature of participation, confidentiality, and the right to withdraw without stating any reason for doing so. Each participant was asked for permission to audio record the interview. In regard to beneficence, participation in Study III and IV does not involve any direct benefits for the study subjects. However, the study aims to contribute with new knowledge about what happens when the intention of the Swedish legislation on identity-release donations is being fulfilled, i.e. when donor conceived offspring contacts the clinic to obtain information about their sperm donor. Research on this matter is limited, and can contribute to develop clinical care and guide policymakers' decision-making within the field.

Recruitment was conducted in consideration of the participants' integrity and autonomy. A prerequisite for recruitment was that the donor conceived offspring had contacted any of the seven clinics in Sweden about obtaining donor information. This implies that he/she was aware of being donor conceived.

Clinic staff provided oral and written information about the study to the donor conceived offspring, and asked if they would like to be contacted by the research group. In such cases, clinic staff provided the offspring's name and contact information to the research group, and a member of the research group contacted the offspring to give further information about the study. Offspring who participated in the interview study were also asked if they were willing to have the research group contact their respective parents for study participation. If the offspring accepted this, the parents of each respective child were contacted by a member of the research group. Thus, there was a small risk of violating the integrity of the study subjects. Before the interviews, all participants were once again informed that they had the right to decline participation or end the interview whenever they wanted without stating any reason.

In terms of non-maleficence, participating in in-depth interviews on potentially sensitive matters may cause distress. For example, parents in Study IV could find it challenging to discuss matters related to infertility, genetic kinship and disclosure, and their donor conceived adult child (Study III) could find it challenging to discuss matters related to being donor conceived. Thus, particular attention was given to participants' emotions during the interview and all participants in Study III and Study IV were offered the opportunity to contact the research group, with available psychological and psychotherapeutic competence, if they felt in need of support.

The aim of the research project was to increase knowledge about the long-term psychosocial consequences of donor conception. Legislation on identity-release donations was implemented in Sweden as being in the child's best interest. However, exploring the consequences of fulfilling the intention of the legislation, i.e. giving identifying information about the donor to the donor conceived child, is a lengthy process considering the donor's identity is not released until the child is of a "mature age". Given that Sweden was the first country in the world to introduce legislation on identity-release donations, the research project has the possibility to benefit patients in other countries where such legislation may have been introduced more recently or has yet to be introduced.

4 Results

4.1 Study I

Chi-square tests analyzing attrition bias showed no significant differences in terms of disclosure intention/behaviour (data not shown). More than half of the participants following OD (61%) and SD (58%) had disclosed treatment with donated gametes to their child. In terms of psychosocial well-being, most participants reported psychological distress within normal range on symptoms of anxiety (mothers 83%, fathers 89%) and depression (mothers 93%, fathers 92%). Furthermore, parents reported low levels of parenting stress, a high satisfaction of their partner relationship. Parents' ratings of their child's emotional and behavioural problems indicated that their children were psychologically well-adjusted, with 95% of mothers and 91% of fathers reporting below the cut-off for indicating emotional and behavioral problems.

The results showed no statistically significant differences between disclosing and non-disclosing families on any of the outcome measures assessing aspects of psychosocial well-being. Moreover, there were no statistically significant differences based on family type (i.e. families following oocyte and sperm donation) with regard to parents' psychological distress, their child's emotional and behavioural problems, or the parents' relationship quality. Finally, no statistically significant interaction effects were found between disclosure status and donation type.

4.2 Study II

Attrition bias

Chi-square tests revealed significant differences with regards to mothers' disclosure of treatment to their child ($p=0.004$). Mothers in SD and OD families who dropped out between wave four (when the child was seven years old) and the present study (wave five, when the child was 13–17 years old) were more than twice as likely to not have disclosed treatment, and non-responding SD mothers were more than three times as likely to be divorced or separated from the child's father compared to responding SD mothers. No significant differences were

found between responders and non-responders with regards to parents' psychological distress (HADS-A and HADS-D), for either mothers or fathers.

Disclosure, psychosocial well-being and difference between treatment types

The results from Study II showed that almost all parents had disclosed the donor conception to their adolescent child, with 85% of OD parents and 94% of SD parents having disclosed. In terms of psychosocial well-being, OD and SD parents reported overall low levels of psychological distress, a good family functioning, high levels of closeness, and low levels of conflict with their child, similar to that of the reference group of parents using IVF with own gametes. Comparisons between family types (OD/SD/IVF) showed no association with psychosocial well-being as indicated by the outcome measures, for neither mothers or fathers. Moreover, the majority of participants reported below cut-off on symptoms of anxiety and depression, as well as levels indicating healthy family functioning. No differences were found when comparing family type differences based on cut-off levels indicating clinical relevance, for neither mothers' and fathers' symptoms of depression, fathers' symptoms of anxiety, or mothers' and fathers' reported family functioning. However, differences were found for mothers reporting above cut-off levels of anxiety ($p=.018$). Post hoc tests revealed differences between OD and SD mothers ($p=.015$), with 31% of SD mothers reporting symptoms of anxiety above cut-off, compared to 7.3% of OD mothers.

4.3 Study III

Results from Study III showed that a majority of participants had received identifying information about their sperm donor, but six participants had not received such information. DCPs further differed in terms of age of disclosure, where about half had been told about being donor conceived during childhood (0-12 years old) and half were told in adolescence/adulthood (15-25 years old).

DCPs' motives and experiences related to searching for and obtaining donor information was described by two themes and five sub-themes (see table 2).

Table 2. DCPs’ experiences of searching for and receiving identifying information about their sperm donor, with themes and corresponding sub-themes.

Donor information can fill different needs	Navigating donor information in a relational context
Understanding more about myself	Balancing stakeholders’ interests
Learning about the donor	Scrutinizing father–child relationship
Searching for new relationships	

The first theme, ‘Donor information can fill different needs’, included three sub-themes highlighting that the significance ascribed to donor information could vary. The first sub-theme described that DCP’s search for donor information could be motivated by a need to understand more about themselves. Consequently, the receipt of donor information could be intertwined with the DCP’s self-concept, causing them to reevaluate “old” information about themselves. For some, this motivation of increasing self-knowledge could stem from a feeling of being different from the parents during the upbringing.

The second sub-theme described that the search for donor information could be motivated by wanting to learn more about the donor. These motivations were more commonly expressed in terms of curiosity, rather than the donor being a part of the DCP’s self-concept. Donor information was ascribed with limited significance in this regard, even though searching for donor information could instil a sense of personal agency by being informed on the donor’s motives for donating and any potential hereditary diseases. However, some DCP’s could worry about the donor having racist attitudes or being motivated to donate only for financial gains.

The third sub-theme described that searching for donor information could be motivated by an interest in getting to know other same-donor individuals, the donor’s own children, and the donor himself. While some hoped for a special bond with the donor, but not within the role of a father, others hoped to get to know their ‘real dad’. Hopes of a close relationship with the donor were related to the DCP having a poor father–child relationship, e.g. due to an emotionally and/or physically distant father. Related to these expectations, the participants

emphasized the donor's lack of obligation towards them, which could instil a fear of being rejected, but also a wish to respect the donor's integrity.

The second theme, 'Navigating donor information in a relational context', included two sub-themes describing that the DCP needs to deal with interpersonal aspects of obtaining donor information, which includes being confronted with multiple stakeholders' interests and what implications searching for donor information may have on the relationship quality with the father.

The first sub-theme described that the DCP had to balance own needs of self-determination and self-exploration with the donor's and parent's right to integrity. For example, participants worried that their quest for donor information could hurt the father. Consequently, some participants refrained from talking about the donor and about being donor conceived, keeping the nature of their conception and their search for donor information secret from friends and partners. For some, these worries about upsetting the father caused hesitation about contacting the donor.

In terms of the donor's right to integrity, some participants described that the clinic delayed releasing donor information in order to first inform the donor about the DCP's request. Having to wait for a second visit to the clinic could lead to disappointment and concerns about not being able to obtain donor information. Others described that this procedure of contacting the donor upon the DCP's request of his identity could cause a pressure of having to contact the donor personally in order to not make him disappointed.

The second sub-theme described that the process of searching for donor information could evoke contemplations about the relationship with the father. The sub-theme further described that the emotional charge of obtaining donor information was related to the perceived relationship quality with the father. That is, some DCPs described a close relationship with their father, which made the absence of genetic relatedness between the child and the father irrelevant, and consequently the search for donor information 'undramatic', both for the DCP and the father. Others described a distant relationship with their father, which were attributed to the fathers' worries of being replaced by the donor. However, when obtaining donor information, the father's worry of being replaced, and the DCP's worry of upsetting their father, could be proven unfounded, instilling a sense of relief. Related to these challenges, several participants expressed a need for additional practical and psychological support in the process of

searching for donor information, but that asking for such support could feel like too big a step.

4.4 Study IV

Apart from one DCP who was still waiting for identifying information, all children of the participating parents had received the donor's name and personal identity number. According to the parents' accounts, their adult children intention to contact the donor, and the extent to which the adult child had initiated contact with the donor varied. Many offspring were interested in the donor, even though this could be combined with hesitation about contacting him, and a few offspring were only interested in knowing who the donor was. Of those DCPs who had been in contact with the donor, a few were regularly meeting with him and/or his family.

The results from Study IV were described by two themes and five sub-themes (see Figure 3). The first theme, 'Navigating (in)visible markers of parenthood' described parents' experiences and reflections on being a parent following sperm donation.

The first sub-theme, 'Parenthood as doing/being' illustrated that parenthood was embedded with dichotomous meanings in terms of the importance of genetic relatedness. For example, parents described parenthood as self-evident considering that they had been present in the child's life from the start of the fertility treatment, thus emphasizing the importance of nurture. Others described that their genetic relatedness with their child made parenthood indisputable, emphasizing the importance of nature. Related to this, some fathers were worried that disclosing the use of donor conception could mean being rejected by their child.

The second sub-theme, 'Resemblance as an asset/liability' described that the experience of parenthood was related to resemblance and social approval. Parents who resembled their child experiences this as an asset as the resemblance could conceal the lack of genetic relatedness. Parents who did not consider themselves resembling their child experiences this as a liability as the lack of resemblance could reveal the lack of genetic connectedness.

The second theme, 'Positioning the donor in a new landscape' described how the parents handled the role of the identity-release donor in relation to themselves and the family. Three sub-themes described the parents' different strategies to

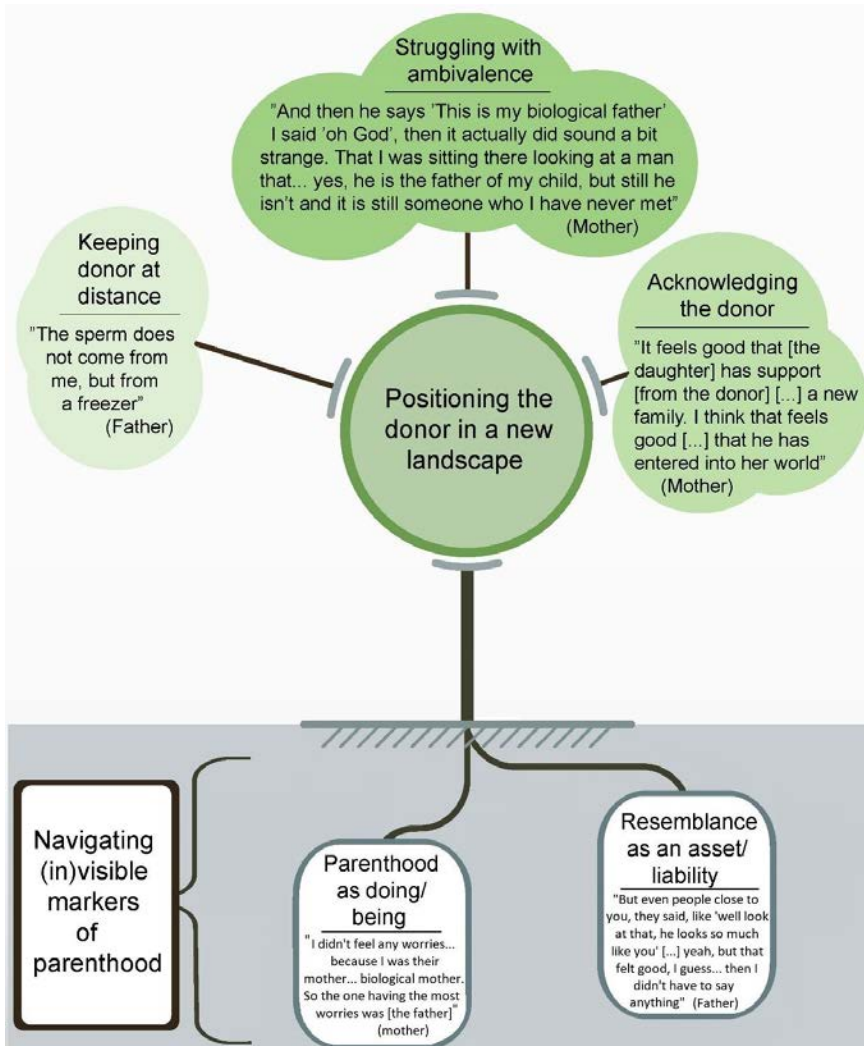
manage the presence of the donor, brought to the fore by the offspring's searching for and receiving information about him.

The first sub-theme, 'Keeping donor at distance' described parents' varying ways of positioning the donor as clearly separated from the family. The donor's 'unavoidable' presence in the family when the DCP obtained donor information, was primarily handled by the mothers, e.g. by talking to their adult child about the donor and supporting their child's quest for identifying information.

The second sub-theme, 'Acknowledging the donor as person/family', described how parents could acknowledged the donor being an individuals in his own right, having personal characteristics, and someone of potential relevance for the offspring and/or the family. While both mothers and fathers could acknowledge the donor as a person, seeing the donor as a part of the family was solely done by the mothers, particularly in families where the parents were divorced.

The last sub-theme, 'Struggling with ambivalence', covered the parents' ambivalent feelings about the donor and his role. For example, several parents struggled with how to position the donor in relation to the offspring and the family, as exemplified by alternating between calling the donor 'father' and 'donor'. Ambivalence was particularly evoked when the child obtained donor information or when the parents got to see the donor. For example, when seeing the donor, resemblance between the donor and the offspring could serve as a manifestation of the indisputable genetic relatedness between the donor and the child. This could create ambivalence regarding social relationships, both between the donor and the child, but also between the donor and the parent.

Figure 3. Illustration of themes, sub-themes, and illustrative quotes in Study IV



5 Discussion

5.1 Summary of the findings

Study I investigated the association between disclosure and psychological outcomes in heterosexual-couple families with donor conceived seven-year-old children. The findings showed that both mothers and fathers in these families report normal levels of anxiety, depression, and parental stress, and that parents reported a high satisfaction with their relationship. Parents further reported their donor conceived child having low emotional and behavioral issues. No significant differences were found between disclosing families and non-disclosing families in terms of psychological distress, parental stress, and relationship satisfaction among parents, nor in terms of the donor conceived child's emotional and behavioural problems.

Study II investigated differences between heterosexual-couple parents with adolescent (age 13-17) children following OD, SD and IVF with own gametes regarding their psychological distress, family functioning and parent-child relationship. The findings showed that the majority of mothers and fathers in donor conception families (OD and SD) report normal levels of psychological distress, healthy family functioning and feeling close to their children and experiencing infrequent conflicts. Donor conception parents were similar to parents who used their own gametes (IVF), with no significant differences found between family types in terms of symptoms of depression, family functioning, or parent-child relationships for either mothers or fathers. However, one difference between the groups emerged; a higher percentage of SD mothers reported anxiety symptoms above cut-off compared to OD mothers.

Study III explored the motives and experiences of adult donor conceived persons (DCPs) who search and receive information about their sperm donor. The results showed that DCPs have various intrapersonal needs that motivated them to seek donor information, and that the process of obtaining donor information involves balancing these needs with those of the clinics, the donor, and the parents.

Study IV explored how parents experienced identity-release donation when their adult children had obtained information about their sperm donor. The results of Study IV showed that parents' experiences were influenced by how they perceived parenthood in the context of nature and nurture. The results also identified that parents managed the presence of the donor in various ways. In Study III, DCPs described largely feeling supported by their parents in the process of searching for information about the donor, while some participants refrained from discussing the donor or their donor-conceived status to protect their father from worry related to the donor. Further, a poor father-child relationship was interpreted by the DCPs as stemming from the father's worry about being replaced by the donor. In Study IV the results showed that mothers tended to be attuned to the fathers' concerns and worries by refraining from talking about the donor. Thus, the results from both Study III and IV highlighted that children and their mothers acknowledged and were attuned to the father's particular vulnerability in relation to the process of searching for and receiving information about the donor.

5.2 Discussion of the main findings

5.2.1 The absence of genetic connections is not related to impaired psychosocial well-being

One of the aims of this thesis was to investigate psychological adjustment and family functioning in families following donor conception. Results from the two cross-sectional studies conducted when the child was seven years old (Study I) and 13-17 years old (Study II) suggested that the absence of genetic connections is not related to impaired psychosocial well-being. Additionally, a majority of parents in donor conception families report low levels of symptoms of depression and anxiety (Study I and II), with similar levels as reported by parents who underwent IVF with their own gametes (Study II), and as reported by the general population (Hinz & Brähler, 2011). Parents further reported low levels of parental stress (Study I), that they are satisfied with their partner relationship (Study I), consider their child to have low levels of emotional and behavioral problems (Study I), and that their family is functioning well (Study II). The findings from Study III and IV support that donor conception families also fare well in the

process of searching for information about the donor. Both mothers and fathers described having strong affectional bonds with their child and described a desire to act in their child's best interest (Study IV), and their (adult) children described feeling supported by their parents in this process (Study III). These results are in line with a systematic review on donor conception families, indicating that DCPs are psychologically well-adjusted and have positive relationships with their parents both in adolescence (Ilioi & Golombok, 2015; Imrie & Golombok, 2018) and in their twenties (Golombok et al., 2023). Thus, it appears that donor conception, or the absence of genetic relatedness, is not associated with decreased overall psychosocial well-being among families with young children or adolescents.

5.2.2 Openness about donor conception and its consequences

Another aim of this thesis was to investigate whether or not there is a relationship between disclosure of donor conception and psychological adjustment in families following OD and SD. In Study I, conducted when the child was seven years old, about half of OD and SD parents had told their child about being donor conceived. At follow-up, when the child was 13–17 years old, around 90% of parents had told their child about being donor conceived, with similar disclosure rates for oocyte donation and sperm donation parents (Study II). At a previous wave of data collection, when the child was 1–4 years old, almost all parents reported intending to disclose treatment (Isaksson et al., 2012). Thus, in Sweden the vast majority of families intend to be open with their child about being donor conceived and have disclosed treatment by the time the child enters adolescence.

In terms of the psychosocial implications of disclosure or non-disclosure, it has previously been suggested that secrecy per se may have negative consequences both for parents and their children (Blyth, 2002). However, no significant group difference was however found in Study I between disclosing and non-disclosing families in terms of the families' psychosocial well-being. These results are in line with previous findings on families with young and adolescent children following SD (Blake et al., 2014; Freeman and Golombok 2012; Golombok et al., 2022; Golombok et al., 2011; Golombok et al., 2013; Ilioi et al., 2017; Kovacs et al., 2015; Lycett et al., 2004), and OD (Blake et al., 2014;

Golombok et al., 2011; Golombok et al., 2013; Ilioi et al., 2017) showing no associations with disclosure and different aspects of family functioning. Related to these findings, and in line with the results from Study I, it has been suggested that there is at present insufficient evidence to support guidelines encouraging parents to disclose treatment to their child from an early age (Pennings, 2017).

However, legislation and guidelines are not only a matter of addressing the psychosocial implications of non-disclosure, but a question of changing attitudes to new family forms and openness, and technological innovation setting limits for the extent to which anonymity can be guaranteed. It was argued that the results from Study I, where no association was found between disclosure and psychosocial well-being, reflect a change in societal attitudes towards greater openness, and that parents who had not yet disclosed were not driven by threat, but rather felt confident about their decision to disclose treatment when the child was older. This was confirmed in Study II, where almost all parents had disclosed treatment to their children before the age of 12 (data previously not reported). However, about half of the DCPs in Study III had been told about the treatment in late adolescence, and findings in Study IV indicated that late disclosure was related to parents' uncertainty about when and how to tell, as well as anxieties such as fear among the fathers of being rejected by their child (data previously not reported).

A possible explanation behind the conflicting findings between the studies in this project is that participants in Study III and IV underwent treatment in the late 1980's and 90's, i.e., before guidelines were implemented instructing parents to disclose when the child was at an early age, whereas participants in Study I and II underwent treatment between 2005 and 2008, and were thus being encouraged to disclose at an early age. These findings correspond with previous studies showing higher rates of disclosure among heterosexual couples treated during the past two decades than earlier periods in Sweden (Gottlieb et al., 2000; Isaksson et al., 2012) and in Finland, with oocyte donation parents following both anonymous and identity-release donations (Salevaara et al., 2013; Söderström-Anttila et al., 2010), as well as attitudes in the general population in Sweden that support disclosure and openness (Svanberg et al., 2003). Indeed, the difference in approach to disclosure found in these studies corresponds with previous results suggesting that secrecy may be related to the parents being encouraged by fertility clinics not to disclose (Daniels et al., 2011), and that disclosure can be perceived as threatening if societal attitudes are unsupportive

towards new family forms (Macmillan, 2022). A recent study with adult DCPs who were born between 1986 and 2002 found that delaying disclosure may be associated with negative outcomes for DCPs (Lampic et al., 2022). Thus, the lack of evidence that non-disclosure is detrimental to psychosocial well-being (Pennings, 2017) may be related to attitudes during the time when parents underwent treatment, and the child's age when matters of disclosure are investigated. It is possible that disclosure is primarily an issue among families who underwent treatment during a time when attitudes towards donor conception indicated that it should be kept secret.

and where the DCP is old enough to search for donor information. Research on the implications of disclosure from a long-term perspective within the context of identity-release is scarce, as treatments have been available for a limited time, and more research is needed to draw any conclusions about the long-term implications of disclosure.

5.2.3 Challenging positions for the father in sperm donation families

While a majority of the parents' self-reports indicated adequate psychosocial well-being in Study I and II, Study III and IV highlighted that non-genetic fathers were challenged in several ways. Again, it should be noted that participants in Study III and IV underwent treatment in the 1980's and 90's, compared to participants in Study I and II, who underwent treatment between 2005 and 2008. Nevertheless, the results from Study III and IV suggested that fathers in SD families could feel challenged, both in terms of being a man and being the legitimate father.

In Study IV, some fathers described feelings of grief and demasculinization associated with being infertile, for example, one father referred to himself as a "gelding" (i.e. a castrated horse). Feelings of a threatened masculinity can be put in context with previous findings showing that male infertility may be associated with a lack of virility, masculinity and psychological strain (Wischmann & Thorn, 2013). In a previous Danish study of 210 men undergoing ICSI treatment, results showed that the ICSI procedure per se was not important for the perception of masculinity, however, in 37% of the participants, the reduced sperm quality negatively affected their perception of their masculinity (Mikkelsen et al., 2013). In line with these findings, new onset erectile dysfunction has been reported by

26% of men after unsuccessful TESE, compared with only 0.4% of men in a group after successful TESE (Akbal et al., 2010).

Results from Study IV also suggested that fathers felt challenged in their role as a father due to their lack of a genetic link with their child. Fathers in SD couples worrying about not being considered the legitimate father has been reported previously (Wyverkens et al., 2017), and was also indicated in the present thesis by both the participating fathers, the mothers (Study IV) and their children (Study III). Part of this challenging position for non-genetic fathers may be related to Euro-American conceptions like family bonds being built on genetic connectedness (Wyverkens et al., 2015). Furthermore, previous studies suggest that men place a greater importance to the genetic link between parent and child than women, both among gamete donation parents (Isaksson et al., 2011), and among the general population (Svanberg et al., 2003). A possible explanation behind these gender differences is that males lack a biological/gestational link with the child. In line with this, the American anthropologist Margaret Mead proposed that “motherhood is a biological fact, while fatherhood is a social invention” (Garbarino, 1993). Even though this thinking was formulated long before oocyte donation was accessible, treatment with donated oocytes has been accessible for a limited time and may not be as ingrained in our culture as the question of how men can be certain of being the “legitimate” father. Thereby, even though there are increasingly varying ways of family building, “genes” and “blood” still have a social and cultural significance in defining family relationships (Nordqvist, 2017) which may affect the perceived legitimacy of parenthood without genetic bonds.

In Study IV, mothers were found to be attuned to the fathers worries, for example by taking responsibility for any discussions about the donor, both within and outside the family. This is in line with previous studies showing that male factor infertility may involve secrecy around the diagnosis, sometimes to the point that women take the blame for the couples’ infertility (Carmeli & Birenbaum-Carmeli, 1994), and that the relatives of the infertile man are less likely to be informed about a successful treatment with sperm donation than the relatives of the woman (Brewaeys, 1996; Cook et al., 1995). In a narrative analysis, all of those who did not learn about their conception until adulthood had been told that their father’s embarrassment and anxiety had prevented disclosure (Kirkman, 2004). In line with this, a recent study by Golombok et al. (2023) with parents following anonymous donations in the UK, found almost all

OD parents had disclosed treatment, but that less than half of SD parents had disclosed treatment by the time the child was 20 years old, pointing to the same pattern where disclosure is more sensitive in families using sperm donation. Results from Study II further indicate that this is a sensitive issue as mothers reported elevated levels of anxiety in sperm donation couples. This was also supported by the DCPs own accounts, as described in Study III, where some expressed their relationship with their father as being poor. However, in consideration of the lack of genetic relatedness, some fathers took particular care to create an affectional bond with their child, as exemplified by one father in Study IV: *'I have done everything to be an incredibly active and connected father since she [the daughter] was a little girl. I was on parental leave with her a lot [...] and I believe that it has meant a lot, for us, for our relationship... that it was extra important for me, to get close to her somehow [...] It's important to make an impression that makes it... to enable you to see yourself reflected in your children'*.

Thus, feeling challenged as a father may not necessarily be related to a challenged fatherhood per se, but may also be related to feeling questioned in terms of masculinity. Even though it was beyond the scope of the studies in this thesis to investigate the ways in which fatherhood and masculinity may intersect, the results indicate that these constructs are closely interconnected. As one father in Study IV described it when thinking about his child contacting the donor: "it's threatening to the fatherhood and to the role of the male in the family".

5.2.4 Implications of requesting donor information for the family

Study IV showed that how parents positioned the donor was related to their (un)troubling positions as parents. Fathers tended to position the donor far away from the family, whereas mothers tended to position the donor as part of the family, particularly when the father was absent. Similar results have been reported, with DCPs expressing more interest in the sperm donor when the father is absent (Freeman et al., 2014) and single and lesbian women being more likely to represent the donor as the father (Kirkman, 2004). Consequently, it has been suggested that (heterosexual) female partners strive to reinforce the man's position as the father (Grace et al., 2008).

Related to the fathers' worries of being replaced by the donor (Study IV), some DCPs described this worry as causing a distance in the relationship to their father (Study III). In this regard, the fathers' worries about the lack of genetic relatedness may have led to its own confirmation. As previously mentioned, studies have shown that men place a greater importance to the genetic relatedness between parent and child than women (Isaksson et al., 2011), and among the general population (Svanberg et al., 2003). This greater importance on genetic relatedness apply for donors as well, with sperm donors reporting a higher level of involvement with potential donor offspring, compared to oocyte donors (Lampic et al., 2014). With a similar logic, the donors' ascribed importance to genes may form a foundation for a close relationship with the DCP, particularly when the non-genetic father is absent. On the other hand, results from Study III showed that in some cases the father's worries diminished when the child met the donor. Thus, meeting the donor also has the potential to resolve the father's unfounded fear of being replaced, and thereby allow the child to freely explore their genetic origins and importantly; improve the quality of the relationship with their father.

Still, the present findings suggest there may be a particularly vulnerable subgroup of DCPs who search for donor information to understand more about themselves from a perspective of having a poor relationship with their father. Such a position is particularly vulnerable considering the lack of obligations from the donor's perspective. Thereby, these DCPs should be offered support in this process. Moreover, the results from Study III highlight that the DCPs' intrapersonal motives and experiences should be seen in the light of family dynamics. That is, if the child is attuned to the fathers' worries about being rejected, it is possible that the DCPs downplay the importance of donor information in order to protect the father. If the intention of the legislation on identity release is in the child's best interest, the parents should also be offered support in managing their own emotional reactions related to this process.

5.3 Methodological considerations

The use of both quantitative (Study I and II) and qualitative research methods (Study III and IV) provided results that were both wide and deep. It enabled descriptions of psychosocial well-being among donor conception families and to make inferences to the target population, while also providing richness and detail to the experiences of donor conception. Furthermore, combining the results of quantitative and qualitative studies can enhance the validity of results (Verhoef & Casebeer, 1997). Still, integration of the results from the four studies should be made with the different methodologies, contexts and populations in mind. That is, Study I and II included parents who started treatment between 2005 and 2008, while Study III and IV included parents who started treatment in the late 1980's and 1990's. Also, Study I and II targeted a study population of all families who had started treatment with donated gametes, whereas Study III and IV specifically targeted the subgroup of families with adult offspring who had contacted the RMCs to obtain donor information.

5.3.1 Study I and Study II

The samples in Study I and II were drawn from the SSGD, which included a population-based sample with high initial response rates. All heterosexual couples starting oocyte and sperm donation treatment in Sweden during a three-year period were approached regarding study participation at all fertility clinics performing gamete donation in Sweden. In terms of external validity, this increase the extent to which the results are generalizable to the target population of donor conception families within the context of legislatively enabled formal systems. Many previous studies in the field rely on self-selected samples representing specific interest groups. For example, samples drawn from the Donor Sibling Registry (e.g., Jadva et al., 2010b), where parents within the context of having used anonymous donations are actively seeking donor information. Such studies are naturally using highly selected samples and cannot be generalized to the total population of families using donor conceptions. Another strength is that the constituent studies included fathers, with comparably large sample sizes. Previous longitudinal studies within the field often include only mothers, and are often hampered by small sample sizes. For

example, the sample in the study by Golombok et al. (2023) included 17 OD mothers and 26 SD mothers, compared to Study II which included 73 mothers and fathers following OD, and 67 mothers and fathers following SD.

However, there are several methodological issues that should be taken into consideration. In Study I, when the child was seven years old, the response rate for OD and SD couples was 57% and 65%, respectively based on figures from the previous assessment. In Study II, when the child was 13–17 years old, the response rate for OD couples, SD couples, and IVF couples was 70%, 60%, and 69% based on the previous assessment, respectively, which may limit the external validity. To investigate if drop-out was related to any systematic error, attrition bias was analyzed in Study I and II. However, no significant differences between responders and non-responders were however found in terms of parents' symptoms of depression and anxiety in Study II. Thus, the risk of drop-out between the assessments being caused by high psychological distress is unlikely. However, this was not investigated in Study I, and it is possible that drop-out due to more symptoms of anxiety and depression have occurred in earlier waves of data collection. Thus, the risk of attrition bias could potentially explain why a significantly larger proportion of SD mothers reported symptom levels of anxiety above cut-off values in Study II, but no such differences were found among SD fathers.

Further, attrition bias was investigated in terms of parents' disclosure intention/behavior. No differences were found between non-responders and responders in Study I. However, in Study II, non-responding mothers were more than twice as likely not to have disclosed treatment compared to responding mothers, which suggests that drop-out may be related to non-disclosure. It should also be considered that parents' disclosure status was based on a study-specific item, where parents' responses were dichotomized into disclosers or non-disclosers. While the aim of Study I was to compare disclosing and non-disclosing parents, it should be noted that non-disclosers included those who intended to disclose later, those who were hesitant, and those who had decided not to disclose. Thus, non-disclosers is a heterogeneous group in terms of their attitudes to disclosure. It has been suggested that parents disclose in 'layers' (Readings et al., 2011), for example, telling their child about having used treatment at the hospital without specifying the use of donor gametes. In terms of external validity, it should also be considered that participants in the SSGD have repeatedly completed surveys, e.g. including questions about, for example, the

intention to disclose treatment, which may have made parents more conscious about disclosure compared to the target population.

Study I and II assessed psychosocial well-being using validated self-report instruments. The parent-child relationship quality was assessed by the degrees to which parents felt close to their child and had conflicts with their child. It has been pointed out that closeness and conflict are important predictors of child development (Driscoll & Pianta, 2011). However, conflicts can be both constructive or destructive (Laursen & Collins, 2009), and it has previously been suggested that conflict is a healthy part of the adolescent's development of autonomy and individuation (Steinberg, 2001). Thus, in terms of construct validity, defined as the extent to which indicators represent a concept that is not directly measurable (Cronbach & Meehl, 1955), it is possible that the two items included in Study II do not fully capture the parent-child relationship quality. Moreover, it is likely that conflict has a U-shaped relationship with the parent-child relationship quality, where both the low and high ends of conflict frequency are associated with a poor parent-child relationship.

Considering that the studies relied on self-reports assessing varying aspects of psychosocial well-being, the respondents were subjected to response bias (van de Mortel, 2008). For example, it has been suggested that the challenges of undergoing fertility treatment may make it more difficult to complain (McMahon et al., 2003). It has previously been emphasized that triangulation, e.g. including additional methods of data collection, can increase confidence in the data (Thurmond, 2001). For example, by including observations of parent-child relationship, or proxy measures of the child's psychological adjustment by, for example, teachers, confidence in the data could have been strengthened further.

5.3.2 Study III & IV

Considering the very low number of DCPs who have searched for information about or established contact with their donor, survey data on the psychosocial implications of contact between DCPs and donors is limited. Thus, it has previously been suggested that policy and ethical debate tend to generalize and quantify qualitative analyses (Freeman, 2015). While the results from Study III and IV may not be quantified, the sample represents a large part of the very

limited target population of DCPs who have contacted the RMCs in Sweden to obtain donor information (n=29 of approximately 60 DCPs who have so far requested donor information), including the parents of the majority of these individuals.

The choice of qualitative method depends, among several other things, on the research question. The focus of Study III and IV was on the participants' experiences; how parents experienced when their adult child had searched for information about the donor (Study IV) and how this process was experienced by the adult child (Study III). There are several qualitative methods, for example, content analysis (Graneheim & Lundman, 2004) that can be used to analyze participants' experiences. An aspect which may be considered when choosing a method is the sample size. Braun and Clarke (2021) suggest that Reflexive Thematic Analysis is appropriate when having a relatively large sample (i.e. more than 10 participants). Reflexive Thematic Analysis is also appropriate when the aim is to capture diversity (Fassinger, 2005). Thus, considering the relatively large sample sizes in Study III and IV, and the relatively unexplored topic of experiences related to obtaining donor information, Reflexive Thematic Analysis was used in these studies to explore patterned meaning across each dataset (Braun & Clarke, 2019).

The trustworthiness of the findings was evaluated by the concepts of credibility, transferability, dependability, and confirmability (Guba 1981). Participants were recruited from all five university hospitals where offspring had obtained identifying information about their donor. Concerning transferability, the recruitment provided a heterogeneous sample of DCPs, mothers and fathers from both urban and rural areas throughout Sweden, with varying socioeconomic and relationship status. One limitation in terms of transferability in Study IV is that relatively few fathers consented to participate. It should also be considered that the study was performed, and parents' and DCPs' experiences were given, within the context of Swedish legislation on identity-release donation. Moreover, participants in Study III were conceived within the first 16 years after the 1985 legislation on identity-release in Sweden when there was negative and ambivalent attitudes towards disclosure among clinic staff and gamete recipients (Gottlieb et al., 2000; Lalos et al., 2007). The study sample in this regard may have different experiences compared to future DCPs contacting the RMCs to obtain donor information. However, from the perspective of the clinics, the study sample is considered transferable to the

population of DCPs (of a mature age) who are eligible to obtain donor information.

Considering credibility, the decision to end data collection was made during the data collection process, when the data had a richness and complexity that could address the research question (Braun & Clarke, 2019). The presented quotations were representative of transcripts. Acknowledging that parenthood following donor conception can be a sensitive topic, interviews were conducted individually to enable the participants to express themselves freely as, for example, women may be reluctant to express positive feelings about the donor in fear of upsetting their male partner (Wyverkens et al. 2017). Considering the varying emotions that may arise during interviews about sensitive topics, the mode and location for the interviews were decided in accordance with participants' preferences to create an environment that felt comfortable for them. To increase dependability, study-specific interview guides were used to ensure that the same topics were covered in all interviews. Furthermore, engagement with the data and analysis was conducted by researchers with different backgrounds in terms of profession (registered nurse, psychologists), and varying research experience of psychosocial aspects of donor conception. Braun and Clarke (2021) emphasize that themes are actively constructed and generated by the researcher, as opposed to "emerging" from the data. Thus, subjectivity is emphasized as being an inescapable aspect of data interpretation. Part of my own subjectivity comes not only from being a psychologist, but also from living in Sweden and growing up during the 1990s. Attachment theory was popularized, emphasizing the importance of parents being attuned with their child's needs, and fathers were, compared to many other cultures, seen as an equally important part of forming a secure attachment with their child. Thus, I see the father as having an important role in child rearing. When analyzing the data, I thus interpret fathers being emotionally distant as something deviant. This may of course differ between different cultures.

6 Conclusions

The overall aim of this thesis was to investigate the long-term psychosocial consequences for heterosexual couple families following oocyte donation (OD) and sperm donation (SD), in the context of the Swedish legislation. Based on cross-sectional data from a prospective longitudinal study, the results show that the vast majority of donor conception families report psychosocial well-being similar to natural conception families, and the general population. Among oocyte- and sperm donation families with seven-year-old children (Study I) and 13-17-year-old adolescents (Study II), parents report a positive relationship with their partner, low levels of parenting stress, low levels of symptoms of depression and anxiety, as well as their family being well-functioning. Parents further reported their seven-year-old child as having low levels of emotional and behavioural problems (Study I), and having low levels of conflicts and feeling close to their adolescent child (Study II). Thus, the absence of a genetic link does not appear to be detrimental to psychosocial well-being. Results from two qualitative interview studies with DCPs who had contacted the RMCs to obtain donor information, and the parents of a majority of those DCPs, however indicated that both parents and their adult children face several challenges in this process. A central aspect of these challenges seems to be the father's emotional reactions to the fact that he is not the genetic father, and how the child, the mother and the father himself is managing these emotions. A further result of the qualitative interview studies is that the extent to which genes influence relationships within the family largely are derived from the importance that is placed on genes by the families. This importance is not solely determined by the parents and their offspring, but also influenced by the culture in which they live. Healthcare can thereby make an important contribution by supporting families in recognizing the challenges of new family forms and of strengthening the parents' beliefs that families can be built without genetic bonds. Furthermore, the results from the studies in this thesis should be seen in a historical context, where donor conception still is a relatively new technique used in medical care, and the acceptance of non-genetic parenthood and new family forms may therefore change in the future in line with the increased use and awareness of these treatments.

7 Points of perspective

7.1 Encourage early disclosure with a seed-planting strategy

Results from Study I suggested that disclosure did not have detrimental psychosocial implications on donor conception families, and it was concluded that parents should be informed about the safety of disclosing donor conception. While the results could also be argued to favor non-disclosure, there are several arguments for encouraging early disclosure, such as the growing evidence suggesting that DCPs being told in early childhood about their conception react with less distress compared to those DCPs who are told later (Blake et al., 2014; Blyth et al., 2013; Ilioi et al., 2017b; Lampic et al., 2022). In addition to this, an important argument in favor of early disclosure is the risk of inadvertent disclosure due to the increasing popularity of direct-to-consumer DNA-tests that enable individuals to find information about their ancestry (Crawshaw, 2018; Harper et al., 2016). Indeed, the number of DNA-tests used by consumers have grown exponentially, from 3 million in 2016 (Harper et al., 2016), to 30 million in 2019, and in 2021 the number was estimated to be 100 million (AMA, 2021). Consequently, it has been suggested that donor conception parents should be informed about the possibility that their child can connect with the donor and other same-donor-individuals using direct-to-consumer DNA-tests (Kirkman-Brown et al., 2022), and that donor anonymity cannot be guaranteed anymore (Harper et al., 2016). Drawing upon these arguments, early disclosure should be recommended to families using donor conception.

In previous research, two major disclosure strategies among parents have been identified (Mac Dougall et al., 2007). The first of these is adopting a “seed planting” strategy, where treatment is mentioned in early childhood so that the donor conception becomes a subject natural to speak about in the family. The second strategy is to adopt a “right time” approach, where disclosure is seen as a one-time event that should correspond with the child’s capacity to comprehend the biologic concepts and the privacy warranted by donor conception. At the same time, a previous study show that determining when the time is right can be difficult, leading to a risk of postponement of these conversations with the child, which has been associated with higher levels of anxiety among parents (Applegarth et al., 2016). Based on the present results, and previous findings outlined in this paragraph, healthcare providers could

suggest that parents start to talk with their child from an early age about being donor conceived, i.e. using the “seed planting” strategy to support the process of early disclosure.

7.2 Support with a long-term perspective to families using donor conception

The sample from Study III and IV constitute a large proportion of the families in Sweden whose DCPs choose to search for donor information. Over the coming years, an increasing number of DCPs with identity-release donors will become old enough to request information about their donors, and as an increasing number of jurisdictions introduce legislation on identity-release donations, the results should be considered in terms of clinical practice.

Guidelines recommend that donor conception families (including both parents and children) should have access to counselling during the process of identity-release (Kirkman-Brown et al., 2022), and a psychoeducational approach with a life-long focus have been suggested (Crawshaw & Daniels, 2019). The results from Study II-IV further supports these claims, and suggest that support to families with DCPs who are in the process of searching and obtaining donor information may focus on family dynamics such as how to deal with the diverging needs within the family (Study III), and questions and potential worries related to the importance of genetic relatedness for the parent-child relationship (Study IV).

Psychoeducation directed to families using donor conception may specifically focus on helping parents to reframe the perceived importance of genetic relatedness for the parent-child relationship, which questions the legitimacy of non-genetic parenthood and give rise to worries and may hinder openness. These challenges should be recognized within a socio-historical context, and parents should be strengthened in that families can be built without genetic relatedness. Indeed, genetic relatedness as building blocks for family bonds is of no greater importance than affectional bonds; the results from Study I and II indicated that donor conception families are well-functioning, and that the absence of genetic relatedness is not detrimental to the parent-child relationship, which is in line with previous studies (Ilioi & Golombok, 2015).

Psychoeducation to families using donor conception should include this information.

Lastly, the results from this thesis indicate that fathers may be particularly vulnerable in relation to the process of disclosure of SD, and of their adult child searching and receiving information about the donor. Results showed that due to worry about upsetting the father, DCPs were hesitant to talk about their interest in the donor, both with parents and friends, and hesitant about contacting the donor. Thus, this highlights that SD parents in particular should be offered support to enable their child to freely explore the conditions of how they came about and furthermore, that this support may have a specific focus on strengthening fathers. It is argued that involving the fathers early to create affectional bonds with their child may facilitate a secure base from which the child, if deemed relevant, can search for donor information later on.

7.3 Obtaining donor information requires a clear formulation of rights and obligations

Results from Study III showed that the clinics' procedure of informing the donor about the DCP's request for his identity could cause the DCP to feel a pressure to establish contact. Thus, DCPs may benefit from having each stakeholders' responsibilities clearly formulated in the process of identity-release. That is, the donor has no obligation to establish contact with the DCP, and it should be emphasized that this lack of obligation applies to the DCP as well and that a prerequisite for inclusion as a donor is having altruistic motives.

Findings from Study III further suggest that the obligations of the clinics as defined by the Swedish legislation on identity-release should also be clarified. The clinic's procedures of only giving non-identifying information about the donor, or delaying identity-release in order to first inform the donor about the request, which was reported by a few participants in Study III, could give rise to disappointment, concerns and worries among DCPs. These procedures are not in line with legislation on identity-release and should be reconsidered to ensure that clinical procedures are in the child's best interest.

7.4 Future Research

In general, studies in this field rely on mothers' self-reports, observations of mother-child relationships, and mainly include children following sperm donation since oocyte donation was made available more recently (to heterosexual couples in Sweden in 2003). Future research should thereby make efforts to recruit fathers and use different methods to determine the functioning of these families. Further, studies should focus on OD families and the potential challenges that they face. A few recent qualitative studies have however been done on OD mothers, with results suggesting that mothers in OD couples may face similar challenges as fathers in SD couples (Imrie et al., 2020; Lysons et al., 2022), but that OD families overall report psychosocial well-being within normal ranges similar to SD families and other family types (e.g. natural conception) (Imrie & Golombok, 2018). Still, more research is needed on families following oocyte donation to determine if the results found in this thesis, i.e. that fathers in SD families are challenged in several ways including the way they perceive themselves as a legitimate father and the ways this challenges their masculinity, is applicable also to motherhood and perceived femininity in mothers in OD families.

Moreover, the results from Study II showing that SD mothers to a significantly higher extent reported symptoms of anxiety indicating clinically relevant levels compared to OD mothers should be further investigated. Longitudinal studies could investigate whether fathers' symptoms of anxiety predict mothers' symptoms of anxiety. For example, interviews exploring how donor conception has affected the relationship dynamics between the couple, and whether infertility has affected the parents gender identity could be explored.

Research on the long-term outcomes for donor conception families is still fairly limited and sample sizes are usually small, particularly in terms of identity-release donations, and in studies on the experiences of obtaining donor information and establishing contact with the donor. A small proportion, only seven percent, of those DCPs in Sweden that are eligible to obtain donor information have exercised this right (Lampic et al., 2022). With regards to the remaining 93% of DCPs, it is not known whether they have not searched for donor information because they do not find the donor information relevant, if they are hesitant to show interest in the donor in consideration of the potential impact on other family members, or if they are unaware of their conception. Due to the risk of the latter, approaching the population would be unethical

considering the risk of inadvertent disclosure. In this regard, it should be kept in mind that participants in Study III and IV are only a small fraction of the total population of donor conception families, and families with adult children requesting donor information. Still, studies investigating the motives and experiences of DCPs who chose *not* to request information about their donor should be conducted. By using long-term cohort designs, families can be included at an early stage of the donor conception process and thereby be familiar with the research study and its aims. Participants to an interview study can thereafter be recruited directly from such a cohort to investigate the issues related to searching information about the donor also in families where the DCPs chose not to request this information.

When it comes to donor conception in the context of identity-release legislation, there are still few studies investigating the psychosocial consequences for families. In the years to come, more research on the impact of these treatments for families, using more sophisticated research methods and large enough samples with a high representation of both mothers and fathers, and of children, will be of importance to determine the long-term psychosocial consequences of family building using gamete donation. The use of donor conception is still a relatively new phenomena, and while it may be concluded that the event of being conceived does not belong to the past, knowledge on how these relationships develop over time is still in its infancy.

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